

INFORMATION NEEDS FOR CARERS FOLLOWING A FAMILY MEMBER'S RIGHT  
HEMISPHERE STROKE

A Thesis

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the degree of Master of Science

By

Christyn Davidson

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Approved July 1, 2019

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## ABSTRACT

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August 2019

Thesis supervised by Sarah E. Wallace, Ph.D.

*Background:* Previous studies have explored information needs for carers of persons with aphasia; however, there is minimal research on information needs of carers with right hemisphere disorder (RHD). RHD describes cognitive and communication impairments a person experiences following a right hemisphere stroke or brain injury. Carers have an important role in rehabilitation and the long-term quality of life of a person with RHD. This study explores the information needs for carers following a family member's right hemisphere stroke throughout different periods of recovery.

*Methods/Procedures:* Participants completed online surveys and a semi-structured phone interview. Analysis of the interviews revealed four major themes in the onset phase, three major themes in the initial rehabilitation phase, and six major themes in the chronic phase.

*Conclusions:* Results suggest the importance of thinking about the delivery of information to carers, the timing of this information, and type of information based on the recovery phase.

## DEDICATION

I dedicate my thesis to the carers and families who selflessly work each and every day to make today better than yesterday through their love and support of their friend or family member. To my mom, who continuously amazes me in her compassion, generosity, and her care for my dad. And to my dad, for inspiring me with his authenticity, continued perseverance, and perfectly timed humor.

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## CHAPTER I

### **Introduction**

The right and left hemispheres of the brain are responsible for different functions while still working together and integrating information between hemispheres. The left hemisphere is highly involved in logic and objective information, math, analysis, memory for names, controlled systematic experimentation, word reading, and language. In contrast, while the right hemisphere has a role in verbal communication, it is responsible for subjective information, emotions, improvisation and intuition, facial recognition, random exploration, visual aspects of reading, as well as visual-spatial information (Bernard, Lemée, Ter Minassian, & Menei, 2018; Kane, N., & Kane, M., 1979). With these unique contributions, both hemispheres contribute to communication and cognitive functions.

### **Role of the Right Hemisphere in Communication and Cognition**

The right hemisphere is involved in the comprehension and production of nonverbal and verbal communication. Spoken communication includes the expression of language through speech, whereas nonverbal language includes gestures, facial expressions, intonation, prosody, and eye contact (Blake, Frymark, & Venedictov, 2013). In addition, the right hemisphere is involved in the use of pragmatics within conversations. Finally, the right hemisphere contributes to comprehension of language and nonliteral language (Blake et al., 2013).

There are specific cognitive functions that are at least in part controlled by the right hemisphere. Areas such as organization, planning, awareness, and reasoning, all of which are part of executive functions, are regulated by areas within the right hemisphere (Blake et al., 2013; Purdy, 2016). Other areas of cognition related to the right hemisphere are attention (e.g., focused, sustained, selective, divided, and alternating) and memory (e.g., short-term memory,

working memory, and nonverbal memory) (Blake, 2016; Blake, Duffy, Myers, & Tompkins, 2002; Tompkins, Klepousniotou, & Gibbs Scott, 2013). Finally, the right hemisphere is believed by some researchers to contribute to the development of theory of mind, which refers to the ability to understand another's feelings, intents, or reasons for their actions in certain situations by thinking outside of one's own self (Balaban, Friedmann, & Ziv, 2016; Winner, Brownell, Happé, Blum, & Pincus, 1998; Blake, 2016).

### **Right Hemisphere Disorder**

The term right hemisphere disorder (RHD) generally describes the deficits in communication and cognition that occur following damage to the right hemisphere. Damage can result from a stroke, tumor, or other head injury (Blake et al., 2013). As a result, impairments in attention, executive functions, memory, and communication often arise. Given that deficits in communication for individuals with RHD are often related to underlying deficits in cognition, they are commonly referred to as cognitive-communication deficits (Tompkins, 2012, Tompkins et al., 2013).

Limited information is available regarding the prevalence of RHD because no consensus has been reached on a clear definition of the constellation of deficits included. However, about 50% of adults with RHD have cognitive-communication deficits based on data from individuals who participated in research studies associated with site of lesion (Benton & Bryan, 1996; Joannette & Goulet, 1994). Other research indicated that 80% to 90% of patients in a rehabilitation setting displayed deficits related to cognitive-communication in combination to other areas of deficits resulting in continued rehabilitation (Blake, et al., 2002; Côte, Payer, Giroux, & Joannette, 2007).

**Cognitive Deficits.** Cognitive deficits that often present in people with RHD include impairments in executive functions, attention, and memory, as well as agnosia, prosopagnosia, and topographical disorientation (Blake et al., 2002; Tompkins, 1995; Tompkins et al., 2013). These deficits vary greatly across individuals with RHD in the areas involved and the severity of the deficits. Regardless, these deficits significantly impact a person’s participation in daily activities.

**Executive functions.** People with RHD experience deficits in all components of executive functions. According to Solhberg and Mateer’s (2001) model of executive functions, there are six components: initiation and drive, response inhibition, task persistence, organization, generative thinking, and awareness (Table 1). These executive function difficulties may contribute to the behaviors displayed in everyday tasks such as poor awareness, problem solving, self-monitoring in social situations, and organizational skills (Blake, 2007; Tompkins, 1995; Tompkins et al., 2013). For example, understanding the steps to complete a task, initiating the task, carrying out each step in the correct order, and problem solving during the task would be difficult for a person with RHD.

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Table 1

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*Components of Executive Function*

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<u>Components</u>	<u>Description</u>
Initiation and drive	Activation or starting of a cognitive system
Response inhibition	Stopping automatic or prepotent response tendencies
Task persistence	Maintain a behavior until task completion
Organization	Organizing and sequencing information
Generative thinking	Creating multiple solutions to a problem and thinking in a flexible manner
Awareness	Monitoring and modifying one’s own behavior

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**Attention.** Attention deficits are apparent across all types of attention: focused, sustained, selective, divided, and alternating. These deficits can present as poor discourse skills including conversation, narrative, comprehension, turn taking, and topic maintenance skills. People with RHD may appear disengaged in conversation; be unable to attend in noisy, distracting environments; or struggle to attend to a task for an extended amount of time (Biel & Hula, 2016; Blake, 2016; Saldert & Ahsén, 2007; Tompkins, 1995; Tompkins et al., 2013).

Unilateral spatial neglect is another attention impairment in which a person with RHD cannot attend to the left spatial area (Corbetta, 2014; Tompkins et al., 2013). There are three types: personal, peripersonal, or extrapersonal. Personal neglect occurs when someone does not attend to the left half of his or her body (e.g., shaving half of their face). Peripersonal neglect refers to reaching distances (e.g., eating only half of a plate of food). Extrapersonal neglect indicates a lack of attention beyond one's reaching environment (e.g., walking into a wall). There is a high prevalence of unilateral spatial neglect post stroke (Blake, 2016; Bisiach, Perani, Vallar, & Berti, 1986; Guariglia & Antonucci, 1992; Halligan & Marshall, 1991).

**Memory.** Consequently, impairments in attention relate to memory deficits experienced by people with RHD (Sohlberg & Mateer, 2001). For example, the right hemisphere is involved in working memory which aids in the encoding, processing, storing, and later retrieval of information; therefore, if a person with RHD is unable to attend to stimuli, this process of encoding, storing, and retrieving is disrupted resulting in short-term memory impairments (Biel & Hula, 2016; Blake, 2016; Tompkins et al., 2013). Thus, this interaction of cognitive systems (i.e., attention and memory) can result in apparent deficits in short-term memory, nonverbal memory, and working memory (Tompkins, Bloise, Timko, & Baumgaertner, 1994).

Short-term memory deficits often experienced by people with RHD include difficulty recalling recent information that was read or heard. In addition, a person with RHD may experience difficulty following multistep directions, remembering to bring belongings (e.g., cane, phone, memory notebook), or recalling medication schedules. Furthermore, deficits in nonverbal memory disrupts storage of spatial and objective information. This creates difficulty for a person with RHD when asked to draw a complex picture that was recently presented to him or her (Smith & Jonides, 1999). Use of strategies to support memory is often suggested; however, people with RHD may not remember to use their memory strategies (Tompkins, 2012).

***Agnosias.*** A common characteristic of persons with RHD is anosognosia (Giacino & Cicerone, 1998; Tompkins et al., 2013) or reduced awareness of deficits, which causes individuals to appear indifferent toward deficits and state unrealistic goals (Tompkins, 2012). Prosopagnosia, failure to recognize faces, can occur due to damage in the right hemisphere to the fusiform gyrus (Tompkins, 1995; Wilkinson et al., 2009). Lastly, one may exhibit topographical disorientation, a loss of environmental familiarity or the confusion regarding location in space; subsequently, he or she may not be topographically oriented in familiar surroundings and may get lost in familiar places (Tompkins, 1995; 2012).

***Communication.*** Communication deficits related to RHD tend to be subtle deficits rather than outright speech production errors or word retrieval deficits. These deficits include reduced comprehension and production of appropriate facial expression, body language, and prosody (Blake et al., 2013). In addition, a person with RHD may display reduced appreciation of shared knowledge, resulting in shallow responses. Aprosodia refers to difficulties with production and comprehension of prosody, such as understanding a question versus a statement (i.e., linguistic aprosodia), or understanding anger in someone's voice versus sadness (i.e., emotional aprosodia)



(Baum & Pell, 1999; Blake, 2007, Blake, 2016; Blake et al., 2013; Ross, 1993; Pell, 1998; Sidtis & VanLanker, 2003; Tompkins, 2012). A person with RHD may present with an affective disorder, which results in reduced ability to comprehend prosodic changes in another's voice and reduced ability to express emotional content conveyed through facial expression, discourse, body language, and gestures. Thus, a person with RHD may display a flat affect. Prosody and affect disorders can explain a person's tendency to seem unmotivated or apathetic or to appear less engaged with others and emotionally distant (Baum & Pell, 1999; Blake, 2016; Ross, 1993; Pell, 1998; Sidtis & VanLanker, 2003; Tompkins, 1995).

**Language deficits.** Language deficits associated with RHD include the ability to understand nonliteral language (e.g., metaphors, idioms, and sarcasm) and inferences, reduced discourse comprehension and production, and reduced capacity to process complex inferences and alternative and ambiguous meanings (McDonald, 2000; Tompkins, 2012). This may be explained by difficulties integrating contextual information and cues to alter their initial inferences. In addition, people with RHD may demonstrate disorganized speech, reduced specificity or excessive details, excessive speech output (i.e., verbosity), reduced speech output (i.e., paucity), or poor topic maintenance caused by deficits in discourse production (Tompkins et al., 2013). Pragmatics may also be affected, causing them to be egocentric, to have reduced understanding of turn taking, to display inappropriate eye contact (i.e., too much or too little), to focus on tangential or irrelevant details, to have impulsive responses, and to select inappropriate topics (Bartels-Tobin & Hinckley, 2005; Blake, 2016; McDonald, 2000; Tompkins, 2012; Tompkins et al., 2013).

