

The Nature of Recovery in Aphasia from Two Perspectives:
A Phenomenological Study

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In Partial Fulfillment of the

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Doctor of Philosophy

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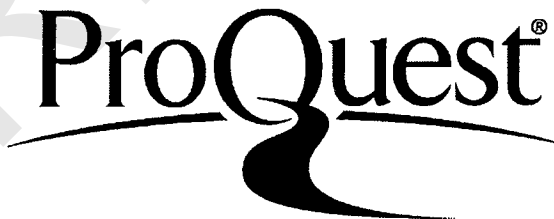
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PREVIEW

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The Nature of Recovery in Aphasia from Two Perspectives:
A Phenomenological Study

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DEDICATION

This dissertation is dedicated to my late father, Mansour Kardosh, and my late mother, Yvonne Kardosh. These two genuine and authentic Palestinians completed each other. Mansour and Yvonne Kardosh remarkably and diligently served the deprived Palestinian community in Israel through their nonstop commitments, tireless efforts, and their own creative ways. These two exceptional parents emphasized the importance of education throughout my life and financially contributed to my academic degrees. They are always in my mind and in my heart. Indeed, I am always very proud of them.

PREVIEW

ACKNOWLEDGMENTS

My thanks and appreciation go to Dr. Jack S. Damico for tolerating me as my advisor throughout all the years it took me to complete my study and to write this dissertation. Certainly, the feedback and guidance that he provided through my degree in general and especially throughout the dissertation expanded my academic horizon and enhanced my modest knowledge. He always supported me by providing suggestions, comments, and even different types of support and assistance. I would like also to thank other members of my dissertation committee: Dr. John T. Tetnowski, Dr. Martin J. Ball, and Dr. Nancye C. Roussel, who always encouraged me and made me feel that I could really finish my dissertation. I thank them for their contributions and their genuine support.

As always, I am grateful to Dr. Audrey Holland who supervised me in my master's degree at the University of Arizona and ensured that I was ready, to some degree, to start my advanced study. She made sure that I became familiar to some extent with my doctoral supervisor's research orientation and clinical approach regarding aphasiology. On the other hand, I must say that I became more familiar with Dr. Holland's clinical focus and academic contributions including research and publications under the supervision of Dr. Jack S. Damico than during my master's degree. This shows how these two distinguished academic authorities are modest and appreciate each other.

On a personal note, I must acknowledge my friend, Patricia, who made it possible for me to complete my degree by letting me stay at her apartment without paying rent for fourteen months. I am truly grateful for her generosity and endless support. Finally, I am thankful for my siblings: Lina and Tawfiq who supported me all of the time, especially after mother passed away.

TABLE OF CONTENTS

DEDICATION	iv
ACKNOWLEDGMENTS	v
LIST OF TABLES	ix
LIST OF ABBREVIATIONS	x
CHAPTER ONE: INTRODUCTION	1
What is Recovery?	3
Role of Speech Language Pathologists in Recovery	5
Recovery in Clinical Aphasiology	6
Expectations	6
Perspectives	7
Complexity in Clinical Recovery	8
This Study	9
CHAPTER TWO: LITERATURE REVIEW	11
Organic Recovery	12
Mechanisms of Change	14
Clinical Aphasiology Intervention	16
Clinical Rehabilitative Recovery	16
Behavioral Recovery	19
Functional Approach Treatment	19
Psychological Recovery	21
Social Recovery	25
Interactional Aphasia	25
Life Participation Approach to Aphasia	32
Complexity in Recovery	33
Pervasive Aphasiology	34
Orientations to Recovery	35
Ambiguity (Uncertainty) in Recovery	36
Summary	38
CHAPTER THREE: METHODOLOGY	40
Research Questions	41
Qualitative Research Design	42
Rationale	42

Principles	43
Principle One: What is going on?	43
Principle Two: Authenticity	44
Principle Three: Perspective-Taking	45
Principle Four: Interpretive	45
Principle Five: Description	46
Summary	46
The Specific Tradition of Inquiry: Phenomenology	46
Phenomenology as Qualitative Research Inquiry	48
Objectives	48
Why Phenomenology is Relevant	49
Participants	50
Participants' Selection Criterion	50
Participants' Recruitment	51
Description of Participants	53
Aphasia Group	53
Caregiver Group	56
Data Collection Procedures	56
Semi-Structured Interviews	57
Background	57
Scope and Techniques	58
Possible Benefits of Semi-Structured Interview	60
Procedure	61
Data Analysis	62
Interpretive Phenomenological Analysis	62
IPA Characteristics	63
IPA Procedure	64
Summary	68
 CHAPTER FOUR: RESULTS	 70
Outline of Data Collection	70
Data from the Aphasia Group	72
Encountering Aphasia	72
Emergence	74
Impact	81
Reacting to Aphasia	99
Emotional Reactions	99
I Have a Problem	103
Avoidance	104
Experiential Metaphors	107
Coping with Aphasia	109
Mechanisms	110
Awareness	128
Contextual Influence	134
Perspectives	135

Expectations	144
Summary of the Aphasia Group Data	148
Data from the Caregiver Group	151
Encountering Aphasia	152
Medical Emergency	153
Functional Impact	157
Reacting to Aphasia	169
Emotional Reactions	170
Realization	179
Avoidance	180
Experiential Metaphors	181
Coping with Aphasia	183
Mechanisms	184
Awareness	201
Contextual Influence	208
Perspectives	208
Expectations	218
Summary of the Caregiver Group Data	221
Comparisons Between the Individuals with Aphasia and the Caregivers	224
Similarities	224
Differences	226
 CHAPTER FIVE: CONCLUSIONS	 230
Responses to the Research Questions	231
Implications	237
Implication One	237
Implication Two	238
Implication Three	239
Implication Four	239
Implication Five	240
Implication Six	240
Implication Seven	241
Implication Eight	242
Limitations	243
 REFERENCES	 245
 APPENDICES	 261
 ABSTRACT	 262
 BIOGRAPHICAL SKETCH	 264

LIST OF TABLES

Table 3.1 Characteristics of the Aphasia Group	54
Table 3.2 Background details of the Aphasia Group	55
Table 4.1 List of Themes for the Aphasia Group based on Interpretive Phenomenological Analysis of Semi-Structured Interviews	73
Table 4.2 List of Themes for the Caregiver Group based on Interpretive Phenomenological Analysis of Semi-Structured Interviews	153

PREVIEW

LIST OF ABBREVIATIONS

ADL:	Activities of Daily Living
ASHA:	American Speech Hearing Association
IWA:	Individual(s) With Aphasia
LPAA:	Life Participation Approach to Aphasia
CVA:	Cardio Vascular Accident
IPA:	Interpretive Psychological Analysis
IRB:	Institutional Review Board

PREVIEW

CHAPTER ONE

INTRODUCTION

Most people take speech and language abilities for granted. These skills have developed naturally and form the mundane social fabric of our lives. We employ communication skills in spontaneous ways in our daily lives within authentic contexts, and these skills enable our transactions of information and our interactions with others (Simmons-Mackie & Damico, 2007); they help define who we are and how we operate in the social world. Therefore, we are often unprepared for the impact of the loss when dramatic events like aphasia (loss of ability to understand and produce language, usually the result of a focal lesion in the brain) occur. Such a devastating event significantly changes the communicative and social capabilities and opportunities of affected individuals. Consequently, the impaired individual must adjust to this impairment and hope for recovery. However, recovery is an extended and complex process.

When faced with the realities of aphasia, it is very possible that the individual with aphasia (IWA) and the family may never have heard the word “aphasia” prior to its onset. Following the acute stage where medical issues involve life threatening conditions that require a focus on basic survival, the IWA and the family may begin to realize that a life-altering situation is emerging for them. During the early days following the onset of the aphasia, they are probably confused; during later days, they gradually become aware of the wide impact that aphasia has made on their lives (Holland, 2008a). Aphasia affects the communication between the IWA and members of his/her social network (Simmons-Mackie & Damico, 2007) such as the family, friends, and coworkers, and this has a profound impact. The IWA and the family become aware that their communication skills and their social

routines following the onset of the aphasia have been altered, and that the typical and expected life enjoyed so effortlessly is changed. Impairment, disability and confusion may ensue. People with aphasia and their primary communicative partners confront various challenges and barriers in their lives. These drastic consequences not only involve the impairments in the language abilities and compromised language skills, but they are also manifested through other aspects of the daily lives of the IWA and his or her family. For example, the IWA may demonstrate negative reactions to aphasia including fear, anxiety, frustration, and depression (Holland & Fridriksson, 2001). Several investigations have reported that the IWA is often excluded from full participation in communication, and that even having a role in daily conversations, receiving necessary information, and having the opportunity to make decisions about their lives becomes problematic (e.g., Le Dorze & Brassard, 1995; Michallet, Tetreault, & Le Dorze, 2003; Parr, 1994; Parr, Byng, Giplin, & Ireland, 1997).

Because of these factors, the IWA experiences a loss of established identity, which can be defined as a psychosocial construct wherein a person establishes who they are and where they are coming from (Taylor, 1994). This identity provides the interpretive background for all the IWA actions and interactions with others and influences others' expectations of how to react and interact with the IWA. Simply put, aphasia has disrupted the personal and the social identity of the individual (Shadden, 2005). Consequently, focusing on aphasia as only a language impairment manifested in communicative performance and language modalities is inadequate and even misleading to some degree (Simmons-Mackie & Damico, 2007). Many of the previously mentioned impact from aphasia changes involve changes in functioning, self-identity, and interaction in the social sphere which are often not

addressed during rehabilitation. This broader impact of aphasia challenges the IWA and the family and must be addressed if effective recovery is the objective (Holland, 2007b).

What is Recovery?

In general, the term “recovery” is a complex and comprehensive concept with a range of meanings. For example, recovery can be considered as a restoration of health following illness or of strength following fatigue (Rosenblatt, 2008). The underlying assumption in the medical model is that recovery involves gradual healing after sickness or injury while the concept of recovery in the rehabilitative model refers to the return, as much as possible, to the life the individual enjoyed prior to the illness (Whitewell, 1999). Recovery could indicate the process of getting back to a normal situation as completely as possible so the underlying assumption involves the idea that although the illness cannot be cured, it is possible that the life of the individual can return as before the onset of the condition (Anthony & Liberman, 1992).

In the traditional medical model, it is often assumed that the patient will be cured if he or she obeys and fulfills the physician’s regulations and demands (Taylor-Sarno, 1998). Holland (2007a) argued that the healthcare service and professionals expect that people will improve significantly if they work hard enough in rehabilitation (Holland, 2007a). The message conveyed by the rehabilitation staff such as the physical therapist, occupational therapist, and the speech language pathologist, is that rehabilitation is where the recovery occurs (Holland, 2007a). The concept of recovery, however, is multifaceted. For example, recovery also involves the psychological aftermath of bereavement by which the person is experiencing grief and loss (Corr, Nabe, & Corr, 2003). Seeing recovery as a restoration in which the individual “moves forward” to a new way of life after a loss incorporates not only

functional and social recovery, but psychological recovery as well. As Rosenblatt (2008) pointed out, recovery can be considered as the return to and a reintegrating into life.

Obviously, these expectations from the rehabilitation process can contribute to the expectations of the IWA and the family regarding recovery in which the individual has to be committed to rehabilitation, has to work very hard and needs to invest in rehabilitation so he or she can overcome the effects of the brain injury. In order to establish recovery, the IWA needs to adopt an active role including full participation in rehabilitation. However, if recovery is not established as expected based on the rehabilitative model, the IWA and the family may feel incompetent, devalued, and helpless.

Based on the examples outlined above, recovery has different meanings when viewed through various lenses such as the medical field, rehabilitation science, mental illness, and bereavement. One common feature of these examples, however, is that recovery takes time in order to reach and establish a specific state. The conceptualization of recovery as discussed demonstrates both similarity and variation when examining the nature of recovery across different sets of expectations. Taken together for the purpose of discussing recovery from aphasia, therefore, the underlying assumptions of the concept of recovery involve the understanding that the state or the condition of the individual has deteriorated to some degree, resulting in two separate conditions of experience—the previous state of functioning which was intact and the current state of functioning which is damaged. The focus of recovery in such a case would be on shifting or modifying the current state, as much as possible, so that it can reach the previous or the normal condition. However, this is still an inadequate understanding of the concept of recovery. In order to capture a thorough and rich

meaning of the concept of recovery, it seems necessary to examine the nature of such recovery through domains other than the medical and rehabilitation models.

Role of Speech Language Pathologist in Recovery

The impact of aphasia for an individual as well as a family illustrates the importance of the recovery process in aphasia. It is vital that any recovery process address the life-altering effects of aphasia on the IWA and his/her family. Treatment during this recovery involves various parties including the IWA, the family, and health care services, including the speech-language pathologists.

According to the Scope of Practice of the American Speech Hearing Association (ASHA), the general goal of a speech-language pathologist's rehabilitative services is to maximize the individual's ability to communicate in natural environments and thus improve their quality of life (ASHA, 2007). This objective is realized by integrating therapeutic services in meaningful contexts and by modifying and enhancing communication behaviors (ASHA, 2001). The aim of the practice of speech-language therapy is to address and contribute to the "amelioration" of difficulties manifested through various disorders (ASHA, 2001). Hence, recovery is an important aspect of the speech-language pathology service.

While the main role of the clinician is to facilitate rehabilitation of the abnormal communicative behavior of the person, the clinician should also provide support to the client and assist in improving the welfare of the individual (Silverman & Miller, 2006). The speech-language pathologist develops an intervention program aiming to help the individual to "regain" as much as possible of his or her communication skills and to develop compensatory strategies to address the skills that were compromised (ASHA, 2007). Obviously, then, the speech language pathologist is interested in establishing recovery.

However, there still remains the need to explore the actual meaning and nature of recovery in greater depth and detail.

Recovery in Clinical Aphasiology

Within the realm of aphasia, recovery can be considered as a critical personal and social journey for the IWA and the family as they seek to reestablish lost functioning. For example, the IWA and the family often hope to regain the language skills that were lost or affected and to return to the previous condition prior to the onset of the aphasia. In the field of aphasiology, recovery is considered an ongoing process, active in nature, and not limited to a specific time or stage (e.g., acute/chronic) (Darley, 1991).

To ensure the best results in assisted recovery, however, one must recognize and embrace the complexity of the recovery process. Recovery in aphasia, including the elements that construct recovery can vary and can mean different things to different people. For example, the views and the interpretations of the IWA and the family regarding recovery may vary and their expectations may influence the recovery process. Based on the understanding of the IWA and the family, they may possibly attempt to seek a cure or they may believe that it is impossible to establish recovery since they consider the condition irreversible. “Getting better,” then, varies based on the views, personal experience, and expectations of the IWA and the family involved.

Expectations

Occasionally, the IWA and the family may experience high expectations involving recovery in aphasia (Taylor-Sarno, 1998). They may anticipate that a full recovery of speech and language skills will take place. The IWA and the family in these situations consider successful recovery to have occurred when the individual has fully returned to previous

levels of communication competence. If this does not happen, it is possible for the persons involved to experience gradually increasing frustration and anger (Taylor-Sarno, 1998).

Sometimes assumptions and expectations of the IWA and the family can be quite different from those of the clinician. Perhaps the IWA and family expect a full recovery to prior functioning, whereas the clinician is focused on maximizing the speech and language performance of the IWA and establishing effective compensatory strategies for impaired skills in an attempt to enhance his or her quality of life (Frattali, 1998). Treatment for the clinician, in such a case, is not considered as culminating in a “cure” in the clinical context; therefore, the clinician is interested in helping to shift the expectations of the IWA and the family away from an ultimate cure towards the concept of optimizing the skills and abilities of the IWA. Another disconnect between expectations of the IWA/family and the clinician could involve the length of treatment. Sometimes families desire continuation in a clinical intervention program for many years (Parr et al., 1997). The realities of insurance limits/Medicare requirements can have negative effects on an individual and family who must withdraw from treatment after a specified time and consider that their expectations were not fulfilled or that they were abandoned by health care services (Parr et al., 1997; Sarno, 1998).

Perspectives

The perspectives of the IWA and the family for recovery will necessarily involve their particular ways of viewing, understanding, and explaining issues based on their own personal experience with aphasia. These personal views of the IWA and the family can demonstrate richness, variation, and complexity about their understanding, reactions, needs, and expectations in aphasia. It is important to explore what accounts for and contributes to

recovery in aphasia through the perspectives of the individuals affected. By considering these insiders' perspectives of the recovery we can gain a deeper understanding of the impact of aphasia in the lives of the IWA and the family.

Complexity in Clinical Recovery

Aphasia results in challenges for communication that affect the behavior and the interaction between the IWA and the family. These personal and social issues inform the perspectives of these two social parties regarding the nature of recovery based on their actual lived experiences with aphasia. Because of this, it seems accurate to state that recovery is an important issue for the IWA, family, and the clinician. Each person's concept of recovery influences expectations, practices, assumptions, and activities which are manifested in the interactions between the IWA, the family and the clinician in the clinical setting and within authentic contexts. For example, in the Palestinian community in Israel, the IWA and family, based on their personal experience, may attribute the recovery from aphasia to their own motivation and willpower, or they may consider members of their social network or religious values as responsible for the recovery process (Kardosh & Damico, 2006). Such views and beliefs are shaped through cultural elements that encompass individuals based on the culture they inhabit and they illustrate the complexity of the recovery process.

Consequently, it is important to consider that recovery in aphasia is not only about physical and functional changes. Rather, recovery can involve various issues manifested through behavior and social interaction. Therefore, it is relevant and also important to consider the views about and the experience of recovery in aphasia of the IWA and those who interact with them on regular basis mainly the family in their social context.

Some individuals with aphasia and their families, in the beginning of the clinical sessions, might inquire and request information repeatedly about their own recovery or whether currently they are demonstrating any signs of recovery. The immediate response of some clinicians to questions about recovery at this point is “I don’t know.” This response could contribute to feelings of uncertainty and insecurity about recovery for the IWA and the family, indicating that recovery is an important issue for the IWA and his/her family. The following is an example of just such a situation. A young clinician in the city of Haifa in Israel was trying to explain to the wife of an individual with aphasia in the initial stage of treatment about the meaning of aphasia. The clinician was trying to help this family understand language disability and the impact it could have on everyone involved. The particular spouse seemed to be listening closely to the clinician, made no interruptions, and mainly nodded her head and smiled to indicate understanding. Following the explanation, the spouse responded immediately and in a spontaneous manner by asking a single question only: “Will he get better?” For her it was important to know whether recovery was possible and if it was realistic that it could be achieved specifically in the case of her husband. Based on such views of the spouse it is possible to assume that recovery from aphasia was important to her concerns, expectations, and goals during the interaction with the clinician in that specific moment.

This Study

The current study investigates the perspectives of IWA and their families regarding recovery. The focus of the study is how the nature of recovery has been constructed and shaped based on the perspectives of IWA and their families. This investigation is designed to

consider and address the similarities and differences between IWA and their families about their views of recovery in aphasia.

This chapter introduced several issues about aphasia including what aphasia is, the impact it has on an individual and his/her extended social circle, and what recovery from aphasia means for different people. In Chapter Two, these issues will be explored in detail and depth, including a review of published academic literature regarding recovery in aphasia, recovery in clinical aphasiology approaches, and complexity in recovery. In Chapter Three, the purposes of the current investigation are stated and the methodology employed in this study is addressed in detail. Chapter Four provides actual data on the lived experience of individuals with aphasia and those of their primary caregivers so that a deeper understanding of the recovery process can take place from the unique perspectives of these two sets of stake-holders. In Chapter Five the results based upon the experiences of these two sets of individuals will be discussed and implications will be provided.

CHAPTER TWO

LITERATURE REVIEW

In an attempt to capture the essence of aphasia as a potentially debilitating condition, it is necessary to consider a formal and a careful definition of this concept including the presentation of a concise description of aphasia (McNeil & Pratt, 2001). Aphasia has been defined as the impairment of language caused by brain damage (Benson, 1979).

Alternatively, Darley (1982) considered aphasia as damage to or the loss of the ability for the interpretation and the formulation of conventional and meaningful language symbols. Based on this definition, aphasia is a multimodality incompetence or loss that crossed all language modalities. Various authorities who offer various descriptions of aphasia illustrate the idea that aphasia can be considered differently according to which definition one is using.

Within the clinical realm, recovery from aphasia is an important issue that affects service delivery and its success in clinical aphasiology. As suggested in Chapter One, recovery can involve different facets within the therapeutic process and can mean different things in different domains within clinical aphasiology. The degree of the recovery in aphasia, the parties involved in the recovery process, the long-term impact of recovery, even the foundational conceptualization of recovery must all be considered when this issue is addressed. In this chapter, recovery and its more important facets will be reviewed and several questions worthy of further study will be examined.

A review of the published academic literature suggests that recovery in aphasia focuses primarily on change (e.g., Holland, 2007a; Frattali, 1998; Simmons-Mackie & Damico, 2001). Hopefully, it involves a beneficial change. However, there seems to be little

agreement as to the nature of this change including the components that contribute to it. What is meant by “change” has not been adequately addressed.

One attempt to understand the concept of recovery as change focuses on the impact on the brain itself. This understanding is based on an organic approach in which the brain has the ability to modify functional and even anatomical structures (Kolb & Whishaw, 2008). Another conceptualization of recovery as change draws from a more behavioral approach. That is, recovery can be considered as a change in the behavioral performance in tasks involving language modalities such as reading comprehension and writing (Simmons-Mackie, 1998) or the increased use of communication and language abilities in daily living activities (Frattali, 1998). In this sense, recovery is about social reintegration and communicative accessibility, and it is accomplished by compensation and collaboration (Simmons-Mackie & Damico, 2001).

Within these two foci, there is little agreement about how one understands recovery in aphasia (Code, 2001). In the following sections of this chapter, various issues and deliberations involving recovery in aphasia will be presented and reviewed. This will enable a greater understanding of the issues surrounding recovery and how they might be addressed.

Organic Recovery

Within the organic approach and according to recent neuropsychological theory, the human brain is capable of flexibility that can create compensation for neurological injury. Such compensation involves some recovery of function, but does not necessarily mean restoring the original anatomical structures responsible for the now-impaired function in the brain prior to the onset of aphasia (Kolb & Whishaw, 2008). Compensation can involve the restoration of the damaged function to some degree following the brain injury but not

completely. Although the ability has been “recovered,” the original behaviors do not necessarily return to the same state as before the onset of the brain injury (Kolb & Whishaw, 2008). That is, people do not actually recover the lost behaviors or abilities, but rather, they develop new ways of functioning to compensate. The individual may compensate for the difficulties and establish new behavioral strategies to perform activities that are restricted due to the brain injury. The individual does not initiate and learn these strategies consciously; rather they develop spontaneously as a result of physiological and/or anatomical changes (Kolb & Whishaw, 2008). This type of neural plasticity is defined as the flexibility of the brain as related to its capacity to change (Holland, 2008b; Kolb & Whishaw, 2008; Raymer et al., 2008). According to a recent review, the central nervous system has an adaptive ability within some neurons and their support cells that may result in functional and/or anatomical change in response to external and internal conditions (Klein and Jones, 2008). Although this potential adaptability seems to operate more robustly in younger than in older brains, even older brains can be adaptive and capable of change (Holland, 2008b).

As outlined above, neural plasticity is involved in such processes as the development and learning of new behaviors as well as relearning lost behaviors due to brain injury in response to rehabilitation (Klein and Jones, 2008). This neuroplasticity operates by facilitating functional and anatomical changes as a result of experience (Kolb & Whishaw, 2008). These experiences can be external, taking place within the environment, or they can be an internal event (Kolb & Whishaw, 2008). During the experience, these adjustments can involve potential changes in neuronal tissue, structure size, cortical thickness, dendritic branching, spine density, and changes in synapses per neuron forms (Kolb & Whishaw,

CHAPTER ONE

INTRODUCTION

Most people take speech and language abilities for granted. These skills have developed naturally and form the mundane social fabric of our lives. We employ communication skills in spontaneous ways in our daily lives within authentic contexts, and these skills enable our transactions of information and our interactions with others (Simmons-Mackie & Damico, 2007); they help define who we are and how we operate in the social world. Therefore, we are often unprepared for the impact of the loss when dramatic events like aphasia (loss of ability to understand and produce language, usually the result of a focal lesion in the brain) occur. Such a devastating event significantly changes the communicative and social capabilities and opportunities of affected individuals. Consequently, the impaired individual must adjust to this impairment and hope for recovery. However, recovery is an extended and complex process.

When faced with the realities of aphasia, it is very possible that the individual with aphasia (IWA) and the family may never have heard the word “aphasia” prior to its onset. Following the acute stage where medical issues involve life threatening conditions that require a focus on basic survival, the IWA and the family may begin to realize that a life-altering situation is emerging for them. During the early days following the onset of the aphasia, they are probably confused; during later days, they gradually become aware of the wide impact that aphasia has made on their lives (Holland, 2008a). Aphasia affects the communication between the IWA and members of his/her social network (Simmons-Mackie & Damico, 2007) such as the family, friends, and coworkers, and this has a profound impact. The IWA and the family become aware that their communication skills and their social

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Because of these factors, the IWA experiences a loss of established identity, which can be defined as a psychosocial construct wherein a person establishes who they are and where they are coming from (Taylor, 1994). This identity provides the interpretive background for all the IWA actions and interactions with others and influences others' expectations of how to react and interact with the IWA. Simply put, aphasia has disrupted the personal and the social identity of the individual (Shadden, 2005). Consequently, focusing on aphasia as only a language impairment manifested in communicative performance and language modalities is inadequate and even misleading to some degree (Simmons-Mackie & Damico, 2007). Many of the previously mentioned impact from aphasia changes involve changes in functioning, self-identity, and interaction in the social sphere which are often not

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In general, the term “recovery” is a complex and comprehensive concept with a range of meanings. For example, recovery can be considered as a restoration of health following illness or of strength following fatigue (Rosenblatt, 2008). The underlying assumption in the medical model is that recovery involves gradual healing after sickness or injury while the concept of recovery in the rehabilitative model refers to the return, as much as possible, to the life the individual enjoyed prior to the illness (Whitewell, 1999). Recovery could indicate the process of getting back to a normal situation as completely as possible so the underlying assumption involves the idea that although the illness cannot be cured, it is possible that the life of the individual can return as before the onset of the condition (Anthony & Liberman, 1992).

In the traditional medical model, it is often assumed that the patient will be cured if he or she obeys and fulfills the physician’s regulations and demands (Taylor-Sarno, 1998). Holland (2007a) argued that the healthcare service and professionals expect that people will improve significantly if they work hard enough in rehabilitation (Holland, 2007a). The message conveyed by the rehabilitation staff such as the physical therapist, occupational therapist, and the speech language pathologist, is that rehabilitation is where the recovery occurs (Holland, 2007a). The concept of recovery, however, is multifaceted. For example, recovery also involves the psychological aftermath of bereavement by which the person is experiencing grief and loss (Corr, Nabe, & Corr, 2003). Seeing recovery as a restoration in which the individual “moves forward” to a new way of life after a loss incorporates not only

functional and social recovery, but psychological recovery as well. As Rosenblatt (2008) pointed out, recovery can be considered as the return to and a reintegrating into life.

Obviously, these expectations from the rehabilitation process can contribute to the expectations of the IWA and the family regarding recovery in which the individual has to be committed to rehabilitation, has to work very hard and needs to invest in rehabilitation so he or she can overcome the effects of the brain injury. In order to establish recovery, the IWA needs to adopt an active role including full participation in rehabilitation. However, if recovery is not established as expected based on the rehabilitative model, the IWA and the family may feel incompetent, devalued, and helpless.

Based on the examples outlined above, recovery has different meanings when viewed through various lenses such as the medical field, rehabilitation science, mental illness, and bereavement. One common feature of these examples, however, is that recovery takes time in order to reach and establish a specific state. The conceptualization of recovery as discussed demonstrates both similarity and variation when examining the nature of recovery across different sets of expectations. Taken together for the purpose of discussing recovery from aphasia, therefore, the underlying assumptions of the concept of recovery involve the understanding that the state or the condition of the individual has deteriorated to some degree, resulting in two separate conditions of experience—the previous state of functioning which was intact and the current state of functioning which is damaged. The focus of recovery in such a case would be on shifting or modifying the current state, as much as possible, so that it can reach the previous or the normal condition. However, this is still an inadequate understanding of the concept of recovery. In order to capture a thorough and rich

meaning of the concept of recovery, it seems necessary to examine the nature of such recovery through domains other than the medical and rehabilitation models.

Role of Speech Language Pathologist in Recovery

The impact of aphasia for an individual as well as a family illustrates the importance of the recovery process in aphasia. It is vital that any recovery process address the life-altering effects of aphasia on the IWA and his/her family. Treatment during this recovery involves various parties including the IWA, the family, and health care services, including the speech-language pathologists.

According to the Scope of Practice of the American Speech Hearing Association (ASHA), the general goal of a speech-language pathologist's rehabilitative services is to maximize the individual's ability to communicate in natural environments and thus improve their quality of life (ASHA, 2007). This objective is realized by integrating therapeutic services in meaningful contexts and by modifying and enhancing communication behaviors (ASHA, 2001). The aim of the practice of speech-language therapy is to address and contribute to the "amelioration" of difficulties manifested through various disorders (ASHA, 2001). Hence, recovery is an important aspect of the speech-language pathology service.

While the main role of the clinician is to facilitate rehabilitation of the abnormal communicative behavior of the person, the clinician should also provide support to the client and assist in improving the welfare of the individual (Silverman & Miller, 2006). The speech-language pathologist develops an intervention program aiming to help the individual to "regain" as much as possible of his or her communication skills and to develop compensatory strategies to address the skills that were compromised (ASHA, 2007). Obviously, then, the speech language pathologist is interested in establishing recovery.

However, there still remains the need to explore the actual meaning and nature of recovery in greater depth and detail.

Recovery in Clinical Aphasiology

Within the realm of aphasia, recovery can be considered as a critical personal and social journey for the IWA and the family as they seek to reestablish lost functioning. For example, the IWA and the family often hope to regain the language skills that were lost or affected and to return to the previous condition prior to the onset of the aphasia. In the field of aphasiology, recovery is considered an ongoing process, active in nature, and not limited to a specific time or stage (e.g., acute/chronic) (Darley, 1991).

To ensure the best results in assisted recovery, however, one must recognize and embrace the complexity of the recovery process. Recovery in aphasia, including the elements that construct recovery can vary and can mean different things to different people. For example, the views and the interpretations of the IWA and the family regarding recovery may vary and their expectations may influence the recovery process. Based on the understanding of the IWA and the family, they may possibly attempt to seek a cure or they may believe that it is impossible to establish recovery since they consider the condition irreversible. “Getting better,” then, varies based on the views, personal experience, and expectations of the IWA and the family involved.

Expectations

Occasionally, the IWA and the family may experience high expectations involving recovery in aphasia (Taylor-Sarno, 1998). They may anticipate that a full recovery of speech and language skills will take place. The IWA and the family in these situations consider successful recovery to have occurred when the individual has fully returned to previous

levels of communication competence. If this does not happen, it is possible for the persons involved to experience gradually increasing frustration and anger (Taylor-Sarno, 1998).

Sometimes assumptions and expectations of the IWA and the family can be quite different from those of the clinician. Perhaps the IWA and family expect a full recovery to prior functioning, whereas the clinician is focused on maximizing the speech and language performance of the IWA and establishing effective compensatory strategies for impaired skills in an attempt to enhance his or her quality of life (Frattali, 1998). Treatment for the clinician, in such a case, is not considered as culminating in a “cure” in the clinical context; therefore, the clinician is interested in helping to shift the expectations of the IWA and the family away from an ultimate cure towards the concept of optimizing the skills and abilities of the IWA. Another disconnect between expectations of the IWA/family and the clinician could involve the length of treatment. Sometimes families desire continuation in a clinical intervention program for many years (Parr et al., 1997). The realities of insurance limits/Medicare requirements can have negative effects on an individual and family who must withdraw from treatment after a specified time and consider that their expectations were not fulfilled or that they were abandoned by health care services (Parr et al., 1997; Sarno, 1998).

Perspectives

The perspectives of the IWA and the family for recovery will necessarily involve their particular ways of viewing, understanding, and explaining issues based on their own personal experience with aphasia. These personal views of the IWA and the family can demonstrate richness, variation, and complexity about their understanding, reactions, needs, and expectations in aphasia. It is important to explore what accounts for and contributes to

recovery in aphasia through the perspectives of the individuals affected. By considering these insiders' perspectives of the recovery we can gain a deeper understanding of the impact of aphasia in the lives of the IWA and the family.

Complexity in Clinical Recovery

Aphasia results in challenges for communication that affect the behavior and the interaction between the IWA and the family. These personal and social issues inform the perspectives of these two social parties regarding the nature of recovery based on their actual lived experiences with aphasia. Because of this, it seems accurate to state that recovery is an important issue for the IWA, family, and the clinician. Each person's concept of recovery influences expectations, practices, assumptions, and activities which are manifested in the interactions between the IWA, the family and the clinician in the clinical setting and within authentic contexts. For example, in the Palestinian community in Israel, the IWA and family, based on their personal experience, may attribute the recovery from aphasia to their own motivation and willpower, or they may consider members of their social network or religious values as responsible for the recovery process (Kardosh & Damico, 2006). Such views and beliefs are shaped through cultural elements that encompass individuals based on the culture they inhabit and they illustrate the complexity of the recovery process.

Consequently, it is important to consider that recovery in aphasia is not only about physical and functional changes. Rather, recovery can involve various issues manifested through behavior and social interaction. Therefore, it is relevant and also important to consider the views about and the experience of recovery in aphasia of the IWA and those who interact with them on regular basis mainly the family in their social context.

Some individuals with aphasia and their families, in the beginning of the clinical sessions, might inquire and request information repeatedly about their own recovery or whether currently they are demonstrating any signs of recovery. The immediate response of some clinicians to questions about recovery at this point is “I don’t know.” This response could contribute to feelings of uncertainty and insecurity about recovery for the IWA and the family, indicating that recovery is an important issue for the IWA and his/her family. The following is an example of just such a situation. A young clinician in the city of Haifa in Israel was trying to explain to the wife of an individual with aphasia in the initial stage of treatment about the meaning of aphasia. The clinician was trying to help this family understand language disability and the impact it could have on everyone involved. The particular spouse seemed to be listening closely to the clinician, made no interruptions, and mainly nodded her head and smiled to indicate understanding. Following the explanation, the spouse responded immediately and in a spontaneous manner by asking a single question only: “Will he get better?” For her it was important to know whether recovery was possible and if it was realistic that it could be achieved specifically in the case of her husband. Based on such views of the spouse it is possible to assume that recovery from aphasia was important to her concerns, expectations, and goals during the interaction with the clinician in that specific moment.

This Study

The current study investigates the perspectives of IWA and their families regarding recovery. The focus of the study is how the nature of recovery has been constructed and shaped based on the perspectives of IWA and their families. This investigation is designed to

consider and address the similarities and differences between IWA and their families about their views of recovery in aphasia.

This chapter introduced several issues about aphasia including what aphasia is, the impact it has on an individual and his/her extended social circle, and what recovery from aphasia means for different people. In Chapter Two, these issues will be explored in detail and depth, including a review of published academic literature regarding recovery in aphasia, recovery in clinical aphasiology approaches, and complexity in recovery. In Chapter Three, the purposes of the current investigation are stated and the methodology employed in this study is addressed in detail. Chapter Four provides actual data on the lived experience of individuals with aphasia and those of their primary caregivers so that a deeper understanding of the recovery process can take place from the unique perspectives of these two sets of stake-holders. In Chapter Five the results based upon the experiences of these two sets of individuals will be discussed and implications will be provided.

CHAPTER TWO

LITERATURE REVIEW

In an attempt to capture the essence of aphasia as a potentially debilitating condition, it is necessary to consider a formal and a careful definition of this concept including the presentation of a concise description of aphasia (McNeil & Pratt, 2001). Aphasia has been defined as the impairment of language caused by brain damage (Benson, 1979).

Alternatively, Darley (1982) considered aphasia as damage to or the loss of the ability for the interpretation and the formulation of conventional and meaningful language symbols. Based on this definition, aphasia is a multimodality incompetence or loss that crossed all language modalities. Various authorities who offer various descriptions of aphasia illustrate the idea that aphasia can be considered differently according to which definition one is using.

Within the clinical realm, recovery from aphasia is an important issue that affects service delivery and its success in clinical aphasiology. As suggested in Chapter One, recovery can involve different facets within the therapeutic process and can mean different things in different domains within clinical aphasiology. The degree of the recovery in aphasia, the parties involved in the recovery process, the long-term impact of recovery, even the foundational conceptualization of recovery must all be considered when this issue is addressed. In this chapter, recovery and its more important facets will be reviewed and several questions worthy of further study will be examined.

A review of the published academic literature suggests that recovery in aphasia focuses primarily on change (e.g., Holland, 2007a; Frattali, 1998; Simmons-Mackie & Damico, 2001). Hopefully, it involves a beneficial change. However, there seems to be little

agreement as to the nature of this change including the components that contribute to it. What is meant by “change” has not been adequately addressed.

One attempt to understand the concept of recovery as change focuses on the impact on the brain itself. This understanding is based on an organic approach in which the brain has the ability to modify functional and even anatomical structures (Kolb & Whishaw, 2008). Another conceptualization of recovery as change draws from a more behavioral approach. That is, recovery can be considered as a change in the behavioral performance in tasks involving language modalities such as reading comprehension and writing (Simmons-Mackie, 1998) or the increased use of communication and language abilities in daily living activities (Frattali, 1998). In this sense, recovery is about social reintegration and communicative accessibility, and it is accomplished by compensation and collaboration (Simmons-Mackie & Damico, 2001).

Within these two foci, there is little agreement about how one understands recovery in aphasia (Code, 2001). In the following sections of this chapter, various issues and deliberations involving recovery in aphasia will be presented and reviewed. This will enable a greater understanding of the issues surrounding recovery and how they might be addressed.