**Motor speech deficits.** Although not typically considered part of RHD, motor speech deficits (e.g., dysarthria) may occur due to right hemisphere damage, which can result in

decreased speech intelligibility. Dysarthria can be characterized by slowed, breathy, incomplete pronunciations because of articulatory breakdowns. In contrast, others may display dysarthric characteristics of normal or rapid rate of speech and present with monotone speech or increased variation in their pitch. Regardless of the presentation of the characteristics of their dysarthria, intelligibility will be disrupted, affecting their efficiency and effectiveness during communication.

### **Effects on Daily Life**

Often people with RHD manage during superficial conversations, but they may appear to be disinterested, insensitive, or rude. Their deficits in attention, memory, and executive function may impede their ability to participate appropriately, maintain a conversation, and follow the conversation. Additionally, their prosodic and affect deficits may reduce their ability to produce extralinguistic aspects of conversation and may also reduce their ability to comprehend these aspects from conversational partners. People with RHD may have decreased insight into others because of their deficits in theory of mind which results in behaviors such as talking excessively or responding minimally (Balaban et al., 2016; Tompkins et al. 2013; Winner et al., 1998). Furthermore, people with RHD may have poor comprehension due to difficulty encoding and processing the conversations or written information (Blake et al., 2013). Interactions can be further complicated by their lack of insight into their deficits. These deficits impact their discourse ability, which can negatively affect their ability to hold meaningful conversations, have and maintain a job, and make connections with others. This may lead to people with RHD feeling isolated. They may also experience a loss of independence due to other impairments such as unilateral spatial neglect and their lack of awareness or understanding of their impairments.

Their communication deficits appear to be subtle but greatly impact their functioning in daily interactions. (Tompkins, 2012).

Due to the deficits people with RHD experience, social involvement may suffer. For example, participation in jobs or hobbies may decline if it requires attending for an extended amount of time. Visual perception deficits may also greatly impact their ability to participate in previous jobs or hobbies. Many people with right hemisphere damage who were employed at the time of their stroke may be laid off, fired, or forced to find new jobs due to deficits (Tompkins, 2012). Other challenges experienced include cognitive-perceptual challenges (e.g., short-term memory deficits, confusion), emotional difficulties (e.g., anxiety, frustration, and depressive symptoms), challenges in daily living (e.g., increased dependence on caregiver for daily activities), relationship challenges that result in strained interactions (i.e., parenting changes; role changes), and financial challenges (e.g., medical bills). The effects of RHD extend beyond changes in the life of the person with RHD; his or her family members and carers are also affected (Egbert, Koch, Coeling, & Ayers, 2006).

### **Carer Experience**

A carer refers to an unpaid spouse, partner, family member, parent, or child who acts as the primary caregiver. Carers encounter challenges associated with stress related to their family member's stroke, the unfamiliar territory of new information and interactions with medical professionals, the emotional impact and shock associated with this tragic event, and the transition into a carer role where new responsibilities arise (Holland & Fridriksson, 2001; Lubinski, 2001; Mach, Baylor, Pompon, & Yorkston, 2019).

The time following a family member's stroke can be very stressful and emotional for the person, their carer, and additional family members. The carer is now placed in a new position to

absorb information about the family member's health and current state during a vulnerable and emotional time (Holland & Fridriksson, 2001). Carers are expected to make sudden adjustments with very little to no preparation as to how their role is going to change. Furthermore, they are interacting with nurses, doctors, therapists, and other rehabilitation team members without necessarily knowing what types of questions to ask or what information they need to know to make informed decisions. They are exposed to an immense amount of unfamiliar vocabulary related to their family member's condition and recovery. Carers are balancing a new set of challenges, including physical, psychological, social, and economic consequences of communication impairments (Lubinski, 2001).

In combination with learning a vast amount of information, the family members experience many positive and negative emotions associated with their family members' stroke. Families manage emotions of joy and happiness related with their family member's survival while having to cope with this sudden, tragic event. Coupled with the gratefulness of their family member surviving, they may also be filled with emotions of fear, anxiety, frustration, grief, and depression learning of the consequences that follow the stroke (Holland & Fridriksson, 2001). According to a crisis model by Webster and Newhoff (1981) (as cited in Holland & Fridriksson, 2001, p. 21), family members' reactions to a crisis progress through four stages: shock, realization, retreat, and acknowledgement.

In the initial stage of shock, family members' comprehension of the incident may be disrupted, making it difficult to learn the information provided by health care professionals. Despite the impact on family member's comprehension, professionals should continue to provide information but repeat this information as needed (Holland & Nelson, 2013). The second stage, realization, occurs when the carer and family member begin to understand what has happened.

During this stage, carers start to retain information. Following realization, a stage of retreat can occur. Retreat can present itself in a variety of ways such as denying that there is a problem, denying that this problem may result in certain deficits, or denying the impact this event may have. The final stage is acknowledgement, which occurs when a carer and family member accept the reality of the condition and the changes that follow the incident (Holland & Nelson, 2013). People experience these stages differently. For example, some people will experience a certain stage for a longer amount of time or even become fixed in that stage while others may transition through all the stages relatively smoothly (Holland & Fridriksson, 2001).

Carers are not only coping with this sudden, tragic event, but they also are having to learn new information and manage an unfamiliar role as their family member transitions through different stages of recovery (Michallet, Le Dorze, & Tétreault, 2001). As stated in an article by Grant and Davis (1997), Stone, Cafferata, and Sangle (1987) found that on average carers spend four to seven hours each day performing caregiving responsibilities. With an increase in responsibilities on the carers, they have reported the demands to be overwhelming (Grant & Davis, 1997). Carers reported increased anxiety due to areas of problem solving, decision making, managing the care of their family member, a loss of knowing oneself, guilt, irritability, depression, and fatigue (Bakas et al., 2016; Grant & Davis, 1997).

In combination with the increase in responsibilities, families are faced with role changes within the relationship. Previous research on informal carers and aphasia has found that there are impacts on a carer's psychological well-being and emotional health because of the family member's impairments and level of dependence on their carer. These challenges influence nearly all aspects of a carer's life (i.e., social, vocational, emotional, physical) (Mach et al., 2019) because they now need to account for their family member's needs and safety. In addition to the

increased responsibility and role changes, carers are at risk to experience depression, stress, loneliness, and other health issues (Tooth, Mckenna, Barnett, Prescott, & Murphy, 2005). Carers also may experience increased responsibilities in household management, caring for their family, financially supporting their family, and in other caregiving duties following a family member's loss of employment (Mach, et al., 2019).

According to Grant and Davis (1996), when taking on these new roles and responsibilities, carers experiences four types of loss: familiar self, autonomous self, affiliative self, and knowing self. A loss of familiar self occurs because of having to assume responsibilities that their family member was responsible for previously. Autonomous self refers to feelings of fear related to leaving their family member for an extended amount of time that can result in a lack of personal time. A loss of affiliative self refers to the loss of changed relationships with family members and friends due to their new responsibilities. Carers may begin to feel alienated or embarrassed due to their family members deficits (e.g., inappropriate topic selection), causing them to withdraw from an adult with RHD (Tompkins, 2012). Last, the loss of knowing self is due to anxiety from coping with feelings of uncertainty and learning to deal with the physical, cognitive, and emotional changes subsequent to the stroke (Grant and Davis, 1996).

This information is known about carer experience following a family member's stroke, but it is unknown if this experience is true specifically for a carer of a family member with a right hemisphere stroke. As previously stated, right hemisphere damage differs greatly from damage to other areas of the brain; therefore, the information needs, the recovery, and the experience following a right hemisphere stroke may impact the carer experience.

**Phases of recovery.** Much like family members who experience different stages of coping, the family member who survived the stroke will progress through three stages of

recovery. Michallet et al. (2001) examined information needs for spouses of persons with severe aphasia following stroke. This study identified three major periods when information is needed for family members during the recovery process: the hospitalization phase, the rehabilitation phase, and the phase followed by the person with aphasia's return home. The results demonstrated some similarities and differences among the information needs within each stage. Throughout each phase, the need for more comprehensive information was noted. Other areas included the need for information on effective methods of communication with their family member and the need for improved social relationships with family members and friends. In addition, participants communicated the need to build a productive relationship with the healthcare professionals to increase their involvement during the caring process. Carers also reported the need for more support with formal support networks (i.e., health care professionals) and community networks, or informal networks (i.e., friends and family). Last, carers reported the need for relief both physically and psychologically (Michallet et al., 2001).

Throughout each phase, carers must adapt their role and responsibilities based on their family member's physical and cognitive deficits. Some responsibilities may include decision making and treatment involvement; coordinating appointments; assisting with motor abilities, transportation, and daily tasks (i.e., bathing, toileting, meal preparation, dressing); monitoring health, medications, financial or legal issues, and end-of-life matters; providing emotional support (i.e., encouragement); and supporting their family member's independence (i.e., goal setting) (Tooth et al., 2005).

### **Carer Education**

Informed carers are vital members of the rehabilitation team during the recovery process; therefore, accounting for the needs of the carer throughout the process is critical to rehabilitation

success (Denman, 1998). In addition, learning the carer's perception of impairments for their family member can aid in understanding the type of information needed for the carer and the delivery of this information to the carer (Avent et al., 2005). According to Denman (1998), the carers of people with aphasia have needs that include areas of support, information, role change, training, and respite care.

At the onset of aphasia, carers reported a significant need for general information about aphasia and its causes because they had had no previous knowledge of strokes or aphasia. Families also wanted to know realistic and prognostic information, other behaviors that they may observe as a result of a stroke, and other resources that will help the family cope with the aphasia (Avent et al., 2005). During treatment, families reported the need for more information about aphasia and the treatment process. Additionally, family members wanted more information to help increase the effectiveness of their communication with their family member with aphasia. Family members also reported the need for information about other behaviors or medical conditions (i.e., depression) that may arise. In the chronic stage, family members reported the need for community-based information (i.e., volunteer opportunities). Psychosocial support, counseling, and hopefulness were reported across all stages (Avent et al., 2005). There may be some similarities in the information needs for carers of a person with aphasia and carers of a person with RHD. However, information needs may differ between the disorders due to the differences of the nature of the deficits associated with aphasia (e.g., word finding) and those associated with RHD (i.e., cognitive-communicative deficits).

Currently, there is minimal research on information needs for carers of a family member with RHD. Furthermore, understanding the type of information that would be most beneficial for carers is difficult due to the variability in the symptoms of the disorder. RHD references an entire



hemisphere without providing any subcategorization (Blake, et al., 2002) to indicate the symptoms or characteristics people affected may display, the location of the damage, or a “type” of RHD. This proves to be difficult when relaying information needs to families because it involves a constellation of symptoms that may or may not be present. This also has impeded the development of evidence-based treatments, which affects the research related to instructional programs for caregivers (Blake, 2007). Furthering research to better understand the needs of carers from their personal experience can improve the supports and knowledge of the carer and their family member during stroke recovery.

Therefore, the purpose of this study is to explore the information needs for carers following a family member’s right hemisphere stroke throughout different periods of recovery.

## CHAPTER II

### **Methods**

#### **Research Question**

What do carers of people with RHD describe as their information needs at stroke onset, during initial rehabilitation, and during the chronic phase of recovery?

#### **Hypothesis**

The researcher (i.e., graduate student) hypothesized that although the communication deficits due to aphasia are different from the cognitive-communication deficits presented in a person with RHD, the carer information needs may be similar. For example, the researcher hypothesized that carers from both populations would report the need for information about stroke and realistic information about the prognosis based on previous findings (Avent et al., 2005; Bakas et al., 2016; Garrett & Cowdell, 2005; Kerr, Hilari, & Litosseliti, 2010). The researcher also hypothesized some additional information needs of carers of people with RHD based on previous research including the need for resources to help the family cope, continued information about RHD, compensatory strategies, information on medical conditions that may arise secondary to a stroke (i.e., depression), and formal support and community support networks.

#### **Qualitative Approach**

This study used a phenomenological approach to understand the lived experiences and perceptions of carers through interviews aimed at collecting experiential information during conversation (Hatch, 2002). The interviews provided the opinions and perceptions of the participants and allowed participants to reflect on their experiences in the natural environment of their home. This procedure presented the participants with the opportunity to express their

opinions and provided the interviewer with the opportunity to clarify and expand on the participants' responses. Personal reports from the participants' experiences offered unique insight into the information they felt is necessary to receive during the family member's recovery across various stages (i.e., at onset, initial rehabilitation, and chronic). Interviews were completed over the telephone to maximize the number and diversity of participants.

### **Participants**

The participants included four informal (i.e., unpaid) carers (3 females, 1 male) of a family member with suspected cognitive-communication deficits and RHD as a result of a right hemisphere stroke. Suspected cognitive-communication deficits and RHD are used to describe the participants because no formal or informal assessments were administered to the family members with right hemisphere stroke. Carers were between the ages of 59 and 70 years ( $M = 65.5$ ;  $SD = 4.03$ ). Two participants were spouses; one carer was a brother; one was a parent.

### **Inclusion Criteria**

All participants were the primary, informal carer for a person with cognitive-communication deficits following right hemisphere stroke. An informal carer was defined as an unpaid spouse, partner, family member, parent, or child who acts as the primary caregiver. As a primary caregiver, the participant had primary responsibility to care for their family member. Their role extended from helping with daily living activities to providing emotional support. The participants reported spending a minimum of 10 hours per week as the primary carer at each recovery stage (i.e., onset, initial rehabilitation, and chronic) (Grant & Davis, 1997). The carer participants were over the age of 18 years at the time of their family member's stroke and under the age of 85 years at the time of the study due to the increased risk of cognitive decline after the age of 85 years (Salthouse, 2010). The researcher inquired about available medical reports to

verify the location of the stroke but did not receive any of this documentation. In addition, the family members were over the age of 18 years at the time of their strokes and were at least one year post onset of a right hemisphere stroke.

### **Exclusion Criteria**

Participants were excluded if they had a history of a neurological disorder or if their previous or current occupation was in the healthcare field.

### **Materials**

The study materials included a telephone, an Olympus Digital Voice Recorder (WS-110), and a Cannon VIXIA HF R800 HD video camera. Additionally, an online survey via Qualtrics™ provided information about the inclusion and exclusion criteria to screen participants (Appendix A). If the participants fit the criteria, they continued to answer additional survey questions pertaining to their demographic information and information about their family member who survived a stroke (see questions in Appendix B). In addition to the survey, the study included the Burden of Stroke Scale (BOSS), a health status assessment, to provide information on the impact of the stroke on functioning and the psychological well-being of the family member (Doyle et al., 2004). It contained eight sections: mobility, self-care, communication, cognition, swallowing, social relationships, energy and sleep, positive and negative feelings. Each section contained questions with a Likert scale (e.g., never, rarely, sometimes, often, always).

The interview guide contained four sections: general information (i.e., deficits related to the stroke), onset information needs, initial rehabilitation/treatment information needs, and chronic information need. Across the four sections, there were a total of 28 guiding questions (Appendix C). The interview consisted of open-ended questions to increase the flexibility in the structure of the conversation (Edwards & Holland, 2013).

## **Procedures**

**Recruitment.** The researcher distributed a recruitment flyer with study information and her contact information to a variety of hospitals, in-patient and out-patient rehabilitation centers, practitioners, and support groups nationwide. Flyers were posted on relevant websites and discussion boards (e.g., American Speech-Language Hearing Association Special Interest Groups). Interested participants followed a link from the recruitment flyer to complete the initial online survey (i.e., screening survey).

**Consent, screening, and initial survey.** Using a link to an online survey via Qualtrics™ (www.qualtrics.com), the participants completed a consent form that offered further information on the study (i.e., purpose, procedures, the risks and benefits, compensation, confidentiality, and the rights of the participants). If they did not meet the criteria, the survey thanked them for their time, and the survey ended. At the survey's conclusion, the information within the survey was deleted. When the participant fit the criteria, he or she continued to answer demographic questions and questions about the family member's stroke (Appendix B) before answering the questions for the BOSS. Each survey asked for the participants contact information [i.e., name, email, number (optional)] to allow the researcher to match surveys and contact participants if there were technical issues. The researcher used this information to contact the participants to complete the interview portion of the research study. After collected, this information was de-identified.

**Interview.** Following the screening, the researcher contacted the participant through the information provided on the survey to set up date and time for the interview. The researcher conducted semi-structured interviews (Edwards & Holland, 2013) with the participants using a telephone. Conducting the semi-structured interviews (Edwards & Holland, 2013) over the

telephone allowed the researcher to expand the area of participant recruitment. Additionally, this format was most convenient for the participants, and this natural and comfortable setting proved to be beneficial for the participants when discussing the family member's stroke and their perspectives on the information needs at each stage of recovery. It allowed the researcher to ask follow-up questions to guide the discussion and encourage expansion on information within the specific areas of interest (Edwards & Holland, 2013).

**Optional medical records request.** Following the interview, the researcher inquired about the family member's interest in participating in the study to obtain medical records to verify the location of the stroke and cognitive deficits. In addition to confirming the location of the stroke and cognitive deficits, the researcher wanted to gain insight to the family member's perceptions of their impairments through the completion of the BOSS. If interested, the researcher provided the participants (either via email or via Qualtrics™ link) with a flyer for them to share with their family member who had a stroke. Participation of the family member who had the stroke was not required for the participant to complete the study. Despite some interest, no family members provided responses.

### **Data Collection**

The researcher recorded the interview using an audio recorder allowing the conversation to be reviewed, transcribed, and coded. The researcher and a trained research assistant (i.e., undergraduate student) orthographically transcribed the questions and responses and typed up the transcripts following the interview.

### **Analysis**

The quantitative data was based on the descriptive information provided by the participants about their family member. The mean and standard deviation were identified for the

length of time (i.e., days) each family member spent in the phases of recovery. The data reported on the BOSS was analyzed following the manual for scoring to obtain a physical limitation composite, cognitive limitations composite psychological distress composite, and total transformed score. Using these scores, the mean and standard deviation was computed for the composite scores.

The transcripts were reviewed by the research team in their entirety to identify emergent themes. Analysis by the research team allowed for comparison to improve reliability within the study and increase the extent and the depth of the analysis and findings. Using a grounded theory approach, the researcher (i.e., CD) and the trained research assistant (i.e., CS) analyzed the data to develop a set of codes based on the participants' responses (Bradley, Curry, & Devers, 2007). This approach is used to establish the main constructs and themes within the interviews. The two researchers compared the results to determine reoccurring themes across the interviewees' experiences. Throughout the comparison, the researchers evaluated different portions of the text to those that have already been placed within a code to confirm that it was consistent with the code previously identified (Bradley et al., 2007). The constant comparison method (Glaser & Strauss, 1967) allowed for the researchers to continuously verify the elements of the existing codes and identify new codes. This process promoted the development of codes that truly reflect the experiences of carers (Bradley et al., 2007). The codes continued to be developed until theoretical saturation occurred (Glaser & Strauss, 1967). At this point, no new codes were identified and the data within these finalized codes reflected the perspectives and experiences of the carers. After the codes were finalized, the two researchers reviewed the complete data while applying the finalized codes to ensure the codes were comprehensive and the data within corresponded to the selected code (Bradley et al., 2007).

## CHAPTER III

### Results

#### Descriptive Data and Demographic Information

Descriptive and demographic data about the participant and the participant's family member was collected through the online Qualtrics™ surveys. The four participants were Caucasian and completed high school. Participants 1 and 2 completed some college and participants 3 and 4 earned their bachelor's degree. Participants 1 (i.e., wife), 2 (i.e., mother), and 3 (i.e., wife) reported that they spend 15 or more hours per week completing caregiving activities and each described their role as a full-time caregiver. Participant 4 (i.e., brother) reported spending 6 to 10 hours per week completing caregiving activities for his brother. He described his role as visiting his brother's house, managing his aides, providing transportation (e.g., therapy, doctor appointments, shopping), and handling financial and legal responsibilities.

The participants completed descriptive information about their family member's stroke and the time spent in each phase of recovery (Table 2). The family members were between 3 years and 10 years 6 months post onset ( $M = 6.105$ ;  $SD = 8.50$ ). At onset, their family member spent between 8 days to 30 days ( $M = 15.75$ ;  $SD = 8.50$ ) in the hospital, 37 days to greater than a year ( $M > 92$ ;  $SD > 58.31$ ) in inpatient care, and all family members were currently living at their home. Participant 1's husband had a second stroke five days following the first stroke, and participant 3's son had a second stroke the day after his first stroke. Participant 2 and 4's family members had one stroke. All of the family members' strokes were thromboembolic.



Table 2

*Stroke Information*

<u>Participants</u>	<u>Number of strokes</u>	<u>Stroke type</u>	<u>Days in hospital</u>	<u>Time in inpatient care</u>	<u>Time in home</u>
P1	2	Thromboembolic	11	44 days	Ongoing
P2	1	Thromboembolic	30	> Year	Ongoing
P3	2	Thromboembolic	8	Acute: 17 days; Subacute: 20 days	Ongoing
P4	1	Thromboembolic	14	105 days	Ongoing

> Year = greater than a year

The participants provided descriptive information about the areas of deficits experienced by their family member (Table 3). All participants reported short-term memory and executive function impairments. Participants 1, 3, and 4 reported attention impairments and emotional aprosodia. Impairments in the expression and comprehension of facial expressions was reported by participants 1 and 3. Participants also reported receiving diagnoses accounting for other areas of impairments that may be experienced following a stroke. These diagnoses included aphasia, dysarthria, hemiplegia, visual disturbance, unilateral neglect, hearing loss, dysphagia, depression, and attentional impairment, which allows for a better understanding of their family member and the type of information needs they may report. Participant 1 reported her husband had received the following diagnosis of hemiplegia, visual disturbance, unilateral neglect, dysphagia, hearing loss, depression, memory impairment, attentional impairment, and displayed inappropriate emotional display such as uncontrollably laughing for no reason. Participant 2 stated her husband was diagnosed with hemiplegia, visual disturbance, and depression. Participant 3 reported her son was diagnosed with hemiplegia, visual disturbance, memory impairment, and attentional impairment. Participant 4 received the following diagnoses for his brother: aphasia, dysarthria,

hemiplegia, visual disturbance, unilateral neglect, dysphagia, depression, and attentional impairment.