Organic Recovery

Within the organic approach and according to recent neuropsychological theory, the human brain is capable of flexibility that can create compensation for neurological injury. Such compensation involves some recovery of function, but does not necessarily mean restoring the original anatomical structures responsible for the now-impaired function in the brain prior to the onset of aphasia (Kolb & Whishaw, 2008). Compensation can involve the restoration of the damaged function to some degree following the brain injury but not

completely. Although the ability has been “recovered,” the original behaviors do not necessarily return to the same state as before the onset of the brain injury (Kolb & Whishaw, 2008). That is, people do not actually recover the lost behaviors or abilities, but rather, they develop new ways of functioning to compensate. The individual may compensate for the difficulties and establish new behavioral strategies to perform activities that are restricted due to the brain injury. The individual does not initiate and learn these strategies consciously; rather they develop spontaneously as a result of physiological and/or anatomical changes (Kolb & Whishaw, 2008). This type of neural plasticity is defined as the flexibility of the brain as related to its capacity to change (Holland, 2008b; Kolb & Whishaw, 2008; Raymer et al., 2008). According to a recent review, the central nervous system has an adaptive ability within some neurons and their support cells that may result in functional and/or anatomical change in response to external and internal conditions (Klein and Jones, 2008). Although this potential adaptability seems to operate more robustly in younger than in older brains, even older brains can be adaptive and capable of change (Holland, 2008b).

As outlined above, neural plasticity is involved in such processes as the development and learning of new behaviors as well as relearning lost behaviors due to brain injury in response to rehabilitation (Klein and Jones, 2008). This neuroplasticity operates by facilitating functional and anatomical changes as a result of experience (Kolb & Whishaw, 2008). These experiences can be external, taking place within the environment, or they can be an internal event (Kolb & Whishaw, 2008). During the experience, these adjustments can involve potential changes in neuronal tissue, structure size, cortical thickness, dendritic branching, spine density, and changes in synapses per neuron forms (Kolb & Whishaw,

1998). These alterations affect the equilibrium of excitation and inhibition of neural networks in the brain.

In addition to the anatomical changes within this organic approach, functional recovery in the brain involves the brain's attempts to physiologically and functionally reorganize activities in the brain that have become limited and restricted. One of the mechanisms of this functional reorganization in aphasia is the involvement of the residual and the spared structures in left hemisphere regions that may have been engaged in language function prior to the onset of the aphasia (Raymer et al., 2008). Known as "concept map extension," recovery of function incorporates the expanded cortical language region in the left hemisphere (Thompson, 2000a). Another mechanism of functional reorganization in aphasia is the restoration of lost language functioning to the preserved regions in the right hemisphere that are typically homologous to the language areas (Raymer et al., 2008).

Mechanisms of Change

It is currently speculated that the primary mechanism for these organic changes is usage based. That is, the individual's loss of a particular function results from cortical tissue damage and the individual then exhibits functional failure due to organic changes. Since functions are behaviorally established, there is then a need to re-establish the impaired function (Klein and Jones, 2008). Accordingly, neuroplasticity involves the ability of the brain to perform and respond to attempts to re-learn lost functioning (Klein and Jones, 2008). This principle highlights the importance of functional use of the brain for both maintenance and improvements of abilities. When specific circuits in the brain become inactive through reduction of its role during the performance of tasks for a period of time, these circuits start to degrade and their neural responses are decreased (Klein and Jones, 2008). Therefore,

inadequate use of a brain system can lead to increased or additional deficiency of the subserved function. This can then lead to shifting this particular function to residual brain areas (Klein and Jones, 2008).

Assuming these are the organic mechanisms involved in recovery from aphasia, it is still not clear how the variables recruited actually perform language functions following the brain lesion (Thompson, 2000b). For example, there is controversy about the role of the preserved regions in the left hemisphere as well as whether impaired functions shift to the right hemisphere (Raymer et al., 2008). There are studies that demonstrated that when the improvement involves the right hemisphere, a complete recovery cannot be achieved (e.g., Belin et al., 1996). In addition, the right hemisphere can be involved in aphasia recovery by recruiting attention, memory, and executive function to support the language recovery (Crossen et al., 2005). Hence, this view sees the language recovery as facilitated by the support or the contribution of the right hemisphere which is also responsible for serving other brain functions.

One of the reasons for the confusion as to how language recovery is accomplished is that the research in neuroplasticity was not translated, used, and addressed explicitly in the aphasia treatment investigations. The research involved mainly animals, computer simulation, and people who are normal speakers (Raymer et al., 2008). Therefore, it is important to measure the actual changes in neural networks during the course of recovery in aphasia.

These issues serve to highlight the complexity of recovery in aphasia, even when just considering the organic processes involved. It is necessary to explore the nature and actual variables involved in recovery in order to develop a full understanding of the phenomenon.

Indeed, recovery in aphasia is not only about the brain and the lesion. There are other factors that it is necessary to address seriously and indepth.

Since the nature and the mechanisms of neural plasticity are not fully understood, it seems clear that a full understanding of brain recovery in aphasia is not yet available. It is not known exactly what neural changes could take place in the nervous system after the injury in aphasia. It is necessary to consider whether the concept of organic recuperation indicates a partial recovery or a full recovery with a complete return of function.

Clinical Aphasiology Intervention

Clinical aphasiology has changed remarkably over the last decade (Holland, 2008b). Traditional rehabilitation of an IWA focused on seeking recovery through remediation in linguistic and psychological impairments involving communication (Simmons-Mackie & Damico, 1996). In this model, clinical aphasiologists engaged in aphasia treatment involving increasingly complex activities that aim to explicitly facilitate recovery by improving the individual's communication functioning (Simmons-Mackie & Damico, 1999). This behavioral orientation to recovery is manifested through different aspects of the clinical intervention program, including the clinical evaluation and treatment measures which are used, with the overarching objective being to seek and establish recovery. This particular concept of aphasia is based on underlying theoretical foundations of behavioral approaches including the corresponding assumptions, objectives, strategies, and tasks involved in these clinical approaches.

Clinical Rehabilitative Recovery

Rehabilitation is usually a prime consideration when recovery of function is the objective. In this focus, positive change emerges when the 'patient' is committed to

rehabilitation and working hard in therapy sessions. The termination of rehabilitation is introduced when recovery as a beneficial positive change is considered to be achieved. (Holland, 2007a). Traditionally, the focus of this type of aphasia therapy has been on improving the linguistic or cognitive processing resulting in the improvement of language performances (Simmons-Mackie, 1998, 2008).

Certain language modalities seem to have better recovery after aphasia than others; for example, comprehension is sometimes considered as having the best prognosis for recovery of function. Several studies have reported that a high number of individuals with aphasia demonstrated recovery of comprehension at a greater rate as compared with expressive language. Additionally, a higher percentage of individuals with aphasia improved in oral language as compared with written language (Kenin & Swisher, 1972; Lomas & Kertesz, 1978). However, recovery can be found in all the various language modalities (Basso, Capitani, & Moraschini, 1982).

In traditional clinical aphasiology intervention, recovery implies improvement of language performance. Accordingly, aphasia test batteries are used in order to measure the improvement. Recovery is reflected as change in terms of test scores, and clinical intervention is considered as the means to accomplish this change. These procedures are based on the assumption that a valid assessment demonstrates language proficiency in general (Murray & Chapey, 2001; Simmons-Mackie, 1998). For example, the clinician can use the Western Aphasia Battery (Kertesz, 1982) as a measure of change so recovery becomes defined as increased performance of the IWA on activities from the test batteries involving language modalities such as naming and writing.

Despite linguistic gains, however, many people with aphasia experience residual communication difficulties that dramatically affect their daily lives. These long term effects are often not addressed by traditional aphasia intervention. Consequently, psychological and social problems may not be addressed by traditional aphasiology treatment (Simmons-Mackie, 2008). Further, such standardized measures as the Western Aphasia Battery do not reflect what the IWA can do in his or her authentic communicative activities in daily living (Simmons-Mackie & Damico, 1995). For instance, these measures do not capture the potential increases of communicative success and adaptive strategies of the IWA. Therefore, a philosophical shift is necessary to consider the impact of aphasia as it affects the psychosocial functioning of the IWA (Simmons-Mackie, 1998).

Communication accomplishes the dual objectives of the transaction of information between people as well as the social affiliation of individuals (Simmons-Mackie & Damico, 1995). The concept of recovery in the mainstream intervention is based on the assumption that when information exchange improves, then social interaction will improve (Simmons-Mackie, 1998). The understanding of communication and recovery is inadequate to some degree and lacks important issues that should be addressed. Instead, what actually constitutes interaction can be the social affiliation, collaboration, and face saving skills combined with the language skills (e.g., Goffman, 1959; Simmons-Mackie & Damico, 1996).

In this clinical intervention approach, the recovery is based on the performance of structured activities involving the language modalities which occur in an experimental setting to some degree. It is necessary to question whether the performance of the IWA in these tasks would actually demonstrate rich and implicit description of the recovery in aphasia. This typical clinical approach does not provide actual information about what constitutes the

concept of recovery in aphasia. In addition, recovery is not considered manifested through the authentic interaction during the conversation between the IWA and his or her primary communicative partners. Instead, this clinical intervention program seems to have an experimental orientation based on controlled and structured clinical activities.

Behavioral Recovery

Functional Approach Treatment

Communicative competence refers to appropriate use of language (Hymes, 1972). It involves the understanding of the way language works in social interactions and within the individual's culture (Holland, 1991). Such pragmatic skills are relatively better preserved in aphasia than other language components such as syntax and phonology. Often the IWA will use gestures more effectively to communicate than speech or writing (Holland, 1996).

Therefore, the focus of the clinician is to help the IWA to accept the notion that language breakdowns are inevitable and unavoidable to some degree (Holland, 1991). The goal of the clinician in this scenario is to facilitate the establishment of successful communication, regardless of the modality used. Treatment focuses on effective ways to use preserved language skills which allow the IWA to communicate with others. When the message of the IWA can be understood, then his or her poor articulation and grammatical errors can be ignored (Holland, 1996).

One option of the clinician is to work with the IWA to develop or establish compensatory strategies which will enable successful communication between the IWA and others. These compensatory strategies aim to create an enabling atmosphere which will facilitate successful communication and maximize the ability of the IWA to understand

others when they talk and communicative partners to understand the message of the IWA (Holland, 1991).

Various types of compensatory strategies have been practiced in clinical aphasiology (e.g., Davis & Wilcox, 1985; Holland, 1977, 1982); for example, comprehension, talking, and augmentative strategies (Holland, 1991). Talking strategies are used to “get the message across” through use of verbal and nonverbal tactics regardless of lexical or grammatical errors. Such strategies include simplifying the message, circumlocuting, or repeating the message (Holland, 1991). Accordingly, in this sense recovery does not involve complete restoration of the abilities that were damaged following the onset of aphasia. Rather, these functional approaches capitalize on residual communication skills by maximizing their use, especially the pragmatic skills of language. Hence, recovery in aphasia here refers to use of preserved skills to compensate for the affected and damaged components (Holland, 1996).

Although language abilities can improve to some degree, it is likely that the IWA will continue to demonstrate language difficulties. Because of this, aphasia is considered to be a chronic problem (Holland, 2008a). The focus is on increasing communication effectiveness rather than examining only the impairment or weakness (Holland, 2007a). Certainly, it can continue to be a challenge to learn to live with the results of aphasia even after rehabilitation. Rehabilitation is only the first essential stage in the long journey of living fully and successfully following a stroke despite the communication problems that ensue (Holland, 2007a). Consequently, it is necessary for the IWA and the family to “fit aphasia in” by learning to move on (Holland, 2008a). In this sense, the degree of recovery in aphasia is not considered as a full or complete recovery and involves sufficient rather than optimal use of language in communication during daily living activities.

Psychological Recovery

People who are affected by aphasia naturally move their attention from restoration of the damaged function to finding improved ways to communicate effectively. The individual does not focus simply on what isn't working, but rather, he or she begins to look for effective ways to incorporate what is still functional (Lyon & Shadden, 2001). From this perspective, aphasia can be considered as a set of challenges in which the IWA must adjust behavior and expectations in order to modify and establish function as much as possible (Parr, 2001). In the early months following the onset of aphasia, the role of the clinician is to maximize the recovery and to limit the impairments. However, since in many cases aphasia does not "get better," the IWA and the family must adapt in order to live successfully with the effects of impairment (Parr, 2001). Based on this perspective of aphasia, the role of the clinician in recovery involves facilitating ongoing adaptation due to the chronic nature of the language impairment.

Counseling in Aphasia. Counseling is considered an integral component of aphasia intervention according to this functional approach (Holland, 1991). Counseling provides an opportunity for the IWA to discuss with the clinician the challenges that he or she encounters during activities of daily living. Careful listening on the part of the clinician increases his or her understanding of difficulties and frustrations that the IWA copes with daily. Additionally, when the IWA is able to express feelings, concerns, anxieties and other issues, his or her experience of well-being is increased. The third aspect of the counseling process is that it presents an opportunity for the clinician to provide the sort of information an IWA needs in order to understand what is happening to them and to adapt and move forward in life. The objective of counseling in this model, then, is to help individuals and families to live as

successfully as they possibly can after the unexpected onset of aphasia, with a realistic understanding of the chronicity of aphasia but also with optimism and resilience (Holland, 2007b).

Webster (1977) summarized the main aspects of communication counseling. Firstly, counseling involves receiving information that the individual and his or her family wish to disclose to the communication counselor. The counselor provides information and helps individuals to clarify their ideas, attitudes, feelings, and beliefs. In addition the counselor provides options for changing behaviors (Webster, 1977). Counseling individuals with communication disorders, such as aphasia, and their families can have several objectives. The clinical counselor aims to help the counseled individuals to grieve for what has been lost and to develop coping strategies as well as enhance resilience. In addition, the communication counselor helps the individual to come to terms with the disorder and to make reasonable adaptations to it. The focus is on capitalizing on strengths to compensate for weaknesses and to live as fully as possible despite the condition (Holland, 2007b). Two important underlying messages are that clinicians should be committed to their counseling responsibilities and that counseling individuals with neurogenic communication disorders is among the most important things clinicians do to influence individuals in their return to their everyday lives (Holland, 2007b).

Coping. As the recovery process continues, there is an emergence of coping strategies that demonstrate that the IWA is adapting to the condition of aphasia and beginning to accept the loss and challenges that now comprise their daily lives. Coping has been defined as the maintenance of an overall sense of meaning and value (Parr, 1994), and coping with aphasia involves practical ways of making life easier (Parr et al., 1997) as people

learn to deal with catastrophic events (Holland, 2007a). Coping is an essential and complex process but is not fully understood (Parr et al., 1997). It is not only about developing strategies or finding ways of feeling better. The IWA is trying to rationalize events and actions affecting his or her life; through the process of coping, the IWA can reach an understanding of how life was until the onset of aphasia and how and why it has changed. Coping involves both limited or enhanced recovery as well as expectations about the future (Parr et al., 1997).

This perspective of coping is based originally on the early work of Kubler-Ross (1969) regarding common reactions and adjustments in which the individual come to terms with terminal diseases. Webster and Newhoff (1981) have argued that families and individuals following stroke consider the situation to be a crisis or catastrophic event. Accordingly, individuals are considered to go through a series of stages or phases, including *shock, realization, retreat, and acknowledgment*, before life can continue in a healthy and a meaningful direction (Holland, 2007b).

In the first days following the onset of aphasia after a stroke, the IWA as well as the family are often unable to take full advantage of the information which clinicians might have to offer them regarding aphasia and its impact. This happens because early *shock* diminishes their ability to absorb new information (Holland, 2007b). *Realization* occurs as the IWA and/or the family begin to appreciate the situation with which they are now faced. Only after this realization has taken place can information about aphasia and its consequences be relevant and productively used by the clinician. The final stage, *acknowledgment*, is not a synonym for “giving up.” It occurs when the IWA is able to recognize the reality of the

situation in terms of making space for his or her changed condition and ideally moving on with life (Holland, 2007b).

Other similar views have been considered concerning how people cope with aphasia (e.g., Tanner & Gerstenberger, 1988). Coping with aphasia involves the understanding, awareness, acceptance, and dealing with the long term notion and the chronic nature of the disorder (Parr et al., 1997). Therefore, recovery can be considered as a process involving dealing with aphasia in which the IWA and the family are adjusting and adapting to the challenges of aphasia.

However, there is little evidence to support “actual” coping stages in aphasia or exclusive single stages in a specific point of time (Lyon & Shadden, 2001), and the actual nature of the coping process has not been well discussed in the literature (Parr et al., 1997). It is also the case that the nature of the coping, especially the appearance or reappearance of responses does not depend only on the IWA and the spouse; rather, it involves their extended social world (Lyon & Shadden, 2001). Also, not all individuals go through every stage, and not all individuals actually reach adequate acknowledgment as the final stage (Holland, 2007b). Additionally, the reactions and adjustments of individuals do not always have a particular successive sequencing, and in aphasia, it is likely that variability exists among individuals who are coping such that there is no common or standard progression through the stages (Parr et al., 1997). Furthermore, coping with aphasia can be considered as dynamic, continuous, and overlapping, and various responses can occur simultaneously (Lyon & Shadden, 2001). Finally, responses of individuals can be cyclic in nature, meaning that a particular individual or social unit may go through a particular stage more than once.

As we can see, our knowledge of the process of coping with aphasia does not provide us with sufficient detail or a thorough enough explanation to fully describe the nature of recovery. The successive stages of coping cannot completely capture the complexity involved in the aftermath of aphasia, including the recovery process. It is necessary to consider the social parties involved as an integrated component of the mechanism of recovery in aphasia. Living with aphasia involves and affects the IWA and other people in his or her social life. These family, friends, and coworkers are the primary conversation partners of the IWA who provide communication for work and social affiliation.

Social Recovery

Interactional Aphasia

Social Construction. The principles of clinical aphasiology encourage the reintegration of the IWA and his/her social network into as full and successful life as possible by using their perspectives and support through social collaboration (Simmons-Mackie & Damico, 1996, 2001; Simmons-Mackie 2008). The attitudes and practices of those who comprise the social world of the IWA as well as environmental influences have great affect on how well this is accomplished. Sometimes limitations experienced by the IWA and his or her primary conversation partners are socially constructed barriers (Parr, 2001), emerging from the communication and the interaction between the two parties. One important issue in interactional aphasia is to focus on improving social integration and communicative accessibility.

Interactional aphasia involves a focus on authentic face-to-face interaction, including how it is systematically accomplished, what variables influence face-to-face interaction and the consequence of neurological damage to the interaction between social partners. We know

that individuals construct their understanding of objects, concepts, and situations through their interaction with others. These face-to-face interactions enable the individuals to mutually co-construct their behaviors, expectations, and beliefs (Damico, Ball, Simmons-Mackie, & Müller, 2007).

In interactional aphasia, conversational partners of the IWA are trained to adapt their own communication style in order to provide appropriate support to the IWA during the communicative act. For example, training the conversational partners of the IWA can provide “communication ramps” enabling access to autonomy for the IWA (Kagan, 1998). Although the language of the IWA may be limited and/or impaired, his or her conversational competence is sustained in many cases through the use of such scaffolds. The collaborative nature of conversation is especially evident in communication with the IWA (Simmons-Mackie, 2008; Goodwin, 1995).

Compensation. IWA’s typically use many compensatory strategies when they communicate (Penn, 2007). Many of the impaired communicative behaviors that manifest in the language of the IWA are opportunities and instances where these individuals learn to compensate or adapt for their difficulties (Penn, 2007). The IWA uses whatever resources he or she has available to allow as complete an interaction with a communication partner as possible (Goldstein, 1948). Various compensations are developed either consciously or unconsciously and can be used effectively. Gradually, the IWA, during the acute stage and as the aphasia becomes more chronic in nature, develops and becomes competent to adapt his or her linguistic ability to the demands of the surroundings in order to interact with successfully others (Penn, 1987).

In clinical aphasiology, it is common to focus on training compensatory strategies. One of the challenges in clinical aphasiology is the unwillingness or inability of the IWA to use the trained compensation strategies outside the clinical session within an authentic social context (Simmons-Mackie & Damico, 1997). The clinical effectiveness of the trained compensations is determined by whether or not they are used in a conversational context (Penn, 1987). The clinical implication of this challenge indicates that it is necessary to capture and understand the complexity and individuality of compensatory processes to ensure their success and effectiveness (Simmons-Mackie & Damico, 1997).

Simmons-Mackie and Damico (1997) introduced and established a definition of compensatory strategies in aphasia. Based on this definition, successful compensatory strategies are developed and used spontaneously, in a natural and systemic manner by the IWA, to overcome communication barriers and to meet the goals of communication involving the transaction of information and the interaction between people such as to control the interaction, to show emotions, and to repair the breakdown of the transaction (Simmons-Mackie & Damico, 1997). Compensatory strategies can be natural and in use before the onset of aphasia (Simmons-Mackie, 2008) while other compensations can be considered as novel behaviors which were unavailable to the IWA prior to onset (Simmons-Mackie & Damico, 1997). The main aim of compensatory strategies is to overcome communicative obstacles created by the aphasia (Simmons-Mackie & Damico, 1997).

Compensations are used flexibly to match the goals of the interaction and the environmental constraints of the event, and they are sensitive to context. That is, the IWA and his or her conversation partner are expected to vary their strategies to meet the contextual

constraints. It is likely that IWA and the conversation partner create compensations specific to their needs, deficits, and abilities (Simmons-Mackie & Damico, 1997).

In order for compensatory strategies to be effective, they must use and modify what the IWA has (Penn, 1987). By focusing on compensations used by the IWA the success of the interaction within a specific social environment can be enhanced to enable the participation of the IWA (Simmons-Mackie, 2001). Compensatory strategies have the potential to overcome communication barriers due to linguistic deficits and impairments (Simmons-Mackie & Damico, 1997).

Therefore, compensation is about recovery in aphasia. Social recovery includes both the ability to repair the transaction of information as well as to expand success in interaction between participants in the conversation. Recovery is created by the IWA and his or her conversation dyad as they collaborate to address their needs, limitations, and restrictions during conversation. In interactional aphasia, recovery is considered in terms of overcoming the conversation barriers established by aphasia. In addition, recovery aims to enable the social inclusion and affiliation in which the IWA is capable and allowed to participate in the social life.

Sufficient linguistic and cognitive flexibility is necessary for both the IWA and his/her conversational partner such that they can work together to create a positive outcome following the onset of aphasia. An authentic context in which to develop these skills can contribute to the successful evolution of positive strategies in recovery (Penn, 2007).

Furthermore, the challenge to the clinician is to capture a good understanding of the needs, strengths and weaknesses of the IWA and to work together to establish a good scaffolding of these characteristics to enable recovery within a natural context. These mutual goals can

serve as guiding principles for the clinician as well as the IWA in the clinical intervention sessions (Penn, 2007).

Collaborative Nature. The principles of the social actions are considered active and dynamic in nature and as the way in which two participants are involved in a process of co-construction of the meaning of any particular social event. Because of this, no person is seen as inactive in the interaction (Damico et al., 2007). Social actions, such as conversation, conflicts, fights, or nonverbal postures are active processes involving participants constructing and negotiating the meaning in a coordinated and joint manner (Simmons-Mackie & Damico, 2007). Collaboration is considered as the foundation of the social action. It constitutes an important component of the social action (Damico et al., 2007).

Conversation is a reciprocally structured activity between participants aiming to accomplish authentic, substantial interaction in actual settings and situations (Simmons-Mackie & Damico, 2007). Conversation can be considered as an interactive event and experience in which the participants are reciprocally negotiating the direction and the meaning of their talk (Oelschlaeger & Damico, 1998a). Importantly, conversation as a face-to-face interaction is always collaborative in nature (Damico et al., 2007). The participants work collaboratively, on a regular basis, to accomplish objectives of their conversation regardless several possible barriers such as aphasia (Oelschlaeger & Damico, 1998b).

In clinical aphasiology, this principle of collaboration has been repeatedly reported and verified in the investigations focusing on natural conversation between people with aphasia and their various conversation partners (e.g., Ferguson, 1996; Goodwin, 1995). Conversation can be considered as the collaboration between the participants who actively

negotiate action and meaning even when one of the participants has impairments which are caused by aphasia (Oelschlaeger & Damico, 1996).

The emphasis in the clinical setting is on the nature of collaboration of social action. Collaboration can be considered successful based on how the dyads are able to negotiate meaning. In addition, the potential for increased accessibility and social inclusion of people with aphasia is often more dependent on their interactional partners than their own abilities (Simmons-Mackie & Damico, 2007). For example, when the IWA initiates a turn during the conversation and indicates verbally the need for assistance in accessing the targeted word, the interactive response of the conversation partner addresses the need of the IWA by providing a word relevant to what the IWA is saying. In other words, the conversation partner participates in the construction of this particular turn. The conversation partner is speaking with the IWA, not for or at him/ her. This collaboration is considered as word search joint production (Oelschlaeger & Damico, 1998a).

This collaborative construction of meaning between people with aphasia and their primary communication partners has been reported in natural settings. The clinical intervention can provide recovery including sufficient communicative accessibility, social inclusion, and structural support for the individual and the primary conversation partners (Simmons-Mackie & Damico, 2007), building on the naturally occurring strategies that occur in such a conversational dyad. The IWA as well as the primary conversation partner use collaboration to assist in overcoming the challenges caused by linguistic and other communicative deficits (Oelschlaeger & Damico, 1998b). In addition, the primary conversation partner has the potential to overcome the neurological impairments and linguistic challenges manifested through aphasia (Oelschlaeger & Damico, 1998a).

Therefore, collaboration is considered as a mechanism of recovery in aphasia in which it overcomes the difficulties and challenges in aphasia. Recovery is not exclusive to the IWA, but also involves the other people who participate in conversations with the IWA (Simmons-Mackie, 2008). Although, collaboration can be inadequate due to the nature and the severity of aphasia, collaboration has the potential to contribute to recovery in aphasia (Simmons-Mackie & Damico, 2001).

As we can see, collaboration is a manifestation of recovery in which social action takes place involving the construction of meaning between the IWA and primary conversation partners. The nature of recovery is such that it involves social parties including the IWA and conversation participants on regular basis. Here the role of recovery is seen to be the ability to overcome barriers created by aphasia with the result that the IWA has adequate communicative accessibility and social inclusion.

Perspectives. During the chronic stage, the IWA can be considered as an ‘experienced’ person who has learned to live with the disability of aphasia and to make adaptation to the demands of the environment (Penn, 1987). The views of the IWA and the primary communicative partners are considered to be insiders’ perspectives since they represent personal accounts based on their own experience of living with aphasia. These experiences include the consequences of aphasia, intervention, recovery, and changes in life styles. It is impossible to capture the impact of aphasia without recognizing and addressing the perspectives of involved parties regarding the impact of aphasia (Simmons-Mackie, 2008).

The insiders’ perspectives regarding the impact of aphasia and the specific life style changes were not widely addressed in traditional clinical aphasiology. The views and

opinions of the IWA and the family were considered subjective, unprofessional, and unreliable. However, these accounts can provide us with original and personal authentication involving people directly affected by and living with aphasia (Simmons-Mackie & Damico, 2001).

The perspectives of the IWA and his or her primary communication partners are based on their own personal experiences and its impact on their lives. These accounts and views determine their demands, responses, concerns, challenges, expectations, and needs (Simmons-Mackie, 2008). Certainly, the accounts of the IWA and the families include issues regarding recovery. The perspective of the IWA and family can contribute to improving the understanding of aphasia and can impact clinical aphasiology including research and practice (Simmons-Mackie & Damico, 2001).

Furthermore, the perspectives of the IWA and the family help to capture indepth and thorough information including the complexity involved in the impact of aphasia. Consequently, the views of the IWA and the family can contribute in expanding our knowledge and maximizing our understanding of all the various aspects of aphasia including recovery.

Life Participation Approach to Aphasia

Life Participation Approach to Aphasia (LPAA) has become a popular model of service delivery for IWA. The focus of LPAA is on the consequences of aphasia, including how the impairment and its disability affect all the individuals involved, including the IWA and his or her surrounding social contexts. It is designed to expand participation in activities, selected by the people with aphasia, and to aid reengagement in life (Chapey et al., 2008). LPAA empowers the client to select and participate in the recovery process including the

selections of goals, activities, and tasks that clinicians use during therapeutic sessions. Since the main aim of LPAA is a rapid return to active life, there is a focus on the authentic life goals of people affected by aphasia (Chapey et al., 2008). LPAA addresses the personal needs of the IWA as well as the surrounding environment (Chapey et al., 2008).

There have been shifts in LPAA from focus on deficits and “cure” to a focus on inclusion and life participation. Within this approach, the clinician is required to address the personal experience of disability and to promote life inclusion and reintegration in society (Chapey et al., 2008). One of the significant values of the LPAA is to enrich life participation which has been impaired by the presence of aphasia. Another important principle of LPAA is how to provide independent, effortless, and smoother access to activities and social connections based on the choices of the client. Treatment is not only carrying on in life, it also involves enhancing participation in life (Chapey et al., 2008).

Based on the clinical perspectives and the principles of LPAA, recovery is about life. That is, recovery in aphasia is viewed as various issues involving quality of participation in life. Recovery is considered as a return to active life and reengagement in social life. According to LPAA, the nature of the recovery in aphasia is about enhancing life participation by providing smooth access to activities based on options provided to the IWA, and reintegration in society by reestablishing impaired social connections and affiliations.

Complexity in Recovery

Complexity in recovery is a well-established finding in aphasiology (Thompson, 2000b). This complexity can involve various issues including the complexity of aphasia as a whole, considerations of the concept of recovery, including incomplete knowledge and controversial issues involving recovery. These issues will be discussed as follows.

Pervasive Aphasiology

Aphasia is a wide domain and is explored and addressed through several orientations in aphasiology (Damico et al., 2007). Different disciplines focus on different specific issues and domains in the field. Therefore, these disciplines vary in what actually is considered and investigated in aphasia. That is, the primary driving force to investigations and the clinical practice in aphasia can vary to some degree across these disciplines.

For example, according to neuropsychology, aphasia is considered based on its involvement in the central nervous system including the nature, extent, and the location of the lesion and the preserved and impaired language functions following the onset. Consequently, aphasia is defined as a system of classification based on a set of types or categories such as language comprehension, language production including speech production and types of language errors such as paraphasia. Some of these types, such as nonfluent aphasia and fluent aphasia, consist of a number of different symptoms and each one is correlated to some degree with specific neural bases and cortical regions. However, there is disagreement in this discipline about the number of types in aphasia. Furthermore, large portions of the cortex are involved in any specific language function (Kolb & Whishaw, 2008). Therefore, the lesion site does not indicate explicitly and exclusively which language functions will be affected.

On the other hand, aphasia involves social parties including the IWA and his or her primary conversation partners according to the interactional aphasia approach. The IWA, just as people in general, has a driving force to establish social affiliation and to be successful during conversation. Therefore, the authentic social authentic context in which conversation

between the IWA and his or her primary partners takes place, should be seriously considered and preserved within clinical aphasiology practice (Damico et al., 2007).

As we can see, there is little agreement within aphasiology about the nature of aphasia such as who is included and identified as an aphasic individual. In addition, there is limited agreement among the aphasiologists about the possible cause for the manifestations or the “symptoms” of aphasia (McNeil & Pratt, 2001). Some investigators and clinicians may not consider aphasia as a set of types of the language disorder. Rather, it is viewed as “aphasia without adjectives” (Darley, 1982). The understanding of what is aphasia and the meaning of aphasia can be challenging to some degree across the different orientations and various disciplines in aphasiology.

Orientations to Recovery

How aphasia is considered is an important issue that affects the concept of recovery in aphasia. For example, if aphasia is considered as damage to the neural network involving language, then the initial reorganization process of this particular neural network is viewed as a recovery process (Thompson, 2000b). This recovery process involves patterns of neural reorganizations including the course and the extent of this act in the brain (Thompson, 2000b).

Alternatively, explaining aphasia based on the authentic face-to-face interactional issues and how they impact social consequences is entirely a separate domain in aphasiology (Damico et al., 2007). Accordingly, aphasia is a chronic disorder in which its consequences extend beyond the linguistic and the cognitive deficits and its impact in the long term is beyond the acute breakdown of communication following the onset (Simmons-Mackie, 2008). Consequently, recovery in aphasia does not focus exclusively on linguistic gains and

changing the linguistic performance (Simmons-Mackie, 2008). Instead, recovery involves authentic face-to-face interaction, compensation, and social collaboration between the IWA and those who interact with him or her on regular basis. Further, recovery involves addressing social barriers that can contribute to social isolation, loneliness, and loss of autonomy of the IWA by promoting his or her membership in a communicating society, establishing social affiliation, and expanding the participation in personally relevant activities (Simmons-Mackie, 2008).

As we can see, the contrasts between these two orientations about recovery and how it is addressed in aphasiology are enormous including their understanding of aphasia, how recovery is considered, the underlying assumptions regarding recovery, and the nature of the mechanisms of recovery.

In clinical aphasiology, the conceptual meaning of recovery is addressed according to the clinical perspectives that are based on the orientations of the various disciplines. The meaning of recovery, as a concept, is manifested through the foci of any particular clinical treatment programs including the objectives, strategies, and activities performed by the IWA during the clinical sessions. The meaning of recovery for any particular IWA, conversation partner and clinician can vary as to the nature of recovery, the extent of recovery, and the social parties involved in recovery.

Ambiguity (Uncertainty) in Recovery

Many issues involving recovery in aphasia are not clearly understood. For example, the underlying mechanisms of recovery in aphasia, especially in the brain, are unclear, including both early and later recovery (Hillis & Heidler, 2002). The nature of these underlying mechanisms of the recovery in the brain still requires further investigation in

aphasiology (Code, 2001). On the other hand, interaction in aphasia and social challenges are complex pervasive issues include many constituents and considerations (Damico et al., 2007). These issues have been addressed in studies based on the interactional approach by employing qualitative research procedures that can capture the richness and address the complexity of the targeted investigation, but there is still much left to be explored (e.g., Le Dorze, Brassard, Larfeuil, & Allaire, 1996; Oelschlaeger & Damico, 1998a; Simmons-Mackie & Kagan, 1999).

In another example of how recovery in aphasia is a complex phenomenon, several factors are considered to possibly affect the extent and the nature of the language recovery. Some of these factors are the site and the size of the lesion, age, education, gender, and motivation. However, the extent of the influence of these variables on recovery is unclear (Thompson, 2000a).

In addition, it seems there is a controversy about the overlap between spontaneous recovery and recovery following intervention. The main question is whether recovery is attributed to treatment and/or to spontaneous recovery (Swindell, Holland, & Reinmuth, 1998). Certainly, the timing of intervention is an important issue that affects potential recovery (Holland & Fridrikson, 2001), including when is the best and most effective time to initiate clinical intervention.

In summary, the complexity of aphasia necessarily leads to complexity in recovery. Additionally, many issues about recovery are not clear or understood in aphasiology. Also, there is controversy about what constitutes recovery in aphasia according to the particular view of a particular discipline. Because of this, there is no firm agreement regarding the

understanding of what recovery actually is (Code, 2001). This lack of consensus affects both clinical perspectives in research and clinical intervention approaches in aphasiology.

Summary

The conceptual meaning of recovery is affected by clinical orientations in aphasiology including both research and clinical practice. What actually constitutes recovery is an important issue that aphasiologists need to consider seriously. Recovery means different things in different domains in aphasiology. That is, the extent, nature, and the mechanisms that establish recovery vary between these domains. Furthermore, recovery involves certain elements of clinical approaches to aphasia including underlying principles, treatment programs, clinical objectives, strategies, and activities. Consequently, the meaning and the driving force of recovery can vary between these approaches.

There is an agreement to some degree that recovery is about change (Holland, 2007a). However, it is not clear about what actually constitutes the change. For example, recovery can be considered as anatomical and functional changes in the brain. Recovery can be viewed also as improvement of language performances in terms of language modalities such as expressive language or auditory comprehension. On the other hand, recovery can be considered beyond the brain and away from controlled experimental clinical tasks involving language modalities. In this perspective, recovery can be viewed as sufficient communicative accessibility, return to social life, and structural support for the IWA and the primary conversation partners.

Importantly, the personal experience of the IWA and their family about living with aphasia would enable us to explore and expand our knowledge about the impact of aphasia on these individuals including their expectations, concerns, weaknesses, and strengths in

recovery after the onset of aphasia. These personal experiences are extremely useful to explore and increase our understanding of the nature of recovery in aphasia and the mechanisms involved in shaping recovery.

CHAPTER THREE

METHODOLOGY

The literature review in Chapter Two demonstrated that there is little agreement in aphasiology about the nature of recovery. Principally, this is because issues involving objectives, expectations, the identity, and the characteristics of the variables that contribute to recovery are varied and complex when viewed superficially and only within individuals. Furthermore, the extent of the recovery varies in degree, and the range of recovery is guided by a number of factors.

In order to better capture, understand, and explain the perspectives and lived experiences of individuals with aphasia and their caregivers, there is a need to more deeply investigate the nature of recovery. This chapter addresses and clarifies issues relevant to the research design employed in the investigation. The current chapter can be divided into five sections. The first section focuses on the research questions for the current investigation including the general question and the several sub-questions of the study. The second section involves discussing the qualitative research design including the main concepts in the methodology – the characteristics as well as principles – of this design, and employing phenomenological research in considering the perspectives of the individuals with aphasia and their caregivers, including their lived experiences with recovery. The third section details the characteristics and the background of the participants in the current investigation. In the fourth section, the data collection procedure for this study (semi-structured interviews) is described while, in the final section of this chapter, a discussion is provided on employing interpretive phenomenological analysis as the principle method of data analysis.

Research Questions

This investigation explores the nature of the lived experiences of the individuals with aphasia and their caregivers regarding the recovery process. The current study attempts to capture the similarities and differences in the perspectives regarding the recovery between individuals with aphasia and their caregivers.

The main research question in this research is: *What are the perspectives of individuals with aphasia involving the nature of recovery in aphasia, as compared with their caregivers?* The current investigation will seek to understand and explain issues relevant to the recovery in aphasia manifested through the perspectives of these two parties. This will be accomplished by comparing of the underlying elements that contribute to construct recovery based on the lived experiences of the individuals with aphasia and their caregivers. The sub-questions in this investigation are specific in nature that contributes to the general research question. These sub-questions are presented as follows:

1. How people with aphasia and their caregivers view aphasia?
2. What are the understandings and the conceptualizations of the recovery process involving the individuals with aphasia and their caregivers?
3. What is the nature and the roles played by the variables involved in shaping the recovery based on the perspectives of the individuals with aphasia and their caregivers?
4. What are the attitudes, expectations, needs, and concerns of the individuals with aphasia and their caregivers regarding recovery?
5. How is treatment involved in shaping the perspectives of the individuals with aphasia as well as their caregivers regarding recovery?

Qualitative Research Design

Qualitative research as a paradigm originated from cultural anthropology and American sociology (Kirk & Miller, 1986). Recently, it has been employed in studies in other disciplines such as education as well as speech and language disorders (Creswell, 2003; Damico & Simmons-Mackie, 2003). Over the past two decades several investigators have encouraged researchers to employ more qualitative research methodologies in the aphasiology research (e.g., Damico, Simmons-Mackie, Oelschlaeger, Elman, & Armstrong, 1999; Holland, 1994; Klippi, 1991). Indeed, since such encouragement, qualitative research designs have been used to investigate and to capture the authenticity and the complexity in various aspects of aphasia (e.g., Ferguson, 1996; Goodwin, 1995; Laasko, 1997; Le Dorze & Brassard, 1995; Perkins, 1995; Oelschlaeger & Damico, 1998a; Simmons-Mackie & Damico, 1997; Wilkinson, 1999) as well as exploring numerous issues involving the impact of aphasia (e.g. Croteau, Vychytil, Larfeuil, & LeDorze, 2004; Michallet, Tetreault, & Le Dorze, 2003; Parr, 1994; Parr et al., 1997; Simmons-Mackie & Damico, 1996).

Rationale

Qualitative research is designed to understand a particular social situation, event, role, group or interaction (Locke, Spirduso, & Silverman, 1987). In general, qualitative research involves a process in which the investigator gradually makes sense of a social phenomenon by contrasting, comparing, replicating, labeling, and categorizing the relevant variables (Miles & Huberman, 1984). Due to the design characteristics of qualitative research, the investigator may understand the individual's world and the meaning of shared experiences between the researcher and individual in a given social setting, especially since the

investigator enters the individual's world seeking to capture his or her perspectives by using the person's own terminology and conceptualizations (Marshall & Rossman, 1989).

A variety of benefits can arise from employing qualitative methodologies in the investigations of social phenomena. Based on methodologies from this research paradigm, the investigator can establish an analysis involving words and images rather than numbers and can capture the authentic nature of the investigated phenomenon and this can be accomplished using a cyclical and generative process rather than testing a particular hypothesis as in experimental research designs (Hammersley, 1992).

Principles

Within the qualitative context, the investigator studies the social setting through interacting with the participants and exploring their perspectives. Qualitative research is oriented to how the participants understand and react to what is happening in the social settings (Creswell, 2003). This characteristic enables the investigator to establish a rich interpretation of participants' perspectives (Janesick, 1994) and to capture the process and its outcome as a product of the participants' social actions (Frankel & Wallen, 1990). In qualitative research the investigator is interested in understanding how things occur and there are principles that enable this objective (Damico et al., 1999). Some of the most relevant principles within this paradigm will be detailed below.

Principle One: What is going on?

Researchers oriented to qualitative research need to learn about the world that they are interested in studying so that they can try to make sense of it (Agar, 1986). This approach is demonstrated in the question: "What is going on?" in which the research is designed so the investigator can explore, describe, and understand in detail a specific phenomenon in context

by studying the relevant series of overlapping events and actions involved within this phenomenon (Damico, Simmons-Mackie, Oelschlaeger, Elman, & Armstrong, 1999). For example, in order to understand how overwhelming aphasia might be to the IWA and his/her family, it would be necessary to analyze the deficits in the communication; the responses of the family; the changes in the interaction that occur between the two parties; and how the physical, affective, and social settings are adjusted as a result of these changes (LeDorze & Brassard, 1995; Parr, 1994). Therefore, the qualitative researcher adopts a learning role in which the researcher attempts to capture the targeted phenomenon rather than a testing role which subjects a hypothesis to possible falsification (Damico & Simmons-Mackie, 2003).

Principle Two: Authenticity

Another principle of qualitative research involves focusing on the phenomenon of interest by collecting data within real and natural contexts which are relevant to human behaviors and the targeted events that occur. This typically enables a deep understanding of the investigated phenomena in the social realm (Silverman, 2005). Since qualitative research was designed to describe how people get on with and actually perform in their daily lives in authentic contexts (e.g., home, work, and other private and public places), the authenticity is a prominent principle and a foundation of the qualitative research. Consequently, methodologies within the qualitative paradigm are designed to understand and describe the elementary aspects of the routine, mundane type of activities and actions in daily life, rather than just addressing what seems atypical or what occurs in strictly controlled experimental contexts (Damico et al., 1999; Silverman, 2006). This enables the investigator to establish a detailed description of the social phenomenon involving the actual experiences of the participants.

Principle Three: Perspective-Taking

A third principle of qualitative research involves the fact that the focus of qualitative research is on the participants' accounts and experiences including the way they make sense of their lives (Frankel & Wallen, 1990). This type of research methodologies involves viewing the events, actions, norms, and values from the perspectives of the people who participated in the study (Bryman, 1988). Consequently, imposing theories and concepts a priori can be considered biased and inappropriate. Instead, qualitative methodologies use a wide set of measures that are interactive and humanistic in nature and that allow the investigator to interact with the participants in such a way that their perspectives are valued and employed in understanding the social phenomena under consideration (Denzin, 1989).

Principle Four: Interpretive

The interpretation of the data is a fourth way that qualitative research is advantageous. By discovering the specific and tangible variables that are used to construct one's ongoing social responses in authentic settings, the researcher engages in a process of discovery and analyzes social, psychological and contextual variables to determine how patterns of these variables give rise to the overt behavioral manifestations that create some sort of social meaning. These meanings are negotiated within the social actors based on the participants' realities. In qualitative research the investigator attempts to reconstruct these meanings and the underlying reasons for them (Lincoln & Guba, 1985). To accomplish this interpretation, qualitative investigation evolves and unfolds during the process of data analysis so that patterns of understanding will emerge to form a broad interpretation (Creswell, 2003).

Principle Five: Description

Essentially, since qualitative research is interpretive in nature, the investigator is expected to provide an explanation of the data demonstrating what variables are involved in meaning construction. This enables deeper understanding and can recommend questions for further research (Wilcott, 1994). In order to accomplish interpretative adequacy, however, it is important to have a rich and detailed description of the phenomenon, the participants, and other contextual variables. The descriptive focus is an important characteristic of the qualitative research paradigm that helps ensure that the objectives of descriptive richness and interpretive adequacy are fulfilled (Creswell, 2003; Damico & Simmons-Mackie, 2003).

Summary

Studying the phenomenon within authentic contexts can enable the investigator to capture and analyze the relevant variables thoroughly (Damico, Simmons-Mackie & Schweitzer, 1995). Consequently, a good and comprehensive understanding is established regarding the behaviors and patterns of interaction that were investigated. It is necessary to capture the complexity of the social phenomena within a context (Guba & Lincoln, 1994).

The Specific Tradition of Inquiry: Phenomenology

Phenomenology is a qualitative tradition of inquiry that was originated from the realm of philosophy. Early in the twentieth century, Edmund Husserl who was a mathematician and a philosopher introduced and promoted phenomenology. Husserl was interested in the fundamental cognitive nature of consciousness. Consequently, he did not consider the neurological or the physiological processes involved in consciousness. Rather, Husserl argued that a group of experiences are characterized by the highlighted awareness that these experiences are assigned and that this assignment is oriented toward what he referred to as

“object-directness” but what we now call “intentionality.” According to Husserl (1925), what the various forms of consciousness such as perception, thought, imagination, anticipation, judgment, and reminiscing share is that they intend objects by which these experiences cannot be analyzed appropriately without considering the expected objects (Zahavi, 2003). Based on Husserl, there is a dynamic relation between perception and its objects in which the human consciousness is always involved in one’s awareness and the way this is interpreted into one’s lived experiences. This interaction between perception and the interpretation through human consciousness are not separated; rather they work together so that the input is supplied by the perceptions and the consciousness actively constructs the objects of experience. Therefore, consciousness is constructed by each individual and their lived experiences are the manifestations of this constructive process. Husserl’s aim was to study the structures of the consciousness involved in these types of world perceptions (Holstein & Gubrium, 2005).

Husserl argued that in order to investigate the structure of consciousness, it is essential to discriminate between the act of consciousness and the phenomena at which it is directed, (i.e. the object that is perceived). This can be possible by the procedure known as epoché which involves “bracketing” all assumptions regarding the existence of an external world. This does not indicate questioning, rejecting, or excluding the reality from the study. Rather, it is necessary to focus more closely and explicitly on the phenomenological given, directed at the object itself, by suspending or neutralizing reality, not excluding it (Zahavi, 2003).

In 1960s and 1970s, Schutz promoted phenomenology in social science by highlighting the notion that in society individuals are always constructing their reality while

attending to their daily lives. She considered the ways people live in the world and how they take their interpretations for granted (Zahavi, 2003). According to Schutz, the focus of the analyst is on how this social world is made meaningful; how its members capture and execute the objects of their experience as if they were detached and differentiated from them. The analyst would study the ways that members of the “life world” would address subjectively what are the objects and events that are essentially of and considered to be real, as available and detached of their attention and presence in the world (Holstein & Gubrium, 2005).

Phenomenology as a Qualitative Research Inquiry

Among others, Husserl and Schutz have contributed to phenomenology as a qualitative research tradition (Zahavi, 2003). They considered the constructed and the interpretive quality of the lived experience as the foundation of knowledge in which the focus is on the individuals who lived through the experience. Consequently, phenomenology aims to study objective phenomena that have been lived through and understood by individuals in their daily lives (Giorgi, 1985). The main characteristics of phenomenology as a qualitative research inquiry are addressed as follows.

Objectives

Phenomenology attempts to understand how people construct meaning through the interaction with others. The researcher seeks to study how the phenomena are experienced in a system of interrelated meanings (Giorgi, 1997). The goal of the investigator is to describe, clarify, and explain situations lived through by the individuals in their daily lives in which these situations are the natural contexts of the targeted phenomena that occurred and were experienced by these individuals. The investigator attempts to capture a description of the constituents of the targeted experience developed by the participants involving the actual

situation as it appears to them, including their interpretations or relevant meanings to the situation as a whole, their feelings as well as their current and previous experiences (Ashworth, 2000).

Lived Experience. Understanding the “lived experience” is an elementary principle of phenomenology. The focus of this qualitative tradition is on apprehending the experiences within the lived context of the participants. The targeted phenomena are investigated through the interpretations of the participants who actually experienced these phenomena in life situations. Hence, the investigator should set away or postpone his or her beliefs and consider the world of the participants by approaching as much as possible the targeted behavior experienced by the participants (Giorgi & Giorgi, 2005). This typically accomplished by allowing the participants in the research to tell the story from their own points of view. This should maintain the reality of the phenomenon as it is lived.

Social Construction. The social construction involves the individuals’ attempt to understand their world where they live and work. These individuals develop ‘subjective’ meanings of their experiences involving certain objects, events, and people. In my opinion, there is richness and variation in these meanings that contribute to the complexity in the views of the individuals. Consequently, the goal of studies involving social construction is to capture the participants’ views of the situation being investigated (Creswell, 2003).

Why Phenomenology is Relevant

As a qualitative research inquiry, phenomenology is appropriate to the current investigation for five reasons. First, phenomenology can enable the investigator to study objectively the experience of the IWA and the family who lived through the process of recovery in aphasia. Therefore, the research would have an insight to the opinions of the

IWA and the family considering aphasia and the recovery process. Second, the researcher can establish the meaning of the recovery in aphasia based on the personal accounts, interpretations, and the understanding of those who experienced and affected by aphasia including the IWA and the family. Third, the system of interrelated meanings and interpretations involving the experience of recovery in aphasia can construct the perspectives of the IWA and the family regarding the recovery, including their responses, expectations, concerns, needs, and strengths. The focus is on the targeted phenomenon, recovery in aphasia, and its context as it presents the “life world” of the IWA and family. The aim is to facilitate a first-hand description, by the IWA and the family, of these situations as they actually occurred from their perspectives. Forth, these meanings and interpretations, based on the experiences of the IWA and the family, would capture the complexity and the dynamic nature of recovery in aphasia. Finally, the goal of phenomenology is to investigate the phenomena as it has been experienced by individuals in everyday life.

Participants

Participants’ Selection Criterion

Criteria were developed to determine the selection of the appropriate participants for the current investigation. The characteristics of the participants had to match specific requirements of this criterion. The requirements of the study are addressed below.

1. Three individuals with a documented diagnosis of aphasia based upon objective test data from a certified speech-language pathologist and who agree to participate in the study.
2. Three family members (one from each of the individuals with aphasia who have agreed to be participants) who have close and frequent contact with the individual

- with aphasia – especially before and during the occurrence of aphasia and its subsequent phase of recovery and who agree to participate in the study
3. For the three individuals with aphasia, the severity of aphasia can range between mild-to-moderate and moderate. This enables these individuals with aphasia to participate actively in the semi-structured interviews so that they may contribute to the study.
 4. The participants with aphasia should be at least one year post onset of the occurrence of aphasia.
 5. The etiological cause of the aphasia for the participants with aphasia is a cerebrovascular accident (CVA).
 6. The participants with aphasia may have received speech and language therapy at some stage following the onset.
 7. The participants with aphasia should have attained at least a high school diploma.
 8. The caregivers must have had close and frequent contact with the participants with aphasia at least five years before the onset of the aphasia.
 9. The education background of the caregivers is similar to the participants with aphasia.
 10. All the caregivers are from the same community and the same region as the participants with aphasia.

Participants' Recruitment

In order to enlist and allocate the participants for this investigation, several steps were undertaken. Initially, contact was established with regional medical clinics, healthcare providers, and rehabilitation centers in the State of Louisiana in the United States. These organizations, centers, and health clinics were expected to be familiar with the health,

medical, and well being issues of the targeted participants with aphasia. Requests were made to these parties to provide the investigator with names of possible participants with aphasia for the study. In order to consider potential participants, the researcher provided a basic explanation about the nature of the aphasia based on the requirements of the current study to enable the contacts in these organizations to understand to some degree the characteristics and the requirements of the targeted participants. Hence, information about possible participants, especially the severity level of the aphasia would be appropriate and relevant to the study.

Potential participants were selected based on first-come first-serve basis as long as they met the criterion requirements of this study. Getting in touch with the potential participants was made by telephone calls or personal contact. Meetings were scheduled with the participants in the community to obtain their agreement to participate in the study and to interview these individuals in accordance with, and approved by, the University of Louisiana at Lafayette's Institutional Review Board (IRB) regulations and guidelines.

The anonymity of the participants in the study is respected and secured. The names of the participants were coded and assigned aliases to prevent any possible disclosure or recognizing the identity of the participants. The transcriptions of the interviews do not compromise the confidentiality of the participants and their anonymity. Any information about the identity of the participants was kept in a safe and locked location. Details involving the personal identifications of the participants and their caregivers were modified in the transcriptions of the interviews.

As required by the university IRB, potential participants were asked if they would agree to voluntarily participate in the investigation, and it was explained to them that they

could withdraw from the study at any time based on their personal free decision. The potential participants were asked to sign an adult participation consent forms prior to the interview. There were two versions of these forms. The first form was a typical and regular consent form designed for the family members. The second form was designed for people with aphasia who experience language difficulties that may prevent their abilities to make informed decisions involving their participation in research.

In the current investigation, the form used with participants with aphasia is based on the work of Kagan and Kimelman (1995). This included their recommendations and suggestions for appropriate modification for individuals with aphasia. Accordingly, this form is designed to enable the participants with aphasia to understand the nature of the study and to make informed decision about participating in the investigation. The form is written in a simple language with short sentences so it can be relevant and taking under consideration the compromised abilities of people with aphasia. This type of consent form includes yes-no questions to confirm the understanding of the covered information prior signing it. Furthermore, the process of verification was used directly after explaining substantial items. The form combined large text, pictographs, and symbols organized carefully (Kagan & Kimelman, 1995).

Description of Participants

This section involves a discussion of the characteristics of the participants with aphasia and their caregivers in the current study.

Aphasia Group

Three individuals with aphasia living in the southeastern region of Louisiana agreed to participate in the current investigation. This group of participants met the requirements of

the investigation. Some of the demographic characteristics of the participants with aphasia are detailed in Table 3.1. In addition, background details regarding the specifics of each individual's diagnosis of aphasia are provided in Table 3.2.

Table 3.1 Characteristics of the Aphasia Group

Participant Alias	Gender	Age (years)	Region	Religion	Education	Occupation
DR	Female	60	Urban	Christian	B.A.	Nurse
MN	Female	74	Urban	Christian	B.A.	Secretary
KN	Male	61	Urban	Christian	M.A.	Administrator

DR. DR is a sixty year-old female living in Lafayette, Louisiana. She is single and lives alone in her residence. However, her sister lives on a cross street less than one block away from her and her niece and her family (including two grandnieces) live next door to DR and all of them frequently interact. DR completed a bachelor's degree in nursing at the Louisiana State University. She worked as a nurse at a hospital in Lafayette in the intensive care unit and the oncology department for a long period of time. DR had a stroke one and a half years ago resulting in aphasia. DR was planning to retire before the onset of the stroke and aphasia. She received only several speech-language pathology sessions following the onset. DR attends the aphasia support group meetings on a regular basis.

MN. MN is seventy four year-old female from a Cajun background. She is a catholic Christian married with three children, including two daughters and one son. MN lives with her husband in Lafayette, Louisiana. MN attends church services (mass) at least once a week.

Table 3.2 Background details of the Aphasia Group

Participant Alias	Cause	Onset (Years)	Aphasia Severity	Associated Diagnosis
DR	CVA	1;6	Moderate	None
MN	CVA	3;0	Moderate	Rt. Hemiparesis
KN	CVA	5;6	Moderate	None

She received a bachelor's degree in secretary science at the University of Louisiana at Lafayette. She is a multilingual speaking English and French. MN worked as a secretary in a bookkeeping agency in Lafayette. She had a stroke three years ago resulting in a right hemiparesis as well as moderate aphasia. MN had to retire from her job as a secretary after the onset of the stroke and the aphasia. She received speech-language pathology sessions on a regular basis following the onset. MN attends the aphasia support meetings on a regular basis.

KN. KN is sixty one year-old male who lives with his spouse in Crowley, Louisiana. He has three master's degrees. KN worked as a director for an organization that provides manufacturing agencies in Louisiana with services such as creating and maintaining improvement, quality marketing, and providing technical solutions. KN had a stroke five and a half years ago that left him with aphasia. He had to retire after the onset of the stroke and the aphasia. KN received speech-language pathology sessions following the onset in several occasions. He attends the aphasia support meetings on a regular basis.

Caregiver Group

Three caregivers of the participants with aphasia agreed to participate in this investigation. All the caregivers in this group received an explanation about the study and signed the consent forms.

DRC. DRC is sixty five year-old Christian female living in Lafayette. DRC is the oldest sister of DR and she is six years older than her. DRC lives very closely to DR across the street in the same neighborhood. She is very familiar with DR and these two sisters meet on regular basis.

MNC. MNC is seventy seven year-old male married to MN. He lives with MN in Lafayette, Louisiana. MNC is multilingual speaking English and French to some degree. He holds a bachelor's degree from the University of Louisiana at Lafayette and is retired from business.

KNC. KNC is sixty year-old female married to KN. She currently has a fashion consulting business and works four days a week. The couple has been married for ten years. They live together in their home in Crowley. KNC is a Christian and she goes with KN to church masses on regular basis.

Data Collection Procedures

Semi-structured interviews were employed as the primary data collection technique with each participant in the current investigation. Based on semi-structured interview, the investigator focused on obtaining information from the participants involving their perspectives on recovery from aphasia.

Semi-Structured Interview

Background

The semi-structured interview is a qualitative data collection technique frequently used in the social science research. This type of interview is commonly employed to explore issues involving the lived experiences of individuals in complex social settings. The format and guide for conducting semi-structured interviews is based on the scope of questions created by the investigator who is interested in exploring certain areas and the participant responses (Smith & Osborn, 2003). For example, the aim of this type of interview is to understand the participant's views and to have insight into particular issues. Hence, the semi-structured interview is designed to get the interviewee to talk freely and openly to ensure obtaining indepth information about the agenda of the interviewer.

Before meeting with the participant, the investigator prepared a general set of questions for the interview and was prepared to use these as a way to engage the participant in an interview that operated as a dialogue. Consequently, the interview tended to be conversational in nature. According to the progress of the interview, the interviewer changed the order of the questions or the way they were phrased. To ensure understanding and cooperation, the investigator/interviewer provided frequent explanations of what he was doing when he asked the questions, and carefully monitored the interviews so that he could clarify if there was some comprehension difficulty. At times, the investigator/interviewer left out previously prepared questions that appeared unnecessary. The flexible nature of this type of interview allowed new questions to be introduced during the interview as a result of the responses of the interviewee. This resulted in a dialogue wherein the interest of the respondent tended to lead the course of the interview.

In general, this form of interviews aims to obtain views and opinions from the participants. It provides the tools to discover the culture of the informant, personal accounts of the world, behavior, values and beliefs (Westby, 1990). The individual has the opportunity to select the important information to share with the investigator. The main focus of these interviews is to obtain a “vivid description” of the participants’ lives experiences and beliefs (Westby, 1990). Importantly, the investigator can capture the crucial and the fundamental elements as well as the meaning of each participant’s life by exploring the insights and establishing the accounts of the individual (Jenesick, 1994).

Accordingly, the semi-structured interview in the current investigation is designed to explore the world through the eyes of the participants being interviewed and addressing events, actions, norms, and values regarding the recovery in aphasia.

Scope and Techniques

Importantly, the semi-structured interview is structured to establish and maintain a comfortable and productive relationship between the investigator and the respondent during these interviews (Westby, 1990). In the beginning of the encounter, the interviewer must establish trust, rapport, and authentic communication patterns with the participants that will be maintained throughout the interview (Jenesick, 1994). This will ensure that participants will be more at ease and more willing to and collaborate with the investigator in telling their stories. This will enable more opportunity to disclose information about sensitive issues that may be relevant to the investigation.

In terms of the actual process of interviewing, the investigator/interviewer gradually introduces open ended questions that can assist the participants in sharing their experiences. To accomplish this objective, the investigator/interviewer has to carefully structure the right

kind of question in the right kind of ways. The investigator/interviewer employs both descriptive and structural questions during the interview (Westby, 1990). Descriptive questions are broad and general in nature allowing the participants to describe their experiences, daily activities, and objects as well as people in their lives (e.g., “Tell me about living with KN just after his aphasia.”). These descriptions provide the interviewer with a general idea of how the participants view their world (Westby, 1990). In the current investigation, the participants discuss issues regarding recovery in aphasia. The following are examples of open ended descriptive questions used in the current investigation about aphasia and recovery in aphasia:

1. Can you go back and tell about your experience with having aphasia if you can remember?
2. Tell me a little bit about the therapy you’ve had with the clinicians I’m interested in how you saw that over time?

Structural questions are employed to explore the responses of descriptive questions that facilitate the interviewer to discover what is important to individuals with aphasia or their caregivers. These questions tend to provide more specificity and greater detail. The primary kinds of structural questions involve experience questions (e.g., “Can you tell me about an actual experience that you had when you ‘decided not to join the gang?’”) and example questions (“Give me an example of ‘she is just not the same person that she was.’”).

Based on the work of Spradley (1979), this interview procedure enables the investigator/interviewer to ask a set of general questions to get the interviewee to address issues relevant to the investigated matter. Additional questions will be employed to obtain more specific information and relevant examples as follow up to the interview’s statement

(Spradley, 1979). When a topic or line of inquiry pursued in the interview appears to be exhausted, the investigator would move to another topic relevant to recovery by asking a general question followed by more specific questions. The following are general questions involving moving to other issues about recovery in aphasia used in the current investigation:

1. In terms of recovery what did you see the things that really helped out?
2. Tell me about your hopes for the future?

Each interview was terminated when the main topic was fully addressed. The duration of the interview was at least sixty minutes. The interviews were digitally audiorecorded and these digital productions were carefully transcribed orthographically.

Within these interviews, it is generally the case that certain issues and words will be repeated within the answers of the participants and these are followed up with other questions. In this way, important categories of knowledge are manifested through these words and issues (Westby, 1990). The investigator attempts to understand the relationship among these categories and the nature of the issues being studied (Westby, 1990).

Possible Benefits of Semi-Structured Interview

In general, there are various benefits of using the semi-structured interviews. First, this form of interviews is considered as less invasive to the individual. Second, the interviewer develops a relation between him or her and the respondent that generally results in information about the reasons and the relevant topics of the interview that acts to prepare and make the respondent comfortable to discuss sensitive issues. Third, semi-structured interviews can be oriented toward the interaction between the involved two parties (Silverman, 2006). For example, the informant has the opportunity to ask questions to the interviewer who can provide relevant information to the informant (Westby, 1990). Fourth,

the interviewer can obtain indepth and the rationale regarding relevant issues by the respondent. Fifth, the interviewer can probe the informant to talk about certain issues or to clarify complex questions, and to confirm his or her answers. Sixth, the interview can be easily documented by either audiorecording or videorecording the interviewing session.

Procedure

Settings and Schedule. For each participant, the following procedure was employed for each interview.

- Each of the six participants (three individuals with aphasia and their three caretakers) were interviewed separately in a quiet room containing a table, a digital auditory recording device (Sony IC Recorder ICDPX720), and the two parties to the interview (investigator/interviewer and participant).
- Each of the six participants was interviewed once for at least one hour. The only exception to this was KN who had two 40 minute interviews due to time constraints.
- The interviews occurred in the University of Louisiana at Lafayette Speech, Language and Hearing Center located in Burke-Hawthorne Hall (with one exception – MNC preferred to be recorded in his home). These interviews were conducted in quiet therapy rooms at the center with little or no auditory or visual distraction from other individuals.
- The time post onset for the participants with aphasia were calculated based on the period of time between the onset of the aphasia and when these interviews were administered.

- All the interviews, involving the participants with aphasia and their caregivers are designed according to the semi-structured interview format.
- The semi-structured interviews were audio recorded in a digital format after obtaining the participants' permissions.
- The interviews were orthographically transcribed after they were terminated. Copies of the transcriptions are provided in the appendices on a compact disk which is attached to this dissertation's back cover.

Data Analysis

Data analysis within the qualitative research paradigm is designed to describe the investigated phenomenon, to explain its foundation as well as any meaning that these phenomena hold in the individuals' lives and in the system of the social activity (Janesick, 1994; Denzin, 1989). According to Geertz (1973), the researcher aims to create a rich description of the investigated phenomenon and to fully understand why the event happened (Damico, Simmons-Mackie, & Schweitzer, 1995). Consequently, data analysis is a systemic procedure to establish a careful interpretation of the data collected and to achieve a good understanding of how social actions and social experiences are created and maintained (Damico et al., 1999). This is an ongoing generic process in which the analysis is developed from information obtained by the participants. Specifically, phenomenological research employs analysis of significant statements, the generation of meaning units, and the development of core description (Moustakas, 1994).

Interpretive Phenomenological Analysis

Following the completion of seven transcripts that were based upon the digital auditory recordings, the completed transcripts were reviewed and analyzed by the

investigator. The data analysis in the current investigation is based on Interpretive Phenomenological Analysis (IPA) developed by Jonathan Smith in mid 1990's (Smith, 1996). IPA is common in qualitative research in the psychology realm. It was originated in health psychology and has been recently used in various domains in psychology including social, clinical, and counseling (Smith, 2004). However, IPA is employed in other disciplines outside the psychology realm as well. This type of data analysis aims to explore indepth the participant's personal lived experience and how the person makes sense of his or her experiences (Smith, 2004). In general, the researcher attempts to have an insight into the individual's personal world and to take his or her perspective. Further, the investigator tries to explore how the participant's who come across particular situation perceive these situations. This type of analysis is phenomenological in nature (Giorgi & Giorgi, 2003) since the investigator attempts to suspend his or her reality, and to make sense of the participant's social and personal experience based on his or her perception of events as well as objects.

IPA Characteristics

Typically, the IPA can provide indepth interpretation of the data with a small group of participants or even a set of case studies (Smith, 2004). The investigator is usually engaged in a process of interpreting the meaning and making claims about the participant's emotional state and thoughts involving the area of concern. The focus is on meaning obtained through a persistent engagement with the text and a process of interpretation (Smith & Osborn, 2003). In general, the analysis of all the transcripts will look for patterns of interaction and derive categories and definitions of behavior from the data (Smith, 1996).

IPA is flexible in nature in which its techniques can allow unpredictable issues or themes to evolve during the analysis. Further, IPA is a multi-stage process involving

different stages and levels of interpretation. It is possible to use this type of analysis with adults whom English is not their first language. However, it is necessary to provide guidance for employing IPA in qualitative research with different populations (Smith, 2004).

IPA Procedure

IPA is a step by step approach involving multiple readings of the transcripts (Smith, Jarman, & Osborn, 1999). Each transcript is carefully and thoroughly reviewed. The analysis cycle of IPA is designed to determine whether experiences reported by the participants form a pattern of meanings in which their experiences, perceptions of events as well as behaviors, and emotional responses contribute to construct an interpretation. IPA involves a series of seven interrelated stages to establish an understanding of each participant's lived experience with the recovery in aphasia. A discussion of these specific stages of analysis follows.

Stage One. The analysis begins with a close reading of all the transcripts. The investigator gains a general sense of the information. The investigator jots down in the margin of the transcript any initial ideas as they are generated and invoked by the statements of the participant (Osborn & Smith, 2008). These notes involve thoughts, observations, and reflections that occur while reading the transcript. It is likely that such notes include any the language used, recurring phrases, comments, and the investigator's questions (Smith, Jarman, & Osborn, 1999).

While engaging in reading the text in the current research, the investigator makes notes to document points that were considered. These written comments and ideas can be considered as initial notes (Smith & Osborn, 2003). This stage aims to make the investigator familiar in general with the data. Multiple readings of the transcripts can increase and expand the understanding of the data in different and new levels.

The investigator in the current study made a general impression of the content of the transcripts including information reflecting the whole meaning about recovery in aphasia that was manifested through the interviews.

Stage Two. The second analysis stage follows the previous step combining both the transcripts and the written notes. Additional notes can be added by focusing on the notes written on the transcript's margin in Stage One. This stage of the analysis involves documenting the evolving themes titles by transforming the initial notes into concise phrases aiming to capture the essential content of the transcript. During the second reading, the investigator identifies words, terms, questions, summaries, metaphors, concepts, and experiences that summarize the content of the data, and to place them on each transcript. The focus of this stage is on transforming these notes to themes that are more concise and abstract (Smith & Osborn, 2003). It is important to tie any evolving themes and the actual participants' statements in the transcripts. Finally, the analysis in Stage Two ties those themes with relevant statements that the participants may contribute. This act is the beginning of the patterning process.

In the current investigation, these items reflected upon the attitudes, expectations, objectives, and activities in the participants' perspectives regarding recovery in aphasia manifested through the interviews.

Stage Three. The current stage is designed to seek connections between the items and the brief statements that were made (Biggerstaff & Thompson, 2008). Refining the emerging themes in the current investigation began in this stage. The investigator as an analyst considers the relationship between the various emerging themes based on their sequential relation, as in their chronological order in the transcript (Biggerstaff & Thompson,

2008). In general, three types of data are available in the transcripts including the actual words of the participant, the original written notes, and the written transformations. Additional themes can evolve resulting from this sequential connections process. These new themes are considered as the product of the cyclical nature of qualitative research methodologies. The process of linking the emergent ideas, including the refined terminology, the deeper thematic connections, and further abstractions, with the actual sentences of the participants can ensure that the interpretation is still based on and relate to the collected data (Smith & Osborn, 2003). This act or process indicates that the analysis is not separated from the data.

Stage Four. The current stage is designed to further refine the emergent themes using all the generated data from the previous themes. This stage involves the analytical sequencing between the emerging themes in which the analyst attempts to make sense of the connections between them. The investigator addresses any possible connections among the themes based on the logical relations (Osborn & Smith, 2008). Some themes can be grouped together, whereas others may differ or have hierarchical relationships, as subordinates or higher ranking level, with each other (Osborn & Smith, 2008). The investigator considers the similarities, differences, extensions, and contradictions between these themes. In general, the current stage helps to clarify these emergent themes into overall themes.

In the current investigation, Stage Four involved refining the coding, by evaluating the clusters of emerging themes written on the transcript, to determine if they actually reflect the data elicited from the transcribed interviews involving the recovery in aphasia.

Stage Five. The process of refining the emergent themes continued further in Stage Five. The current stage determined the coherence between the themes and the original

interview data. The analysis involved the transcripts and the emergent themes including the recently created ones in Stage Four as well as the preserved themes from the previous stages. The on-going nature of the analysis is demonstrated in the current stage. When the themes were clustered, the investigator produced a table of themes that are ordered coherently based on the principles that determined this ordering such as logic, functionality, or causality (Osborn & Smith, 2008; Smith & Osborn, 2003). These clusters or themes were reviewed and descriptive statements were established illustrating each one.

Stage Six. The current stage is designed to establish a single primary set of themes by including the resultant themes produced in Stage Five. These themes are compared across participants and a coordinating of the various themes occurs (Osborn & Smith, 2008). All the coordinated themes are maintained and considered as emergent form from the data and the analysis. The criteria to select the themes must be established to determine which themes should be highlighted (Denzin, 1989). For example, commonality across transcripts demonstrating whether the themes carry across a number of transcripts. Another example can be the richness of some themes within the primary source of data, despite their less frequent in occurrence across participants. This may contribute to explore other aspects of the interpretive accounts of lived experience.

Stage Seven. This final stage is designed to establish a statement to report the results of the analysis involving the descriptive data as extracts obtained from the transcripts and quantitative data in terms of consistency across participants (Smith & Osborne, 2003). This can contribute to explain the nature of the prominent or the outstanding themes by relating them to the original data (Smith & Osborne, 2003).

In the current study, a comparison occurred across the participants in the two groups, to determine the most relevant and tangible components and features that constructed the perspectives involving recovery in aphasia. The **final stage** involved comparing, by focusing concurrently on similarities and differences between the two primary sets of themes involving the two groups, to determine the shared and the distinctive features that make up the perspectives of the participants about the recovery.

Summary

The IPA type of analysis is an ongoing process in which the investigator is involved in elaborating an intensive procedure requiring time, effort, and caution. However, the cyclic process of the interpretation as well as the nature of the data collection technique, based on the interaction between the two involved parties, ensure to capture the richness and the indepth of the interpretation. In addition, the emergent themes and the extracts from the transcripts would demonstrate the connection between the interpretation and the data in which the analyst is trying to understand from the point of view of the participants making sense of their own daily lives and experiences. In my opinion, this data analysis procedure can establish rich description and productivity by which a set of themes evolves from the transcripts. Furthermore, the current procedure enables the analyst to have an insight to personal experience of the participants and to capture the richness and the complexity involving their perspectives.

The current study employed a qualitative method of enquiry known as phenomenology to investigate recovery in aphasia based on the description of the lived experience of three individuals with aphasia and their caregivers.

The interpretive phenomenological analysis allows the investigator to understand the nature of the recovery in aphasia based on the perspectives of the IWA and their caregivers. According to the interaction between the interviewer and the participants, enables to address the elements constructing the insiders' views and personal accounts involving recovery. Importantly, this investigation highlights the shared and common ingredients between these two groups. Chapter Four and Chapter Five involve the results of the current study.

CHAPTER FOUR

RESULTS

As described in Chapter Three, data were collected to address the general research question and the sub-questions involving the constituents that construct recovery in aphasia based on the perspectives of individuals with aphasia (IWA) and their caregivers. In this chapter, the findings of the study will be reported. In order to accomplish this goal, this chapter is divided into six primary sections. First, a description of the data collected for the current investigation is provided. The relevant circumstances and the scope of the data collection highlight that this study was comprehensive and thorough. Second, the emergent themes from the data analysis of individuals with aphasia are presented. Third, a discussion of the results for the participants with aphasia is provided. Fourth, the emergent themes from the data analysis of the caregivers of individuals with aphasia are presented, and followed by a discussion of the findings for the caregivers in the fifth section. Finally, a comparison between these two groups is made in the sixth section that addresses the primary research question and sub-questions.

Outline of Data Collection

The current study is a phenomenological inquiry that provides a detailed description of recovery from aphasia as experienced individuals with aphasia and their caregivers. As discussed, phenomenology enables the systematic study of the underlying meaning of recovery in aphasia based on the lived experience of these individuals and their families. The data source for this study consisted of six semi-structured interviews; three interviews with individuals with aphasia, and three interviews with the caregivers of these individuals. These semi-structured interviews in the current investigation were sufficient to provide stories

about events, actions, norms, and values regarding recovery in aphasia through the eyes of the participants being interviewed. Data analysis focused on the main question: *What is the nature of the construct of recovery in aphasia based on the perspectives of the individuals with aphasia, as compared with their caregivers?*

The interpretations of these semi-structured interviews contributed to the understanding of the meaning that recovery held for the IWA and the investigator was able to derive categories and definitions of behavior from the participants regarding the recovery process. This analysis procedure established a rich description in which a set of themes emerged from these interviews. Further, this procedure enabled the investigator to have an insight to the personal experience of the participants and to capture the richness and the complexity regarding their perspectives about recovery in aphasia.

Six participants (three individuals with aphasia and their primary caregivers) were interviewed separately in the spring of 2010. These participants were categorized into two groups; the Aphasia Group including three individuals with aphasia, and the Caregiver Group including three caregivers of these individuals with aphasia. The participants in these two groups live in south Louisiana, United States. Information about the participants with aphasia in the Aphasia Group including their personal details, based on the requirements of the investigation, was obtained from clinical supervisors at a clinical center. The participants in the two groups were interviewed separately in the University of Louisiana at Lafayette Speech, Language and Hearing Center located in Burke-Hawthorne Hall. All these interviews, except one, were administered in isolated therapy rooms at the clinical center with no interruptions from any party. One caregiver was interviewed in his residence based

on caregiver's own request (MNC), with no interference from any party. The participants in these two groups were interviewed for approximately one hour each.

As was discussed previously, this data analysis process provided an insight to the lived experiences of the IWA and their caregivers. Therefore, themes and patterns were found from the data analysis procedure that provided a thick and rich description regarding the underlying meaning and the nature of recovery in aphasia. Since they are the focus of this study, the first set of themes described and discussed in detail are those from the Individuals with Aphasia. To best describe the process of recovery from their perspectives, each theme and their identified sub-ordinates will be described and documented according to the procedures of interpretive phenomenological analysis.

Data from the Aphasia Group

Themes that emerged from the analysis from the Aphasia Group consisted of four super ordinate themes (encountering aphasia, reacting to aphasia, coping with aphasia, contextual influences) with ten themes grouped under these major domains. Each of these themes and their sub-categories are provided in Table 4.1 and will be discussed in depth below.

Encountering Aphasia

The first super ordinate theme that was identified from the data set may be described as Encountering Aphasia. This theme revolved around the initial experience of the IWA involving the perception of aphasia as it occurred. That is, the initial experience of the stroke and its impact in the early stage as perceived by the participants. Each of the IWA stated that this actual occurrence in their lives was their first encounter with aphasia in their experience. None of them reported knowing other aphasics personally or having

Table 4.1 List of Themes for the Aphasia Group based on Interpretive Phenomenological Analysis of Semi-Structured Interviews.