Table 3

*Reported Diagnoses by Carer*

Area of Impairment	<i>P1</i>	<i>P2</i>	<i>P3</i>	<i>P4</i>
<i>Memory</i>				
Short-term Memory	√	√	√	√
Long-term Memory			√	
<i>Executive Functions</i>				
Initiation and Drive	√		√	√
Response Inhibition	√	√	√	√
Task Persistence	√		√	√
Organization	√			√
Generative Thinking	√			
Awareness	√	√	√	
<i>Attention</i>				
Sustained Attention	√		√	√
Selective Attention	√		√	√
Divided Attention	√		√	√
<i>Emotional Aprosodia</i>				
Comprehension	√		√	
Expression	√			√
<i>Facial expression</i>				
Comprehension	√		√	
Expression	√		√	
<i>Received Diagnosis</i>				
Aphasia				√
Dysarthria				√

Hemiplegia	√	√	√	√
Visual Disturbance	√	√	√	√
Unilateral Neglect	√			√
Dysphagia	√			√
Hearing Loss	√			
Depression	√	√		√
Memory Impairment	√		√	
Attentional Impairment	√		√	√
Other	Inappropriate emotional display such as uncontrollably laughing for no reason			

### Burden of Stroke Scale

Each participant completed the BOSS, providing their perceptions of how their family member’s stroke and resulting deficits (e.g., mobility, self-care, swallowing, energy and sleep, communication, cognition, social relations, and negative and positive emotions) impact their life (Table 4). Higher scores on this scale indicate greater perceived limitations (i.e., 100) within that domain, while lower scores indicate the desired health state with no perceived limitations (i.e., 0) (Doyle et al., 2004). The participants total transformed scores range from 21.48 to 48.83 out of 100 (M = 33.69; SD = 10.47). The physical limitation composite ranged from 9.62 to 63.46 out of 100 (M = 36.06; SD = 19.63) and the cognitive limitations composite ranged from 14.71 to 50.00 out of 100 (M = 27.95; SD = 13.40). The psychological distress composite ranged between 26.47 to 42.65 out of 100 (M = 35.66; SD = 6.61). Participants 1 and 4 rated the physical limitations highest, whereas participants 2 and 3 rated the psychological distress highest. Overall, participant 4 reported the greatest impact within each section on her family member’s

functioning. Participant 1 had the next highest score for the overall impact on her family member’s functioning. Participant 2 had the third highest score for the overall impact her son’s stroke has had. Participant 3 had the lowest values in each category except cognitive limitations composite.

Table 4

*Burden of Stroke Scale (Scores: 0-100)*

Participants	Total Transformed Score	Physical Limitation Composite	Cognitive Limitations Composite	Psychological Distress Composite
P1	37.50	42.31	26.47	41.18
P2	26.95	28.85	14.71	32.35
P3	21.48	9.62	20.59	26.47
P4	48.83	63.46	50.00	42.65

### Interview Data

The researcher collected qualitative data from one-on-one telephone interviews with each participant. Participants responded to questions within the interview describing information they felt was most valuable across the three phases of recovery—onset phase, initial rehabilitation phase, and chronic phase—in addition to general information about their family member’s impairments. Participants reflected on their experience and provided insight and suggestions for information needed at each stage. There were 168 identifiable statement units from the interviews related to each phase of recovery. At onset, there were 41 identifiable units. During the initial rehabilitation phase, there were 49 identifiable units and during the chronic phase, 78 statement units were identified. These information needs within each phase will be discussed separately.

**Onset phase.** Related to needs at onset, four themes emerged: (a) barriers to information, (b) right versus left brain function, (c) recovery timeline and recommendations, and (d) information about symptoms (Table 5).

**Barriers to information.** Barriers to information referenced anything that impeded the transfer of information from medical professional to the participants. Participants 1, 2, and 3 discussed emotional aspects that disrupted their comprehension of information due to a “*shock phase*” or an “*exhaustion phase*”. Another barrier was related to their unfamiliarity of medical terms and language. Participant 1 said, “*to give them [healthcare professionals] credit, they did tell me this stuff. And from my perspective, it’s [my lack of understanding was] because I have no understanding what they’re talking about.*” Participant 3 discussed how her son was studying occupational therapy, and he often interacted with the medical professionals because he could speak” and then “*dumb it down*” for his mother to understand. Additionally, another barrier to information discussed was the severity of their family member’s medical condition. For example, participant 2 reported that her son was not expected to survive which reduced the amount of information she was given about his cognition, communication, and swallowing deficits. Last, each participant described that they lacked the knowledge to ask more questions.

**Right versus left brain function.** Each participant reported a lack of previous knowledge about the different functions and impairments associated with the right and left hemisphere of the brain. Participants 3 and 4 described the usefulness of visuals to show the brain location affected and explain the function of that area. Participant 4 reported,

*Well, it was clear that the right brain obviously controlled the left side, which I knew, but they made it very clear that his attention to tasks and attention to, you know, those that we participate in activities. Speaking of rewards [his brother’s ability to take on a project and understand the benefit to completing a project] he had a hard time with that and that’s controlled by the right side, too, or the part of the brain that was severely damaged.*

***Recovery timeline and recommendations.*** The three of the four participants reported the need for information about the recovery timeline. For example, participant 2 wanted to know which skills her family member would regain right away and how long certain skills would take to relearn. Participant 3 referenced the need to know about recommendations and the timing of treatment, recovery time, and rehabilitation (i.e., inpatient, outpatient, home transfer). She said, “[I wanted to know] how his recovery would evolve and what they were recommending: OT [occupational therapy], PT [physical therapy], and speech [speech-language pathology]; and how to anticipate how long each of those things would take.” Additionally, participant 4 reflected on the helpful information provided from medical professional about his brother’s recovery.

***Information about symptoms.*** Three out of four participants reported the need for information about the roles of different medical professional providing services to the carer’s family member following the stroke. For example, some participants reported not knowing why their family member was being seen by a speech language pathologist and not initially understanding that swallowing is within their scope of practice. Participant 1 described her confusion stating, “You think, ‘oh, he speaks fine, he doesn’t need a speech therapist. He’s speaking fine.’”

Participants reflected on the need for information about their family member’s symptoms (e.g., swallowing impairments, visual impairments) to increase their understanding of their family member’s current deficits and resulting behaviors. For example, Participant 1 discussed how she constantly asked, “Why? Why? What’s going on? Why did he do this? Why did he do that?”

Participant 2 discussed the information she was provided regarding her son’s tracheostomy. She said, *“Well, I didn’t even know much about the trach except that I guess that was for his breathing. Maybe because he wasn’t swallowing properly or whatever.”*

Participant 4 shared the detailed information provided to him by the neurologist at the time his brother’s stroke. He reported, *“Well I thought it was very thorough, the neurologist from the stroke unit at the [hospital] was very thorough in his description.”*

Table 5

*Onset Phase*

Themes	Selected Participant Quotes
Barriers to Information (15)	P2 <ul style="list-style-type: none"> <li>– Truthfully, I think you’re in sort of a shock phase that this is happening because he was so healthy.</li> </ul>
Right Versus Left Brain Function (6)	P1 <ul style="list-style-type: none"> <li>– If I had known that there was that much of a difference between right side, left side strokes. I would have happily drilled everybody that I came in contact with and asked a bazillion million questions.</li> </ul> <p>P4  <ul style="list-style-type: none"> <li>– Well, it was clear that the right brain obviously controlled the left side, which I knew but they made it very clear that his attention to tasks and attention to, you know, those that we participate in activities. Speaking of rewards [his brother’s ability to take on a project and understand the benefit to completing a project] he had a hard time with that and that’s controlled by the right side, too, or the part of the brain that was severely damaged. They also showed me the extent, they showed me the visuals of the MRIs or whatever was done to show me the extent of the brain damage.</li> </ul> </p>
Recovery Timeline and Recommendations (6)	P4 <ul style="list-style-type: none"> <li>– So, you’re asking questions about, maybe [when] this [skill] will return around and when will I know this and what will I see two months out or three months out.</li> </ul>
Information About Symptoms (9)	P2 <ul style="list-style-type: none"> <li>– Well, I didn’t even know much about the trach except that I guess that was for his breathing. Maybe because he wasn’t swallowing properly or whatever. He just had to have it. I didn’t know. I just thought that was procedure, you know?</li> </ul> <p>P4</p>

- Well I thought it was very thorough, the neurologist from the stroke unit at the [hospital] was very thorough in his description. The first night I was kind of shocked that he was so thorough and said that, “Your brother had a massive stroke and he will never have use of his left arm. You’ll be lucky if he’s able to transfer from a bed to a wheel chair. He may be able to walk a little bit, but it would be with help.” He also described brain functions in terms of tasks saying he will have a very hard time taking on projects [task maintenance] or understanding the benefit of it or wanting to carry through a particular project [task maintenance]. And he also said that night my brother would be very short and very demanding and there would not be any restrictions of his talk [response inhibition] and there would be a lot of swearing and commenting on people [response inhibition], and no social decorum [reduced pragmatics] and so on. And then in terms of swallowing, they had a very good special therapist [speech language therapist] come down and describe [it].

**Initial rehabilitation phase.** During the initial rehabilitation phase, three areas of informational needs were reported: (a) detailed impairment information, (b) general and specific treatment information, and (c) specificity of timeline and recommendations (Table 6). During this phase, participants reported the necessity of getting specific information about their family member’s condition and the need to better understand RHD to provide support at the rehabilitation facility and during the transition home.

**Detailed impairment information.** Participants felt it was important to be informed of their family member’s impairments to increase understanding of their family member’s behaviors. Participant 1 reported having to ask many questions to understand the complexity of the deficits. Participant 1 reported, “*I would have loved to know how complicated it would be, so I could have asked what I can expect at home.*” She later reflected on the information she was given about her husband’s impairments, including the unilateral spatial neglect and his attitude. She continued to describe the information provided saying, “*They told me over and over again that this would be the speech therapist. I suppose that he would think he could accomplish way bigger and better stuff than he would be able to.*” In addition, as participant 3 described her husband’s cognitive impairments, she reflected on the complexity of RHD saying:



*—because the impairments are not something you can see. You know, when you have a broken arm you say, ‘oh, don’t go near that arm,’ but with anything that involves cognition, it’s very hard to know what’s going on in the brain no matter what comes out of the mouth.*

**General and specific treatment information.** Within general and specific treatment, four subthemes developed: (1) rationale for treatment, (2) rehabilitative progress, and (3) techniques and compensatory strategies.