SUPER ORDINATE THEMES	THEMES	SUBORDINATE THEMES
Encountering Aphasia	Emergence	What happened before?
		Onset of Physical Weakness
		What is going on?
		Hospitalization/ Realization
		Aphasia Emerging
	Impact	Functional Organization
		Symbolic Modalities
		Too much Stimulation
		Physical Weakness
		Financial Concern
Reacting to Aphasia	Emotional Reaction	
	"I have a problem"	
	Avoidance	
	Experiential Metaphors	
Coping with Aphasia	Mechanisms	Clinical Intervention
		Support Mechanisms
		Compensation
		Social Affiliation
		Practice
	Awareness	Recovery as Change
		Incomplete Recovery
		Acceptance: "A new road"
Contextual Influences	Perspectives	Prior Identity
		Locus of Control
	Expectations	Time
		Reality

any experience with this disorder although one IWA (MN) did mention during the interview that her mother had a stroke. Consequently, their personal encounter was the first time in their lives in which they started to become familiar with aphasia to some degree.

Accordingly, the participants in the Aphasia Group first attempted to understand what was happening to them when the stroke occurred. The themes that richly describe their encounters were as follows.

Emergence

The first theme that was identified with the experiences of encountering aphasia from the IWA data set may be described as Emergence. Since this theme is a recounting of that sudden and frightening incident and given that these individuals were narrating their lived experiences with aphasia and their process of recovery, it is not surprising that each of them started their discussions with an initial or precipitating event – the emergence of the medical emergency known as stroke and the subsequent aphasia that was the result of this neurological incident. Interestingly, the recalled event of emergence was quite similar in narration structure and focus across the three IWA.

What happened before the onset? Rather than starting with the actual stroke, each of the IWA started their recounting by attempting to identify potential precipitating events that might have led to the stroke and subsequent aphasia. Having had time to reflect upon the emergence of aphasia for months, each IWA appeared to design a narrative in which some potential reasons were understood and that could set the context for the medical occurrence. That is, the first aspect of lived experience (and encounter) with the emergence of aphasia was an attempt to understand what had happened to them and why so that they could attempt to make sense of their situation. First, they reported what happened before the stroke; what

events or circumstance might have led to the occurrence of the stroke. Although this happened with all three IWA, one IWA (KN) had repeatedly mentioned this earlier explanation (the high fats he was eating) to the interviewer in other discussions and so did not mention it during the interviews for this study. The other two IWA, however, talked about their early and initial experience focusing on what actually happened just before the onset of the stroke, especially what they were doing prior the onset. This is demonstrated in the following examples.

In the first illustration below (Example 4.1), DR has just engaged in conversation with the interviewer and immediately starts describing an earlier medical procedure that she believes was relevant and (maybe) even a precipitating cause of her stroke. She believed that a surgery approximately three weeks earlier was a possible reason for her stroke:

Example 4.1 (Appendix A, DR Interview, Lines 6-7, and 9-11)

6 Ehmm the first thing ehmm I remembered because I had ehmm I've was
7 having surgery
...
9 About three weeks I was paused and one afternoon I woke up after taking a
10 nap and then I was confused and I didn't know where I was or ah (.) or why I
11 was there

Whether the surgery was a variable in her stroke is not known. There was no such indication in her medical chart. However, this was a part of her explanation and/or rationale. As can be seen in this excerpt, DR had reflected upon her health and medical state prior to the stroke and tried to find some reason for her stroke. Since DR went through a surgery prior to the onset, she created this as a rationale for her stroke. Interestingly, this type of explanatory device was also echoed with MN. Before describing her stroke, she also mentioned surgery and a cessation of her blood thinning medication (Coumadin):

Example 4.2 (Appendix B, MN Interview, Lines 17, and 19-20)

- 17 I had surgery with thyroid take my Coumadin off
...
19 For five days no Coumadin for Monday Tuesday Wednesday Thursday and
20 Friday was my surgery with my thyroid

As we can see, MN also had an explanatory rationale for her stroke. Even though her speech was telegraphic at this point, it is clear that she had stopped taking her medication several days prior to the onset because of her surgery. She then had thyroid surgery and the next day she had her stroke. In these two instances – as well as with KN’s non-recorded earlier discussion, there appeared to be a need for a rationale for why the strokes occurred so that the IWA could better make sense of this emerging event.

Onset of Physical Weakness. The actual stroke was accompanied by a number of physical symptoms. The one emphasized by both IWA (DR, MNC) was the onset of physical (motoric) weakness. In both instances, the IWA stressed the initial understanding that something might be wrong because of a sense of weakness. For each IWA the weakness emerged and was the initial experience as perceived by the participants in the Aphasia Group. DR is a case in point. This individual recognized her physical weakness approximately at the onset of the stroke. At a particular point, the IWA for the first time started to recognize that physically there was something happening. That is, DR, a nurse by training, started to realize that something was going on with her physical coordination. The following example outlined how physical weakness was demonstrated during onset.

Example 4.3 (Appendix A, DR Interview, Lines 42-43, and 45-46)

- 42 And I have a key to go in and stuff but I couldn’t get the key in so I couldn’t
43 even (.) tab
...
45 So I was I couldn’t even go to open the door and the little boy was saying
46 “open the door come in come in”

It was difficult for DR to unlock the door and to open it located between her house and the house of her niece. DR's fine motor control was affected over this period of time and this led her to ask the question that all three of the IWA recounted asking themselves as they were going through the physical symptoms of the strokes – What is going on?

What is going on? Once the potential rationale for the stroke was discussed and the IWA then proceeded to pick up the narrative during the actual occurrence, they discussed the fact that something unusual was happening to them and they again tried to make sense of the experience. Most salient to DR and MN were the symptoms of physical weakness (KN experienced less of this given his lesion away from the motor strip in the frontal lobe of the cortex). These symptoms led to an attempt at “sense-making” that was more immediate. Again, while KN did not discuss the initial stroke experience in these interviews, the other two individuals with aphasia considered what was happening to them at that moment. This is demonstrated in the following example:

Example 4.4 (Appendix A, DR Interview, Lines 48, and 50-51)

48 So it took a while for to get them to bring me to the door
...
50 And when I got in my niece was saying and she was like “why open the door
51 and come in” and come in” and they should realized that something is wrong

In this example, DR has realized she cannot talk and that something is wrong and she sought help from her niece next door. She arrives at the niece's door and the family members attempted to bring DR inside the house. The niece wanted to know why DR couldn't open the door by herself. DR believed that these family members began to consider that something unusual had happened to her. The confusion and awareness of immediate problems was foremost in DR's mind as she sought assistance. In the next excerpt, a similar experience is related by MN:

Example 4.5 (Appendix B, MN Interview, Lines 104-105, and 107-110)

104 I came back and I looked at the papers and I tried I love to read and I looked
105 and I thought I moved myself I can't see that
...
107 The paper well at all ehmm and my eyes there was something wrong with me
108 and uh (.) I told that to my husband I said "I can't read the paper like that" he
109 said "MN it's probably because you had the surgery why don't go and rest for
110 a while"

MN felt that she couldn't see the newspaper she was trying to read at home following the surgery. MN believed that something was going wrong with her. When MN tried to ask her husband about this issue, he recommended that she needed to rest for some time.

In both of these incidents, there were narratives about emergence of difficulties that were unexpected and disconcerting. In both cases, the IWA sought help or explanation from others and were somewhat confused. In retrospect, however, both sought rationales for their difficulties and had started forming a narrative of this lived experience.

Hospitalization and Realization. The narratives that were used to discuss emergence of aphasia were not limited to the actual strokes themselves. Rather, each recounting also included more information on the medical efforts and the resulting impairments. For example, there was a definite precipitating realization for each IWA in the hospital context that stressed their difficulties and the realization that this was a serious medical event. Two of the individuals with aphasia (DR, MN) talked about how family members took them to the hospital and they were admitted and stayed at the hospital for several days. Certain medical procedures including examinations were performed on these participants and it was during these procedures that the IWA had their primary realization of medical trouble. For DR, a nurse, the emergency room triggered her realization.

Example 4.6 (Appendix A, DR Interview, Lines 56-58)

56 You know so I was like well everything is gonna be okay ehm I can go home
57 you know but then I realized I was there for the emergency room for about
58 three hours or something by the time I got there I got a room

DR believed that everything was going well at the hospital and she would return home. However, DR became aware that she was in the emergency room for several hours and was admitted to stay at the hospital. Since she was a nurse, this fact was dramatic for her and she realized that she was in trouble. MN had a similar realization when the physician in the emergency room asked her questions and she was not able to answer them:

Example 4.7 (Appendix B, MN Interview, Lines 235-236, and 238-239)

235 He said “what time is it?” I said “I don’t know I’m telling you it’s one two
236 three” and I said I counted one two three four until twenty four
...
238 I couldn’t say it and you see they had my blood pressure stop my blood
239 pressure was high (.) my uh listening to my heart

The inability to perform simple and basic informational tasks requested by the attending physician led MN to the realization of stroke. The inability to tell time and to respond so inappropriately by counting demonstrated to MN that she was in trouble medically-speaking. The hospital staff took MN’s blood pressure and listened to her heart beat. They found that MN’s blood pressure was high and she was admitted to the hospital.

Two of the IWA (DR, MN) recalled how the medical staff attempted to diagnose the presenting symptoms and to discover their medical conditions. The following example demonstrates this in the recounting by DR:

Example 4.8 (Appendix A, DR Interview, Lines 60-61, and 63)

60 Yeah a yeah (.) after a while I knew something but you know ehmm I still
61 wasn’t connecting a stroke
...
63 I was just confused you know they were thinking maybe it’s the medicine

DR believed she was confused and the medical staff attributed her confusion to the medicine she was taking. Since she was not directly familiar with a stroke and possible subsequent aphasia, this possibility did not suggest itself to her. MN, an individual less medically-oriented, recounted a similar experience in example 4.9:

Example 4.9 (Appendix B, MN Interview, Lines 268-271)

268 And doctor George was mad (laughing) and I could say “oh lord I don’t have
269 any have any heart attack that’s good to me” and then (.) doctor John asked
270 another question and then I think doctor John said “I think she must have a
271 stroke”

In MN’s recounted experience, the physicians consulted and determined that she had a stroke (Lines 270-271). For MN and for DR, this was a precipitating event that reinforced both of their realizations of the seriousness of their conditions.

Aphasia Emerging. It is interesting that the initial attention by the IWA and the medical personnel were oriented to the stroke, the neurological activity. However, the real concerns emerged later when each IWA realized that after the stroke there were residual effects that had to be addressed. The most tangible sub-ordinate theme was how aphasia had emerged and was perceived by the individuals. Reportedly each of the participants in the Aphasia Group came across aphasia for the first time in their lives when they were actually diagnosed.

At a particular point, the IWA started to recognize their aphasia to some degree. That is, these individuals were not familiar with aphasia prior onset. Therefore, the emergence of aphasia was considered as the initial encounter with aphasia. At this time, the attention of the IWA focused on how aphasia evolved in the early stage. Two of the participants in the Aphasia group talked about this experience. However, one participant didn’t address how his aphasia has emerged at all (KN) in the study interviews. The following example

demonstrates how DR realized the emergence of the residual effects collectively referred to as aphasia:

Example 4.10 (Appendix A, DR Interview, Lines 69-71, and 73)

69 The first night so the first thing in the morning my doctor who a good friend
70 and grew up and stuff that was he first thing he started verbally try “can you
71 talk to me?” And stuff and I was just try to tell him
...
73 “Let me tell you” and I couldn’t you know and then I have

In this example, a physician approached DR at the hospital and asked if she could talk to him. DR was familiar with the physician and she even considered him as a friend. While DR intended to talk with the doctor and knew exactly what to say, DR for the first time couldn’t express herself. This was also echoed with MN.

Example 4.11 (Appendix B, MN Interview, Lines 171-176)

171 And she gave it to me and in between that I wrote in that room I am MN is I
172 can’t remember the words and I did the same thing all I could say some name
173 three or four times the same time and I let it there and so when my friends
174 came in to my house this is on Sunday in the afternoon and I said “there is
175 something wrong with me” she said “what?” I said “look at that paper I said
176 the same thing over the same thing the same thing over and then I can

This was an unusual occurrence in that appears to be reduced to the realization of her aphasia. She wrote a sentence on a sheet of paper at home and, because she reported writing the same words repeatedly, MN started to be aware of the extent of her problems. She shared her experience with a friend who came to visit her at home. MN showed this friend and described her repetitive writing to this friend. It seems MN started to realize that for the first time something happened to her writing.

Impact

The second primary theme that emerged as a subset of encountering aphasia from the data set of the Aphasia Group revolves around the recognition of the impact of the stroke and aphasia upon the IWA. Since these individuals went through negative changes involving

their typical abilities and behaviors following the onset and emergence of the stroke and aphasia, it is natural to note those changes. In relating their lived experiences after the emergence of the medical condition, the individuals with aphasia considered the impact of having aphasia. Discussed at various times throughout their interviews, the IWA introduced changes involving various aspects of their lives that were based upon their resulting impairments and disabilities. Essentially dealing with settling into the idea and the reality of what it means to be limited; what it means to recognize what those limitations are, they discussed a wide range of experiences and the reactions to this new state of identity – being aphasic. Often, exhibiting these concerns through direct statements and beliefs about the changes noted, these descriptions and discussions were colored by concerns and emotions. These feelings could vary in nature and the IWA could sense a mixture of emotions. That is, the individuals might feel upset, angry, sad, and frustrated with the impairments and disabilities exhibited as a result of aphasia. Furthermore, the individuals with aphasia expressed concerns about the difficulties they experienced in aphasia.

Functional Orientation. The transcript analyses suggest that there were a number of impact features within the lived experiences that were identified by these IWA. However, these were often expressed in terms of functional abilities and skills within various activities that could no longer be effectively navigated. Consequently, the functional orientation best represents a primary sub ordinate theme within impact. That is, although during the discussions the actual set of symptoms involving a group of features that represent symbolic and linguistic impairment were sometimes detailed, they were typically within a functional framework. Since the IWA are not experts in behavior analysis or oriented to the underlying skills and abilities that mark our “professional” jargon about aphasia, this is not surprising.

The three participants with aphasia exhibited in their discussion (and in their behaviors during interview) a set of characteristics that highlighted their aphasia to some degree. These characteristics can be considered as evidence of their aphasia. According to these participants in the Aphasia Group, aphasia was manifested mainly through problems with communicating in real world settings; talking with other individuals and engaging in conversations. On the other hand, several features that also characterized the aphasia of the participants involved domains alongside talking with other individuals including comprehension and the production of written material.

One characteristic that appears to be a component of the lived experiences based on changes in the functional orientation involved the perception that communication was much harder due to immediate and sustained changes in how they could communicate, especially due to irrelevant and improper use of words and their meanings. That is, particular words didn't represent what these individuals actually intended to say. All three IWA described their recognition that interacting was different after the emergence of aphasia. This was the primary impact statement used by all three IWA.

In the following example (4.12), DR quite effectively described the impact of such a drastic change in her ability to communicate. Her characterization revolved around the idea that “*everything flips for her*” when she was trying to communicate effectively. In her case, she described how she now experienced the un-controllable use of inaccurate or irrelevant words when talking with other individuals:

Example 4.12 (Appendix A, DR Interview, Lines 642, and 644-647)

642 Everything flips for me

...

644 Flip okay we're talking about our last group ehmm some of the people come
545 and say “ma'am” is no I mean no means yes ehmm ladies are ma'am men are

646 sir so if I sometimes I say ehmm “ma’am” they say “sir” and they “excuse
647 me?”

In this example, the interviewer asked DR what she meant by “flips for” (Line 642). For DR this was a description of both how she produced some words when she intended the opposite meaning and how these and other inappropriate words flipped both her meaning and how she now felt about and approached verbal interactions. DR stated that she discussed this experience (the use of words with meanings opposite to the targeted ones) with other members of the aphasia support group because it was so problematic. While DR talked with people, she sometimes used the word “yes” instead of “no” (Line 645). Sometimes, DR used the word “ma’am” when she addressed males during the conversation instead of the appropriate word “sir” (Line 646).

MN echoed this observation and she also believed that while the conversation partners might be aware of her use of inappropriate words, it still changed the interaction. This concern is demonstrated in the following excerpt:

Example 4.13 (Appendix B, MN Interview, Lines 142-143, and 145-146)

142 And she wanted to know how’s I doing and (.) I don’t remember what I
143 answered
...
145 And she asked me another question and I said something else not the right
146 word probably (.) and she said to me “MN (.) give the phone to your husband”

While MN did relate to experiences like DR’s first example (4.12) that demonstrated the flip in meaning due to inaccuracy, the above example (4.13) illustrates her experience with a flip in her expectation for interaction. In this excerpt, MN was answering questions asked by her cousin during a phone call following her surgery. It was during this phone call that MN had a revelation about her effectiveness as a communicator. When trying to talk with her cousin, MN believed that she didn’t express herself sufficiently in her attempts to

answer questions (Lines 145-146). As a result, her role as a communicator was greatly diminished in the eyes of her cousin; this was so much the case that her cousin preferred to speak to her husband instead of MN who was her closest relative. MN did not know exactly what she said but she suspected that it was problematic due to the continuance of the phone conversation.

KN also exhibited a “flip” in his expectations. Oriented to functioning in a fairly high level administrative position, in his first interview he discussed how things changed after his stroke and the subsequent aphasia.

Example 4.14 (Appendix C, KN First Interview, Lines 66-68)

66 Well (..) I felt I could go back after ehmmm while (.) ya’ know but when I tried
67 to do my job and help them it was toppy turby (..) they didn’t know what I wanted
68 wanted (..) the I need them for doing that

KN expressed this similar idea of “topsy turvy” (Line 67) on several occasions in this first interview. He insisted that he was functioning at a high level but that the others were confused due to their expectations. Although they may have been genuinely confused by his interactions, he placed the problem on them rather than on himself (Line 68). The impact, however, was the same – a lack of success that negatively impacted and “flipped” his role.

Another frequent manifestation of the functional limitations that impacted the IWA were their varied uses of the term “**couldn’t**”. Used in a way synonymous with the term “disabilities”, the “couldn’t” usage was about difficulties or restrictions in engaging and performing activities based on the contexts of interest for the IWA. All three of the participants in the Aphasia Group talked about their limitations in the performance of speaking activities in their daily lives. These three participants reported limitations in talking with other people. To the extent that they focused on these experiences, for example, two of the participants in the Aphasia Group reported restrictions in activities involving talking with

people. This is presented in the excerpts (4.15 and 4.16) below. In both of these cases, the IWA (DR and MN) were anticipating an inability to effectively communicate. For example, in Example 4.15, DR describes being able to move about in the social world (Line 195) but having problems in communicating.

Example 4.15 (Appendix A, DR Interview, Lines 194-197)

194 The hardest ehmm the biggest thing was (.) getting around and I described it as
195 beening I was in the sa silent world and (.) I could drive and get what I need
196 but until somebody would approach me and ask if I needed anything I knew I
197 couldn't tell him anything

The admission that, "I knew I couldn't tell him anything" (Lines 196 & 197) directly points to the loss of functional communicative effectiveness when needed by the IWA. This experience was echoed by MN in Example 4.16. While discussing a shopping trip, she also experienced an example of disability when trying to communicate:

Example 4.16 (Appendix B, MN Interview, Lines 440-441)

440 Couldn't say a word couldn't say anything that my oldest daughter came to
441 Walgreens gave a big old tablet thick all these pencils that you could erase

As can be noted in Line 440, MN also believed that it was difficult for her say any words and to talk with other individuals. As a result, she recognized the impact of aphasia on her activities of daily living; especially those that involved verbal social interaction.

It is interesting to note that the third IWA (KN) did not typically speak as much about his inability to communicate. As evidenced in his two interviews, he continually stressed his belief in his improvement in speaking and did not stress his verbal difficulties. However, the "couldn't" experiences and expectations were none-the-less evident in his interviews. In his first interview, the one that most directly focused on his experiences subsequent with the onset of his aphasia, he stated that, "he couldn't do his job as well..." when asked why this was the case, he said that there were complex relationships with others that needed to be

massaged and that he was not longer able to do so. This is an admission of his disability with others albeit at a perceived higher level of functioning. However, the interviewer did note difficulty following KN during some conversational interactions even when less complexity was involved.

The “couldn’t” expectation was not just evident in speech or conversation. Two of the participants (DR and MN) also suggested difficulty with writing and with the symbolic use of numbers (e.g., making change, writing checks). For example, DR discussed the loss of her writing abilities and her use of numbers early in her discovery of aphasia and its impact. She discusses this when reviewing her emerging realization about what the aphasia did to her daily activities. Again, the sub-theme of “couldn’t” as expectation from a functional perspective comes through.

Example 4.17 (Appendix A, DR Interview, Lines 162-163)

162 You know first thing they started in writing then alphabets and stuff I couldn’t
163 write I couldn’t remember and it was just like numbers it had no meanings to it

In the current example, DR reported how difficult it was for her to write letters and she related it to not being able to remember (Line 163). However, this was a distinction of loss of meaning rather than a loss of memory. Later she clarified this and she used the “remembering” of meaning several more times. She was more explicit in this example about the loss of symbolic functioning with numbers. This was more directly stated, “...numbers it had no meaning to it” (Line 163) and she related that back to the loss of symbolic functioning with letters (i.e., “and it was just like numbers”). Again, the expectation was the creation of a limitation or disability manifested by the term “couldn’t”.

Symbolic Modalities. Although it should have been expected, the second subordinate theme most frequently noted under “impact” related to the most frequent

characteristic of aphasia in the literature – difficulty in the symbolic modalities. Each of the IWA not only focused on the loss of function in important contexts, they also described these losses in terms of the major kinds of symbol systems impaired. Over the four interviews (two for KN) the functional impairments were discussed in terms of difficulties speaking and comprehending, reading and writing, and (at least in the case of DR and MN) a reduced ability to deal with numbers as dates and/or as money. It should be stated, however, that all the characterizations of difficulties in these modalities were not necessarily manifested by the same descriptions and through the same behaviors of each IWA in this group. That is, all the participants with aphasia did not share exactly the same characteristics and their aphasias were not characterized by the same features. While nearly all the “primary” symbolic modalities were noted (KN did not discuss number problems), similarities and differences regarding the characteristics of aphasia were found across all participants in the Aphasia Group.

Regarding the specific aspects of symbolic and linguistic impairments, the IWA included reduced production of spoken language, impaired comprehension, poor comprehension of written information, and reduced production of written material. In effect, their descriptions suggested that the manifestation of aphasia can be grouped into a set of features based on the language impairment and communication difficulty in various modalities that served various functions.

The verbal modality was most often described by the IWA in that they discussed difficulties *speaking* (57 times). As documented in Examples 4.12 to 4.16, the speaking difficulties were both glossed (Examples 4.14 to 4.16) and a bit more specific when describing word finding problems and word confusions (Examples 4.12, 4.13, 4.16). Often

these descriptions of modality-specific difficulties were emotionally-laden. MN, for example, described her verbal difficulties with both the functional realization of “couldn’t” and with a gloss of inability to talk. As noted in Example 4.18, she also provided more emotion through a metaphorical description. This is amply represented when she talked about the impact of aphasia on her language and her loss of driving privileges due to her poor communicative ability:

Example 4.18 (Appendix B, MN Interview, Lines 707-709)

707 Shows me no reason (.) I had no I didn’t fall nothing but I thank god that I can
708 do this so I didn’t drive for four months and two weeks and to me that I was in
709 jail when I was couldn’t drive couldn’t talk exactly (.) it was like I was in jail

The employed metaphor describing how the verbal problem and the driving problems made her feel like she “was in jail” (Line 709) richly describes her perceptions.

Finally, with regard to the symbolic modality of speaking, since aphasia involved the IWA and other people who interact with them, the verbal impact was generally experienced as a number of social obstacles that emerged during conversation. DR indicated this in her comments in Example 4.15 when somebody would approach her and she “...couldn’t tell him anything”. Even with family or close friends, the impact of speaking difficulties obstructed social integration and the communicative accessibility between the IWA and the conversation partners. MN expressed this with family (a cousin and her daughter) in Examples 4.13 and 4.16 and she also expressed this type of social difficulty with one of her closest friends. As noted in Example 4.19:

Example 4.19 (Appendix B, MN Interview, Lines 481-483, and 485-488)

481 (.) I took friends they called me when my daughter left you see she left and my
482 other friend uh came to see me and they would talk but you see what I felt like
483 nobody was talking looking at me

...

485 They were looking at well my husband or somebody else but my only friend
486 I've knew the most she and I will sit sit on each other when they call me on the
487 phone I would never say the right ehmm (.) time as fine as time I could not say
488 it correctly

In this example, friends of MN came to visit her after MN's daughter had left for the day. According to MN, there was no contact and interaction between her and these friends during the conversation. MN believed she was not engaged in the conversation with her friends and MN felt excluded from the conversation to some degree.

These perceptions of difficulties in the symbolic modalities were also manifested in *auditory comprehension*. On 38 occasions across the transcripts, there were indications of poor comprehending on the part of the IWA. Some were discussed during fairly simple tasks like picture pointing as a component of speech therapy (See Example 4.20):

Example 4.20 (Appendix A, DR Interview, Lines 133-135, and 137-138)

133 Yeah one of the first things they bring you are the different articles that you
134 have to bring under there (.) and they may give you like three or four different
135 articles and they ehmm
...
137 Yeah ehmm a mirror a ehmm a comb a brush little things and stuff so just to
138 remember articles

In this excerpt, DR was not even able to point to the objects named in the therapeutic task. While she referenced this difficulty as “to remember articles” (Line 138), it was evident that the problem was comprehension of the verbal command. Whether due to auditory input problems or word finding in the reception modality is difficult to say. The result, however, is a comprehension problem even in a controlled setting with little or no auditory distraction.

In other instances, the comprehension problems that were reported were in much more demanding contexts like group conversations (see Example 4.21). This inability to follow the conversations of others was commented on by all three IWA. MN, for example,

discussed problems in noisy contexts and when several people were conversing. This can be noted in the following example:

Example 4.21 (Appendix B, MN Interview Lines 588-589, and 591)

588 Seven or eight people sitting down I (.) will not understand what they are really
589 saying

...

591 Yes I do have troubles a lot of troubles with that

She noted that this was a problem in family gatherings, as well as, during activities like support group. While the context is different in terms of conversation and the number of interactants – each of these making it a more complex comprehension task – it is also a much more essential comprehension task that the IWA could not perform.

KN also discussed comprehension problems, but in less direct and more complex settings. As noted in the following excerpt (Example 4.22), he discussed conversational interactions as a war and that he needed the best information to be successful:

Example 4.22 (Appendix C, KN First Interview, Lines 132-137)

132 Vice? From by the smallest communicating in a job is something like war if
133 you think you have mission and (..) sometimes in a war you communicate
134 very quickly your communication must be quickly vice from by the smallest
135 detail is not the problem when you're at war (..) you have to do things (.) I
136 want this done I want that done (.) let's do that but you need information from
137 them (.) that a problem (.) I didn't always understand them (..) now what I

In using a war metaphor for his job as an administrator and his need to communicate, KN also discussed his inability to understand the ideas and the needs of his staff (Lines 134 and 135). It was a realization that he was hesitant to make, but he did suggest that this complex type of comprehension difficulty was one of the reasons he had trouble returning to his job after his stroke. Again, while these examples were often couched in terms of functional problems, they actually centered on auditory comprehension difficulties.

Aphasia can be evident in various domains of the language. That is, the characteristics of aphasia were not exclusively demonstrated in the verbal expression or the auditory comprehension needed when talking with other individuals. The other two primary symbolic modalities employed so often in our culture (reading and writing) were also frequently mentioned. Regarding *reading*, there were 21 mentions of problems here across all three IWA. This often manifested as a reduction of the reading and/or writing habit primarily because of the new difficulty in comprehending or formulating the written word. DR, for example, discussed a change in her reading habits due to difficulty. This can be noted in Example 4.23:

Example 4.23 (Appendix A, DR Interview, Lines 481-483, and 485-486)

481 Silently yes you know (.) yeah not a novels or any kind of that I have little
482 ehmm articles you know the magazines it has maybe three or four little ehmm
483 (.) word articles and then not a long life two or three pages on there
...
485 But articles take me a long time sometimes it takes me two days to get it I
486 eventually get through it you know

In this example, DR was discussing the changes that had an effect on her daily activities. She discusses not being able to read much for pleasure since she read novels. This was no longer possible for her since she tended to get lost in the longer passages. She stated, however, that when she does manage to read, she does so silently and reads short magazine articles. However, even with these short pieces of text, she requires a lot of time and effort, even across several days. Simply put, reading required a lot of effort invested by DR. In her interview, MN also expressed problems with reading and typically did not talk about this modality. When pressed, she spoke about how difficult reading had become and how her clinician, while she was in the hospital, tried to get her to read – something she could not

complete. As demonstrated in Example 4.24, even the simplest reading task appeared difficult for her.

Example 4.24 (Appendix B, MN Interview, Lines 432-433)

432 And I went here in Lafayette General and the girl would come and get the book
433 and tell me say this word again” and she say that over and over again

In this example, when her clinician asked her to read from a book, she could not even read single words. The clinician employed a repetition strategy that did not seem to work. MN was presented with a paperback and even trying to respond after the clinician that was not effective.

In a similar fashion, *writing* was also problematic. Although it was only mentioned explicitly six times, it was discussed as a problem. In example 4.17, for instance, DR discussed her inability to write – even remember the alphabet – when clinicians tried to get her to use writing as a compensation for her poor verbal expression. Not surprisingly, however, writing was even more impaired and the clinician abandoned this strategy.

Example 4.25 (Appendix A, DR Interview, Lines 162-163)

162 You know first thing they started in writing then alphabets and stuff I couldn’t
163 write I couldn’t remember and it was just like numbers it had no meanings to it

KN also discussed writing problems when he returned to his job. He stated that it took him more time to prepare memos and reports and that this slowed down the activities that he was responsible for at his work site (See Example 4.26 below).

Example 4.26 (Appendix C, KN First Interview, Lines 78-82)

78 Well (..) I guess there were some problems with my writing (.) ya know? When
79 I tried to do my job and send memos out (..) it took time to do them (.) some
80 people could they said they made no sense and they could not they were use to
81 my memos but were not sim the same (..) kind of hard for me to read too (..) so
82 I knew a problem and one of the uh (.) chiropractors that we went to look with

Finally, each of the IWA talked about performing activities when using numbers and numerical symbols. Actually, *problems with numbers* as symbols, were more often discussed than were writing problems (18 times). This is likely because all three of the IWA were used to dealing with their own finances and could no longer do so. They could not pay bills, reconcile accounts, or even write checks easily. These difficulties with numbers involve limitations in the use of numbers as symbols. One participant (DR) reported limitations and restrictions in money exchange and writing checks that required the use of numerical symbols. This is illustrated in the following examples.

Example 4.27 (Appendix A, DR Interview, Lines 208-209)

208 Numbers is ha a bit trouble for me I had money I would just start with even
209 ehmm tens or twenties

DR found it difficult to deal with money because of the symbolic value. She compensated by handing cashiers larger bills and simply accepting the change given to her. Her difficulties, however, were not only with recognizing cash. She also talked about her limitation with the use of numbers and money during check writing as can be seen in Example 4.28:

Example 4.28 (Appendix A, DR Interview, Lines 345-347)

345 Realize with numbers (.) I can't write a check (.) I cannot write it so I've had to
346 write them again and again and again and I would write them and then they
347 come back and check it before

With checks, DR became aware of her difficulty because she could not properly write a check and deal with the symbols for the numbers as currency. While she attempted to pay her own bills and still pay with checks, she needed to use multiple checks to get it right and many still came back to her as incorrect. In Line 345 she mentions her realization about her check writing difficulties. Eventually she had to get her niece to review her checks whenever

she wrote them. This numbers difficulty was often mentioned by DR – even when summarizing her general problems – as can be observed in Example 4.29 below.

Example 4.29 (Appendix A, DR Interview, Lines 203-206)

203 All of a sudden I I rendered that I had problems you know (.) and I didn't know
204 how to say dysphasia you know first thing I couldn't do is money so
205 everything last and stuff I ha can't even now you know I have troubles with
206 numbers

While both MN and KN also expressed problems with money and numbers, they did so less than DR. This participant (DR) mentioned these types of difficulties 12 out of the 18 times that numerical problems were mentioned. Since she was single and without a live-in partner, this is understandable. She was responsible for her own bills and the other two IWA relied more on their spouses.

Too Much Stimulation. The third sub ordinate theme that appears to fit under the theme of impact – and one that was discussed by the three IWA – involved auditory over-stimulation. Two of the IWA addressed this issue by talking about clarity issues while in loud contexts. They talked about the lack of clarity in hearing but their perceived problem with “sharpness” actually focused on their being over-whelmed by noise in their environments. These two participants (DR and MN) believed that their ability to handle background noise was affected to a much greater extent than before their strokes. These IWA perceived background noise as often being too intensive and prolonged so that it was difficult for them to put up with and tolerate this type of stimulation. In Example 4.30, DR discusses problems in support group because the background noise linked with the possibility of multiple participants talking at the same time was “too much” (Line 555) for her.

Example 4.30 (Appendix A, DR Interview, Lines 553-555)

553 No this is one of the support group stuff she was talking about us the same
554 thing too if I have if we have to go in just small groups you can in a big big
555 large thing it is too much stimulus is gonna start close you in

DR felt uncomfortable in these situations since she could not tolerate intense stimulation. Similarly, this is illustrated in the extract taken from the interview with MN.

Example 4.31 (Appendix B, MN Interview, Lines 679-680, 682, and 684)

679 Right here let's say in my house it could be a pen and I'm looking to see the
680 noise uh keeps with me
...
682 That bothers me
...
684 I don't know it's just I'm thinking it's a big thing that fell and it's like nothing

For her part, MN discussed the unexpected impact of background noises. They seem louder to her, as if some large object has fallen (Line 684) when the object was actually small. When asked, she reported that background noise in the home was distracting and bothered her (Line 682). MN felt uncomfortable and even distracted it in this situation.

While KN did not discuss auditory over-stimulation outside of a functional context, he did indicate a similar problem at his jobsite. Among the list of points he made about the changes that had occurred at work since his stroke, he mentioned that some rooms were too distracting because of noise. In Example 4.32 he suggests that he simply realized that he could not function well in those rooms because of the auditory stimulation and so he avoided them (Line 193).

Example 4.32 (Appendix C, KN First Interview, Lines 156-159)

156 (..) To gets hard som I think have some problem with some rooms at work (..)
157 they (..) sometimes it is too hard to kin con concentrate when I am in a room
158 the noise (..) is distracting (..) too much to listen otherwise (..) so I don't go to
159 those rooms much

The recognition that they could not longer easily deal with loud auditory environments was a tangible problem for these three IWA. Upon reflection, however, this is not surprising given that an inability to deal with auditory distractions is a common symptom discussed in the aphasia literature (Brookshire & Nicholas, 1984).

Physical Weakness. The fourth sub ordinate theme discussed with respect to the impact of their aphasia was closely tied with Activities of Daily Living (ADLs). Each of the IWA commented on changes in physical strength and endurance in that each IWA discussed a change in their physical capacity to perform activities. While the participants in the Aphasia Group didn't believe that they had paralysis and didn't quite understand the term "paresis", they did talk about physical changes that helped contribute to ADLs. For instance, one participant (MN) talked about the physical weakness she has experienced following the onset. This physical weakness was most often manifested in a limited range of balance and a change in the ability to perform familiar physical activities. As noted in Example 4.33, MN realized soon after her stroke that physical weakness was a real problem. She was especially concerned about balance and how it affected toileting activities (Line 529).

Example 4.33 (Appendix B, MN Interview, Lines 528-530)

528 Well I didn't know what I'm going to do what I'm saying you know and even
529 going on sit down on the toilet I was almost fall down because I couldn't
530 realize the balance of me going sitting up and down you see

Financial Concern. Finally, the IWA were concerned about fiscal issues. The occurrence of aphasia did create financial difficulties for each of the IWA. Because they were ill and had medical bills, and because they could no longer work when these medical bills were created, this was the fifth most common impact variable for these IWA. Obviously, the life of the IWA changed to some degree following the onset of the aphasia and the stroke. Due to the symbolic and physical problems that often accompany aphasia, this

impairment often greatly impacts one's occupation. Too often aphasia compromises the career and the profession of the IWA following the onset. As one of the participants (DR) in the Aphasia Group talked about the impact of the aphasia on her occupation following the onset, she was asked about how her life has changed. She responded as noted in the following example (Example 4.34):

Example 4.34 (Appendix A, DR Interview, Lines 188-192)

188 When after ehmm I've got back how I was I I was I was ehmm (.) hoping after
189 I had just retired and I was planning go back to work but not in the hospital and
190 stuff so when I got there na naturally ehmm concern was money and stuff like
191 that but then once that was said and stuff how's I gonna manage by myself by
192 my (.) within myself it's a so ehmm

As noted in Line 189, prior to the onset of aphasia, DR planned to retire from her job as a nurse at the hospital and then to supplement her retirement with supplemental work; she considered other options where she could work as a nurse. However, the aphasia resulted in a loss of ability to work and, consequently she was concerned about her financial status following the onset (Line 190) and how she would be able to manage by herself.

Across these three IWA there were very definite ways that the impact of aphasia was manifested and felt by these individuals. Rather than a medical definition and a diagnosis of a focal lesion of the brain as their understanding of aphasia, these IWA defined aphasia based upon its impact upon them individually in their daily lives. They were functionally and fiscally changed for the worse; they were not longer able to effectively use their symbolic modalities, and their physicality was significantly changed. The impact noted after emergence actually led the IWA to react to the aphasia and this reaction – a trigger due to impact – makes up the third super ordinate theme in the process of recovery.

Reacting to Aphasia

The second super ordinate theme that was identified from the data set in the Aphasia Group involved the reactions that were generated as a result of the impact made by aphasia on each individual. Each IWA had discussed the emergence of the impairment and then quickly started realizing the impact that it had on their daily lives and this resulted in their personal reactions to these encounters with aphasia. These reactions are triggered by barriers experienced by the IWA regarding the interaction between her or him and the context (including other individuals). The IWA exhibited reactions regarding the impact experienced during various kinds of interactions with the environment – especially the conversations between the IWA and others.

These reactions appeared to be an intermediate stage between the recognition of the actual impact of aphasia and the ways that the IWA cope with this condition (coping with aphasia makes up the next super ordinate theme). Although the themes within this super ordinate category were not necessarily discussed in the temporal order described below, the various descriptions and the temporal and causal linkages in each interview enabled the researcher to organize the reactions into a kind of sequential order. This order appears to have four thematic stages: Emotional reactions to the realized impact of aphasia, recognition of personal difficulty, avoidance as a temporary solution, and a consolidation of these reactions through experiential metaphors before actual coping responses were systematically employed. Each of these themes is discussed below.