*Rationale for treatment.* The participants reported a need to receive information about the rationale for treatment and treatment activities. Participants often expressed confusion about treatment activities. When discussing a family member’s swallowing treatment, participant 2 reported that the therapist “*did nothing except for come in and have him suck on a lollipop.*” Furthermore, participant 2 discussed dysphagia-related diet restrictions:

*People kept saying “oh he couldn’t have some yogurt” or whatever, so I would sneak some yogurt in there and try, and I know she was worried about it because she would say, “you can’t give them anything,” you know, “or they’ll choke.” But I was determined for him to get better.*

Some confusion about receiving speech language therapy, diet restrictions, or therapy activities (i.e., lollipop) may be a result of a lack of rationale provided by therapist to aid the carer’s understanding. Participant 3 responded, “*It just seemed so weird that he was getting speech therapy when he was speaking, but we didn’t know enough about what speech therapy did.*” It was important to the participants to understand various aspects of treatment, so they could gain a complete understanding of their family member’s treatment and methods to support their family member.

*Rehabilitative progress.* The participants were adamant about receiving information about their family member’s treatment progress. Participant 3 reflected on the information received when she or her children visited their family member. She stated, “*If one of us were*

*going, we tried to all alternate, they just were like you know, ‘We have inspected him today, and he’s all good,’ like no we want specifics and we weren’t getting that out of this facility.”*

Participants 2 and 3 reported leaving a notebook in the room for medical professionals to write notes about treatment because their family member was unable to communicate effectively.

*Techniques and compensatory strategies.* During treatment, the participants felt it was important to receive information about techniques and compensatory strategies to learn how to support their family member during non-treatment times or in the future at home. Participant 1 discussed compensatory strategies used by her family member while eating. *“So, he chewed and swallowed. The next thing he had to do was put his finger in his mouth and sweep his finger and make sure there was no food left over there on the left side.”* Participant 1 reported on her husband’s aprosodia and affective deficits and discussed that during conversation *“if I wanted him to know I was upset, I had to tell him”* because he could not comprehend her tone of voice or facial expression.

*Specificity of timeline and recommendations.* Finally, information about timeline and recommendations was important for the participants to receive so they could begin to plan for their family member’s treatment and future return home. Participant 3 reflected on the financial aspect of treatment reporting, *“How many days are you covered? How much is this going to cost out-of-pocket?”* Other participants reported having received some information about how their family member’s recovery. Participant 3 stated, *“They were very restrictive in their time frame information.”*

Table 6

*Initial Rehabilitation Phase*

Themes	Selected Participant Quotes
Detailed Impairment Information (11)	P1

	<ul style="list-style-type: none"> <li>- They gave me a lot of information on left neglect and that was important. They gave me a lot of information on his attitude, what he thought his abilities would be and what they actually were, and the number one thing that it just jumped out at me when we got home. They told me over and over again that this would be the speech therapist. I suppose that he would think he could accomplish way bigger and better stuff than he would be able to and no reasoning with him would convince he could not.</li> </ul> <p>P3</p> <ul style="list-style-type: none"> <li>- Even little things [impairments] that we didn't observe because they kept telling us he masks really good. To have a conversation with him, you wouldn't know that he has any cognitive issues, but if you're with him they become apparent. So, we were taught how to anticipate and help him through and not make him feel demeaned in any way, and that was really important to his recovery. We don't want to treat a sixty-something- year-old like a six-year-old.</li> </ul>
<p>General and Specific Treatment Information (27)</p>	<p>Rationale for Treatment (8)</p> <p>P2</p> <ul style="list-style-type: none"> <li>- [dysphagia treatment] I asked the speech person lots of things of why they do this? why they do that? but it was like talking to a wall, so it was like it didn't get anywhere.</li> </ul>
	<p>Rehabilitative Progress (7)</p> <p>P4</p> <ul style="list-style-type: none"> <li>- Well I think in the same way they had people that were more two-week or three-week summations of progress. They were monthly, but they did make people available if I had any questions. But they would have complete review sessions in which each of the therapists would participate in and nurse, there must have been five or six people and they'd sit around the table and my brother and I, and they would give us an overview of each situation: swallowing, talking, physical and they did that at each facility we participated in so the reviews were very good. And again, they made themselves available if I had any questions, but they were very good at knowing what it was they were attempting to do and what the progress was, and what they would be working on.</li> </ul>
	<p>Techniques and Compensatory Strategies (12)</p> <p>P1</p> <ul style="list-style-type: none"> <li>- In the acute rehab department their goal isn't just to keep your husband or person alive, just keep him alive, it doesn't matter what type of life he has just keep him alive, but in acute rehab it's like 'let's make things good for home.'</li> </ul>
<p>Specificity of Timeline and Recommendations (8)</p>	<p>P3</p> <ul style="list-style-type: none"> <li>- Another important component of this whole thing, I don't know if your study covers this, is the financial stuff that we weren't prepared to know. How many days are you covered? How much is this going to cost out-of-pocket? And all those things that became like a huge picture in it.</li> </ul>

P3

- We pretty much got the same answers from anyone we asked. We got ‘well there’s a curve and you can expect this much at a week, two weeks, a month, six months,’ as if it was just like it would never deviate from that amount but in the moment, we sort of just shrugged and said, ‘oh alright’. It’s been two weeks and now he can hold a glass, ‘oh that’s good they said he would be two weeks.’ But did we miss something? And if it was 15 days does that mean he’s never going to get things back because he didn’t do it at 14; they were very restrictive in their time frame information.

P4

- Well the same as before [what he wanted to know in the onset phase], it’s to review the stages as to which he is at [the rehabilitative progress his brother had made] and what to expect down the line and what the results of therapy have produced up to this point.

**Chronic phase.** Following the initial rehabilitation phase, all the participants reported additional information needs as their family member transitioned from the rehabilitation phase to home. The participants described five specific informational needs: (a) information on supports for carers and patients, (b) impairment specific information, (c) treatment and treatment options, (d) compensatory strategies and home practice, and (e) hope (Table 7).

***Information on supports for carers and patients.*** Reflecting on this phase, all of the participants reported numerous times the helpfulness of support groups and connecting with other families affected by stroke to learn about the variety of opportunities and experiences. In discussing the most important information to receive as a new carer, each participant responded with joining a support group and the importance of having that support network when going through this experience. Participant 3 responded, “*Actually support, having a support system in place because you can’t do it all even though you feel like you kind of should. And because it’s a 24/7 thing, that it’s okay to not get it all done.*” Participant 2 stated, “*Probably the most helpful thing was when I ran into other stroke people.*”

***Impairment Specific Information.*** Throughout the interview, all of the participants provided information about their family member's impairments due to their stroke. When discussing their family member's impairments, participants 1 and 3 referenced experiencing a new normal with their family member. Receiving information on their family member's impairments may have helped them to better understand the changes that may occur secondary to a 'new' normal. Participant 1 reported:

*When my husband's stroke first happened, and then he survived. I thought he was the same as he was before the stroke, personality and everything. And, what I realized was that he wasn't. And so, I had to learn who this new person was, and it would have been easier if I was not expecting him to be exactly the same personality as he was before. ... but it's almost like, who is this guy?*

Participant 3 reflected on the idea of this 'new normal' saying, *"But nowhere along the line did anybody explain what it meant long-term."*

Learning about their family member's impairments would provide helpful information about their abilities and the support they may require. Participant 1 said, *"But is he going to need help? Should you let him cook his own food? You know, that kind of thing."*

Participant 2 discussed her family member's lack of inhibition during conversations, *"Well, filtering is very difficult because you don't even know what's going to come out of the mouth sometimes."* In addition, participant 3 discussed her family member's decreased understanding of his impairments, *"he is totally convinced that he's at 125% of his game. Where in actuality today he's around 65-70% of cognitive abilities."* Left neglect was reported about as well by participant 1 who said, *"The brain doesn't know that it [the left side] does [exist]. So, it's the same as if that left side doesn't exist."*

When thinking about information provided for the chronic phase, the three of the four participants reported that some information was relayed to them before their family member came home. They felt this information was very helpful in preparing them for some of their family member's impairments and support needs. Despite the information provided, they also reflected on the information they continued to learn after their family member's return home. Their understanding of their family member's impairments. (e.g., severity and type) and support needs improved over time with trial and error strategies.

***Treatment and Treatment Options.*** During the chronic phase, all of the participants reported continued treatment for their family member. Some people were still in speech therapy whereas others ceased when they met their goals. Participant 1 discussed her experience when her husband transitioned home:

*He still needed some speech therapy, not how to speak and eat, but how to understand the world and what the heck is going on, how to be able to read a news story and understand the plot or the meaning, that kind of thing.*

Three of the four participants reported some uncertainty if their family members should continue with certain therapies. Each discussed a time when their goals were met, and they were discharged. Following treatment, each of the participants reported searching for opportunities and finding treatment options for their family member to address continued deficits. Guidance from medical professionals through increased information about treatment options and treatment recommendations was thought to have been helpful to assist the participants as they navigate this phase of recovery.

Additionally, other participants wanted to know supplementary treatment options such as vision therapy (participant 1). The participants also mentioned finding other types of therapy (e.g., music therapy, water therapy) for family members with RHD, but wished they had had

more guidance in this process. Participant 4 mentioned a friend's suggestion to get his brother involved in a program at a nearby university for speech therapy and other opportunities. He also found the music therapy through this program but transitioned from music therapy to a poetry course. Participant 4 mentioned the usefulness of having this recommendation to continue treatment and finding new opportunities for his brother.

***Compensatory Strategies and Home Practice.*** In addition to understanding treatment, the participants felt it was important to learn compensatory strategies or have home practice to continue to work with their family members. Participant 1 stated, *“So, yes, the ability to have information so I wouldn't have to do trial and error would have been great.”* She further mentioned some strategies she used with her family member to keep him feeling independent. She stated, *“And these are things that he usually doesn't know that I've done. He just has he doesn't—when we fix dinner, I'll do his plate and put all his silverware on the right side.”*

The participants stated that they wished they had received more tasks to do at home. Participant 2 responded, *“Probably if they would give me more ideas, you know what I'm saying? Like if they would have said about reading [recall tasks]. I don't know, we played cards. I just—like I said, [we play] Scrabble now.”* Participant 3 felt similarly wishing for more activity ideas to do with her husband stating, *“Yea, probably about the problem solving; maybe they could have helped me with better strategies to help him.”* Participant 3 further reflected on the idea of receiving more guidance with tasks and strategies saying, *“It would have been wonderful, and I get it, they don't have any more of a path into his brain than I do, but because they see it more frequently, maybe a little more guidance would have been good.”*

*Hope.* The importance of providing hope to the participants was evident throughout each interview. Many reflected on the idea that their family member continues to get better, even if it is small improvements after many years since their stroke. Participant 1 said,

*One thing I was told was a year and two years after he was [unintelligible] he'd be where he was going to be. And there'd be no more rehabilitation and that's wrong. That's wrong, that's totally, totally wrong. He is, every day in cognition and attitude and, acceptance and ability to deal with things is getting better and better and better every day. It gets better.*

Table 7

*Chronic Phase*

Themes	Selected Participant Quotes
Information on Supports for Carers and Patient (12)	<p>P2</p> <ul style="list-style-type: none"> <li>- Join a support group. Join a stroke—there is one at Mercy so if you're in Pittsburgh hospital they do have support groups there. It took me a while to find the support group. So, join a support group. I guess so that you can see—I mean no two strokes are the same but, cause, you know, someone could be left side affected or right side affected, you know, like [son]'s arm is bent – some have flaccid arms. But like, just learning things all through the years of seeing it happen or dealing with people. So read up, and I would say sometimes they think when you ask a lot of questions, they're not so thrilled with it, but I'd say ask a lot of questions, if you can.</li> </ul>
Impairment Specific Information (23)	<p>P1</p> <ul style="list-style-type: none"> <li>- When my husband's stroke first happened, and then he survived. I thought he was the same as he was before the stroke, personality and everything. And, what I realized was that he wasn't. And so, I had to learn who this new person was, and it would have been easier if I was not expecting him to be exactly the same personality as he was before. I mean all the things that they told me, 'Oh, he's going to be irritated' and all these things are going to happen and they're going to frustrate him, and he's going to think he can do things that he can't do, all of that's true, but it's almost like, who is this guy? I remember thinking that a lot, and that is something, it's not bad, he wasn't bad, he wasn't a bad guy. It's just that he, he was different, and we were married for 28 years before the stroke, so you're used to a person being a certain way, and then you go home and they're not. It was all part of trial and error; how do I act? how do I do this? how do I convince him? how do we communicate?</li> </ul> <p>P1</p> <ul style="list-style-type: none"> <li>- But is he going to need help? Should you let him cook his own food? You know, that kind of thing. Will he be able to get a job? How difficult will it be for him to learn a new task and is he going to</li> </ul>



understand a public situation? You know, somebody yells, “Fire!”, is he going to know what that means. If somebody is going to rob a store where he’s at, does he know he should be afraid? you know, that kind of thing or are you going to need to say, “that guy has a gun so don’t make him mad.”

P1

- The brain doesn’t know that it [the left side] does [exist]. So, it’s the same as if that left side doesn’t exist. So that makes driving completely—if you don’t know something can come from the left when you’re driving, then you don’t know to look, and that means he will never be able to drive. It’s a—he still—we still have to pay attention to, because you know he does his own shaving and stuff, so we have to pay attention to make sure he actually got everything off the left side, you know, all the whiskers and everything. Sometimes, a lot of times, there’s food left on the outside of the left side of his mouth that he doesn’t even know is there.

P2

- Well, filtering is very difficult because you don’t even know what’s going to come out of the mouth sometimes.

P3

- He doesn’t sit in a chair and say poor me, but his decision making is really dreadful. So, we’ve had situations where he decided to make breakfast and instead of a bowl of cereal, he decided that he would make himself an egg. So, he turned our gas stove on, and it didn’t ignite so he went to the next burner and left the first one opened, instead of closing it and tried a second burner. Well the second one didn’t work and neither did the third, fourth, or fifth. I was out of the room approximately a minute and I could smell the gas, so we were able to take care of it, but he puts himself at risk because he thinks he can do these things and doesn’t have the mental support to continue with them. So that’s just one example. He doesn’t remember to turn water off, so things overflow and its little things like that. He’s very impulsive and compulsive. It’s like a singular thought and if he doesn’t accomplish that thought immediately, it just stays with him until it happens; even if its two days later, I know it’s gnawing at him until he does it. We were painting a door, it was all taped and we put on the prime coat and like an hour later he pulled all the tape off, because it has to come off, but we hadn’t done the other two coats of paint. It’s just little things that could create bigger problems, but then again, he doesn’t shy away from a task, he knows it needs to be painted.

P3

- But nowhere along the line did anybody explain what it meant long-term; like oh and then he’ll come home in three months and then you have your ‘new normal.’ Well, that was a little broad and there were so many things impacting that we weren’t prepared for financially and logistically and programs that were out there that could have been more help to us initially.

	<p>P4</p> <ul style="list-style-type: none"> <li>- [referring to his brother's response inhibition] he's very direct, very demanding, but does have some understanding that "I shouldn't be that way," and will apologize. I did ask questions about that and how to deal with it. I mean as a caregiver, I'm going to be doing this for who knows what length of time, you have to make sure that you're not being an enemy, you have to be a friend. It's important to understand how to deal with it, so that you don't have constant conflict.</li> </ul>
<p>Treatment and Treatment Options (13)</p>	<p>P1</p> <ul style="list-style-type: none"> <li>- So, they stopped the speech therapy right away. Once he got to the point where he could swallow, and he knew to clean his face and not leave food in his mouth on the left side, because he never really lost his ability to speak. They didn't spend much time on his cognitive stuff, you know. There wasn't any exercises we could do. I wasn't told to show him pictures of people's expressions or anything like that.</li> </ul> <p>P1</p> <ul style="list-style-type: none"> <li>- And like I said, once we got out and they had the therapist come to the house, that speech therapist, she came maybe two times and said "oh, he's doing fine," and she left. He still needed some speech therapy, not how to speak and eat, but how to understand the world and what the heck is going on, how to be able to read a news story and understand the plot or the meaning, that kind of thing. He's since learned, and we've worked on, but the speech therapy ended, I think, sooner than it should have, since it involved all this other stuff, not just talking.</li> </ul> <p>P3</p> <ul style="list-style-type: none"> <li>- It was very paper-wise generic, like what he should continue, and he should go see his doctor and get scripts from the doctors. And then he went to the new speech clinic and they were able to go back to the other facilitators and they were able to get the information of where he was so they could do testing.</li> </ul>
<p>Compensatory Strategies and Home Practice (16)</p>	<p>P1</p> <ul style="list-style-type: none"> <li>- Sometimes I do things and he doesn't even know that I've done them. I'll put his clothes in a certain place where I know he will see them. I will clean out his pockets and rearrange things so that they're more convenient for him. I'll take things that might have been in his left pocket that he will never find once he's put it there and I'll put it in his right pocket. And these are things that he usually doesn't know that I've done. He just has he doesn't—when we fix dinner, I'll do his plate and put all his silverware on the right side.</li> </ul> <p>P2</p> <ul style="list-style-type: none"> <li>- Well, I think what was helpful was when they were trying to read him something or he would read it, now mind you I still did not know a whole lot about his peripheral vision so I'm not sure how good he was reading but he did – that's one thing they did do, they took a sheet of</li> </ul>

paper and they drew a long down the one side likes a yellow marker because he would not focus clear – he would not turn his head all the way to the end of the sentence. You know what I’m saying? So, they did do that and gave me the papers for him to practice reading and then just to put a big bright yellow, it was like a book mark, big bright yellow thing down to the side so he knew he had to go clear to the edge to read it, so they did do that. That helped. Because before in church and he is reading—I like, I don’t have that – I should think of taking that, but instead I run my finger clear over there so that he sees that he is missing that left side, you know, turning his head all the way. That’s the problem. He just wants it to be straight ahead and it’s not always there—you need to move your head left to right to read.

Hope (6)

P1

- One thing I was told was a year and two years after he was [unintelligible] he’d be where he was going to be. And there’d be no more rehabilitation and that’s wrong. That’s wrong, that’s totally, totally wrong. He is, every day in cognition and attitude and, acceptance and ability to deal with things is getting better and better and better every day. It gets better.

P3

- [medical professional] would say ‘after 18 months he’s not going to make much progress,’ but that hasn’t really been true; he’s made a lot of progress and I don’t feel we were given much hope, I guess of a better recovery.

## CHAPTER IV

### **Discussion**

The purpose of this study was to examine the perceived information needs of carers following a family member's right hemisphere stroke across three different points of recovery: onset phase, initial rehabilitation phase, and during the chronic phase. These needs shifted and increased in the specificity of information needed as family members transitioned through these phases. There was a need for better understanding of their family member's impairments and how to support their family member as time post stroke increased.

At the onset of their family member's stroke, carers reported the need for general information such as the difference between right and left brain functions, timeline and recommendations, and medical professionals' roles. They reported some barriers to understanding information such as emotional aspects (i.e., shock, exhaustion), a lack of knowledge about the medical terms, and the severity of their family member's condition impacting the amount and type of information shared (i.e., survival versus deficits associated with the damage). During the initial rehabilitation phase, participants reported the need for general and specific information such as progress, treatment strategies, and rationale of treatment and activities. Similar to the onset phase, there was a need for information about impairments, timeline, and recommendations. After their family member had transferred home, the participants reported the continued need for specific impairment information, general and specific treatment information, and information about compensatory strategies and home practice. Other themes that were presented in the chronic phase were the need for information about supports and the need to provide hope when delivering this information. As their family member made improvements and transitioned through the recovery phases, the information

desired changed based on the circumstances of each phase and the needs of their family member at that time.

### **Differences Across Phases**

**Important symptom information.** The major difference evident across the phases was the amount and the specificity of the symptom information desired by carers. The amount of information and the content of the information differed across the phases and were likely due to the readiness of the carers to receive information. Similar issues related to readiness and timing of information sharing were reported caregivers in a study by Bakas and colleagues (2016). At the onset of the stroke, Avent et al. (2005) discussed the need for generic information about aphasia and its causes due to family members who reported a lack of knowledge about strokes and aphasia. During treatment and at the chronic phase, the families continued to need information about aphasia.

During the onset phase in this study, when the participant's family member was in a medically fragile state, the extent of symptomatic information needed focused more on understanding the location of the stroke, the cause of the stroke, and the surgeries to follow (i.e., craniotomy, craniectomy, and tracheostomy). A similar finding was discussed by Cameron, Nagile, Silver, and Gignac (2013), which found less information was needed initially (i.e., acute care) as compared to the vast amount of information needed during the initial rehabilitation. Additionally, the content of the information needs was similar to previous studies that identified a need for general information about stroke and the cause of the stroke because of the carers lack of previous knowledge (Avent et al., 2005; Garrett & Cowdell, 2005; Kerr et al., 2010). Although, studies reported similar findings in the need for general information about the stroke and the cause of the stroke, this study differed in the need to understand the location of the stroke

and the difference between right hemisphere and the left hemisphere of the brain. Due to the suddenness of the stroke, at the onset participants wanted to know about the immediate care and the actions taken to keep their family member alive. Because family members were undergoing surgeries to manage brain swelling, breathing, or swallowing impairments related to the stroke, there was more value placed on information about symptoms associated with the surgeries rather than the very detailed and specific information about those associated with cognitive-communication deficits. Furthermore, Avent et al. (2005) discussed the emotional impact reported by the participants throughout this phase. Similarly, Garrett and Cowdell (2005) stated similar reports from their participants that also limited the amount of symptom information they could manage (Avent et al., 2005). Given the suddenness of this event, the emotional impact, and the uncertainty of their family member's condition, the information needs at the onset focused on general information about the stroke and relevant information about their family member's current condition (e.g., surgeries, general symptoms)

The information desired in the initial rehabilitation phase shifted as participants observed symptoms and behaviors associated with RHD (e.g., reduced problem-solving skills). This generated more questions about their family member's condition, as they wanted to know detailed information to begin to understand the impairments. Similarly, in reported information needs for aphasia, there was a need for continued information about impairments (i.e., aphasia) and coexisting behaviors during the rehabilitation phase (Avent et al., 2005). Despite these similarities of the specific impairment information needs reported by carers of a person with aphasia and the participants within this current study, the content of the impairment information reported differed greatly due to the inherent differences in aphasia and RHD. As the participants had the opportunity to interact more with their family member, their impairments and the impact

of the impairments were more noticeable. With the complexity of RHD, understanding the impairments their family member displayed became very clear during this phase of recovery as the participants began to prepare for the chronic phase when medical professionals would no longer be as easily accessible to answer impairment related questions.