Emotional Reactions

Once the individuals with aphasia recognized that they were impaired due to the aphasia (as manifested by the impact that each one experienced in their personal life), they

exhibited a host of emotional reactions. Some of these were fairly early in the post-morbid time-frame while others were developed more slowly and appeared to have a precipitating incident. These reactions included various forms of fear, worrying, anger, or sadness experienced by the IWA. That is, the IWA responded to the impact of aphasia and the barriers that were raised. All three of the participants in the Aphasia Group talked about their reactions.

Some of the reactions occurred very early in the process, even while emergence was occurring. This is not surprising since there were suddenly medical and functional changes in the IWA. Some of these were mentioned under the first super ordinate theme of Encounters with Aphasia. These emotions and reactions were generally (and understandably) more often oriented to initial fear and/or confusion. For instance, MN experienced a strong emotional reaction while in the early stages of the medical event. As noted in Example 4.35 and in Example 4.36 she was cognizant of her medical condition and she was afraid she was going to die.

Example 4.35 (Appendix B, MN Interview, Line 496)

496 I was scared because at that time (.) I thought I might die soon

In the current example, MN she actually admits to being scared and this was due to her belief that she might die due to the stroke (Line 496).

When pressed about this reaction later in the interview, she became upset reviewing her experiences and she started to cry. Example 4.36 provides even more evidence of her initial emotional response.

Example 4.36 (Appendix B, MN Interview, Lines 250-252, and 254)

250 I was strong (.) I could see (.) and finally (.) they sending me up to sixth floor
251 and when I thought to myself (.) I remember well I said dear god please don't
252 die with me (crying)

...
254 Take care of my children and my grand children

As noted in Line 250, she was not afraid until they admitted her. At that time, she realized the severity of her medical emergency and became afraid. According to MN, she prayed to live and asked God to take care of her children and grand children.

For each of the IWA, however, the initial emotional reactions were not the only ones that they reported. In fact, in all three IWA, later emotions triggered by living with the impact of aphasia were given priority. MN, for example, later returned to the discussion of her emotional state and discussed how she reflected on her condition after the medical emergency was over. As noted in the following excerpt (Example 4.37) she reflected upon her aphasia several weeks later and linked it to her experience with her mother (Line 275).

Example 4.37 (Appendix B, MN Interview, Lines 273-275, and 277-279)

273 And when I've heard that word may be I may have heard it (.) on Sunday
274 evening in the afternoon (.) and when I thought I'm seventy one years old and
275 I've had a stroke because my mother has had I don't know how many strokes
...
277 Ehmm may be (.) more than only strokes she had (.) take apha here's another
278 word ehmm that she had with her heart (.) but anyway (.) I thought to myself
279 (.) well (.) I'm very (.) I was very upset

Remembering back to the difficulties that her mother had with strokes, she stated that she became very upset during those times of reflection (Lines 278-279).

KN also reported an interesting emotional response when facing the impact of his aphasia. As discussed in the previous super ordinate theme, he had particular difficulties dealing with complex social settings. In Example 4.14 he stated that even when he wanted to communicate appropriately, everything just got "topsy-turvy" (Line 88). He also expressed difficulty with auditory comprehension at this work site (Example 4.22). With experience in the workplace, KN reported to his physician (Example 4.38) that he reached to a point that he

became frightened in the mornings before going to work (Line 50). Even though he realized that talking and working with people shouldn't be problematic (Line 52), it was something that he could not negotiate well and he could not forget his problems.

Example 4.38 (Appendix C, KN Second Interview, Lines 49-53)

49 (.) He understand that I was letting him know that I was I got to a point that I
50 was in the mornings I was certainly getting scared in the mornings just well but
51 going to the office and working with people I just I was just (..) I know
52 working with people and talking with people so that part of being would you
53 scared you just you're gone I mean you just forget about that but the thing is

When the interviewer showed interest in this reaction, KN responded to the interviewer's question about his fear a few lines below the initial statement (Example 4.39).

Example 4.39 (Appendix C, KN Second Interview, Lines 57-60)

57 Yes just one of those things that that that's what the neurologist said "it's just k
58 kind of a normal thing for some people" that (.) 'cause again myself I could
59 understand why in the morning that I was (.) I would get (.) scared or
60 concerned or would be worried about those levels

KN believed that his fear was common and he was told by the neurologist that his fear was "a normal thing for some people" (Line 58). However, KN felt concerned and scared in the mornings for a long period of time following the onset and these feelings helped motivate him to seek solutions (see Response to one's condition). Similarly, DR also expressed emotional reactions. During the interview, for example, she was discussing her attitude and in responding to a question from the interviewer, she stated that she was depressed and recognized how hard it was to address her condition since it was very emotional (See Example 4.40).

Example 4.40 (Appendix A, DR Interview, Lines 579-582)

579 Yeah (laughing) that helps but not always you know but it's you know (.) at
580 first like I said very depression you know and ehmm it's hard to even to get
581 into a door you know to open the door to get into ehmm a room or something
582 (.) be able to ehmm interact you know that's hard

DR admitted depression in the early stage following the onset. However, she also believed that it was a challenge for her even to be physically available and to interact with other individuals. She suggested that while recovery was hard, it was a challenge that she had to take upon herself. Overall, these emotional feelings, while quite salient could vary in nature across the participants in this group. Further, the individuals with aphasia could even sense in themselves a mixture of emotions. That is, these individuals could feel afraid, angry, sad, and frustrated following the onset. These were common emotions.

I Have a Problem

As a result of the emotional reactions to the various impact variables noted by each IWA, all the participants in the Aphasia Group realized that they had a problem that required some effort to overcome. Of course, the problems experienced by the participants in this group were a combination of the impact of the aphasia and their emotional reactions to these problems. DR, for instance, described a very specific problematic realization triggered by her inability to deal with her finances (Example 4.41). While she knew she had problems with speaking, she responded to that difficulty with avoidance so she could overcome that barrier – at least superficially – (see next theme) but when she could no longer handle her own finances, the “sudden rendered” (sudden realization) (Line 203) occurred to her.

Example 4.41 (Appendix A, DR Interview, Lines 203-206)

203 All of a sudden I I rendered that I had problems you know (.) and I didn't know
204 how to say dysphasia you know first thing I couldn't do is money so
205 everything last and stuff I ha can't even now you know I have troubles with
206 numbers

MN also recognized that she had problems when she realized that she could no longer function within a social group setting. In Example 4.42 she discusses her problems with

group interactions and then states, “Yes I do have troubles a lot of troubles with that” (Line 591).

Example 4.42 (Appendix B, MN Interview, Lines 588-589, and 591)

588 Seven or eight people sitting down I (.) will not understand what they are really
589 saying

...
591 Yes I do have troubles a lot of troubles with that

While problem realization may not have been long in coming in some cases, for KN this realization took a while (see Example 4.43). In discussing his difficulties, KN suggested that this realization took two years:

Example 4.43 (Appendix C, KN Second Interview, Lines 33-34, and 36-40)

33 It was one of these things just it took a while I didn’t realize ‘till probably it
34 took me about two years to realize (.) you have a problem

...
36 I realize for me it that these just things coming were getting better and I didn’t
37 understand ‘cause I had two seizures in the middle of that which kind of like
38 you get to a point is it drop you start coming up and you have a seizure and
39 then you drop and that’s that (..) so it took a while for me to to understand (.)
40 and I start looking in the computers and watching and (.) internets

By his own accounting, KN became aware that he had a “problem” (Line 34) nearly two years after onset of his aphasia. He believed that he needed time to realize that because he felt that he was recovering, but then he had a relapse or decline based on the seizures that occurred after initial recovery (Lines 36-39).

Avoidance

Once the realization of problems that were difficult to handle occurred to these IWA, another link in the reaction change occurred. In all three IWA, there was a period of avoidance. This consisted of avoidance of other people, social situations, and even avoidance of thinking about what they needed to do next. Based on the lived experiences of the participants in the Aphasia Group, the IWA anticipated potential challenges in various

situations. Since these challenging situations were often considered as unpleasant or demanding, avoidance was an initial reaction to these challenges. The IWA attempted to avoid situations like entering conversation situations with particular individuals, socializing with large groups, shopping, and talking on the telephone. Two IWA talked about avoidance several times. DR (Example 4.44) responded to the interviewer's question about activities following the aphasia and discussed overt avoidance:

Example 4.44 (Appendix A, DR Interview, Lines 224-226, and 228)

224 Ehmm ehmm maybe about four five months (.) you know like I said I was
225 driving and stuff and stuff but sometimes I couldn't even go to ehmm (.) a
226 store I would may be driving and I say (.) I didn't have the courage
...
228 You know I found you know so that was hard

DR was able to drive in her surroundings and even to go to the store. However, she was incapable of entering the store to buy products. DR believed she was not ready to perform this act. She described this situation as “that was hard” (Line 228). This was a challenge for DR. As it was discussed in a previous example (Example 4.15 lines 194-197), it was a challenge for DR to talk with others at the store in the early stage following the onset. In the current example, DR attempted to avoid talking and interacting with people inside the store that was considered as a challenge for her in the early stage. Similarly, avoidance as a reaction was also employed by MN (Example 4.45).

Example 4.45 (Appendix B, MN Interview, Lines 212-214, and 216-217)

212 And we left (.) and she drove me back to Lafayette General and (.) I knew then
213 that there is something wrong with me and I knew somebody down the road on
214 the emergency and I said like “I don't want to see anybody”
...
216 Because there is something wrong if he asked me question I can't say the
217 right things

When MN was admitted to the hospital, she was aware that something was happening. MN was familiar with a person near the emergency room at the hospital. It was likely that MN would meet this person at some point. She was concerned about the possibility of having difficulties during talking with this individual. Therefore, MN preferred to stay away from this situation so she wouldn't have to talk with him based on the difficulties that she may encounter when talking with others.

The IWA attempted to avoid conversation in particular situations as a mechanism to address the challenges in aphasia. This is demonstrated in the following example.

Example 4.46 (Appendix A, DR Interview, Lines 408-410, and 412)

408 So that's why if the telephone rings I never answer it because one of them has
409 to come back and ehmm (.) I can read reprove it and stuff if I do ehmm a
410 message I can only get it correct
...
412 Because it involves time

Previously, DR talked about how difficult it is for her to talk on the phone with other people. It was a challenge for DR to follow what the caller was saying. In this example, DR believed that she needed time to both comprehend what was said and to respond (Line 412). DR didn't talk on the telephone with others "I never answer it" (Line 408). If the caller left a message, she would listen to it and repeat it again so she could understand it (Line 409). DR avoided talking on the phone so the caller would leave a message that she could repeat several times to understand.

It is interesting that the IWA discussed these types of avoidance strategies 11 times during the interviews but they were always discussed as happening during the initial periods of aphasia. That is, within the first several months post-onset. Over time, however, the IWA modified these avoidance reactions to aphasia and started interacting more. The tendency toward avoidance in each case was overcome by the caregivers and some medical personnel

who realized that a more suitable response to the condition of aphasia was necessary. This issue will be discussed under the next sub-ordinate theme.

Experiential Metaphors

Eventually each of the IWA moderated their reactions concerning aphasia. Over time – and by the time they were being interviewed for this study – each one had less emotional and more mainstream reactions. Much of this is due to the various responses to aphasia that were implemented after a short period of time in the lives of these IWA and their caretakers. These experiences make up the last super-ordinate theme. However, the IWA did gradually learn to discuss and describe their aphasia and their reactions to this disability state. In many of these instances, metaphorical descriptions were employed when discussing aphasia and its recovery. Metaphors are often used as an attempt to understand complex phenomena or phenomena that we have yet to fully integrate into our personal understanding. Metaphors are ways to use the creative and visual aspects of language to understand via comparison. That is, as Lakoff and Johnson (1980) suggest, the essence of the metaphor is to understand one thing by describing it as another. For example, metaphors contributed to the recognition of aphasia based on the perspectives of the IWA regarding aphasia. Through the use of metaphors during discussion and as the mental frames within which to operate following aphasia, the IWA create an interpretation of their experiences of having aphasia. Through metaphor these aphasia experiences are expressed and implemented.

Metaphor can be considered as an experiential extension of the impact of aphasia in which the IWA carry on these elements into lived experience. That is, the experiences of the IWA were derived from how aphasia affected various aspects of the life. The use of metaphors by the IWA about the impact of aphasia is illustrated in the excerpt below.

Example 4.47 (Appendix B, MN Interview, Lines 707-709)

707 Shows me no reason (.) I had no I didn't fall nothing but I thank god that I can
708 do this so I didn't drive for four months and two weeks and to me that I was in
709 jail when I was couldn't drive couldn't talk exactly (.) it was like I was in jail

Within this excerpt, MN considered the challenges she encountered in the early stages following onset. These challenges consisted of physical challenges as well as challenges in social action. For instance, it was difficult for MN to drive her car or to verbally interact. MN described her experience based on these difficulties as being “in a jail” (Lines 708-709). That is, MN believed she couldn't move in her surrounding by driving and she was incapable of effective conversations with others. Therefore, the implications of these challenges within MN's life were considered catastrophic; she used a metaphor to demonstrate its impact.

DR also used metaphor to relay her reactions and emotions states when facing the challenges of aphasia. This can be noted in the following extract taken from the interview with DR.

Example 4.48 (Appendix A, DR Interview, Lines 244-248)

244 Well I can't I'm having troubles with someone hears and I was telling them
245 ehmm we were talking about the other day exactly ehmm the best way I can
246 descry describe it what like I had one when I had one with my stroke when I
247 first started I was like a like a tunnel world and now it's gotten better and it
248 opened up

In this example DR is discussing some of her discussions from group therapy with other individuals with aphasia. She shared with other members of the support group about her own experience in aphasia. She related that at first it was difficult for her to comprehend language and to talk following the onset of aphasia. To effectively describe her difficulties and limitations, she compared aphasia to being “in a tunnel” (Line 247). That is, challenges in listening and talking contributed to keep MN away from interacting with other people, thus she viewed her challenges as living in solitary and in isolation from other individuals.

Further, the tunnel began to open up indicating a positive change and moving forward in aphasia. As we can see, the experience of DR including aphasia and recovery was represented through this metaphor.

Coping with Aphasia

The third super ordinate theme was a consequence of the first two and involves the actual responses made as a reaction to the state of aphasia by the IWA and his/her significant others. Understandably, this super ordinate theme was the most frequently and deeply discussed by the participants and typically demanded the most time during each of the interviews. Of course, since the interviews focus on the lived experiences of these participants and since they have had to live with aphasia and have tried to respond as they can to it, the emphasis of this theme is predictable. Overall, the discussions that create this theme involve the set of mechanisms that were employed as a response to specific challenges and the impact of aphasia and the evolving awareness that became a consistent organizing force in the daily lives of the IWA.

As the last super ordinate theme demonstrated, the IWA realized that their aphasia had a real impact within their lives. As the IWA became aware of the limitations that she or he went through, awareness was established that revolved around moving forward in life despite their aphasia. That is, the IWA realized that she or he moved progressively over time and that specific measures were required (and employed) in order to address aphasia. Importantly, while the IWA were aware that moving forward was necessary, it was not accomplished by attempting to become their old premorbid selves. Rather, recovery was interpreted as simply moving back toward how the IWA was before the onset. These responses to the aphasia, guided to some extent by basic interpretations of recovery, were

derived from how each IWA perceived that they lived through aphasia; they constructed responses to this disease state.

Mechanisms

In discussing their reactions (see last super ordinate theme) to the initial state of aphasia, the IWA essentially set themselves up for responses of several types. Although these were described in various ways, many of their responses could correctly be seen as a set of mechanisms oriented to overcoming aphasia. In all, there appeared to be five primary mechanisms that were discussed: clinical intervention, support, compensation, social affiliation and practice. According to the lived experiences of the individuals with aphasia, these mechanisms were considered as a set of tools used to answer and to address the impact and the challenges in aphasia. This group of tools was employed across many contexts that involved social actors of various types including the IWA, members of their families, and extended social collaborators such as their clinicians, work colleagues, friends, and health care professionals.

Clinical Intervention. One frequently discussed response mechanism in the Aphasia Group involved clinical intervention. This was the primary mechanism that was discussed by the IWA. They tended to discuss it first when talking about their “response to aphasia” narrative and each one introduced their experiences with clinical intervention themselves (rather than it being introduced by the interviewer). Of course, given that the interviewer was perceived as a clinical aphasiologist and the interviews were conducted in a clinical context (the speech and hearing clinic), it is possible that the IWA stressed these activities initially to be more oriented to the interviewer and the clinical process. Based upon the extent to which

clinical intervention was re-introduced and the time given to it, however, it is still a primary mechanism even if the IWA were influenced by the clinical nature of the interview context.

Based upon their lived experiences during their perceived periods of recovery, each IWA reported that they were referred to a speech-language pathologist for a particular and limited period of time as a medical response to their aphasia. During the clinical sessions that resulted, the clinicians engaged in similar activities and had the IWA carry out particular tasks. Through these tasks, the clinicians intended to elicit responses from the IWA based upon their communicative difficulties with a stated objective of remediation. The IWA attempted to perform these requested activities in the therapeutic contexts and always under the supervision of the clinician. According to the IWA, these tasks often consisted of repetitive activities directed at simple symbolic processing. For example, in one activity employed for all three IWA, the clinicians designed activities around the ability to follow commands or the clinician asked the IWA to answer particular questions that were often simplistic and straightforward. In another activity discussed by all IWA, the clinicians required confrontational naming. That is, the IWA looked at a card with an object pictured on it and attempted to name the objects. For the most part, the IWA did not discuss why these activities were employed but, rather, simply followed the directions and guidance of the clinicians. In fact, while they did describe approximately 11 different activities between them, none of the IWA provided much of an explanation or rationale for what they were asked to do; they simply followed the instructions of the clinicians and trusted that these activities were oriented to recovery. For example, in the following excerpt (Example 4.49) DR discussed one activity and her response during aphasia therapy.

Example 4.49 (Appendix A, DR Interview, Lines 133-135, 137-138, and 140-141)

133 Yeah one of the first things they bring you are the different articles that you
134 have to bring under there (.) and they may give you like three or four different
135 articles and they ehmm

...

137 Yeah ehmm a mirror a ehmm a comb a brush little things and stuff so just to
138 remember articles

...

140 And start with a couple you know and then (.) little words and stuff at first they
141 were get me to talk back to them

As illustrated in this example, DR discussed the actual activity from a procedural perspective and then simply described her expected reaction (Lines 140-141). She was presented with a set of real objects and she was expected to identify these items within a confrontational naming format (Line 137). It should be noted that as with all other examples provided across all the IWA, the activities and their responses were detailed but at no time did the IWA discuss why these activities were chosen and how they impacted on recovery from aphasia. As DR stated, she was required by the clinician to say the words relevant these objects that were presented to her (Line 138) and she simply described it as to “get me to talk back” (Line 141). DR believed that the focus was to elicit a verbal response from her based on a request given by the clinician but as with all other intervention descriptions, only this procedural description was employed.

MN also discussed intervention from a procedural perspective. As noted in Example 4.50, she simply described the activity and her expected response.

Example 4.50 (Appendix B, MN Interview, Lines 432-433)

432 And I went here in Lafayette General and the girl would come and get the book
433 and tell me “say this word again” and she say that over and over again

As may be noted above, the therapy was directed toward reading individual words

from a book. She did not describe this activity as reading but, rather, as another form of confrontation naming; MN was presented with a book by a clinician and was required to repeat designated words of the clinician. MN described that task as “say this word again” and she did so (Line 433). Once MN said the word after the clinician, the clinician repeated it numerous times “and she say over and over again” (Line 433). Consistent with each of the descriptions of intervention activities, the IWA describes the procedure used with a focus on the verbalization required but no rationale or explanation for what was required was provided. In every instance provided during the interviews, the IWA simply accepted what was required.

While there was a focus on the procedures that they performed as the IWA explained their intervention experiences, they also provided occasional evaluative reactions about the experience or the clinician. This suggested that while there was a tendency to place themselves in the hands of their clinicians, the IWA did have some reactions that they remembered and discussed regarding therapy. For the most part, these evaluative statements were positive about the clinicians but indicated that intervention was a difficult activity. DR, for instance, overtly praised her clinician when recalling her intervention experiences (Example 4.51)

Example 4.51 (Appendix A, DR Interview, Lines 100-102)

100 She was awesome oh Lord but ehmm “do you have a light on?” And I was
101 “yeah light everybody has a light” but she says “put (.) flip the wit ehmm the
102 switch on”

In this example, DR first commented on her clinician and then recalled the activity required. The clinician was described as awesome first then an activity (following commands) was described. In Example 4.52, the IWA was more evaluative about the

intervention tasks. The IWA encountered challenges during the performance of this particular clinical activity and this was often the focus on the IWA lived experiences about intervention. Several of these challenges experienced by the IWA are illustrated below.

Example 4.52 (Appendix A, DR Interview, Lines 146-148)

146 Oh ehmm it was very hard it was very very hard for me and stuff because I
147 couldn't remember or categorize different things you know (.) and there were
148 two three balls one over there if I can (.) categorize them and things like that it

In this example, DR believed it was a challenge for her to carry out the clinical tasks (Line 146). She was required to provide names and to group particular articles (Line 147). These challenging tasks aimed to elicit a response from DR by grouping and providing the names of targeted objects. DR believed that she was incapable of performing the task “couldn't remember or categorize different things” (Line 147) but she persisted. Similarly, a challenge during clinical sessions is presented in the following excerpt.

Example 4.53 (Appendix B, MN Interview, Lines 435-437)

435 It made me feel like zero bad horrible because I felt here I am in my mind I can
436 say exactly what I want to say I can say the whole story but I can't say
437 anything

In this excerpt (Example 4.53) MN provided an evaluation of the clinical experience by stating her negative feelings about her performance. MN provided a negative evaluation of her performance and she described how she felt “made me feel like zero” (Line 435). MN held the belief that she was familiar with what she intended to say, but she couldn't say it (Lines 436-437).

Overall, however, each of the IWA recalled clinical intervention positively. Although they did not question what was done in therapy and did often evaluate their own performances (or at least how difficult the tasks were to them), each IWA appeared to believe that their clinical intervention was effective and allowed them to respond to aphasia and to do

so as a move forward. That is, the IWA considered the clinical sessions, including the clinician and the clinical tasks, as an attempt to overcome challenges in aphasia. The following statement by DR is illustrative of what was noted in all three of the IWA (Example 4.54):

Example 4.54 (Appendix A, DR Interview, Lines 418-422)

418 Ehmmm Bettie was she did things on both and stuff but all the times that when
419 we get into therapy she realized (.) like even when I go to the reception if I
420 needed to do my ehmm schedule (.) I could write it so she came back and said
421 “okay but the book I’m gonna help you how to (.) write a note a small note”
422 you know check it off you know that’s how therapy helped me

In the current example, DR stated that she was capable of some functional writing (her daily schedule) and so the clinician took this residual skill and expanded it (Lines 419-420). This was an example that she provided about the functional and beneficial nature of her intervention. DR could carry out an actual activity involving writing that she “needed to do” (Line 420) and the clinician became aware of DR’s writing potential. Subsequent to that, DR was required to perform a clinical task by writing “a small note” under the clinician’s supervision (Line 421). DR believed that this specific clinical task designed by the clinician contributed to address her aphasia “that’s how therapy helped me” (Line 422).

Overall, clinical intervention was viewed as the first and most tangible response mechanism toward aphasia. During their interviews, each IWA initiated discussion about intervention, discussed the tasks involved and provided evaluations about how difficult this activity was for them. However, the evaluations about the clinicians and the overall benefits of intervention were positive. The IWA considered intervention a positive step toward their eventual recovery.

Support Mechanisms. A second response mechanism discussed by the IWA involved two types of support that they received throughout their recovery periods. Each

IWA discussed some degree of familial support and each discussed the role of an aphasia support group as being beneficial as they moved toward recovery. Throughout discussions about these supportive groups, there was frequent collaboration between the IWA and their support mechanisms. Within these contexts, collaboration took the form of active and dynamic interactions by which two social parties (the IWA and family members or support group) were involved in this mechanism. Collaboration can be considered as an interactive action in which these two social parties were reciprocally negotiating the direction and the meaning in aphasia and they worked together in a coordinated and joint manner attempting to address difficulties in aphasia.

Throughout the interviews, the IWA did discuss their *family members* as being supportive of their attempts at both recovery and their struggles to overcome the daily problems created by aphasia. While the family was defined differently by each IWA according to their circumstances, these family members (e.g., caregiver, siblings, nieces, and children) were considered as a vital recovery mechanism. According to the IWA, these family members functioned as care givers and they often performed certain acts seeking to provide care and assistance to the IWA. Initially, these individuals provided help to the IWA by escorting and staying with the IWA at the hospital when the stroke and aphasia emerged. In addition, these individuals performed several activities following the onset involving the IWA. This is illustrated in the excerpt below while MN was discussing her attempts to respond to her aphasia.

Example 4.55 (Appendix B, MN Interview, Lines 463-465)

463 My daughter wanted to stay at her room I wanted to stay at my own house
464 because ehmm my (.) uh let me see something ehmm then Annie my daughter
465 the nurse took care of me of everything all the time and I figured I go to

As noted above, MN talked about her daughter who wanted MN to stay with her after she was discharged from the hospital (Line 463). However, MN preferred to go back to her own house. When MN went back to her own place, however, her other daughter (“the nurse”) provided her with assistance and care. MN described the assistance provided by her daughter as “the nurse took care of everything all the time” (Line 465).

Not only did the families provide needed assistance and care to overcome the medical issues, familial caregivers became constantly responsible for additional and various activities following the onset. These were usually activities that had been carried out by the IWA prior to the onset of aphasia.

Example 4.56 (Appendix A, DR Interview, Lines 238-242)

238 My sister mostly my sister that’s my that a (.) on a daily daily (.) minutely
239 hourly you know everything with (.) her you know and stuff but ehmm she
240 would come up and she would help me and ehmm (.) if I needed anything she
241 was behind me now I can pretty much do it myself ehmm except one the
242 telephones that’s that I I

DR believed that her sister constantly helped her all the time”with everything” (Line 239). DR described the care giving role of her sister as “she was behind me” (Line 241).

According to DR, her sister always provided assistance that DR required. This description of consistent support is similarly presented in the extract taken from the interview with KN.

Example 4.57 (Appendix C, KN Second Interview, Lines 232-236)

232 So she had to learn things (laughing) very different and everything from doing
233 the banks the moneys the you know going to the computers were had all the
234 nets the banks stuff in it and things like that for a while it’s been very hard for
235 her like if you want to spent some time with her you will find out that (.) she
236 it’s been a very hard with her now I guess by the a year ago my mother the one

In this example, the spouse of KN became responsible for particular activities following the onset. The caregiver started to deal with the family financial issues including on line bank services (Line 234). KN believed that this new role was a challenge for the

spouse by which it took a lot of her time and she was fully engaged with these activities (Line 235).

In addition to providing assistance regarding activities of daily living, the family served as support mechanisms in therapy practice and in other therapy related activities. That is, these family members encouraged the IWA to engage in talking with other individuals seeking to answer their aphasia. Two of the IWA talked about how their family members contributed in these situations. In the following example, DR responded to a question asked by the interviewer about the importance of the aphasia support group to her recovery.

Example 4.58 (Appendix A, DR Interview, Lines 559-563)

559 Oh we were laughing at this earlier at first I didn't think (.) I don't you know I
560 don't be able to do this (.) what do I have to support from them? What what
561 can I don't need anything you know that was my attitude at first and then they
562 said "no try us" and that was my sister you know (.) she said "do this for (.)
563 you" and I said "why?" She said "okay then do it for us"

DR initially didn't believe that she should attend the meetings of the aphasia support group. She questioned whether this group could actually contribute to her recovery (Line 560). DR held the belief that she was independent and didn't need anything from other individuals (Line 561). However, her sister negotiated with DR about the potential utility of these meetings. Initially, her sister tried to explain to DR that she personally would benefit from the support group (Line 562). However, when DR questioned this assertion her sister changed strategies and suggested that she and the family would benefit from DR attending the group's meetings "okay then do it for us" (Line 563). Similar indications of familial intervention were interspersed throughout the lived experiences discussed by the three IWA. This can also be illustrated in the excerpt below.

Example 4.59 (Appendix B, MN Interview, Lines 443-445)

443 She gave all that and she said “mom you keep talking” she would make her
444 cell and call people (.) and make me talk with her and I said to her “don’t feel
445 lying on mom” (.) read that paper read this” they determined with me you see

In this example, MN’s daughter was the supportive agent. In this role she made various attempts to address her mother’s aphasia. She encouraged MN to talk (Line 443). The daughter made contacts with other individuals on the phone and she then got her mother (MN) on the phone to talk with them (Line 444). The daughter also asked MN to read aloud a certain paper that she provided. MN described these attempts as “they determined with me” (Line 445).

One IWA talked about the collaboration between several family members including her sister, her niece, and her grandnieces in attempting to help DR with her speech. DR reported working alone on how to say certain things or to complete in writing a particular document especially writing checks. Afterwards, the IWA approached her sister or her niece requesting help. These two family members assisted the IWA accordingly by examining her attempts and providing feedback regarding her performance. In the following example, DR responded to a question asked by the interviewer regarding the collaboration between herself, her sister or her niece.

Example 4.60 (Appendix A, DR Interview, Lines 231-234)

231 Oh sure sure you know and they were always very very support you know but
232 ehmm sometimes I get to a ehmm a shadow (.) you know she’d come if I’m
233 trying to write something she’ll ehmm how they say I started he ends it you
234 know that type of thing ehmm

DR believed that her sister and her niece were supportive (Line 231) and beneficial. Initially, DR made attempts to write a specific document. DR encountered challenges in her writing attempts. She described these challenges as “a shadow” (Line 232). Her sister or the

niece approached DR and provided her with assistance. DR described the collaboration between herself and these family members as “I started he ends it” (Line 233). The family members reviewed and then (if necessary) completed DR’s attempts in writing. As we can see, DR and the caregiver or the niece worked jointly to overcome her challenges in writing by which DR initiated the writing attempts and the caregiver or the niece completed these attempts.

The IWA did discuss the advantages of the *aphasia support group* and how this group also assisted as a response to their state of aphasia. In all three instances, the IWA attended an aphasia support group on regular basis. Social affiliation was manifested through the meetings of the support group. That is, individuals with aphasia gathered together in a group setting and shared ideas and feelings. They also exchanged their personal experiences about aphasia. The experience of having aphasia including challenges was considered as the common ground between these group members. All three of the IWA believed that attending the support group was beneficial as an attempt to address aphasia. This attitude is represented in the excerpt below.

Example 4.61 (Appendix B, MN Interview, Lines 608, and 610)

608 It helped me it helped me because I could hear it

...

610 I think seeing other people with the same trouble that I had helped me.

In this example, MN touted the value of the aphasia support group (Line 608). Within this context, MN not only met with other individuals with aphasia, she shared her story of aphasia with them and they did the same to her. This in itself had great value to her and she described this social affiliation as “seeing other people with the same trouble” (Line 610). The commonality between MN and other members of the group was their aphasia but this

commonality enabled her to share all that she was and all that she felt about aphasia.

According to MN, the social affiliation in the support group was beneficial for her (Line 610). This belief in the power of the aphasia support group as a viable support mechanism in response to the state of aphasia was shared by all three participants with aphasia.

It should also be mentioned that these two groups (family and aphasia support group) not only provided various types of support for the IWA but that they also served as the key constituents in another response mechanism, social affiliation. This will be discussed later in this chapter.

Compensation. Both in direct discussions and through indirect references, the application of compensations as responses to aphasia were also raised as mechanisms for recovery. In most of the instances in which it was discussed, compensation was used to enable successful communication and interaction between the IWA and other individuals. Additionally, the compensations that were discussed were most often in reference to current or recent experiences rather than experiences early post-onset. This is one of the reasons that it might be inferred that avoidance as a mechanism decreased as sufficient compensations were established. In each of the IWA a set of strategies were employed to address implicitly or explicitly the challenges in aphasia. These compensations frequently were used during the conversation between the IWA and other people. Based upon the comments by the IWA, these compensations created a more successful atmosphere between the IWA and his or her conversation partners.

While there were a number of compensations that were used by the three IWA (One of the IWA had developed a wide range of compensations that had been noted and analyzed for a research paper on the development of such strategies), not all were discussed explicitly

during the interviews. Three general types, however, were described. First, the IWA discussed a compensation that involved how the IWA prepared and requested sufficient time from their conversational partners so the IWA could finish talking with no interruptions. A second type of compensation discussed focused on how the conversation partner could enable the IWA to understand what he or she said to the IWA while a third involved how the IWA got his or her message across by using verbal and nonverbal means. Further, some of these strategies were developed by the individual, the caregiver, or other resources. Examples of the three types just mentioned follow:

The first type of compensation might be described as “*Give me a minute*”. The IWA during the conversation with other people employed this particular strategy in an attempt to overcome challenges in aphasia. Initially, the individual introduced himself or herself as a person who had aphasia. Afterwards, the IWA explicitly requested that the conversation partner to be patient and to provide the time to the IWA so he or she could finish talking with no interruptions. That is, the compensatory tool prepared for a smooth interaction between the IWA and the conversation partner. This measure could contribute to overcome challenges and barriers during conversation with the IWA. One participant in the Aphasia Group talked about this tool. This is presented in the excerpt below.

Example 4.62 (Appendix A, DR Interview, Lines 218-221)

218 And actually deal with it and then I can start verbally come out and say “this is
219 the first thing I have to tell you I’ve had a stroke I’ve had dysphasia give me a
220 minute to go slowly” and stuff that that usually I preferred to see if people I
221 don’t know they’ve had a stroke what wrong with me you know

In the current example, DR believed that she could deal with the aphasia when she talked with other individuals. Over time DR developed a compensatory strategy in which she would initially share with the conversation partner that she has a stroke and aphasia (Line

219). Subsequently, DR requested that the conversation partner to be tolerant by allowing her to speak slowly as “give me a minute to slow down” (Line 219-220). DR prepared the ground so she could talk with others and to participate smoothly through the conversation. DR believed that disclosing to the conversation partner about her stroke and aphasia could contribute to make them familiar with her situation (Line 221).

Similarly, by the use of a specific compensatory strategy, the IWA made the effort to overcome the challenges manifested through the conversation. MN discussed a strategy whereby she explicitly requested from the conversation partner to *talk slowly*. This strategy could enable the IWA to participate more actively to some extent during the conversation. This is illustrated in the following example.

Example 4.63 (Appendix B, MN Interview, Lines 595-596)

595 I'll keep doing it (.) if I say it wrong I say “excuse me I have this but wait I
596 wanna just don't talk too loud for me”

In this example, when MN encountered difficulties during the conversation, she informed her conversation partner that she has aphasia. Afterwards, MN requested that her conversation partner to speak slowly during the conversation so that MN could comprehend and participate more actively in the conversation.

Several of the discussions involved another compensation regarding the use of alternative ways to approach interaction while accommodating the aphasia. In an attempt to enable the individual to express what he or she wanted to say, the IWA tried to employ different methods of overcoming the challenges in aphasia. For example, the IWA discussed using gestures to communicate with other individuals or they might have employed writing as a communicative strategy to overcome unintelligible or confusing speech. Some of these findings of *another way* are presented in the following two examples.

Example 4.64 (Appendix A, DR Interview, Lines 596-597, and 599-600)

596 I can ehmm (.) it doesn't bother me (.) okay if I don't have any ysphasia I can find
597 another way

...

599 It doesn't shot me out okay give me a minute now let me try and tell this in
600 another way (.) you know through gestures and stuff like that

DR believed that she over time she became less concerned about the challenges aphasia (Line 596). She believed that after a while aphasia didn't keep her away from interaction "it doesn't shot me out" (Line 599). DR focused on what she could do in these situations. According to DR, she used any mean necessarily so she could talk with other individuals. She described this as "let me try this in another way" (Lines 599-600). DR attempted to talk with other people by the use of gestures (Line 600). The use of gestures was considered by DR as an optional mean to communicate with other people.

Example 4.65 (Appendix B, MN Interview, Lines 546-548)

546 After fifty years so I told my daughter Annie I said "Annie when I'll see
547 people there I need to tell them something" and so she bought this and so I
548 picked that with me and I if I couldn't say I would tell them about it

In this example, MN was concerned regarding meeting people in an annual event and how she could talk them (Lines 546-547). MN told her daughter about her concern. The daughter brought a book to MN that she could use in this meeting. When MN was experiencing verbal difficulty, she used the book to talk about a relevant topic (Line 548).

Again, it is interesting to note that as the IWA discussed recovery over time, the mechanism of avoidance was reduced while compensations were discussed as eventual responses to the aphasia. Further, some of these were not developed in clinical intervention but, rather, by the individuals with aphasia as they eventually negotiated their states of aphasia themselves. In accordance with the progression of compensations, the next mechanism also began to be highlighted as a response mechanism to aphasia.

Social Affiliation. The IWA frequently discussed the importance of family, friends and other acquaintances as one of the reasons that they progressive became more social and started responding to their states of aphasia. In this sense, social affiliation was an important response mechanism. Within their interviews each IWA discussed belonging to and interacting with their families and with other social groups (especially the aphasia support group) in which the group members gathered together and shared their own experiences. As discussed previously, these two entities (family and aphasia support group) not only provided support in terms of assistance with daily living and understanding the state of aphasia, they also provided a context for social affiliation. As time post-onset progressed, family and the aphasia group started becoming more important as not only supportive resources but for social affiliation as well. The commonality between the family members and the IWA and the support group contributed to moving forward in aphasia. All the participants in the Aphasia Group talked about social affiliation in both of these groups. Several illustrations of social affiliation are provided below.

Example 4.66 (Appendix A, DR Interview, Lines 528-534)

528 Ehmmm (.) something before what would be the best (.) probably the best
529 thing we have one of the little ehmm (.) support group there one of the newest
530 little girl who came in and she was saying ehmm the noise is in the stimulus in
531 the whole the world the new world how it changed and stuff and that's what I
532 told her and said I guess the best thing I can say again is like in a tunnel you
533 know (.) and every day there's something new I have to channel a new
534 channel channel?

In this example, DR talked about a member of the support group who talked about her hearing acuity (Line 528) and the changes she experienced with aphasia (Line 529). DR shared with this member and the rest of the support group as well her own experience by describing aphasia as a “tunnel” (Line 530). It was a challenge for DR to hear and to talk with others. DR believed that she encountered new challenges all the time (Lines 531-532). It

seems these two individuals were sharing with each other, in front of the rest of the group, their own experiences regarding the aphasia and the commonality they have in terms of the challenges they came across in aphasia. Obviously, this illustrates the gains of the social affiliation in the support group. Again, instances of opportunities for social affiliation are presented in the extract below.

Example 4.67 (Appendix C, KN Second Interview, Lines 430-434)

430 That but I'd like to be work with people and help them I've been watch you
431 know I was watching with our aphasia group and I think the most things for me
432 is to go to that meeting so much for me for them I don't (..) it's going to be
433 it would comf very comfortable for me not because I'm going to get is
434 going be something great for me all that

In the current example, KN discussed his benefits from the support group. KN enjoyed “working with people” (Line 430). KN believed that it was important for him as well as other members to attend these meetings (Line 432). KN with held the belief that support group was very useful for him. He described it as “going be something great for me all that (Line 434). It seems that KN gained from the social affiliation in the support group by being with other members of the group.

Practice. The final sub-theme within theme of mechanisms for recovery involved the tendency for each of the IWA to engage in self-initiated practice. From very shortly after the onset of aphasia and even at the initial stages of clinical intervention, each IWA appears to have started working on various tasks and skills on their own. Frequently described as working on desired tasks “again and again and again” (Example 4.68 below) each IWA discussed working on communicative activities over and over to get better at them. In each instance, this tendency toward practice was oriented to performing certain activities that the individual actually used in his or her own life. These activities were executed on regular basis by the IWA such as daily or weekly. These activities involved the use of language such as

writing checks, paying bills, and buying items at the store. The IWA at some stage practiced performing these activities jointly with another individual such as the caregiver. On the other hand, the IWA practiced alone these activities at some point. Originally, these activities were initiated by the IWA or the caregiver. One participant in the Aphasia Group talked about functional practice. This is demonstrated in the following example.

Example 4.68 (Appendix A, DR Interview, Lines 345-347)

345 Realize with numbers (.) I can't write a check (.) I cannot write it so I've had to
346 write them again and again and again and I would write them and then they
347 come back and check it before

In this example, DR became aware that she couldn't write numbers and to write checks (Line 345). The activity that was performed revolved around writing checks. DR practiced writing checks several times alone by herself (Line 346). Afterwards, family members approached her and examined her performance (Line 347). Writing checks as an activity involved DR who practiced alone how to write checks and family members provided feedback about her writing attempts.

While much of the practice involved functional skills chosen independently by the IWA, some were initiated by the IWA, a family member, or external resources such as the clinician. These tasks involved reading and writing. One participant in the Aphasia Group talked about practice. This is presented in the excerpt below.

Example 4.69 (Appendix A, DR Interview, Lines 504-506)

504 By myself by myself (.) I've actually read regroup and I call it in the box (.) I
505 go to this little room I have and I have to take stimulus every day and I'm
506 trying ehmm to (.) concentrate myself I have to (.) I have to do that again

DR stated that she practiced alone by herself (Line 504) and she was motivated to do this so that she could recover. DR carried out a group of tasks. One task executed by DR involved reading. Another task that she performed was about categorizing certain items. DR

also provided the names of designated articles in one task (Line 504). According to DR, she executed these tasks daily and frequently “I have to take stimulus every day” (Line 505). DR was motivated and focused to perform these tasks repeatedly “I have to do that again” (Line 506).

Awareness

According to the IWA, as their experience with aphasia increased and they created a number of mechanisms as a response to the state of aphasia, they also developed an increasing awareness of what aphasia meant to them in their daily lives and how they would have to change. Awareness is a second primary theme that emerged from the super ordinate *Coping* theme. Awareness is about the realization gained through the long-term experience with aphasia and its consequences after the initial impact has been addressed. In this sense, awareness is different from the super-ordinate theme of *Reaction*. As discussed previously, *reaction* involved the behaviors that were generated as a result of the impact made by aphasia on each individual. Each IWA had discussed the emergence of the impairment and then quickly started realizing the impact that it had on their daily lives and this resulted in their personal reactions to these impacts. The behaviors discussed under *reactions* are triggered by barriers experienced by the IWA regarding the interaction between him or her and the context (including other individuals).

Awareness is the gradual sets of realizations that each IWA gained through long-term experience with aphasia and their responses to it. According to the interviews, the IWA initially became aware of what was going on that made an impact on him or her following several months of experience with aphasia. Within this awareness, the IWA began to recognize the limitations that he or she experienced involving language. On one hand,

awareness was centered on the recognition established by the IWA regarding recovery in aphasia. That is, the IWA realized that aphasia moved forward over time. Further, awareness also involved how the IWA made the effort seeking to establish recovery. That is, the IWA was aware of certain tools used for compensation in order to address aphasia. On the other hand, the IWA recognized the amount of moving forward in aphasia. Based on the living experience of the IWA, recovery in aphasia was established but only to a certain level or extent. The IWA viewed and interpreted recovery based on experience. The interpretation of recovery involved the basic representations of moving forward in aphasia and awareness is the realization of this process and progress. There appear to be three sub-themes under the theme of *awareness*: Recovery as change, incomplete recovery, and changing perceptions.

Recovery as Change. During their interviews each IWA discussed the realization their individual situations had changed and that aphasia and its consequences moved forward over time. This is illustrated in the excerpt below.

Example 4.70 (Appendix B, MN Interview, Lines 573-577)

573 Mem many many people now tell me now on the phone you sound like
574 yourself because otherwise my voice was lower when I had my stroke ehmm
575 and I'm interest to call somebody on the phone let's say "could I have this a
576 kind of give me a dollar a dozen for a for crawfish how much is please?" Or if
577 they talk fast and I say "excuse me I had aphasia and please"

In this example, MN was aware that her aphasia has diminished somewhat. She believed that people let her know about her improvement (Line 573). MN provided an actual example of moving forward. She presented how she could order a meal over the phone. The meal order included what she would order, quantity of the food, and how to ask about the price of the meal order (Line 576).

On the other hand, recovery also had evolved and was established in other language skills such as understanding spoken language and literacy including reading and writing.

Two participants in the Aphasia Group talked about recovery in these language skills. This is presented in the following example.

Example 4.71 (Appendix C, KN Second Interview, Lines 121-124)

121 Would understand and certainly you with with as my aphasia as my (.)
122 certainly my brain was coming back together and finding my (.) my
123 communication which was getting stronger and (..) because my (.) my hearing
124 was getting better because then I can understand what people were asking

KN recognized that his aphasia moved forward and his communication had improved “which was getting stronger” (Line 123). He was also aware that his ability to comprehend has increased allowing him to understand what his conversation partners were telling him (Line 124).

According to the living experience of the participants in the Aphasia Group, the nature of the recovery in aphasia was not static. Rather, they realized that recovery was gradual and progressive in nature and that they had to have patience and some expectations for change. In each case, the IWA noted these changes not only in their language and communication, but in other areas as well. One element of recovery as change involved personal change. That is, the IWA moved from dependence or some degree of reliance on others (e.g., working jointly with other individuals), toward greater independence in which the IWA started to perform certain activities alone with no assistance. One participant in the Aphasia Group talked about this type of personal change. Personal change is illustrated in the following example.

Example 4.72 (Appendix A, DR Interview, Lines 238-242)

238 My sister mostly my sister that's my that a (.) on a daily daily (.) minutely
239 hourly you know everything with (.) her you know and stuff but ehmm she
240 would come up and she would help me and ehmm (.) if I needed anything she
241 was behind me now I can pretty much do it myself ehmm except one the
242 telephones that's that I I

DR believed that she and her caregiver worked jointly together. The caregiver was constantly available to collaborate with DR and to provide her with assistance and support “she would come up and she would help me” (Line 240). DR described the caregiver’s support as “she was behind me” (Line 241). DR believed that she moved from working jointly with the caregiver toward performing particular activities independently now “I can pretty much do it myself” (Line 241). The recovery of DR was considered as a change in which DR moved from collaboration toward independence to some degree.

There was also a growing awareness that recovery also involved social change. That is, the IWA moved from less socialization toward greater interaction with other individuals. The IWA went through change in which the individual could talk with other individuals and share with them about his or her personal life. Two participants (DR, KN) talked about social change. This is presented in the extract taken from the interview with DR.

Example 4.73 (Appendix A, DR Interview, Lines 590-591, and 593-594)

590 And then (.) now at first to me was just just ehmm ehmm personal business
591 you know
...
593 Now I’ve got ehmm my ehmm personal things out now (.) I guess ehmm in my
594 ehmm on the same track you know

DR believed that she kept matters to herself without sharing them with other individuals in the early stage following the onset “personal things are out now” (Line 593). Recently, DR was able to disclose and share these personal matters with others. DR moved forward from keeping these personal issues to herself only toward sharing them with other individuals. Similarly, social change is illustrated in the following example.

Example 4.74 (Appendix C, KN Second Interview, Lines 304-307)

304 It won’t wont ‘till like I said mostly within the last two years were I’ve learned
305 much more speak and stro and teach to listen and hear those ehmm you know it

306 it goes both and front those are the things I had to learn much more much more
307 comfortable when I learned that I became both a teacher and a student

KN believed that in the last two years he progressively changed in talking directly to people and talking with people (Line 305). He described the interaction between him and others as “it goes both and front” (Line 306). He felt “comfortable” with these changes (Line 307). KN believed that he moved forward over time in his interaction with other people.

Incomplete Recovery. The second aspect of awareness about recovery from aphasia involved the realization that any recovery would be incomplete and that the IWA recognized that aphasia moved forward only in limited ways and that recovery coexisted with residual challenges. That is, although moving forward has evolved or established, several challenges and impairment would remain. Two of the participants Aphasia Group talked about incomplete recovery. This is illustrated in the following excerpt.

Example 4.75 (Appendix B, MN Interview, Lines 587-589, and 591)

587 I feel better but what bothers me the most is that a group let’s say five six
588 seven or eight people sitting down I (.) will not understand what they are really
589 saying

...

591 Yes I do have troubles a lot of troubles with that

In the current example, MN believed that she moved forward “I feel better” (Line 587). However, she recognized that participating in a conversation with a group of people was a challenge for her. It was difficult for MN to understand what the conversation partners were actually saying (Line 588). She described her challenge as “I do have troubles a lot of troubles with that” (Line 591). Incomplete recovery in reading is presented in the following example.

Example 4.76 (Appendix A, DR Interview, Lines 481-483)

481 Silently yes you know (.) yeah not a novels or any kind of that I have little
482 ehmm articles you know the magazines it has maybe three or four little ehmm

483 (.) word articles and then not a long life two or three pages on there

Obviously, DR believed that she was able to read silently but she couldn't read an extensive long printed document "not a novels" (Line 581). DR was capable to read small articles published in magazines (Line 482). She believed that she couldn't read a long article, but she was capable to read only a short article "two or three pages on there" (Line 483). DR was aware that her reading moved forward but particular challenges remained including reading aloud and reading an entire book or a long article.

Acceptance: It is a new road. Acceptance is another sub ordinate theme under the theme of awareness and involved how recovery needed to be eventually viewed by the IWA. The nature of recovery in aphasia was derived from how the IWA lived through aphasia. This sub ordinate theme was designed by the basic interpretations of the IWA in terms of the recovery in aphasia. That is, perception was considered as how the IWA interpreted moving forward in aphasia based on his or her lived experience. Perception involved metaphors representing the core of experiencing and understanding recovery by using other terms. That is, metaphors about recovery were based on the insights and the interpretations of the IWA regarding moving forward in aphasia. A metaphor about the recovery in aphasia is illustrated in the extract taken from the interview with DR.

Example 4.77 (Appendix A, DR Interview, Lines 319-322, and 324-325)

319 Yeah (.) it is it is ehmm one of the things that (.) I guess another thing I can do
320 just ehmm describe as I was on a path (.) and with the stroke and stuff I had to
321 go re droop (.) a little in a different path and every time I get into new ehmm
322 would (.) dysphasia and anything like that it's a new (.) road
...
324 And I get on it if I am off I get off and get on again and I try something else (.)
325 I'm always trying if I have (.) verbally I have to find a way to express myself

In the current example, DR described how she was before the onset as "I was on a path" (Line 320). Recovery was represented by DR as moving to a "different path" (Line

321). Each time she encountered challenges, she would always go through “a new road” to overcome challenges (Line 322). DR represented her attempts to address aphasia as going through different roads “I get off and get on again and I try something else” (Line 324). In other words, these roads represented a set of mechanisms employed by DR to overcome these challenges. DR believed that she should try any mean necessary “to find a way” so she can express herself and talk (Line 325). Again, a metaphor about recovery is presented in the following excerpt.

Example 4.78 (Appendix C, KN Second Interview, Lines 302, and 304-307)

302 Not talk with people but to talk to people it’s a different thing
...
304 It won’t wont ‘till like I said mostly within the last two years were I’ve learned
305 much more speak and stro and teach to listen and hear those ehmm you know it
306 it goes both and front those are the things I had to learn much more much more
307 comfortable when I learned that I became both a teacher and a student

In this example, KN differentiated between “talking with people” and “talking to people” (Line 302). He believed that his social interaction has changed in the last two years. KN considered that it involved talking to others and listening to them (Line 305). This change was represented by KN as “I became both a teacher and student” (Line 307). He believed that that the interactional change he experienced combined talking as a teacher and listening as a student. As we can see, the interactional change was represented by the use of a particular metaphor.

Contextual Influence

The fourth super ordinate theme in the data set of the IWA addresses the context within which the state of aphasia and its recovery occurs. It must be remembered that this interpretive phenomenological analysis is oriented to how the participants make sense of their recovery experiences and this sense making is dependent on the meanings that

particular experiences and events hold for the participants. While such interpretations are dependent on the actual experiences of living with aphasia, they are also reliant on the contexts within which these experiences are interpreted. Particularly, what perspectives and expectations formed the contextual influences within which the lived experiences were interpreted? This theme is different from the other three super ordinate themes in that it involves less direct experience with aphasia but is more oriented to providing the background from which those experiences are interpreted. That is, rather than focusing on the way that the IWA organize their lived experiences as they describe them, this super ordinate theme provides insight into how and why the lived experiences were interpreted as they were. Based upon the interviews with the IWA, there were two recurrent themes that served as contextual influences with several subordinate themes employed within each of these themes. These involve the IWA perspectives and their expectations.

Perspectives

The first theme categorized under the super ordinate theme Contextual Influence involves the perspectives that each IWA brought with them into the state of aphasia. As one's mental view or outlook, perspective is an interpretive filter employed to organize each IWA's experience with aphasia. In effect, one's perspective supplies the emotional/affective climate within which the IWA operate during recovery. For example, how motivated, persistent, or discouraged an individual is during recovery is based upon this mental outlook. There were two primary sub ordinate themes that created the IWA perspectives, Identity prior to the stroke and locus of control.

Prior Identity. The first contextual sub ordinate theme under perspectives involved who the IWA considered her/himself to be before the onset of the aphasia. Since one's

outlook is structured by her/his self-image or identity, who one was, what were one's competencies, what were one's strengths and weaknesses, and how have these changed since the onset of aphasia are all influenced by how one views her/his current state and prognosis for the future. Of course, there are a number of variables that make up one's sense of self or identity and not all of these facets can be described. However, based upon analysis of the IWA interviews, each individual's identity before onset appears to be heavily influenced by four facets: communicative proficiency, faith, education, and occupation.

The first facet of prior identity appears to be each individual's *expertise and proficiency with communication*. That is, how proficient a speaker and/or social actor the IWA was considered prior the onset of aphasia. This facet is important because the IWA and others that they interact with tend to compare the IWA communicatively before and after their stroke. In effect, this is a kind of bellwether for comparison. For their part, each IWA talked about the communicative facet of their identity prior the onset. This is demonstrated in the following excerpt in which KN discussed his previous communicative expertise and set this premorbid effectiveness against what he is now capable of doing. Example 4.79 illustrates this when he is describing what he wants in rehabilitation:

Example 4.79 (Appendix C, KN First Interview, Lines 30-34)

30 Remember (.) what do I do the best is my communication as a leader and as a
31 director that that was my best times for me (..) when I do it as a director that
32 was my best job that I do now communication is one of the things that I want
33 to keep working to get better these are the things I think about at times (..) you
34 know I can't help thinking of all of this

In lines 30 and 31 he states that his communication was his strong point when he was the director of a research facility. However, due to the aphasia he is no longer capable of effective communication in such an institution and he focused on changing this by working

toward a strong recovery from his aphasia (Line 33).

In a similar manner, DR discussed her effectiveness with both verbal and written language prior to her stroke and how the aphasia has changed her to the extent that she is no longer able to easily read or work with numbers

Example 4.80 (Appendix A, DR Interview, Lines 278-280)

278 Ehmm I loved to read and then numbers numbers (.) numbers almost I I can't
279 ehmm write time I know the phone is there but to say the time it is gonna tell
280 me at least a minute to be verbally come out and is verbally

In this example, DR expressed how she enjoyed and appreciated reading before the onset of the aphasia when she stated, "I loved to read" (Line 278). She also talked about numbers. DR found it difficult to verbally tell the time or to write it down. Her proficiency as a language user is revealed in the way she achieved juxtaposition between what she was capable of before the aphasia versus what she was left with after the onset of the aphasia. Without question, each of the IWA created a contrast between the change in their use of language and this both motivated and vexed each of them.

Faith was another facet that contributed to shape the identity of the IWA. Based upon their interviews, all three of the IWA value their faith and the power of prayer as a sustaining influence from their premorbid state. For each one faith was based on the religious values of their Christian denomination (all three were Roman Catholic) and various facets of each one's faith was discussed. The IWA highlighted the importance of faith by talking about using their faith to sustain them through prayer or by engaging in church activities for religious and social reasons. For example, KN discussed the sustaining value of his faith and the social values as well. This is illustrated below.

Example 4.81 (Appendix C, KN Second Interview, Lines 579-583)

579 At the first part of it it was oh I was a hundred percent back I came back I was
580 already back to catholic but very very strong (..) and then it was about two
581 years ago I back to the came to the point (.) did I was where I have very strong
582 priest friends that I still you know maybe every month we go to lunch and just
583 to talk about different things (.) some days won't anything about prayers than

In this example, KN stated that part of his re-entry into society was through his church and because of his faith in that church. He stated that he had gone back to his faith as a catholic prior the onset of aphasia, that he was “a hundred percent back” (Line 579) and that his religious beliefs were “very strong” (Line 580). Importantly, he discussed the practical aspects of faith as well when he discussed how meeting every month with a group of friends including a priest (Line 582) assisted his recovery. KN and his friends in these meeting discussed their religious beliefs and he believed that he could “talk about different things” (Line 583) in a kind of sheltered environment.

MN also discussed her religious perspective and how it helped form her identity as well. Several times she discussed the uses of prayer to sustain her. Typically, she mentioned prayer as a way to keep her spirits high and hope sustained rather than praying for a cure or healing. As noted in the following two examples (4.82 and 4.83), she sought faith to sustain her and her self-identity rather than as a solution to recovery from aphasia. She stated:

Example 4.82 (Appendix B, MN Interview, Lines 712-713)

712 The only thing in me that I made to pray I had a lot of faith and that helped me
713 for many reasons

In this example, MN indicated her robust faith by stating, “I had a lot of faith” (Line 712) and she mentioned the sustaining power that faith has for her through prayer “I made to pray” (Line 712). She believed that her faith contributed to her recovery but that this contribution was somewhat indirect rather than contributing to a direct cure (“and that helped

me for many reasons” - line 713). This is also evident in Example 4.83 where she is discussing prayer as a way to help her keep working to get better. As noted in the excerpt,

Example 4.83 (Appendix B, MN Interview, Lines 456-457)

456 I I hoped that this I prayed that I asked that I keep keep better that I will be able
457 to talk like I used to talk

MN highlighted her faith in prayer and because she prayed she hoped that she would work more to “keep keep better” (Line 456) so that she would improve. She prayed for the motivation to work toward recovery that would enable her to talk as she previously did before the onset “to talk like I used to talk” (Line 457).

It is interesting that in all three cases the IWA were tied to who they were within their faith and within their church practices prior to the onset of aphasia. They continually referred back to matters of prayer, belief, and church activities while talking about their living with aphasia but they rarely discussed faith and prayer as a kind of divine intervention to cure them. In fact, in each instance that prayer was discussed, it was never a prayer for a cure. Rather, in 6 of 8 instances the prayers were for understanding or the sustaining of what they perceived as the hard work that would be needed to improve (see locus of control).

In addition to language capacity and religion, *prior education* was another variable that assisted in the constructed the identity of the IWA. Each IWA independently mentioned their education and how it shaped them. All three IWA had college degrees and each had used their degrees as vocational paths. That is, each was a professional that employed their college education to get and hold jobs in their professions. The importance of being educated and how this formed their identities prior to the onset of aphasia can be seen in the various ways that they discussed their educational achievements. For example, MN spent time discussing both her high school and college education and offered numerous examples of her

success in school. In the following excerpt she was speaking of her success as a student and as a leader in high school:

Example 4.84 (Appendix B, MN Interview, Lines 328-329, and 331-332)

328 Carmel in Lafayette from one to the twelfth and I thought to myself I was in
329 charge (.) of ehmm (.) debate and a I loved to talk
...
331 I love my friends and I had a so many things like treasury of year a secretary of
332 year

As noted here (and elsewhere), MN participated in various activities at the school. She was involved in the debate team (Line 329) and she stated that she was good at it since “I loved to talk” (Line 329). MN also talked about her roles at the school as a debate team officer when she stated that she served as both the treasurer and the secretary over two years (Line 331).

The value of education in constructing the previous identity of KN was noted numerous times within both interviews that were conducted. As may be noted in this next example (4.85), KN often discussed his education at elite universities and mentioned that he had multiple graduate degrees:

Example 4.85 (Appendix C, KN Second Interview Two, Lines 297-298)

297 I was I was (.) when (laughing) when you go through my resume’ you’ll see
298 that that I’ve got three masters

Several times he discussed his multiple degrees (Line 298) and from these instances (6 times in two interviews) it is clear that it was important for him to inform the interviewer of his educational background prior to the onset of his aphasia since it is one important constituent of his identity.

Linked to education, *occupation* was the fourth facet that most appeared to help construct the identity of the IWA. In all three cases, the focus was on occupations just prior

to the onset of aphasia and all of the participants in the Aphasia Group talked about their occupational background. For DR the focus was on her understanding of medical issues and her ability to read charts.

Example 4.86 (Appendix A, DR Interview, Lines 359, and 361-362)

359 I had numbers before

...

361 You know ehmm through work and stuff (.) I had ehmm (.) read sheets graphs I

362 was in this ehmm mag match mag ehmm director

DR talked about how she was familiar with numerical figures before the onset of the aphasia “I had numbers before” (Line 359). She used to read graphs in her profession as a nurse “I was in this” (Line 362). DR explained her use of numbers was based on her occupation as an administrative nurse and then a director (Line 362). As we can see, nursing contributed to DR’s identity prior to onset and helped her shape her response to her aphasia.

Similarly, occupation as part of the identity of the IWA is presented in the following extract taken from the interview with MN.

Example 4.87 (Appendix B, MN Interview, Lines 400-401, and 403-404)

400 And so (.) he looked at my daughter and he said “your mom must love to do
401 things about money”

...

403 And he said “my mom is always done that she has working right now” and two
404 or three books of accounting I’ve done that and he asked me and he said to me

As this example shows, MN was eager to speak about her occupation as a bookkeeper. She used this experience with cognitive testing by a physician to tout her experience and premorbid facility with numbers and accounting. The physician evaluated her at the hospital immediately following the onset of her stroke and aphasia and the testing involved executing numerical calculations. MN’s daughter attended this evaluation and the physician commented on her mathematical proficiency (Lines 400-401). MN stated that her

daughter attributed MN's performance to her professional background "mom always done that" (Line 403). According to MN, the daughter also mentioned that MN was familiar with accounting "books of accounting I've done that" (Line 404).

Locus of Control. The other sub ordinate theme that helped the IWA shape their perspectives was locus of control. This involves a consideration of whom or what was responsible for addressing and modifying the state of aphasia if recovery is to occur. While data on locus of control suggests that there are two types of control (internal locus of control and external locus of control), in the cases of these three IWA internal locus of control was primarily operating. Each of these three participants held themselves personally responsible for moving forward in recovery from aphasia. Each IWA expressed a belief in self determination requiring sufficient willpower to address aphasia. Similarly, each discussed the effort that they invested in their various responses as they tried to cope with their aphasia (See "coping with aphasia" section above). For instance, in Examples 4.88 and 4.89 MN discusses her determination to work for recovery. In the first example she actually states that she is very determined (Line 430) and she tried to illustrate this by relating a clinical experience in the following example.

Example 4.88 (Appendix B, MN Interview, Lines 430, and 432-433)

430 Well I'll tell you I'm very determined

...

432 And I went here in Lafayette General and the girl would come and get the book
433 and tell me "say this word again" and she say that over and over again

MN recalled how her clinician required that MN perform certain clinical tasks and that she was persistent in her responses (Line 433). MN further illustrated her self-determination and her belief that she was responsible for change (internal locus of control) in

the following example when she stated that “I’m not gonna stop...I’m gonna keep going until the end” (Lines 697-698).

Example 4.89 (Appendix B, MN Interview, Lines 696-698, and 700-701)

696 The girl in the Lourdes told me that many people like me would stop I said
697 “not me I’ve got German French and Cajun and I’m not gonna stop about
698 anything I’m gonna keep on doing it until the end”
...
700 Yeah I would cry and cry and they said “Miss MN most people would stop” I
701 said “not me I’m sorry let me get myself and I’ll keep on going with it”

Even when the clinician attempted to persuade MN that people with aphasia would usually stop when the therapy effort was so difficult, MN responded that she would continue to make the effort “not me...I’ll keep on going with it” (Line 701).

KN also discussed his belief that he was responsible for his change or recovery and he illustrated this by discussing how reliable and focused he was when presented with a task. In the following excerpt he is talking about any task assigned to him and he states that given the responsibility, “it will get done” (Line 29).

Example 4.90 (Appendix C, KN First Interview, Lines 364-365)

364 Because that’s what I do (..) I take it on myself to improve (..) you give me a
365 task and you said okay (.) okay you are in charge (.) it will get done (..) and

Perhaps a more direct indication of internal locus of control was provided by DR when she responded to a question asked by the interviewer: “how important is your effort you think in recovery?” She stated,

Example 4.91 (Appendix A, DR Interview, Lines 496-499, and 501)

496 Effort a lot ehmm a lot (.) you know I have what ehmm I’ve said it before I
497 write ehmm (.) words (.) I use falsh cards and I have different ehmm topics or
498 articles or even it could just like one word let’s say words that’s times a
499 flash card what time is it?
...
501 Flip it over and write verbally out

DR believed that she made the effort to address her aphasia “effort a lot” (Line 496). She practiced by performing several task including. DR practiced writing specific words. She identified words in a visual naming task “use flash cards”. She practiced telling the time “flash card what time is it” (Line 499) and read it aloud (Line 501). DR invested effort in an attempt to address aphasia and it was manifested through her performance of these tasks. Further, DR practiced and performed therapy and practice activities on regular basis to assist with recovery from her aphasia (see “practice” as a sub ordinate theme above). She was committed to work hard and to invest time as well as energy as an attempt to address aphasia.

Example 4.92 (Appendix A, DR Interview, Lines 504-506)

504 By myself by myself (.) I’ve actually read regroup and I call it in the box (.) I
505 go to this little room I have and I have to take stimulus every day and I’m
506 trying ehmm to (.) concentrate myself I have to (.) I have to do that again

DR discussed the amount of practice she employed for several tasks on daily basis (Line 504). She was determined to make the effort daily attempting to practice “I have to take stimulus every day” (Line 505). She was driven through her diligent attempts to focus on doing these tasks frequently “I have to do that again” (Line 506).

Expectations

The second theme included under the super ordinate theme of Contextual Influence involves the expectations that the IWA bring to the interpretative process. Expectations are crucial because they often provide evaluative criteria that may serve as the measure of change or improvement when recovery is addressed. Whereas the theme of perspective supplied the substance underlying emotion and affect, expectations provide a basis for the evaluative yardstick that is employed when describing and rating one’s recovery. When the IWA considered what has happened or would happen during recovery over time,

expectations served as contextual background. Although some of the variables considered under this theme have been employed elsewhere (i.e., see the sub ordinate themes under “awareness”), when they were used to project recovery expectations, they also fit under this category. Two sub ordinate themes were identified as accounting for most of the expectations that were discussed: time and reality.

Time. As described previously, each IWA employed the expectation that recovery occurred over time. Skills and abilities were constantly described using a “then-and-now” framework and through the constant use of past and future considerations when discussing recovery. This was most often manifested in the ways that the IWA juxtaposed their difficulties in the acute stages of recovery with how those difficulties were reduced over time. Consequently, it must be stated that time served as an operational contextual influence. In fact, each IWA viewed their recovery as moving forward over time and the states of change in recovery were distinguished through this temporal window. The use of time as context for change was necessary for the IWA because it provided them with comparisons (then-now; past-present-future change). The IWA considered time as a sequential element that contributed to movement in aphasia. This tendency to interpret recovery as a constant moving forward over time is presented in the following example.

Example 4.93 (Appendix C, KN First Interview, Lines 36-38)

36 So then everything is getting better and better and that’s what the uh doctor my
37 doctor uh said “you’re over time (..) you will get better and better” (.) and
38 neurologist said “you will be a hundred percent eventually”

KN was discussing his recovery and while reporting what his physician said, he suggested that he was getting better (Line 37) but then he revised this to add the temporal

component, "...said you're...over time you will..."(Line 38). This type of temporal framework was employed in nearly every case where recovery was discussed.

DR, for example, discussed her progressive movement toward independence and she set the temporal context with "now I can pretty much do it myself..." (Line 241):

Example 4.94 (Appendix A, DR Interview, Lines 240-242)

240 Would come up and she would help me and ehmm (.) if I needed anything she
241 was behind me now I can pretty much do it myself ehmm except one the
242 telephones that's that I I

Based upon this excerpt, it appears that the caregiver at some point approached DR and provided her with assistance. DR previously needed help and support from the caregiver, but recently she became more independent in performing these activities. It is interesting to note that this temporal context was used to make projections about recovery in aphasia at any point of time. MN, for example, projected her fears for her potential long-term impairment with a similar temporal focus to the future:

Example 4.95 (Appendix B, MN Interview, Lines 313-315, and 317)

313 But ehmm (..) uh I can say that I was very very upset (.) I was very very upset
314 (..) because I thought that ehmm (..) I remember when my mom had a stroke she
315 couldn't drive (..) and I had someone take care of her all the time
...
317 And I thought ehmm what is going to happen to me now

In this example, MN expressed her emotions and concerns early in her recovery. She related her stroke to what happened to her mother who previously had a stroke (Line 314). According to MN, her mother was incapable to drive following her stroke. A caregiver was assigned to provide her with assistance. At that point, MN projected forward. She was concerned and uncertain regarding her expectations for recovery in the future "what is going to happen to me now" (Line 317).

The use of time as a contextual variable should not be surprising given the fact that human beings tend to code life temporally and our narratives are based upon a temporal dynamic. However, with these IWA time was more than the cycle of days, hours, and minutes, it was also the basis for marking the changes and the making comparisons that define recovery. In every sense of the term, it had contextual relevance.

Reality. The second variable to influence expectations was based on the stark realities of illness and deficit. That is, the realization on the part of the IWA that illness and injury has consequences and that these consequences are tend to remain –albeit often in improved states over time. Consequently, each IWA was pragmatic in his or her projecting forward regarding recovery in aphasia. The IWA expected that recovery would progress but only to a certain extent. That is, full recovery based on the identity of the IWA was not projected forward; the IWA didn't expect to return to her/his premorbid state. Closely linked with the ways that the IWA cope with aphasia in the previous super ordinate where greater awareness occurred, the reality of illness and injury tempered the expectations of the IWA when they did project recovery into the future. In a sense, each IWA used this reality to reach a compromise between his or her projections regarding moving forward to recovery and his acceptance of the aphasia. That is, the IWA attempted to find a common ground between expecting recovery and the acceptance of residual challenges that may remain over time. One participant talked about expectation combining acceptance and incomplete recovery. This is presented in the following extract taken from the interview with DR.

Example 4.96 (Appendix A, DR Interview, Lines 299-303, and 306)

299 (.) Ehmm I think I can get to at least some part you know ehmm I don't think I
300 will get to go back to the work that I was you know because it deals with so
301 many computers but ehmm numbers and times and medicine and stuff ehmm I
302 don't think I can do that (.) you know but eventually to get some sort of (.)

303 other than some kind of work (.) you know

...

306 Realistically I've never been able to do what I did before

DR expected that she would have a part time job "at least some part" (Line 299). She didn't believe that she would return to her nursing job prior the onset "to go back to the work that I was" (Line 300). DR explained that her nursing profession involved computers, numbers, and medicine. She didn't believe that she was capable to carry out these activities "don't think I can do that" (Line 302). DR established realistic expectations. She hoped that at some point she will find a job. DR didn't believe that she would work as prior the onset "never been able do what I did before" (Line 306).

Summary of the Aphasia Group Data

When analyzed both individually and as a group, the lived experiences of the individuals with aphasia do suggest several patterns of interest with respect to their recovery from aphasia. These IWA see the process of recovery as a completely new experience that is unexpected and wholly disruptive to their lives and the lives of those around them. Not surprisingly, each IWA has framed these experiences as a narrative focusing on themselves as the chief agents and, consequently, the first person perspective is employed throughout. The narrative, as structured by the super ordinate themes, focuses primarily on the IWA with others as contextual backdrops and was described as a kind of journey back *toward* normalcy. This journey appears to have three distinct phases (that make up three of the super ordinate themes): 1) encountering aphasia, 2) reacting to aphasia, and 3) coping with aphasia. Although these three phases of the journey were not always related in a chronological order (only one IWA did use such a temporal progression), the movement to aphasia with its disruption and then the struggle back toward pre-morbid states was consistent. Interestingly,

the encounter with aphasia and the process of how they each tried to cope with the state of aphasia were the most salience phases (themes) in that the relating of the encounter with aphasia was always the most emotional part of the interviews while ways that coping was constructed were always the longest parts of the interviews. Seen as an on-going journey, the fourth super ordinate theme (Contextual Influences) was not explicitly discussed but arose as each IWA related their journeys; the ways that the three phases of recovery were described and given their salience were governed by these influences. Overall, the lived experiences were told as a story and the foci were generally on the coping phase. Each of the four super ordinate themes will be summarized in more detail below.

The experience of recovery was first described by relating the *emergence of the stroke and its impact*. In fact, each IWA started at the beginning to relate the actual encounter with the stroke and their aphasia. It wasn't the actual stroke that was used as the starting point by these IWA but, rather, their attempts to understand why it happened ("what happened before?"). Each IWA started with what they believed was the reason for the stroke. They then described the actual medical emergency as they remember it and, once the realization of danger struck them, they all described the realization of change and aphasia. Once the medical emergency was over, each IWA (somewhere within their interviews) discussed the impact of their state of aphasia describing the consequences based first upon loss of mundane but important functions and then discussed other various facets of their disabilities (problems with the major symbolic modalities, being over-stimulated, having discernable physical weaknesses and financial concerns). Interestingly, these descriptions are not unlike some of those described by Lezak (1990) when she talked about how neurological impairment creates problems with perplexity, distractibility and fatigue.

The *reactions* to the encounter with aphasia made up the next theme and segment of the discussion. These individuals had a variety of reactions to their states of aphasia and, although they discussed them across the entire recovery period, they appeared to be a more salient component of their lived experience in the initial stages of recovery. Just as Lezak described it, there were various emotional reactions like fear, confusion and depression that tended to serve as initial reactions. Some of these persisted in the IWA and some diminished. In all three IWA there was also recognition and a realization of the extent of the problems due to aphasia. All three also discussed some experience of avoidance of people, places, and/or activities due to their aphasia and its impact. Each of the IWA described having a variation of these reactions from the time of the emergence until present day but the reactions tended to diminish and change once the IWA made an effort to try and cope with their aphasia.

The *coping with aphasia* segment of recovery is the most extensive and is a consequence of, or a response to, the recognition of problems. There were two themes that were consistently discussed as major categories of coping: developing awareness and employing mechanisms to try and overcome the aphasia. Increasing awareness of aphasia and the need to cope with it revolved around recognition of the need for change and how that should occur. All three IWA recognized and discussed recovery as change to one's current levels of performance but appeared to also be aware that recovery would never get them to pre-morbid levels. Indeed, the last aspect of their coping awareness was that the aphasia and its recovery would likely represent something new. This was always discussed as an acceptance of where they were at the time of the individual interviews. There were five general categories of coping mechanisms that they each discussed. First, clinical intervention

which involved professional assistance, followed by the support provided by family and friends (and an aphasia support group) and then various independent compensations as coping. These three along with personalized practice on what they were most bothered by in their states of aphasia and employing socialization to provide context were the additional keys to their coping mechanisms. There was a pattern that suggested that once they started trying to cope with their states of aphasia, the emotional reactions and avoidance tended to be reduced. This was true in all three cases.

It is important to note that the interpretation of these three phases of recovery was influenced by several factors that seem to provide a *context for the experiences* of recovery. Based upon their comments and how they personalized their experiences, their perspectives based upon their prior identities before the stroke and on the rather consistent tendency to believe that they were most responsible for any recovery that occurs (intrinsic locus of control) provided the actual motivation; their expectations for how much time they would need to continue recovery tempered by the reality of aphasia as a permanent state help indicate their awareness of progress and need for more improvement.

Data from the Caregiver Group

As in the Aphasia Group, this set of super ordinate themes and the themes and subordinate themes within them are described and discussed in detail. They are the themes that have arisen from the interviews with the caregivers. In this section, each super ordinate theme, their themes, and subordinates themes will be described and documented according to the procedures of interpretive phenomenological analysis. Similar to the Aphasia Group, themes that emerged from analyzing the data set of the Caregiver Group consisted of four super ordinate themes (encountering aphasia, reacting to aphasia, coping with aphasia,

contextual influences) with ten themes grouped under these major domains. Each of these themes and their sub-categories are provided in Table 4.2 and will be discussed in depth below.