In the chronic phase, marked by the transition home, the amount of impairment information reported doubled from the amount reported in the initial rehabilitation phase. Despite continuing to receive outpatient treatment, there was no longer immediate access to medical professionals; therefore, similar to other studies that participants reported the continued need for aphasia-based information (Avent et al., 2005), participants in the current study seemed to place a great need for receiving detailed impairment information related to RHD because they were now fully responsible for their family member's safety at home. In addition, understanding the impact their family member's deficits would have on their everyday lives was important. One study reported that the information needed at home depended upon the physical, cognitive, and/or communication difficulties (Cameron et al., 2013). Some of the participants quit their jobs to attend to the needs of the family member while another brought in outside help to support his brother's impairments. Egbert and colleagues (2006) found that following the stroke, both the carer and the family member's encountered employment challenges due to impairments secondary to their family member's stroke. The impairment information needed focused on the cognitive-communication deficits and unilateral neglect that are associated with RHD differing from previous studies in the needs reported for aphasia-based information (Avent et al., 2005). The participants felt more information about their family member's impairments would have improved their interactions with each other and may have alleviated the continuous trial and error pattern as they struggled to learn how to interact and support their family member's needs.

Coupled with this learning process, carers were faced with many new challenges as a result of their family member's impairments; therefore, understanding the deficits associated with RHD helps to improve the carers knowledge of the supports needed to allow their family member to function as independently as possible and maintain the highest quality of life.

**Barriers to information.** The participants reported little to no previous experience with strokes or RHD. In addition, none of the participants worked within the medical field; thus, they had no previous experience or exposure to their current role as a carer. This created some barriers during the transfer of information from medical professionals to the carers. Unfamiliarity in the situation coupled with the emotional impact, the medical terminology, and uncertainty in the types of questions to ask all negatively impacted this transfer of information.

At the onset of the stroke, the participants reported a "shock phase" or an "exhaustion phase" when they were unable to process and recall some of the information provided. They also reported that they simply were not ready to receive a vast amount of specific information. The timing of information received and the difficulty understanding medical information is a common phenomenon described in other studies examining caregivers' experience, Holland and Fridriksson (2001) discussed the emotional impact a family member's stroke has on both the carer and the family member which disrupts the carers ability to process and retain the information immediately following the stroke. The emotional impact was referenced in this current study as participants mentioned the shock and exhaustion felt in those initial days that hindered their ability to process the information provided. In another study, both the patients and the carers interviewed reported a disruption in the transfer of information due to their emotional state. This impeded their comprehension and ability to remember the presented information (Garrett & Cowdell, 2005). Given the emotional state, it is important to understand appropriate



timing and delivery of the message based on the readiness of a carer to receive this information. Providing multiple exposures to the information can enhance a carer's understanding. Similar to participant reports in this study, previous research discussed participant statements that drawings, pictures, and scans helped them to understand the information provided by medical professionals (Garret & Cowdell, 2005).

These findings are supported by the 'Timing it Right' framework. This framework describes that carers informational needs changes over time (Cameron et al., 2013; Cameron et al., 2014). Their findings suggest that the program is helpful for those with limited experience with strokes, difficulty obtaining information, and trouble understanding the health care system (Cameron et al., 2013).

Additionally, the participants limited exposure to medical terms prior to their family member's stroke negatively affected their understanding of the information presented to them. Söderström, Saveman, and Benzein (2006) discussed a "mutual misunderstanding" (p. 710) observed between family members and medical professionals that impeded the family member's understanding of medical and technical terms about illnesses and the equipment. This lack of understanding can result in carers not asking questions and therefore receiving even less information. Similar to a study on carers of an individual with aphasia, there was a lack of knowledge as to what questions to ask about their family member's current condition and future condition (Avent et al., 2005). Not understanding what questions to ask disrupts the transfer of information from the medical professionals to the family members. Medical professionals need to assist in answering questions of carers before they are aware they need to ask these questions (Avent et al., 2005). Last, the severity of their family member's condition also restricted the amount of information provided if the medical professionals were uncertain about their survival.

Rather than providing information about the right hemisphere and the impairments associated, the information provided focused on the steps that were taken to keep their family member alive (e.g., surgery).

One participant reported an experience that did not fit into the experiences described by other participants. Specifically, participant 3 described the struggles her family faced in receiving information related to two specific barriers. She described that the amount of people the facility was providing services to and the distance the facility was from her home as inhibiting her ability to gain the knowledge she would have liked during the initial rehabilitation phase. She stated,

*To do it over again, we would have kept him local, and not in the greatest facility, but [a facility that] kept on top of it where they had 11 people on the floor instead of 1,100 like in the hospital, where they [medical professionals] were all caring for him.*

### **Similarities Across Phases**

The need for information about compensatory strategies was reported in the initial rehabilitation phase and the chronic phase. With the deficits associated with RHD, participants desired strategies to improve their interactions with their family member and to increase the safety and independence of their family member. Participants discussed a need to learn how to compensate for their family member's problem-solving skills, left neglect, the lack of awareness of deficits, and poor response inhibition. A need for compensatory strategies was also reported by carers of people with aphasia; however, these strategies focused on improving communicative interactions due to the deficits associated with aphasia (Avent et al., 2005). In the current study, the participants reported learning how to compensate for these cognitive-communication impairments through trial and error but to increase safety and independence of their family member, it would be important to learn about these from medical professionals earlier during rehabilitation.

### **Emotional and Psychosocial Support**

Throughout recovery, there is a need for emotional and psychosocial support for carers and their family member. Providing emotional support and psychosocial support helps families connect with other people who are experiencing or have experienced similar situations. In addition, it helps family members cope with the loss they may be experiencing or the obstacles they are encountering. Providing support and hope can help families to know they are not alone (Avent et al., 2005; Michallet et al., 2001).

The need for information about community-based support groups for both the carer and the family member was apparent based on reports from each of the participants. The participants expressed how valuable it was to connect with people who had been through something similar. This model of caregiver training as described by Off and colleagues (2019), used a cohort model for caregiver training and education during aphasia rehabilitation. The researchers described via a case study, how a family caregiver counseling group provided an opportunity for an experienced carer to share various experiences she and her husband encountered during his recovery (e.g., a successful dinner outing without a wheelchair or communication improvements). Similar reports were found in other studies as participants discussed the usefulness of connecting with a group or others who have experienced similar situations (Avent et al., 2005; Garrett & Cowdell, 2005). Support groups provided a platform for carers to learn about available research studies, community volunteer opportunities, supports for home (e.g., equipment), helpful resources (e.g., books, magazines), and emotional support through the connections made with other's experiences.

Participants often discussed the helpfulness in connecting with other carers at support groups or in the community who were going through similar experiences. A study on the care of

a person with dementia or other chronic illness reported a similar finding with their participants. Connecting with others allowed carers to problem solve together and offer solutions based on previous experiences while also providing emotional support for each other throughout their journey (Bourgeois, 2019). Another article discussed the helpfulness of a support group for both the carer and their family member as it proved to be a place of encouragement and a place of connectiveness (Egbert et al., 2006). There was a need for emotional support by connecting to others who were facing a similar experience, which relates to a finding by Michallet et al. (2001) that discussed the need for emotional and practical support for spouses of an individual with aphasia.

In addition to the need for information about support groups, there was a need for hopefulness provided by medical professionals for both their family member and the carers. Carers reported various information needs at the different phases of recovery, but they wanted this information to be delivered in a way that still provides hope. Hope is an incredibly important facet during recovery. Hope is needed to keep both the carer and their family member positive and motivated to continue to work during this recovery process. The carers in the current study reported that there was a lack of hope given about their family member's future improvements after a certain time period post stroke. Many disputed this and stated that their family member continued to make improvements, noting that even if these were small gains, they were still improvements. Similarly, Avent and colleagues (2005) found the need for positive expectations about the future or hopefulness for family needs for aphasia across all points of recovery. Participants within this study stressed their need to stay hopeful rather than having medical professionals provide information that takes this hope away by only providing negative information. It is necessary to provide realistic information, but there is a need to deliver this

information in a manner that provides hope to keep these carers and their family member motivated (Avent et al., 2005).

### **Differences in Information Needs for RHD and Aphasia**

Despite many similarities between the reported information needs about aphasia and the needs about RHD, the most apparent differences are those related to the nature of each disorder and the distinct challenges associated with each. These differences arose in the types of impairment specific information, the compensatory strategies, and treatment activities provided. The outright communication deficits associated with aphasia of communication differ greatly to the deficits related to RHD. Impairments observed in a person with RHD are not obvious communication deficits but instead have this underlying cognitive component (i.e., attention, memory, executive function) that results in communication impairments, such as their inability to make inferences during conversation or understand the prosody in someone's voice. Individuals with RHD can superficially function in conversation, whereas people with aphasia show a variety of communication breakdowns across communication modalities because of the damage to the communication centers in the left hemisphere. These differences change the treatment techniques (i.e., compensatory strategies), treatment goals, and the impairment specific information sought by carers. Avent and colleagues (2005) reported the participants' need for communication skill training such as how to maximize communicative effectiveness or how to facilitate interactions. In contrast, the needs reported by carers of an individual with RHD focused on compensatory strategies for cognitive skills such as problem-solving abilities, left neglect, short-term memory, working memory, affect, prosody, and anosognosia.

### **Clinical Implications**

These findings are clinically relevant to medical professionals to increase their understanding of the type of information carers want and the specificity of this information based on the time post onset. Impairment information needs appeared to shift based on the challenges encountered, the capabilities of the family member, and the factors associated within each phase (e.g., surgeries/survival, treatment/improvements, daily needs/life at home).

Additionally, when providing information, it is important for medical professionals to consider not only the type of information desired by carers, but also the manner in which they deliver the information to families to enhance their understanding. It is important to simplify the information into understandable terms and to provide multiple exposures to the information (i.e., repetition, visuals). Clinicians can create this type of information in written pamphlets and also discuss it with carers (Garret & Cowdell, 2005). To support a carer's comprehension, clinicians should work to identify the stage of processing (i.e., shock, realization, retreat, and acknowledgement) to determine when to provide information and how to communicate that information.

Furthermore, by understanding the type of information warranted by carers can assist in their ability to ask relevant questions. This lack of knowing what questions to ask was similar to a finding by Avent et al. (2005), thus the need for medical professionals to guide these questions for families is apparent in both carers of an individual with aphasia and those with a person with RHD.

Avent et al. (2005), also identified the reported need to deliver the desired information in a way to provide hope. This finding relates to the reported needs by current study participants during the chronic phase of recovery. Providing realistic, but hopeful information is extremely important for the carer and their family member to hear during the chronic phase. A clinician can

provide hope by recognizing that a person with RHD will continue to make improvements throughout recovery while acknowledging that these improvements may not be as drastic as the gains made in those initial months following the stroke.

### **Limitations and Future Research**

Although the participants provided valuable information to inform clinical practice, the sample size in the current study limits the application of the findings. Data only included perceptions and experiences of information needs from four participants. It is possible that differences would arise based on the experiences of other carers depending on the severity of their family member's stroke, their family member's post-stroke deficits, and the relationship to the family member (e.g., spouse versus parent). This study only accounted for information from a spouse (i.e., two wives), a sibling (i.e., brother), and a parent (i.e., mom). Both the limited sample size and lack of variability within the relationship to the family member with a stroke, results in reduced generalizability of the information. Another limitation was the lack of information about the person's specific impairments. The research team tried to account for this limitation by including the family member with a stroke to gain medical record information, but this was not a requirement for carer participation, and therefore, this information was not obtained.

Finally, due to personal experience of the researcher (CD) having a family member with RHD, there was potential for a possible bias in the data analysis. The researcher tried to control the bias by having another judge analyze the data separately to allow for a constant comparison method.

Future research is needed to develop these findings further to be used both in research and clinical settings to help improve the transfer of information to carers after a family member's

right hemisphere stroke. The lack of information within this area warrants further investigation to help improve carers understanding of what questions to ask, how to gain information, the deficits experienced by their family member, and various community support needs. With continued research, designing question guides to help support carers so they know what types of questions to ask and when to ask these questions would help improve the transfer of and access to relevant information. There is a need to provide educational techniques and materials that matches the family's needs and abilities as indicated by Eames, McKenna, Worrall, and Read (2003) to improve carers' understanding and provide information to access helpful materials. In addition, there is a need to research and identify techniques to increase hope such as caregiver involvement, interaction with other survivors of stroke, spirituality, realistic possibilities, and active participation for carers. (Bays, 2001) in relation to RHD. It is important to understand how the specific information needs and support needs for carers of a family member with RHD differ from those with other neurological diseases or damage (e.g., aphasia, dementia, Parkinson's Disease).



## CHAPTER V

### **Conclusion**

The purpose of this research was to identify the information needs reported by carers of a family member following a right hemisphere stroke. Understanding the type of information carers would like to receive and at what point they want to receive this information can improve the delivery of information from medical professionals to carers as their family member transitions through the phases of recovery. It also can assist carers within each stage in asking appropriate and important questions to better prepare themselves for their family member's impairments and the challenges they may experience. It is the responsibility of health professionals to prepare patients and their families for the journey they will endure during their continuous recovery process.

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Appendix A

Inclusion

1. Did your family member have a stroke?
  - a. Yes
  - b. No
2. Was their stroke on the right side of their brain?
  - a. Yes
  - b. No
3. Were you over the age of 18 years at the time of your family member's stroke?
  - a. Yes
  - b. No
4. Are you under the age of 85 years old?
  - a. Yes
  - b. No
5. Are you the primary caregiver at least 20 of hours per week immediately after their stroke, during treatment, and following treatment?
  - a. Yes
  - b. No
6. Are you a paid to care for this individual?
  - a. Yes
  - b. No
7. Do you have medical training?
  - a. Yes
  - b. No
8. Have you had to care for anyone in the past?
  - a. Yes
  - b. No
9. Does your family member have cognitive impairments?
  - a. Difficulty remember information?
  - b. Difficulty attending to information?
  - c. Difficulty problem solving?
  - d. Difficulty participating in conversations?
  - e. If you're not sure, click this box.
10. Is your family member at least 1 year post right hemisphere stroke?
  - a. Yes
  - b. No
11. Was your family member at least 18 years old at the time of the stroke?
  - a. Yes
  - b. No

Exclusion

1. Do you have a history of a neurological disorder?
  - a. Yes
  - b. No
2. Was your previous or current occupation in the health care field?

- a. Yes
- b. No

Great! This study is a good fit for you. I have some questions about you and your family member. If you are not sure about an answer or want to provide additional information you will have an opportunity to discuss these further during the interview.

Appendix B

Descriptive information about your family member who had a stroke

1. Does your family member display any cognitive or communication impairments?
  - a. Difficulties with memory
    - i. Short-term memory: Remembering something that happened only an hour ago.
    - ii. Long-term memory: Remembering something from many years ago.
  - b. Executive dysfunction
    - i. **Initiation and drive:** Beginning a task
    - ii. **Response inhibition:** Trouble self-monitoring
    - iii. **Task persistence:** difficulty staying on one task
    - iv. **Organization:** Organizing and sequencing of information
    - v. **Generative thinking:** Flexibly thinking of many solutions to a problem
    - vi. **Awareness:** monitoring and modifying one's own behavior
  - c. Difficulties attending for long periods of time
  - d. Difficulties attending in noisy/distracting environments
  - e. Difficulties attending to more than one thing at a time
  - f. Difficulties understanding emotions the tones of others
  - g. Difficulties expressing emotions through their tone
  - h. Difficulty understanding other's facial expressions
  - i. Difficulty expressing through facial expression
2. Date of stroke:
3. Location of stroke:
4. Time in hospital:
5. Time in rehabilitation in-patient care:
6. Time in home:
7. Relationship to your family member:
8. How many strokes did your family member have?
  - a. When was the first stroke?
    - i. Month
    - ii. Year
  - b. When was the most recent stroke?
    - i. Month
    - ii. Year
9. What kind of stroke did your family member have
  - a. Thromboembolic ("clot")
  - b. Hemorrhagic ("bleed")
  - c. I don't know
10. Has your family member received any of the following diagnosis?
  - a. Aphasia
  - b. Dysarthria or apraxia of speech
  - c. Hemiplegia (weak arm/leg)
  - d. Visual disturbance
  - e. Unilateral neglect
  - f. Swallowing impairment

- g. Hearing loss
- h. Depression
- i. Memory impairment
- j. Attentional impairment
- k. Right hemisphere disorder
- l. Other: \_\_\_\_\_

11. Is your family member currently receiving any therapy or treatments?

Demographic information about you – what is your:

- 1. Date of birth:
- 2. Gender:
- 3. Race:
- 4. Level of Education:
- 5. Previous or Current Occupation:
- 6. Do you live with your family member?
  - a. Yes
  - b. No
- 7. Who else provides care for your family member?
- 8. Describe your previous role in the family. [i.e., child care, income producer (full-time), income producer (part-time), homemaker]
- 9. Describe your current role?
- 10. How many hours do you spend doing care giving activities each week?
  - a. 1-5 hours per week
  - b. 6-10 hours per week
  - c. 10-15 hours per week
  - d. 15 hours or more per week
  - e. How did you hear about this study?

## Appendix C

Thank you for taking the time to talk with me. I am a graduate student at Duquesne University for speech-language pathology. I am interested in learning about people who are caring for someone who had a right hemisphere stroke. I want to gain insight to your perceptions of the information that would be beneficial to you and your family member as you transition through different phases after his or her their stroke. I have some questions pertaining to some of the challenges your family member may have, and the information needs you feel would be beneficial during three stages of recovery. First, I will ask general information, then information about the onset, then information about the initial rehabilitation and treatment, and then information about after treatment. You can ask questions or follow up at any time.

### **General Information**

1. Tell me about some of the challenges your family member experiences related to communication, memory, attention, or problem solving.
2. Tell me about some of the challenges your family member experiences related to speaking or swallowing.
3. Describe how you learned to support your family member in daily activities (i.e., communicating, organizing).

### **Onset Phase**

**This phase refers to the time right after your family member's stroke before they left the hospital for treatment.**

4. What information were you given about your family member's cognition, communication, and swallowing at the onset of your family member's stroke?
5. What information do you wish you received about your family member's cognition, communication, and swallowing at the onset?
6. What questions do you wish you asked about your family member's cognition, communication, and swallowing at the onset?
7. Do you wish you had been provided more information about your family member's impairments?
  - a. If yes, can you provide specific examples of information you think would have helped you better understand your family member's impairments?
8. What information did you feel was helpful that you received during the onset phase?
9. Is there anything else about the information or supports in the onset phase you want to share with me?

### **Initial rehabilitation/treatment**

**This phase refers to the time when your family member was receiving treatment, either inpatient or outpatient treatment.**

10. What information were you given about your family member's cognition, communication, and swallowing abilities at the initial rehabilitation stage?
11. What information do you wish you received about your family member's cognition, communication, and swallowing at the initial rehabilitation stage?
12. What questions do you wish you asked about your family member's cognition, communication, and swallowing at the initial rehabilitation stage?
13. Tell me about the information (i.e., results) shared with you following the assessments (i.e., progress, performance).
14. What types of activities did your family member do in speech-language therapy? For example, putting things in the correct order, naming as many animals as you can in 1 minute, planning a party, solving word problems, visual scanning?
15. Tell me about any speech-language assessments given to your family member.
16. What information (i.e. results) were shared with you following the assessments (i.e. progress, performance)?
17. Describe any home activities your family member was given and if any, how involved were you with this work?
  - a. Were you given directions on how to support your family member's attempts at the homework?
18. Describe the information you were provided with about the therapy activities (at home or within the sessions) and the rationale for these activities?
19. Do you wish you had been provided more information about your family member's impairments in the initial rehabilitation/treatment?
  - a. If yes, can you provide specific examples of information you think would have helped you better understand your family member's impairments?
20. What information did you feel was helpful that you received during the initial rehabilitation/treatment?
21. Is there anything else about the information or supports in the initial rehabilitation/treatment you want to share with me?

**Chronic phase (i.e. after treatment)**

**This refers to the time when your family member transitioned home following treatment.**

22. What information were you given about your family member's cognition, communication, and swallowing following treatment?

23. What information do you wish you received about your family member's cognition, communication, and swallowing following treatment?
24. What questions do you wish you asked about your family member's cognition, communication, and swallowing following treatment?
25. Do you wish you had been provided more information about your family member's impairments in the chronic phase?
  - a. If yes, can you provide specific examples of information you think would have helped you better understand your family member's impairments?
26. What information did you feel was helpful that you received during the chronic phase?
27. Is there anything else about the information or supports in the chronic phase you want to share with me?

**Conclusion Question**

28. Based upon your experience, what information do you think is most critical for a new carer?