Encountering Aphasia

As previously discussed, the first super ordinate theme that was identified from the data set in the Caregiver Group is somewhat consistent with the Aphasia Group and may also be described as Encountering Aphasia. However, this representation of the encounter was different between the two groups. For the Caregiver Group, while this super ordinate theme centered on the initial experience of the caregivers involving the perception of stroke and the resultant aphasia as it took place, the experiences were not as detailed nor were they especially oriented to a progressive type of realization (not unexpected since they were not directly experiencing the medical incident). It is true that the caregivers encountered the reality of the stroke as a medical emergency and these caregivers handled the situations. Their experiences, however, are less detailed and more oriented to the medical emergency and health considerations of the IWA. It was interesting to note, however, that each caregiver did mention that that the actual occurrence of the aphasia in their lives was their first encounter with this disability in their experience. None of these caregivers reported personally being familiar with other individuals with aphasia or having any experience with this disorder. As a result, the caregiver initially made the effort to comprehend what was going on to the IWA when the stroke happened. This super ordinate theme and its components are described in depth.

Table 4.2 List of Themes for the Caregiver Group based on Interpretive Phenomenological Analysis of Semi-Structured Interviews.

SUPER ORDINATE THEMES	THEMES	SUBORDINATE THEMES
Encountering Aphasia	Medical Emergency	
	Functional Impact	Communicating
		Socializing
		Shopping
		Occupation
Reacting to Aphasia	Emotional Reactions	Observed in the IWA
		Experienced in the Caregiver
	Realization	
	Avoidance	
	Experiential Metaphors	
Coping with Aphasia	Mechanisms	Familial Support
		Clinical Intervention
		Compensation
		Social Affiliation
		Practice
	Awareness	Recovery as Change
		Incomplete Recovery
		Acceptance: “Bipolar Person”
Contextual Influences	Perspectives	Prior Identity
		Locus of Control
	Expectations	Time
		Reality

Medical Emergency

Consistent with the Aphasia Group, the first theme that was recognized regarding the experiences of encountering aphasia from the caregivers’ data set may be described as a kind

of emergence, *medical emergency*. Again, while this theme is describing the abrupt and alarming event and given that these caregivers were narrating their lived experiences with aphasia and the process of recovery, it is not surprising that each caregiver began the discussion with the first or sudden event of the medical emergency. It is interesting to note that all the three caregivers to some degree shared in their recall the event of emergence in terms of such an emergency narrative.

The caregivers started their description of the encounter with aphasia by identifying one or more of symptoms that suggested to them that their loved ones (the IWA) were in some kind of medical distress. While the IWA with aphasia discussed several stages or segments in their descriptions, the caregivers essentially only talked about the alarming symptoms that told them something was wrong. That is, the caregivers initially tried to understand what was happening to the IWA and tried to make sense of their situations. For example, one caregiver (MNC) reported his awareness that his wife (MN) was not responding appropriately:

Example 4.97 (Appendix E, MNC Interview, Lines 6-10)

6 And came back Saturday afternoon and I think the stroke occurred sometime
7 Sunday mid afternoon and she was taken to Lafayette General doctor John
8 who was her internist ehmm examined her and called in some doctors and they
9 have said “she have a stroke” ehmm (.) I could see she really ehmm reacting
10 the way she was and that was something wrong but couldn’t put my finger on

As illustrated in this example, MNC had noticed something was wrong and this resulted in a trip to the emergency room. MNC stated that he “...could see really ehmm reacting the way that she was that was something wrong” (Lines 9-10) but that he “...couldn’t put my finger on it” (Line 10). MNC did not describe the symptoms well but recounted that they occurred.

The other two caregivers, however, were more descriptive in recounting the medical emergency. DRC, for example, highlighted the onset of the physical (motoric) weakness as her alarming symptom. DRC came across DR's physical weakness and started to be aware that physically there was something happening to the IWA. The following excerpt outlined how physical weakness was demonstrated during the onset.

Example 4.98 (Appendix D, DRC Interview, Lines 10-16)

10 Cross the street from my daughter (.) and she was able to ehmm (.) leave from
11 her house and she locked her door with her keys and ehmm and she walked
12 and crossed the street she got to my daughter's house ehmm she was able to
13 knock on the door but she could no longer she couldn't make herself ehmm
14 take her key out and unlock the door which was something she always did and
15 you know she could hear my daughter say ehmm ehmm "come in" you know
16 "DR come in" and DR told me that she could hear her but she couldn't she

According to the caregiver, when DR realized that something was happening, she left her house and crossed the street toward her niece's house (Lines 9-10). When DR arrived to her niece's house, she couldn't physically pull out her key and unlock the door that she usually did previously (Lines 13-14). DR was unable to open the door and to go inside (Line 16). Additionally, DRC received input from her daughter who had first had contact with DR during the stroke. The daughter related both the physical weakness symptoms as well as trouble with communicating:

Example 4.99 (Appendix D, DRC Interview, Lines 16-20)

16 "DR come in" and DR told me that she could hear her but she couldn't she
17 wasn't reacting you know so finally my daughter went to the door and she let
18 her in and ehmm in the beginning she was able to communicate very little
19 ehmm (.) her speech ehmm she was able to say things like you know "I'm
20 sorry I'm sorry something happened" ehmm

In this example, DRC considered the second symptom of communicative change. When DRC's daughter (DR's niece) let DR inside, DR spoke with her niece and her speech and communication were very limited "able to communicate very little" (Line 18). As we can

see, DRC believed that DR had unusual symptoms (motor control, communication) that were affected in a particular period of time and this led DRC to make a decision to go to the hospital.

The third caregiver, KNC, also described how she realized via a set of symptoms that something was not normal with KN. In KNC's only discussion about this, she relates that KN went to the room of the caregiver in the morning and was talking with her (Example 4.100):

Example 4.100 (Appendix F, KNC Interview, Lines 3-5, and 7-8)

- 3 Okay it was five and a half years ago (..) when I woke up that morning he
4 came to the room and he couldn't speak (.) only very clearly but ehmm it
5 didn't make any sense at all
...
7 It's very clear but it made no sense at all (..) and actually at first I thought
8 he was giving a round that's his nature but ehmm he wasn't (.) we called the

In this recounting, KNC realized for the first time that the speech of KN was clear but irrelevant "didn't make sense at all" (Line 5). Since the caregiver couldn't understand what KN was saying, this was an alarming symptom. The initial impression of KNC in the early stage was that KN was putting on an act, "he was giving a round" (Line 8) based on his nature and identity before the onset. When she discovered that this was not a playful act, she called 911.

While the medical emergency was precipitated by the occurrence of alarming symptoms, each caregiver also discussed the continuance of this emergency within the hospital. In their narratives, each caregiver did discuss the verification of their fears of stroke from the medical staff. Two of the caregivers talked about how family members escorted the IWA to the hospital in which the IWA were admitted and stayed at the hospital for several days. The medical staff interviewed the IWA as a medical procedure in which the IWA were required to answer questions. The medical staff attempted to identify the medical condition

of the IWA that emerged. This is illustrated in the following extract taken from the interview with DRC.

Example 4.101 (Appendix D, DRC Interview, Lines 36-43)

36 Some (.) yes but she was (.) she was aware where she was (.) her confusion
37 was in that she couldn't (.) she couldn't get out what is wrong like some of the
38 doctors would come in and they would ask her you know "DR you know where
39 you are?" And at first ehmm she would say yes or no ehmm (.) I guess because
40 I know her because we our daily lives you know some of the things they were
41 asking her I knew that she knew the answer but she was baffled by not being
42 able to say it (.) so some of the doctors at first they thought that ehmm she was
43 confused just to where she was (.) but when the doctors left you know ehmm

As can be noted, DRC believed that DR was required to answer questions asked by the doctors. DRC was aware that DR was familiar with the hospital and its procedures since she worked there and because she knows her sister "I guess because I knew her" (Lines 39-40). DRC believed that DR was confused by not being able to verbally come out with the answers of these questions (Lines 41-42). Consequently, the medical staff considered that DR was disoriented in term of location "confused to what where she was" (Lines 42-43).

Functional Impact

As in the Aphasia Group, the second theme under encountering aphasia that evolved from data set of the caregivers centered on the recognition of the impact of the aphasia upon the IWA and the caregivers. Given that the caregivers experienced negative changes that the IWA went through regarding their typical abilities and behaviors following the onset of the stroke and aphasia, it would be expected that the caregivers are very aware of the impact that aphasia has had as a result of strokes. Based on their lived experiences after the emergence of the medical condition, the caregivers considered the impact of having aphasia. Discussed at various times throughout their interviews, the caregivers shared their beliefs about changes that the IWA went through regarding various aspects of their lives that were based upon their

resulting impairments and disabilities. Indeed, the caregivers became essentially aware of the meaning of the limitations that the IWA went through and recognized the nature of these limitations. These caregivers discussed a wide range of experiences and the reactions to this new state of identity of the IWA as being aphasic individuals. These discussions included the caregivers' beliefs that the IWA were often emotional due to their aphasia and that the IWA often felt angry, sad, and frustrated with the impairments and disabilities manifested as a result of aphasia. While the caregivers frequently discussed the impact of aphasia on the behaviors of the IWA, they did not discuss the impact of the aphasia on themselves. That is, the impact only focused on their loved ones with aphasia. This may be due to the way that the interviews were conducted (i.e., discussing the IWA) but each caregiver was given ample opportunity to discuss their feeling – and did so – but not with regard to the observed impact of the aphasia.

It is interesting to note that although many of the manifestations of aphasia discussed by the IWA were also mentioned by the caregivers, they were typically organized and presented differently. Rather than discuss various manifestations as problems by themselves as the IWA did when discussing specific behaviors, the caregivers discussed all of the manifestations from a functional perspective. These were often expressed in terms of functional abilities and skills that involved the use of language in various activities that could no longer be successfully performed by the IWA. As a result, the functional orientation best represents a primary theme within impact, in which the actual set of symptoms involving a group of features that exhibit symbolic and linguistic impairment were usually within a functional framework.

Communicating. The three participants in the Caregiver Group illustrated in their discussions a group of features that characterized the aphasia of the IWA to some degree. These characteristics can be considered as evidence of the aphasia that they witnessed in their daily lives. Based upon these caregivers, aphasia was manifested mostly through problems in communicating in real world settings; talking with other individual and participating in conversations. Conversely, a number of features that also highlighted the aphasia of the IWA involved domains alongside talking with other individuals including comprehension and the production of written material.

One feature of the aphasia of the IWA evident in the discussions of the caregivers was the perception that communication was much harder due to immediate and sustained changes regarding how the IWA could communicate, especially due to irrelevant and improper use of words and their meanings. That is, certain words didn't represent what these individuals actually intended to say. All three participants in the Caregiver Group described their recognition that the interaction of the IWA was different after the emergence of aphasia. This was the primary impact statement used by all three caregivers.

The verbal modality was most frequently described by the caregivers discussing difficulties speaking (38 incidents). In the illustration below (Example 4.102), KNC considered the impact of such a drastic change in the ability of the IWA to communicate. Her characterization that her spouse "has a way of fluffing around" was centered on the idea that the IWA sometimes doesn't express and say what he actually attempted to communicate effectively. In MNC case, she described how MN now experienced talking indirectly and not straight to the point when interacting with other individuals:

Example 4.102 (Appendix F, KNC Interview, Lines 184-188)

184 KN been very social and he loves people he loves to talk with people and I
185 think he's finding out more people (.) they've been polite (.) but the time take
186 him to say something ehmm (.) people lose interest (.) KN has a way of fluffing
187 around things instead of getting straight to the point he goes all the way around
188 and he tells you the point he had to make

In this example, KNC believed that KN doesn't talk implicitly and openly with people. She stated how KN talks as "a way of fluffing around things" (Lines 186-187) by which KN didn't say exactly and clearly what he intended to say "...getting straight to the point" (Line 187). She described how KN talks as "he goes all the way around" (Line 187). Certainly, this feature contributes to the impact of the aphasia in terms of the interaction between the KN and other people during the conversation. By the time KN managed indirectly to get his message across to other individuals regarding a certain matter, KNC believed that these individuals become less interested in the interaction "people lose interest" (Line 186).

MNC echoed this observation and he also believed that while the conversation partners might be aware of the use of inappropriate words by MN, it still changed the interaction. In this case, MNC described how MN now experienced the out of control use of inaccurate or irrelevant words when talking with other individuals:

Example 4.103 (Appendix E, MNC Interview, Lines 33-37)

33 The main thing is she knows what she wants to say but don't always come out
34 with it (.) like we will be talking about our children we have two girls and one
35 boy and she'll refer to like "I spoke to Dan (.) she said this" or "I spoke to
36 Sam" or "I spoke to Natalie and he said" she gets confused in the gender part
37 of it ehmm

For MNC this was a description of both how MN produced some words when she intended the opposite meaning and how he felt about the usage of inappropriate words in verbal interactions. While MN talked with the caregiver, she sometimes switches between

gender pronouns. MNC considered when MN talked with him about their children, MN used the female gender pronoun “she” to refer to their son Dan (Line 35) or used the male gender pronoun “he” to refer to their daughter Natalie (Line 36). MNC described how MN switches between the gender pronouns as “she gets confused in the gender part” (Line 36).

MNC also considered a similar feature to some degree exhibited by MN during the conversation in which she talks excessively about the same topic without allowing others to contribute to the conversation. This characterization is described in the aphasia literature as press for speech. That is, the speech of the IWA is fluent but the individual speaks excessively with no attempts to stop. Therefore, the conversation partner does not actively participate in the conversation to some degree. When the interviewer asked MNC about press of speech, he addressed the nature of this feature in the example below:

Example 4.104 (Appendix E, MNC Interview, Lines 152-156)

152 That got worse because ehmm (.) like last night (laughing) I don’t know who
153 she was talking to it might be one of her cousins in Houston and she didn’t
154 come for air in twenty minutes on and on and on (.) now my youngest daughter
155 Natalie the nurse when MN starts she says “mama stop you’ve gone through
156 this already just change the subject”

While MN talked on the phone to her cousin who lives in Houston, MNC believed that MN was excessively talking with no stops for a long period of time. MNC referenced to MN’s talk as “she didn’t come out of air” (Lines 153-154). The daughter pointed out to MN that this topic was already fully covered by her during the conversation (Lines 155-156). As a result, the daughter requested from MN to stop talking about the same topic and to shift to another one.

Another feature that was mentioned by the caregivers during the interviews was word finding (or retrieving words). This was characterized by the caregivers as the IWA’s “*recall*”. That is, the IWA exhibited difficulty in seeking targeted words to use during talking. Two

caregivers (KNC, DRC) believed that the IWA knew what they want to say but they were unable to actually express these words. This is illustrated in the following example:

Example 4.105 (Appendix F, KNC Interview, Lines 212-213, and 215-216)

212 But he continues to go around and he gets really aggravated I said “I don’t
213 know what are you talking about” and his recall is not very good
...
215 People names a ehmm (.) and association ehmm (.) with people with a place
216 or a thing you know that person I was talking about

As can be noted, KNC stated that the “recall” of KN was poor and inadequate (Line 213). The caregiver believed it is difficult for KN to remember words that he intended to use during the conversation such as specific names of people and locations (Line 215). She recognized that KN talks about a specific person in an indirect way so he doesn’t explicitly come out with the person’s actual name “...that person I was talking about” (Line 216).

DRC echoed this observation and also believed that she as the conversation partner was aware of her sister’s difficulty using appropriate words. This is demonstrated in the following excerpt:

Example 4.106 (Appendix D, DRC Interview, Lines 49-50)

49 But once I guess in the beginning ehmm she wasn’t able to say things but I
50 knew that she knew them

While DRC was certain that DR was aware and even familiar with what she intended to say during the conversation in the early stage following the onset, but she believed that it was difficult for DR to come out and actually say the targeted words as she wanted. DRC believed this was a significant problem with communication when DR was trying to fit in with others.

Over and over again these descriptions of modality-specific difficulties were manifested through the interaction with other individuals. DRC, for example, described how

DR had problems with speaking. The caregiver expressed how difficult speaking had become and how her clinician while DR was at the hospital tried to get her to talk by responding to questions in Example 4.107 below:

Example 4.107 (Appendix D, DRC Interview, Lines 93-96)

93 Ehmm yes we ehmm it was a matter of (.) I would say two t weeks period two
94 three weeks period you know she got by into it (.) and ehmm (.) that was hard
95 for her because she realized again she (.) they would ask her questions (.) and
96 she knew the answers but she couldn't verbalize it

In this excerpt, the clinician asked DR specific questions (Line 95). The clinician requested from DR to verbally respond. DRC believed that DR was familiar how to answer these questions but it was a challenge for her to verbally come out with the answers “that was hard for her” (Lines 94-95).

The communicative limitations of the IWA can also involved poor performance of activities involving the understanding of spoken words. For example, KNC discussed the limitations of the IWA that she witnessed during the verbal interaction. KNC considers the daily living activities were performed poorly by her spouse in which this type of activities were centered on understanding of spoken words. This is illustrated in the following example.

Example 4.108 (Appendix F, KNC Interview, Lines 148-151)

148 Limitations meaning as far ehmm writing to communication to multitasking
149 that was terrible at the beginning (.) it would take everything I had to say “KN
150 could you pick up the key from the buffet and lock the door and get the book
151 out of the car?” Could not do it

KNC talked about how difficult it was for KN to write and to communicate following the onset of the aphasia. She also believed that KN was restricted in carrying out multiple verbal commands given by the caregiver. These commands required the ability to handle almost at the same time more than one task. Obviously, the performance of multiple

commands involved comprehension of spoken language to some degree. KNC described how KN poorly performed the multitasking activity as “...couldn’t do it” (Line 151).

Socializing. It is interesting to note that since aphasia affects the IWA and other people who interact with them, the caregivers viewed the second most salient impact as one involving a set of social obstacles that evolved during conversation. Of course, this overlaps with the previous communicating theme but there was a clear differentiation between communicating as a primary function and how it affected socializing so division into these two themes appears justified. DRC indicated this in her comments in Example 4.109 when DR went to the supermarket she was “not being able to talk” with other people such as the staff. While discussing a shopping trip with DR, she also witnessed an example of disability that DR experienced when trying to communicate:

Example 4.109 (Appendix D, DRC Interview, Lines 154-155)

154 Ehmm like even ehmm the challenges that she had to meet with (.) like to go to
155 the store at first ehmm not being able to talk I mean I always went with her and

As can be noted, DRC believed that it was a “challenge” for DR to interact with people (Line 154). One limitation that DR went through in the early stage following the onset was to go to the store but she couldn’t talk with people. It seems that DRC recognized the impact of aphasia in terms of DR’s performance of activities in daily living especially engaging in conversations with others.

Even with family or other individuals the impact of speaking difficulties obstructed social integration and the communicative accessibility between the IWA and the conversation partners. KNC commented on this both as a communication and a socialization process when she discusses how KN’s poor conversational organization and inability to get to the point caused people to “lose interest” when he was socializing with them (Example

4.102). In his interview MNC also discusses problems with socialization in Example 4.104. He suggests that MN's tendency to dominate the conversation and maintain a rather extended turn (due to press for speech) is very detrimental to socialization – even with family.

These perceptions of difficulties in socialization were also manifested in auditory comprehension. In no less than six instances, a single caregiver (KNC) discussed how poor comprehension affected the KN's ability to socialize. For example, she discussed how his comprehension difficulties resulted in problems not only with straightforward communicative interaction, but also how it negatively impacted his ability to understand and appreciate a joke. (See Example 4.110 below):

Example 4.110 (Appendix F, KNC Interview, Lines 87-91)

87 Communication I mean just being able to talk (.) ehnm so express a joke he
88 can't get it so by the time you've explained it you've lost the meaning of just a
89 simple little or "did you see that bird?" By the time he get that bird we've
90 passed you know so those ehmm (.) communication has been really the most
91 and that why

In this excerpt, KNC believed that KN was not even able to understand humor through grasping the meaning of a joke. She described this difficulty as "...lost the meaning" (Lines 88-89) in which the problem was even manifested in the comprehension of "simple" spoken words so KN couldn't understand what she said. KNC also highlighted that KN needs a lot of time and effort from him as well as from the caregiver in an attempt to understand what she says such as regarding the bird they saw together (Lines 89-90).

DRC also commented on the problems with auditory processing and comprehension when discussing why DR did not like to go out at first and attempt to socialize. As discussed in Example 4.111, for instance, DRC discusses problems in the conversation that DR encounters because the background noise related to the possibility of several participants talking at the same time.

Example 4.111 (Appendix D, DRC Interview, Lines 235-239)

235 Things like I said in the beginning we ehmm (.) she really couldn't take a lot of
236 (.) a lot of people coming over so she really had to try ehmm kind of shield her
237 in sense you know from a lot of distractions and stuff and she only recently
238 now she started to have ehmm like music in the background now you know
239 ehmm and television on

It seems the conversation and the numbers of interactants made it a complex activity for DR in the early stage following the onset. DRC believed that it was difficult for DR to tolerate the presence of a group of people who came to visit her in the early stage following the onset. DRC stated that DR in this specific setting “couldn't take a lot of people” (Line 235). This background noise during the group conversation was described as a “lot of distractions” (Line 237).

Finally, within other communicative systems, the caregivers found other socialization problems as an impact on the IWA. KNC discussed problems with KN when writing as a social action. In Example 4.112, for instance, KNC discussed the inability of KN to write a letter about the Easter holiday; his attempts at communicating through print were confusing to others and she (KNC) was uncomfortable with his performance and the resulting reactions of others (Line 341):

Example 4.112 (Appendix F, KNC Interview, Lines 340-342)

340 Several people mentioned that they have got that letter they couldn't
341 understand that attachment with it (.) it didn't quite make sense I didn't want to
342 read them (laughing) (.) he ask me the placement of letters about recollection

Shopping. As in the Aphasia Group, the caregivers also saw the negative impact of aphasia across other domains of activity. That is, the characteristics of aphasia were not exclusively manifested in the verbal expression or the auditory comprehension needed engaging in socialization. Two of the three caregivers discussed how the results of aphasia

stopped the two female IWA from shopping for a time post onset. This can be noted in

Example 4.113:

Example 4.113 (Appendix D, DRC Interview, Lines 156-159)

156 Ehmm to get to a store anyway she knew what she wanted and to come so easy
157 to us like to go and find that article if ehmm (.) if she didn't know where it was
158 in the store she can walk up to someone and ask them she couldn't read the
159 words though

While discussing a shopping activity, DRC believed that at the early stage following the onset of the aphasia it was difficult for DR to read words written on her list about specific items she aimed to purchase. DRC described this difficulty as “she couldn't read the words” (Lines 158-159). DR had to present the written words regarding the targeted items to the staff at the store in order to show her their locations and since she could not do so for a time, she did not shop.

Difficulty with the symbolic use of numbers (e.g., making change, writing checks) also resulted in shopping difficulties. For instance, DRC discussed the loss of DR's writing abilities and the use of numbers following the onset of the aphasia. DRC discusses how to address the impact of aphasia on DR's daily activities.

Example 4.114 (Appendix D, DRC Interview, Lines 167-170)

167 But ehmm at first exchange of money was very hard for her (.) so what she did
168 she made sure that ehmm (.) she would do whatever she had to do without
169 having to talk so she couldn't write her checks because she couldn't write the
170 numbers so she ordered to cash and she always (.) she would do like twenty

In this example, DRC believed that it was a challenge for DR to exchange money when she bought items (Line 167). DRC discusses the limitations of DR in writing checks (Line 169). She explained this restriction by relating that back to DR's limitations of symbolic functioning with written numerical symbols “because she couldn't write numbers” (Lines 169-170).

Occupation. Finally, the caregivers also discussed how aphasia can impact occupation and the career of the IWA. Certainly, the IWA financially and fiscally changed for the worse to some degree following the onset of the aphasia and the stroke. Obviously, the language of the IWA could have played a role in the occupation of the IWA prior the onset. In fact, jobs and employment usually involves the interaction between the individual, coworkers, and customers. Consequently, aphasia can compromise the career and the profession of the IWA following the onset of the aphasia. All the caregivers discussed the impact on the occupation of the IWA following the onset. This is presented in the following excerpt.

Example 4.115 (Appendix E, MNC Interview, Lines 266-269)

266 She'll spent money on them now she's spending her money because she
267 gets social security she get some new payments and ehmm she also worked
268 for an agency and then after she had her stroke (.) she couldn't do the minutes
269 and talk to the people on the phone so they released her of that job and so (.)

In this example, MNC stated that MN worked as a secretary in a book keeping agency before the onset of the stroke (Lines 267-268). Her job involved typing documents and talking on the phone with other people. According to MNC, MN could no longer perform these activities at work (Lines 268-269). As a result, MN was forced to leave her work "they released her form that job" (Line 269) and this appeared to have a detrimental effect on MN.

Other caregivers also noted the importance of the occupational impact as illustrated in the extract taken from the interview with KNC.

Example 4.116 (Appendix F, KNC Interview, Lines 494-497, and 499-501)

494 Hardest things ehmm was when he worked at this company he just sat there the
495 whole day and that was very detrimental to him I find ehmm about that was
496 one of the depression came in ehmm he was not in any social with any one and
497 he was more stuck in a room
...
499 It was it was a difficult situation and I'm glad that he left and that gave him a

500 purpose at that time to get up and get dressed and go (.) but once he was there
501 it was not good I think

Following the onset of the aphasia, KN returned to his job at the agency and it was important for him “that was very determined to him” (Line 495). However, KNC believed that going back to work was a challenge for KN “it was a difficult situation” (Line 499). KN was uncomfortable to work again in the agency “he just sat there” (Line 494). KNC believed that it was emotionally devastating for KN to be socially isolated at work “he was not in any social with any one” (Line 496). Therefore, KN was forced to leave the agency by which the caregiver was happy about his departure from this job.

Clearly, across these three caregivers there were very definite ways that the impact of aphasia was manifested and sensed by these individuals. These caregivers viewed aphasia based upon its impact on the IWA within their daily lives. The IWA were no longer able to effectively use their symbolic modalities, and their social spheres were dramatically reduced. While the impact of the aphasia did create financial difficulties for the IWA, the caregivers were more concerned not with the loss of a paycheck as much as they were concerned about the loss of self esteem and the identity that each IWA had developed based upon their professional careers. Two of the caregivers believed that these careers were no longer viable after the emergence of the aphasia and they were cognizant of the negative impact. The impact noted after emergence actually led the IWA and the caregivers to react to the aphasia and this reaction – a trigger due to impact – shaped the third super ordinate theme in the long journey of recovery.

Reacting to Aphasia

The second super-ordinate theme that was identified from the data set in the Caregiver Group involved the reactions that were generated as a result of the impact made by

aphasia on the IWA and the caregivers. Each caregiver had discussed the emergence of the impairment and then quickly started realizing the impact that it had on the IWA daily lives and this resulted in the personal reactions to these impacts. These reactions are triggered by barriers experienced by the caregivers regarding the interaction between the IWA and the social context. The IWA as experienced by the caregivers exhibited reactions regarding the impact during various kinds of interactions with the environment – especially the conversations between the IWA and others.

These reactions seemed to be an in-between stage between the recognition of the actual impact of aphasia and the ways that the IWA and the caregivers cope with this condition (coping with aphasia shapes the next super ordinate theme). Essentially, this super ordinate theme was not discussed in the temporal order described below. That is, the various kinds of descriptions in each interview with the Caregiver Group do not seem to have a successive order in nature as they are illustrated in this super-ordinate theme. There appear to be four thematic categories: Emotional reactions to the realized impact of aphasia, realization of the state of aphasia, avoidance as a temporary solution, and a consolidation of these reactions through the use of experiential metaphors.

Emotional Reactions

The first theme under *reacting to aphasia* involved emotional reactions to the aphasia. Based upon the caregivers' experiences, there were two types of emotional reactions that were discussed. The first centered on the observed reactions of the IWA and the second were reflections by the caregivers on their own emotions as they attempted to deal with the state of aphasia and their changing situations themselves. Some of these emotional reactions were in the early stage following the onset of the aphasia whereas others were developed

more slowly and even emerged gradually. These reactions included various forms of sadness, embarrassment, or frustration/anger that the IWA went through and the caregivers witnessed; the caregivers themselves were also depressed at times, embarrassed and frustrated. All three of the participants in the Caregiver Group discussed both types of reactions.

Reactions Observed in the IWA. The caregivers often mentioned the emotional reactions of their IWA when discussing their lived experiences with the state of aphasia. There were approximately 43 different notations concerning emotion within the caregiver interviews. Most of these discussed depression or frustration although anger, sadness, embarrassment, inappropriate fixation on some comment, and fear were also mentioned. Some of the discussed emotional reactions were triggered almost immediately following the onset of the aphasia, even while emergence was happening (see Examples 4.35 through 4.40). This is not surprising since there were sudden medical and functional changes in the IWA that the caregivers experienced. For instance, DRC reported how DR reacted when she was admitted at the hospital in the early stage of the emergence:

Example 4.117 (Appendix D, DRC Interview, Lines 52-54)

52 Ehmm just in her facial expressions sometimes ehmm things like what actually
53 in the hospital when people come in when doctors come in to talk to her she
54 was she was embarrassed for them to see that she couldn't speak

In this example, the medical staff approached DR to medically evaluate her condition when she was admitted at the hospital “doctors come in to talk to her” (Line 53). However, it was difficult for DR to talk with these individuals “she couldn't speak” (Line 54). DR felt uncomfortable and ashamed during the medical evaluation. The caregiver described DR's reaction as “she was embarrassed for them” (Line 54). As we can see, the medical evaluation contributed to the negative feelings that DR experienced.

Similarly, emotional reactions occurred at various times following the onset. That is, these responses didn't occur exclusively in the early stages of aphasia as illustrated in the following example.

Example 4.118 (Appendix D, DRC Interview, Lines 243-246)

243 Yes about a year and a half now but it's and in the beginning you know ehmm
244 her personality (.) I found that she ehmm there was a sadness about her and
245 you know I could s I knew my sister and I could see that in her and now I'm
246 seeing more ehmm little more like hardiness

DRC believed that DR's behavior changed following the onset "in the beginning" (Lines 243-244). The caregiver believed that DR was feeling grief and sorrow following the onset in that "there was sadness about her" (Line 244).

The emotional reactions by the IWA were often due to specific incidents within the state of aphasia that triggered specific frustrations or depression. Since they had to interact in the world, the IWA were often faced with barriers due to their aphasia and these often elicited emotional responses that were observed by the caregivers. In Example 4.117, the importance of context and situation is demonstrated as a trigger for various emotions on the part of the IWA. In this example, the caregiver discussed how "someone might have hurt" the IWA. That is, how the social accessibility of the IWA has been threatened and compromised in a particular situation.

Example 4.119 (Appendix D, DRC Interview, Lines 195-200)

195 Know for like something in the supermarket now and ehmm sometimes those
196 experiences were good and sometimes they weren't sometimes ehmm (.)
197 ehmm she would come home and if someone might have hurt her you know by
198 she would ask him ehmm ehmm "could you please help me I have a little
199 trouble with speaking" and she said you know her pride was because a lot of
200 times was they they couldn't understand or didn't have the patience to listen to

DRC talked about how DR went to buy items at the supermarket (Line 195). She approached an individual who was likely a member of the staff seeking help. DR explained

to the individual that she has aphasia and requested assistance (Lines 197-198). According to the caregiver, it was constantly difficult for people either to understand what DR was saying “they couldn’t understand” (Line 200) or these individuals didn’t have the tolerance to listen to her when she talked “didn’t have the patience to listen” (Line 200). DRC believed that these events had a negative impact on DR when the conversation between DR and others was obstructed “someone might have hurt her” (Line 197).

While the triggers were sometimes due to singular incidents, sometimes they were exasperated by regular contextual factors. In the following example, KNC was discussing how difficult it was for KN to return to work. He had been the director of a center but could no longer function well enough to perform his duties. Consequently, he was placed at another site with diminished responsibilities. However, this placement did not go well. As discussed by KNC, his difficulty at his job made KN depressed.

Example 4.120 (Appendix F, KNC Interview, Lines 492-497)

492 He is because this is (.) to be honest this has been very fulfilling for him it
493 gives him more purpose it gives him somewhere to go ehmm I think one of the
494 hardest things ehmm was when he worked at this company he just sat there the
495 whole day and that was very detrimental to him I find ehmm about that was
496 one of the depression came in ehmm he was not in any social interaction with any
497 one and he was more or less stuck in a room

KNC talked about how KN went back to his job at the agency and it was important matter for him since his job “has been very fulfilling for him” (Line 495). However, KNC believed that returning to work was a challenge for KN “one of the hardest things” (Lines 493-494). She was convinced that there was no interaction between KN and others at work “he just sat there” (Line 494). KNC believed that it was emotionally devastating for KN to be socially isolated at work “he was not in any social interaction with any one” (Line 496). The

caregiver even described his social exclusion as “he was more or less stuck in a room” (Line 497) and this was “very detrimental to him” (Line 495).

The resultant depression for KN (and the other IWA at times) affected KN in terms of his overall attitude and functioning. He had trouble sleeping and the depression had an impact away from work as well. In the following excerpt (Example 4.121), KNC responded to the question about how long KN has been dealing with the depression since the stroke:

Example 4.121 (Appendix F, KNC Interview, Lines 443-446)

443 Ehmm probably so but then noticeable in the last two years and ehmm one
444 because he was having ehmm he would wake up in the morning he would have
445 racing thoughts and and just he would it’s funny because he would tell that “I
446 did always bad in my life” (.) which is constantly hard and so in the morning

KNC described the negative reactions observed in KN in the mornings over the last two years. She characterized his fixation on negative aspects of his past as an aspect of his depression when she discussed his “racing thoughts” (Line 445). KNC believed that on regular basis KN reflected negatively on his life and on the impact of aphasia following the onset. It seems that KN, as the spouse witnessed, considered what happened in his life as a negative outcome “I did always bad in my life” (Line 446).

At times frustration and/or anger was also discussed by the caregivers. In each case mentioned, the frustration was directly related to some actual failure that the IWA experienced when trying to function in the world. For instance, KNC often noted that KN got frustrated – especially at her – when things proved too difficult. She discussed this in Example 4.122 when discussing communicative problems:

Example 4.122 (Appendix F, KNC Interview, Lines 211-213)

211 Remained the same (.) he’s ehmm if he manages to the main point then okay
212 but continues to go around and he gets really aggravated I said “I don’t
213 know what you talking about” and his recall is not very good

KNC was explaining KN's tendency to diverge from his conversational topic and not to be efficient in his communication; she described this as he "continues to go around" (Line 212). When this conversational wandering occurred and KNC became confused and could no longer follow what KN intended to say, KN became irritated and annoyed in this situation "he gets really aggravated" (Lines 212-213).

Of the three caregivers, MNC was the most detailed regarding anger as an emotional reaction that arose from the IWA. He stated that he and his wife (MN) did not usually go out anymore and try to interact due to their communication difficulty and their angry reactions toward one another. He related several incidents where she became angry but primarily focused on when they attempted to go out to eat or shop:

Example 4.123 (Appendix E, MNC Interview, Lines 176-177, and 179-181)

176 a month together (.) we go out and eat (.) but it's just its hell living this
177 constant constant deal
...
179 And I feel it's best not to say anything (.) then she gets mad that I don't talk and
180 I don't tell her "well if you say what you need to say when you want talk to
181 me" I don't do that I would say "what are you trying to say?"

MNC believed that it was a challenge to interact with MN on regular basis "it's just a hell living this constant constant deal" (Lines 176-177). He was convinced that the best option for him was not to talk with MN "not to say anything" (Line 179). However, MN became upset with the caregiver for avoiding talking with her "she gets mad" (Line 179). MNC stated that these emotional reactions caused serious difficulty in his family.

Overall, the caregivers were very aware of the emotional reactions of the IWA. While they tended to see these emotions as understandable given the state of aphasia, the emotions made the recovery process very different from before and very difficult for both the IWA and

the caregiver. Try as they might, the caregivers still reacted themselves – and not always in the most advantageous manner.

Caregiver Emotional Reactions. As mentioned previously, the caregivers also discussed their own emotional reactions to the aphasia. While these emotions were not always explicitly discussed (as the IWA observed reactions often were), their emotions did form a background for many of their experiences and were often mentioned indirectly (e.g., “I started to get angry about what she said”). These reactions are also understandable since aphasia does not only affect the IWA. Rather, aphasia also affects the caregivers who interact with the individuals with aphasia on regular basis and have had their own lives greatly changed due to the presence of this disability in their loved one. Within this situation, the caregivers as well as the IWA can encounter challenges in certain situations involving the interaction between the state of aphasia and the world. Additionally, since the caregiver often is the primary interactant with the IWA and the primary mediator between the IWA and other individuals, they are placed in situations that may invoke numerous emotional reactions. The caregivers reported feeling frustrated or embarrassed at times about how the IWA interact with others or upset with the IWA or even themselves when they experienced problems. Two of the participants in the Caregiver Group (KNC, MNC) most often discussed these reactions. The responses of the caregivers are illustrated in the following examples.

Example 4.124 (Appendix F, KNC Interview, Lines 362-365)

362 No he won't he jokes around a lot for instance he comes all that with the jokes
363 ehmm funny and he thinks that's the thing I wanted to say he thinks he's funny
364 but he's not (.) and it come out really terrible sometimes and it's embarrassing
365 (.) that's very hard for me particularly in the restaurant

In the current example, KNC described how KN's humor occasionally was unpleasant and appalling to her (Line 362). She believed that occasionally KN's humor is not

amusing or entertaining “it comes out really terrible sometimes” (Lines 363-364). KNC didn’t appreciate the humor of KN and she felt unease in these situations. The caregiver was uncomfortable with KN’s humor and how he made jokes with people “it’s embarrassing” (Line 364). This was a challenge for KNC in this context “that’s hard for me” (Line 365).

In Example 4.125, the caregiver reported that the IWA was convinced that the caregiver and the daughter were unable or unwilling to understand what she says. This was frustrating to the caregiver since he believed that the entire family tried extremely hard to accommodate the IWA and her changed communicative circumstances.

Example 4.125 (Appendix E, MNC Interview, Lines 108-113)

108 No no before she had the stroke she had no problems with her speech (.) and
109 after she had that stroke that’s when I noticed things were getting worse you
110 know her communication (.) I personally feel that she knows what she wants to
111 say (.) but it doesn’t come out the way she wants it (.) and then like she flips it
112 around that me or her daughter Natalie here is that ehmm we are not trying to
113 understand

MNC discussed how the speech of MN changed following the onset “things were getting worse” (Lines 109-110). MNC believed that MN is familiar and know what to say but her communication doesn’t represent what she intended to say “doesn’t come out the way she wants it” (Line 111). It seems MN was under the impression that the conversation partners including the caregiver and the daughter are responsible for her failure and, at times, she blamed them for the manifestation of her aphasia “she flips it around” (Lines 111-112). According to the caregiver, MN held the belief that it is these two conversation partners who didn’t attempt to understand what she said (Lines 112-113).

Naturally, since social action is the context within which aphasia is so obviously manifested, many of the emotional reactions are embodied within the social interaction between the IWA and other individuals. In communication friction points can temporarily

occur between these two parties during the conversation. That is, a clash can emerge to some degree between the IWA and the caregivers during the conversation in which it can be put on hold for some time. Two of the participants in the Caregiver Group (KNC, MNC) talked about the friction between them and the IWA. This is illustrated in the following extract taken from the interview with KNC.

Example 4.126 (Appendix F, KNC Interview, Lines 221-227)

221 Worse he gets more aggravated because he was so patient with me and he still
222 is but I can see it and because I get frustrated too so it's a constant struggle a
223 constant work at his (.) so when it gets too tough I walk away and we start
224 over you know so it work constant because he and I has been married ten
225 years so only five years after we've been married that he had the stroke so
226 we've been longer with the stroke than without the stroke (laughing) it's tough
227 ehmm so it's been a challenge

In this example, KNC felt frustrated during the conversation with KN (Line 222). She believed that KN was frustrated as well “he gets more aggravated” (Line 221). The caregiver described their conversation and their reactions as a “constant struggle” (Line 222). She also believed that this challenging situation can escalate over time “it gets too tough” (Line 223). As a result, when KNC couldn't tolerate this situation, she withdrew from the conversation “I walk away” (Line 223). Therefore, the interaction between KN and the caregiver was suspended and brought to a standstill at that point. Afterwards, KNC and KN were engaged once again in the conversation “we start over” (Lines 223-224). This type of interactional difficulty and the resulting emotion was echoed by MNC.

Example 4.127 (Appendix E, MNC Interview, Lines 179-181)

179 And I feel it's best not to say anything (.) then she gets mad that I don't talk and
180 I don't tell her “well if you say what you need to say when you want talk to
181 me” I don't do that I would say “why are you trying to say?”

In this situation, even though MNC did not state that he was angry as well, it was clear from his intonation and rate of speech when recounting these types of experiences that he was angry in these types of situations.

Realization

Throughout the interviews, the caregivers recognized that at some point the IWA became aware of their aphasia. Based upon the living experiences of the caregivers, the IWA gradually recognized what happened to them to some extent. That is, these individuals recognized that they have aphasia and would have to live with this condition. The caregivers believed that this resulted in the IWA becoming more comfortable with their aphasia. That is, the caregivers believed that the IWA recognized the negative changes they went through and the challenges they come across based on how they were before the onset and they came to some kind of acceptance. This is consistent with the lived experiences of the IWA as well. Two participants in the Caregiver Group (DRC, KNC) talked about the realizations on the part of the IWA. This is illustrated in the extract taken from the interview with DRC.

Example 4.128 (Appendix D, DRC Interview, Lines 460-462, and 464-465)

460 And now she realizes you know even like coming here and all that even with
461 the gains that she made and she made tremendous gains ehmm she realizes also
462 makes her realize how much she's lost

...

464 So ehmm (..) she has said to me that "I don't know that I will ever be the
465 same" she says so I don't know ehmm (..) she hasn't given up hope you know

DRC believed that DR realized the extent of her aphasia and its impact that she experienced "how much she's lost" (Line 462). DR questioned whether at some point she would reach a full recovery so that she might function as she did prior to the onset "I don't know that I will ever be the same" (Lines 464-465). As we can see, DR recognized the

changes she went through in terms of the impact of her aphasia. Again, realization of the aphasia is represented in the excerpt below.

Example 4.129 (Appendix F, KNC Interview, Lines 416-420)

413 Yeah some of that has been his determination and that's the biggest he is
414 determined more than anyone I know to try to beat this thing and I think he has
415 some realization that you know he has some limitations that he constantly try
416 with it because he really believes that he's going to get a job (.) and
417 particularly with ground postorium and I don't find that realistic and I don't
418 see that but that something I'm not taking away his striving for that but I don't
419 see that but he's determined and that's what is going to happen now how much
420 of that is determination are being realistic I don't know

In this example, KNC discussed KN's determination about having a job in the future "he's going to get a job" (Line 416). He expected to have a job in a certain agency (Line 417). However, the caregiver believed that KN was aware to some extent of the negative changes he went through following the onset in terms of restrictions "some realization ... he has some limitations" (Line 415). KNC believed that these limitations can contribute to how likely it will be for KN to have a job.

Avoidance

Another reaction recognized by the caregivers on the part of the IWA involved an avoidance reaction. Consistent with the reactions to aphasia that was described by the Aphasia Group, avoidance was recognized by the caregivers as an act carried out by the IWA attempting to respond to their challenges within the state of aphasia. Again, the caregivers did understand these reactions by the IWA given that they had to deal with challenging situations that could have been considered unpleasant or demanding. Avoidance was as an attempt taken by the IWA to keep away from these situations. For instance, DRC (Example 4.130) discussed how DR reacted to a certain challenging situation the early stage following the onset:

Example 4.130 (Appendix D, DRC Interview, Lines 181-187)

181 Problem for her that like if she went out ehmm like for a couple of hours it
182 would've been easy you know to drive up to a window and at any you know
183 fast food place and you have to talk and say what you want and ehmm so that
184 wasn't an option for her she couldn't do it (.) so she always made sure that she
185 would ehmm ehmm (.) go to someplace like ehmm in a supermarket or
186 whatever she was where she could pick up you know an item that she could go
187 through the registrar you know and that was a kind of coping thing

In the current example, DRC believed that if DR wanted to buy a meal from a fast food store, DR needed to talk with the staff to order her meal “you have to talk and say what you want” (Line 183). DRC believed that DR at some point was incapable to order her meal “she couldn't do it” (Line 184). Consequently, DR would go to a supermarket or other food stores in which she actually collected what she wanted to eat “she could pick up an item” (Line 186). Afterwards, DR approached the register to pay for her meal. That is, DR avoided talking by not having to actually order her meal. Rather, DR brought her food to the staff and paid for it. DR described this avoidance act as “a kind of coping” (Line 187).

It is interesting that the caregivers discussed these types of avoidance strategies 10 times during the interviews. However, they were largely discussed as happening during the initial periods of aphasia; that is, throughout the first several months following the onset. However, the caregivers discussed that these avoidance reactions to aphasia were modified over time to some extent in that the IWA started interacting more. However, the caregivers did not explicitly discuss why or how avoidance was eventually declined or diminished as a mechanism to address aphasia.

Experiential Metaphors

Metaphors are often used as an attempt to understand the surrounding environment by constructing meaning and to make sense of the world. As it was discussed previously, metaphors are ways to use the creative and visual aspects of language to understand via

comparison. As in the Aphasia Group, metaphorical descriptions were utilized when discussing aphasia and its recovery. Through the use of metaphors during discussion and as the mental frames within which to operate following aphasia, the caregivers created an interpretation of their experiences as the impact of aphasia; through metaphor these aphasia experiences are expressed and employed. For instance, the caregiver (DRC) used metaphors to talk about the impact of the aphasia on the IWA. This is illustrated in the extract taken from the interview with DRC.

Example 4.131 (Appendix D, DRC Interview, Lines 265-267, and 269-276)

265 And so ehmm in her personal life she she has commanded her personal life too
266 so when this happened it was it was hard to see somebody who are ehmm (..) it
267 broke her you know really it broke her
...
269 Because she was always she was ehmm (..) in control of her life ehmm you
270 know her decisions that she had to make ehmm she relied on herself for a lot of
271 things (..) and ehmm it was hard for her to ehmm (..) to have to ehmm ehmm
272 although we shared a lot of stuff there was her personal life you know like her
273 ehmm her finances and things like that that she didn't have to reveal (..) but
274 when this happened to her she was in the process of going through ehmm she
275 was getting ready to retire (..) so they're a lot of things that we also had to help
276 with

DRC believed that DR was responsible for her private life prior the onset “she commanded her personal life” (Line 265). It was a challenge for DRC to witness what happened to DR (Line 266). DRC described the negative impact of the aphasia on DR as “it broke her” (Line 267). According to DRC, DR was self reliant and independent prior the onset “in control of her life” (Line 269). However, the family had to provide assistance to DR following the onset. The family engaged in many matters of DR’s personal life since she is single and lives alone at home. That is, DR was not ready to share her personal life with family members “didn’t have to reveal” (Line 272). The family provided assistance to DR with her financial issues because she before the onset planned to retire from her nursing job

(Line 275). DRC believed this negative impact by which DR moved from self reliance and independence toward dependence and relying on others to some degree was considered as a challenge for her “it was hard for her” (Line 271). As we can see DRC described, using the metaphor, how DR drastically and remarkably changed to the worse following the onset of the stroke and the aphasia.

Coping with Aphasia

The fourth super-ordinate theme that was identified from the data set in the Caregiver Group involves how the IWA and their caregivers actually responded to the aphasia. Certainly, the discussions of the caregivers centered on this super ordinate theme and systemically required most of the time for each of the interviews. Indeed, since the interviews revolved around the lived experiences of these participants who were engaged and who made attempts to contribute and respond as they could to the state of aphasia, the focus of this theme is unsurprising. On the whole, the discussions that create this super-ordinate theme involve the set of mechanisms that were used as a response to certain challenges, the impact of aphasia, and the emerging awareness that guided the daily lives of the IWA and their significant others.

As it was discussed through the interviews, the caregivers realized that aphasia had a real impact on the IWA following the onset. While each caregiver became aware of the limitations that the IWA went through, awareness was established that centered on moving forward over time. That is, the caregivers realized that the IWA moved gradually over time, regardless of their aphasia, and that particular measures were used seeking to address aphasia. As the caregivers recognized that recovery was established, by moving forward to a certain point, it was also recognized by the caregivers that a full recovery was unlikely.

The caregiver responses to the aphasia, driven to some degree by basic interpretations of recovery, were derived from how each caregiver lived through aphasia and the IWA responses to this condition. Several explanations of the recovery in aphasia were represented by the caregivers through the use themes and terms different from those of the IWA. These representations and terms employed by the caregivers can be viewed as the core of the individual's insights about moving forward in aphasia.

Mechanisms

As it was discussed in the Aphasia Group, a set of responses was essentially constructed by the IWA and the caregivers to orient toward positive recovery in aphasia. While these mechanisms may vary somewhat from those described and discussed by the IWA themselves, several of their responses were considered as a group of mechanisms oriented to overcoming aphasia. Five major mechanisms were discussed by the caregivers: Familial support, clinical intervention, compensation, social affiliation, and practice. Based on the living experiences of the caregivers, these mechanisms were considered as a set of tools employed by social parties seeking to address and to respond to the challenges and the impact of aphasia. That is, these mechanisms involved social parties including the IWA, family members such the caregivers, and external parties such as the clinicians who were oriented to overcome the impact and challenges in aphasia.

Familial Support. The most frequently discussed response mechanism in the Caregiver Group involved families of the IWA and the support that they provided to the IWA. Given that the interviews focused upon their perspectives, familial support as the primary mechanism that was discussed by the caregivers is not surprising. This subordinate theme involved the support that the IWA received from family members throughout their

recovery periods. Each caregiver discussed in depth the familial support as being beneficial as the IWA moved toward recovery. Throughout discussions about this supportive group, there was frequent collaboration between the IWA and their families. Within these contexts, collaboration took the form of active and dynamic interactions by which two social parties; the IWA and family members were engaged in this mechanism. Collaboration can be considered as a reciprocal action in which these two social parties were jointly negotiating the direction and the meaning in aphasia and they worked together in a coordinated and mutual manner attempting to address challenges in aphasia.

All through the interviews, the caregivers did discuss the family members of the IWA as being supportive of the efforts of the IWA in terms of recovery and their struggles to overcome the daily challenges created by aphasia. As the family was defined differently by each caregiver based on their circumstances, these family members (e.g., caregiver, siblings, nieces, and children) were considered as an essential recovery mechanism. Based upon the caregivers, these family members provided care and were responsible for the IWA following the onset of the aphasia. That is, these individuals performed certain acts seeking to provide care and help to the IWA. Despite the support that the IWA might have received from clinicians and/or the aphasia support groups, the old motto, “there is a tie that binds us to our homes”, does ring true with these participants. Initially, these family members provided assistance to the IWA by escorting and staying with the IWA at the hospital when the stroke and aphasia emerged. Further, these individuals performed several activities involving the IWA as part of their roles as caregivers following the onset. All the caregivers talked about the role of family members in providing care and help following the onset. This is presented in the excerpt below.

Example 4.132 (Appendix F, KNC Interview, Lines 114-117)

114 Ehmm (.) humility is number one and ehmm (.) patience I learned toward
115 patience with KN than I wouldn't do it at all ehmm (.) it is a different ehmm
116 different situation ehmm yeah those two things ehmm (.) learned to be a
117 caregiver all the time take the responsibility ehmm for everything

KNC believed that she went through changes following the onset. She became more modest “humility is number one” (Line 114). She also became tolerant to KN compared with prior the onset “I wouldn't do it at all” (Line 115). KNC believed that she changed and constantly became a caretaker available and responsible for KN “learned to be a caregiver all the time” (Lines 116-117). In the following excerpt (Example 4.133), DRC talked about the advantage of the family members.

Example 4.133 (Appendix D, DRC Interview, Lines 373-374, 376-379, and 381)

373 another thing (.) I really think (.) DR coming along ehmm was because you
374 know ehmm we knew her you know and I already knew her likes and dislikes
...
376 The things that ehmm (.) her routine in the beginning we've asked how did I
377 know it it's just that I knew her you know so I don't know how people who (.)
378 have a stroke and have aphasia you know they're coming like the speech
379 therapist and stuff like that ehmm they don't have that advantage of knowing
...
381 All of those things you know so it's just knowing her I knew

A noted in this example, the caregiver believed that the advantage of the family members was that they were actually familiar with DR “we knew her” (Line 374). That is, these individuals were aware of the nature and the identity of DR. The caregiver believed that the family members were used to the habits and the lifestyle of DR “her routine” (Line 376) and her intentions and preferences “likes and dislikes” (Line 374). DRC compared between the family and the clinician regarding knowing DR. The caregiver believed that the clinician didn't have the benefit of being really familiar with DR “they don't have the advantage of knowing” (Line 379). DRC was certain that she knew her sister very well “it's just knowing

her” (Line 381).

Familial caregivers provided needed assistance to the IWA following the onset. These caregivers became constantly responsible for additional and various activities involving the IWA following the onset. These activities were usually performed by the IWA prior to the onset of aphasia. All the participants in the Caregiver Group talked about these activities that they performed for the IWA. This is presented in the following example.

Example 4.134 (Appendix D, DRC Interview, Lines 285-289)

285 Right right and ehmm (.) not being able to trust her decisions after she had the
286 stroke you know like things as simple as ehmm (.) ehmm relying on herself to
287 get a bill out on time you know because of the days of the week and numbers
288 and stuff like that ehmm and writing the bills and stuff like that she (.) ehmm at
289 first we actually had to write her bills out (.) and then she took that was another

As illustrated in this example, DRC believed that DR changed regarding her independence following the onset of the stroke and aphasia. DR stopped relying on herself to complete the bills on time (Lines 286-287). DRC explained that these bills involved numerical information “days of the weeks and numbers” (Line 287). She also believed that writing was actually needed to complete the bills (Line 288). Family members completed and wrote DR’s bills in the early stage following the onset “we actually had to write her bills” (Line 289). Familial support was also illustrated in the extract taken from the interview with MNC.

Example 4.135 (Appendix E, MNC Interview, Lines 96-102)

96 So I brought her to the airport I loaded the luggage and I told her bye and I
97 hope that she had a good time (.) she immediately tell me “well aren’t you
98 gonna come in to see if I get everything all right?” I brought the luggage to be
99 scanned (.) so we were talking she said “I don’t know who will pick me up
100 Sunday” I said “I had all intentions to pick you up and if something happens
101 I will get somebody to pick you up” (.) “well don’t go out of your own way” you
102 see

In the current example, MNC drove his spouse to the airport and took care of her luggage (Line 96). He also escorted MN inside the airport to make sure that everything went well. MNC even carried her luggage inside the airport to be processed by the airport staff “I brought the luggage to be scanned” (Lines 98-99). He also promised MN that he will be available to pick her up from the airport when she will arrive, unless there would have been changes in their schedules (Lines 100-101). That is, MNC performed all the activities that MN needed to do for her travel.

In addition to providing assistance regarding activities of daily living, the family served as support mechanisms in therapy practice and in other therapy related activities. That is, these family members encouraged and motivated the IWA to engage in talking with them or with other individuals seeking to respond to aphasia. All the participants in the Caregiver Group talked about the contribution of family members to answer aphasia. In the following example, DRC responded to a question asked by the interviewer about the importance of the support provided by family members to the recovery of DR.

Example 4.136 (Appendix D, DRC Interview, Lines 364-367, and 369)

364 She was somewhat withdrawn but we realized that the children ehmm ehmm
365 David is eight now and that’s a grandchild well David and Steve ehmm Steve
366 is three now they were able to draw her out in a lot of times and ways that that
367 we want

...
369 So we used the children a lot to motivate her you know and ehmm

DRC believed that DR was socially “withdrawn” (Line 364). DRC was aware that her grandchildren were capable to frequently interact with DR “to draw her out” (Line 366).

DRC believed that these children were used to encourage DR to interact “we used the children a lot to motivate her” (Line 369). This was also illustrated in the following extract taken from the interview with MNC.

Example 4.137 (Appendix E, MNC Interview, Lines 152-156, and 158-159)

152 That got worse because ehmm (.) like last night (laughing) I don't know who
153 she was talking to it might be one of her cousins in Houston and she didn't
154 come for air in twenty minutes on and on and on (.) now my youngest daughter
155 Natalie the nurse when MN starts she says "mama stop you've gone through
156 this already just change the subject"
...
158 She'll stop and they you know they'll talk but ehmm sometime she talks non
159 stop

In this example, MNC described how MN talked on the phone with her cousin. MNC believed that MN was excessively talking with no stops for a long period of time during the phone call (Lines 153-154). However, the daughter requested from MN to stop talking about the same topic during the conversation with the cousin "mama stop you've gone though this already" (Lines 155-156). Afterwards, the daughter requested from MN to move to another topic during the conversation "just change the subject" (Line 156). MNC believed that in this specific situation his spouse moved to another topic and continued to talk over the phone with her cousin (Line 158).

Two participants in the Caregiver Group (KNC, DRC) talked about collaboration with the IWA in which several members of the family, such as the caregivers, worked jointly with the IWA seeking to respond to the challenges in aphasia. That is, these two social parties worked together attempting to address difficulties that the IWA came across in aphasia. The caregivers reported that the IWA approached them seeking assistance regarding how to say particular words during the conversation, or how to write certain letters and words, or to complete written documents such as checks and bills. The caregivers assisted the IWA accordingly by examining the attempts made by the IWA in talking or in writing. This is demonstrated in the following excerpt.

Example 4.138 (Appendix F, KNC Interview, Lines 345-348)

345 (.) He does let me help him on those things and ehmm many times he'll be
346 talking to someone and he can't get what he want to say or he loses his train of
347 thoughts he look at me even my mother noticed he depends so much on me he
348 constantly will turn and ask

KNC believed that she occasionally collaborated with KN during the conversation “let me help him” (Line 345). While KN was talking with other individuals, sometimes he was incapable to express what he intended to say “can't get what he want to say” (Line 346). During the conversation between KN and her mother, KN approached KNC by turning around, looking at her, and to ask for her assistance (Lines 347-348). The mother of KNC became familiar with KN's requests for collaboration “even my mother noticed” (Line 347). As we can see, KN and the caregiver worked jointly to overcome the challenges during the conversation. Similarly, collaboration is presented in the extract taken from the interview with DRC.

Example 4.139 (Appendix D, DRC Interview, Lines 298-301)

298 Right right and then eventually she would she would write the number first (.)
299 she started doing that and bring it for us and that's kind of and the date she
300 would get the date right but she don't she won't mail anything unless we
301 checked it (.) and then gradually she was able to write the number out and

In this example, DR started to complete the bill by writing the number and the date (Line 298). She approached family members to show them her writing attempts “bring it for us” (Line 299). These family members examined DR's writing attempts “we checked it” (Line 301). DR doesn't send the bill by mail until these family members provided feedback about her performance to ensure that her writing was appropriate (Lines 300-301). That is, DR and the caregiver or the niece worked jointly to overcome DR's challenges in writing.

Clinical Intervention. As it was discussed in the data analysis of the participants in the Aphasia Group, one type of mechanism was clinical intervention. According to their

lived experiences, each caregiver reported that the IWA were referred to speech-language pathologists following the onset of the aphasia. That is, these individuals received therapy from clinicians for a period of time as a medical response to their state of aphasia. As an attempt to address the aphasia, the clinicians who worked with the IWA tended to employ a similar set of activities and had similar requirements when they engaged in clinical aphasiology. Throughout these tasks, the clinicians attempted to elicit responses from the IWA based upon their communicative difficulties in an attempt at remediation. The caregivers reported that the IWA attempted to perform these requested activities in clinical contexts and at all times they were under the supervision of the clinicians. These tasks often included repetitive activities oriented to simple symbolic processing. For example, in one task, the clinicians asked the IWA to answer particular questions. In another task reported by the caregivers, the clinicians had the IWA spend time writing the alphabet over and over or putting pictures in a requested order. According to the caregivers, confrontational naming was particularly stressed by the clinicians and so the IWA spent a large amount of time and energy performing rote tasks both inside and outside of therapy. Obviously, each IWA did have some variation in the therapeutic activities that they performed during their clinical sessions. Interestingly, none of the caregivers provided any explanations regarding these activities or made any judgments regarding the appropriateness of these tasks; the IWA and the caregivers (for the most part, see Example 4.142 below) simply followed the instructions of the clinicians who were the perceived experts in seeking recovery from aphasia. However, the clinical process was important to the caregivers and each of them talked about the clinical tasks that IWA were required to perform. Given that they often accompanied the IWA to therapy and sometimes helped them with work outside of therapy, this is expected. In the

following excerpt (Example 4.140), DRC responded to a question asked by the interviewer about aphasia therapy DR received following the onset.

Example 4.140 (Appendix D, DRC Interview, Lines 93-96)

93 Ehmm yes we ehmm it was a matter of (.) I would say two t weeks period two
94 three weeks period you know she got into it (.) and ehmm (.) that was hard
95 for her because she realized again she (.) they would ask her questions (.) and
96 she knew the answers but she couldn't verbalize it

As illustrated in this example, DRC believed that DR received therapy for two or three weeks following the onset (Lines 93-94). DR became familiar with therapy “she got into it” (Line 94). However, it seems that these therapy sessions were a challenge for DR “that was hard for her” (Lines 94-95). While DR was in therapy, the caregiver did not know much about that was happening in the therapy sessions. DRC knew that the clinician required certain task performances from DR (Line 95) and that in this task, DR was required to respond by answering questions asked by the clinicians “they would ask her questions” (Line 95). However, it was difficult for DR to answer the simple questions, DRC stated that “she knew the answers but she couldn't verbalize it” (Line 96).

KNC also discussed intervention from a procedural perspective. As noted in Example 4.141, she simply described the activity and how the IWA was expected to respond.

Example 4.141 (Appendix F, KNC Interview, Lines 314-316)

314 Ehmm be we went there and that's when he used headphones he used tapes and
315 CDs to help you know a Dell or Mac at therapy in outpatient General I tried to
316 help him with flash cards and letters and he had to write his alphabet we did

KNC talked about the tasks that KN performed during therapy sessions as an outpatient rehabilitation service following the onset. In one task, KN was required to listen to audio tapes and compact discs using headphones and computers (Lines 314- 315). The caregiver wanted to collaborate with KN in performing two tasks involving flash cards and

letters “I tried to help him” (Lines 315-316). In one task, KN was expected to respond by organizing successively a series of cards. While in the later task, he was required to respond by writing alphabet letters “he had to write his alphabet” (Line 316).

While there was some focus on the procedures and there was a general trust placed upon the clinicians and the tasks that they required of the IWA, the caregivers did provide some evaluative reactions regarding the clinical treatment received by the IWA. The caregivers considered whether there were any gains and the benefits from the clinical treatment regarding recovery. That is, the caregivers viewed whether clinical sessions and the clinician contributed to recovery from aphasia. Essentially, these evaluative statements were positive about the clinicians but indicated that intervention was a difficult activity. This is demonstrated in the following example.

Example 4.142 (Appendix E, MNC Interview, Lines 142-143)

142 I think it helped her to a degree that ehmm (..) they taught her how to form her
143 words more clearly (.) and one time she had problems to come out with words

MNC believed that MN benefitted from the therapy she received “I think it helped her to a degree” (Line 142). Based upon MNC’s understanding, the clinician focused on how words are generated by MN. That is, the clinician addressed MN’s word finding difficulty regarding how to improve MN’s search and retrieval of targeted words “to form her words more clearly” (Line 143). According to MNC, it was a challenge for MN to find the targeted words “she had problems to come out with words” (Line 143).

Several of the caregivers believed that the therapy activities and the clinicians contributed to recovery in other ways as well. For example, as noted in the following excerpt, DRC believed independence was enhanced by therapy:

Example 4.143 (Appendix D, DRC Interview, Lines 394-399)

394 And ehmm and one of the confidence builders early in the beginning was due
395 to her speech therapist was ehmmm she asked DR in one of the sessions if she
396 was driving and she took this “well no” and she said “well why aren’t you?” (.)
397 And she said “well I didn’t know that I could” and she says “DR you don’t
398 need to speak to drive” (.) so probably that was one of the milestones of her
399 confidence so she got in her car and she drove around the block (.) and she just

In this example, DRC discussed how the clinician contributed to DR’s independence.

The caregiver described the clinician as a “one of the confidence builders” (Line 394). In one clinical session, the clinician talked with DR about driving. The clinician questioned DR regarding why she doesn’t drive (Lines 395-396). DR didn’t consider that she was actually capable of driving “I didn’t know that I could” (Line 397). The clinician explained to DR that there was no relation between talking and driving “you don’t need to speak to drive” (Lines 397-398). Afterward, DR started to drive again, first driving around her neighborhood and then extending her distancing until she was driving around the city again.

It is interesting to note that while the caregivers did not place judgment on the clinicians during the lived experiences, they sometimes did consider – to some degree – whether what was done in therapy and the challenges they came across during the clinical sessions were most efficacious during these interviews. That is, the IWA reflected on and considered the contribution of these clinical tasks to address the aphasia in daily life. For example, one caregiver (DRC) discussed the reluctance of the IWA regarding the clinical intervention. This is illustrated in the following excerpt.

Example 4.144 (Appendix D, DRC Interview, Lines 81-85)

81 And she said “no what’s good those words? I don’t need that word” you know
82 “I can’t say the words I need” you know so (.) she start off like I said with
83 flash cards and ehmm another thing that was hard for her first be able to ehmm
84 (.) I was trying to help her to write (.) well ehmm they wanted us to start off
85 with like ehmm printing and ehmm and it was hard for her because ehmm it’s

DRC talked how DR questioned whether the targeted words used in clinical tasks can be relevant to her needs “I don’t need that word” (Line 81). DRC believed that DR was incapable of saying words that she needed in her daily life “I can’t say the words I need” (Line 82). Upon reflection in the interview, DRC reflected on whether these tasks contributed to recovery; whether the words worked on through rote drill activities were words that were relevant to DR and needed in her life. One of the tasks seems to be confrontational naming by identifying the targeted picture “with flash cards” (Line 83). The clinician required DR to write words “they wanted us” (Line 84). DRC believed that these two tasks were a challenge for DR “it was hard for her” (Line 85).

Overall, clinical intervention was viewed as a response mechanism toward aphasia. During their interviews, each caregiver mentioned the tasks involved. The evaluations about the clinicians and the overall benefits of intervention were nearly always positive in that the caregivers considered intervention as a positive step toward the eventual recovery of the IWA. However, upon reflection it seems there was some reluctance about this mechanism in which the caregivers question the contribution of the clinical intervention to recovery.

Compensations. Through explicit discussions as well as through implicit references by the caregivers, the application of compensations as an answer to aphasia was also used as mechanisms for recovery. In most of the instances in which it was discussed by the participants in this group, compensation was employed to enable successful communication and interaction between the IWA and other individuals. In addition, the compensations that were discussed by the caregivers were most often in reference to current or recent experiences rather than experiences immediately following the onset. That is, a set of strategies were used to address openly or indirectly the challenges in aphasia. These

compensations frequently were employed during the conversation between the IWA and other people. Apparently, these compensations created a more successful setting between the individual with aphasia and his or her conversation partners. Several compensations have been discussed by the three caregivers during the interviews. Compensations are illustrated in several examples below.

Example 4.145 (Appendix E, MNC Interview, Lines 387-389, and 391)

387 When she's speaking or someone is speaking to her often times she you know
388 speak slowly (.) I have aphasia and I can't understand anything if they've
389 spoken too fast
...
391 She said that to them

As can be noted in this example, MNC talked about how MN shared with the conversation partner that she has aphasia (Lines 387-388). She also informed the individual that she couldn't understand when other people talked fast with her (Lines 388-389). MN requested that the conversation partner to slow down when talking with her, "speak slowly" (Line 388). That is, the IWA prepared and requested sufficient time from their conversational partners so the IWA could finish talking with no interruptions. This strategy could contribute to MN's understanding of what the conversation partner is saying. Obviously, it could have enabled MN to more actively participate to some degree in the conversation. Another example of compensations is presented as follows.

Example 4.146 (Appendix D, DRC Interview, Lines 340-344)

340 And another coping skill that she also did (.) was ehmm she decided that she
341 want a tape recorder and she she ehmm bought a tape recorder so that she
342 could ehmm when she was alone she could say words because she said you
343 know "I think I'm saying it right in my mind I think I'm saying it right but
344 when I hear it what I've said I realize" she wasn't saying the correct word

DRC talked about how DR compensated for her "hearing loss" by obtaining auditory feedback regarding her speech using an audio tape recorder. DRC described this as "another

coping skill” (Line 340) in that DR examined how she talked when no members of the family were available to provide her with feedback about her speech (Line 342). DR listened to the audio recording of her speech using the audio tape recorder to evaluate whether she said the words correctly or not. According to the caregiver, DR previously believed that when she talked, she thought that in her mind she was saying the words correctly “I think I’m saying it right” (Line 343). However, when DR listened to what she actually said, using the tape recorder, DR realized that she didn’t talk correctly “wasn’t saying the correct words” (Line 344). This “coping skill” allowed DR to correct her speech by herself. Again, compensation is illustrated in the following excerpt.

Example 4.147 (Abstract F, KNC Interview, Lines 100-103)

100 More more childlike ehmm (..) ehmm may be to (.) I think in some ways (.) to
101 compensate ehmm not to be able as well to communicate with others so he
102 finds a way cover that that problem (.) to mask it ehmm with humor that
103 doesn’t come out as humor many many times

In this example, KNC believed that KN used his humor for compensation. The caregiver believed that KN employed humor “to compensate” (Lines 100-101) for his challenges in aphasia “not to be able to communicate with others” (Line 101). That is, KN attempted to mask his aphasia “he finds a way to cover that problem” (Line 102). As we can see, KNC described how KN used humor as a compensatory tool to overcome the challenges in aphasia.

Again, it is interesting to note that as the caregivers discussed recovery over time, the mechanism of avoidance was reduced; this was likely due to the coping skills that were created and by the fact that many of these coping mechanisms were more effective socially than avoidance. Indeed, these mechanisms (including compensations) were considered as eventual pathway to some recovery from the state of aphasia. Further, some of these

compensations were not developed in clinical settings, rather they were constructed independently by the IWA as they negotiated the states of aphasia by themselves. In accordance with the progression of compensations, the following mechanism also began to be highlighted as a response mechanism to aphasia.

Social Affiliation. The caregivers frequently discussed the importance of family, friends and other acquaintances as one of the reasons that the IWA progressively became more social and began responding to their states of aphasia. In this sense, social affiliation was a significant response mechanism. Throughout their interviews each caregiver discussed how the IWA belong and interact with their families and possible with other social groups in which the group members gathered together and interacted with each other. As discussed previously, this social party (family) not only provided support in terms of assistance with daily living and understanding the state of aphasia, they also provided a setting for social affiliation. Several months following the onset, family started becoming more important as not only supportive resources but as the context for social affiliation as well. The commonality between the family members and the IWA contributed to moving forward in aphasia. All the participants in the Caregiver Group talked about social affiliation. The following excerpt is illustrative of the comments of all the caregivers:

Example 4.148 (Appendix D, DRC Interview, Lines 358-363)

358 Right but I think ehmm (.) the biggest motivation thing for DR on daily basis
359 was ehmm (.) was my daughter's children (.) ehmm (.) we realized from the
360 beginning that in order of DR to talk you know they explained to us that was
361 very important that she verbalize so ehmm (..) and in the beginning like I said
362 she was withdrawn so we knew she wasn't going to talk but we're going to be
363 the people who will get her to talk during the day (.) so ehmm in the beginning

DRC believed that the grandchildren encouraged DR to interact on daily basis “the biggest motivation” (Line 358). Following the onset, the clinicians explained to the family

that it was essential for DR to talk with other people (Line 361). DRC described DR in the early stage following the onset as “she was withdrawn” (Line 362). The family was aware that DR wasn’t talking (Line 362). DRC believed that family significantly contributed to her recovery in terms of talking on daily basis “will get her to talk during the day” (Line 363). While the majority of the social affiliation was with family, friends also could have a powerful impact as described by MNC in the following example:

Example 4.149 (Appendix E, MNC Interview, Lines 58-61)

58 Her friends (.) class mates meet every month and she plans some activities and
59 ehmm like she had the class over one day last month (.) she didn’t tell me
60 thing about (.) I kind of picked up from the conversation she had and I
61 started listening because she had bought you know extra bread chicken salad

MN meets her friends and her old friends that she is familiar with since school. MNC described this group of people as MN’s “class mates” (Line 58). This social group meets on regular basis. These individuals came to visit MN at home (Line 59). MN planned and organized several activities for this social group and provided them with food. MN participated in the conversation with her friends in this social event.

Practice. One mechanism that the caregivers discussed as a powerful mechanism assisting in recovery was the tendency for each IWA to engage in self-initiated practice. That is, each IWA seems to have started working on various tasks and skills on their own shortly following the onset of aphasia and even at the initial stages of clinical intervention. Each caregiver discussed during the interviews that the IWA worked on communicative activities on their own over and over to get better at them. The IWA were oriented to carry out certain activities that they actually employed in their own lives. These activities were performed by the IWA on regular daily or weekly basis. These activities involved the use of language in daily living activities such as writing checks, paying bills, and buying items at the store. The

IWA at some point practiced executing these tasks jointly with another individual such as the caregiver. On the other hand, the IWA practiced alone these activities at some stage.

Originally, these activities were initiated by the IWA or the caregiver. One participant in the Caregiver Group (DRC) talked about functional practice. This is illustrated in the excerpt below.

Example 4.150 (Appendix D, DRC Interview, Lines 204-210)

204 Another thing that was hard for her was like ehmm going to the store to get her
205 medications and in the beginning ehmm it was hard you know like they would
206 ask you ehmm “what is your name?” they’ll ask you address your date of birth
207 and that was another thing that she practice for hours of being able to say her
208 address and you know to say ehmm you know the date the numbers the
209 numbers were a problem because you know her address has a numbers and her
210 phone number

In this example, it was a challenge for DR to go to the store to obtain her medications in the early stage following the onset, “that was hard for her” (Lines 204-205). The staff at the store asked DR questions in which they requested that she provide them with personal information including her name, date of birth, and address (Line 206). DRC believed that DR practiced for hours on how to say her personal details, numbers, and address (Lines 207-208). That is, DR attempted to overcome her challenge regarding answering questions about numbers (Line 208) by practicing on regular basis how to answer these questions.

While much of the practice involved functional skills chosen independently by the IWA, some were initiated by the IWA, a family member, or external resources such as the clinician. These tasks involved reading, writing, or numerical calculations. Practicing these tasks does not represent actual activities that the IWA performed in real life. Two participants in the Caregiver Group (MNC, DRC) talked about practice. This is illustrated in example as follows.

Example 4.151 (Appendix E, MNC Interview, Lines 326-329)

326 And a friend of our daughter in Arizona was a principle and ehmm gave her
327 some math books English books and things work books for her to practice and
328 of course I got I was accused of not (.) working the promise with her I told her
329 “the whole purpose of this for you to read and for your to do it”

MNC talked about how MN received a set of books from a friend of the family. MNC believed that MN practiced various tasks based on these books (Line 327). MN practiced numerical calculations, reading, and writing. He described these books as “work books” (Line 327). MNC believed that MN wanted to practice by collaborating with him. However, MNC tried to explain to MN that the aim was to practice alone unaccompanied by others “for your to do it” (Line 329). Again, practice is presented in the following example.

Example 4.152 (Appendix D, DRC Interview, Lines 466-469)

466 Because I can see she methodical about (.) studying and how she goes about it
467 doing every day for hours not all one time she only ehmm (.) she does it like in
468 spur like twenty minutes at the time and would allow her to focus you know so
469 she’ll back off and do something else and come back to it but ehmm we’re

DRC talked about how DR systemically practiced by herself “methodological about studying” (Line 466). DRC believed that DR invested time and effort to practice tasks on daily basis “she goes about it every day” (Line 467). DR employed a specific strategy regarding how to practice these tasks. Initially, DR attempted to practice for a short period of time “she does it like in spur” (Lines 467-468). Afterwards, DR would stop practicing for a while, followed by returning to practice “come back to it” (Line 469).

Awareness

Based upon the caregivers, as a number of mechanisms were created by the IWA as the response to the state of aphasia, they also developed an increasing awareness of what aphasia meant to them in their daily lives and how they would have to change. Awareness is the second primary theme that was categorized under the super-ordinate *Coping* theme in the

data set of the Caregiver Group. As it was discussed in the Aphasia Group, awareness is the gradual sets of realizations gained through long-term experience with aphasia and how it was addressed.

Throughout the interviews, the caregivers discussed how they initially became aware of what was happening to the IWA and that growing awareness made an impact on them following several months of experience with aphasia. Within this awareness, the caregivers began to recognize the limitations that they experienced involving the language of the IWA. On one hand, the awareness revolved around the recognition established by the caregivers regarding recovery in aphasia. That is, the caregivers realized how aphasia moved forward over time. Further, awareness also involved how efforts were made seeking to establish recovery. That is, the caregivers realized that particular compensatory mechanisms were employed in order to respond to aphasia. On the other hand, the caregivers recognized that aphasia moved forward, but only to a specific level or extent. The caregivers considered and interpreted recovery based on the experiences that they gained over time. There seem to be three subordinate themes under the theme of *awareness*: Recovery as change, incomplete recovery, and changing perceptions.

Recovery as a Change. Throughout the interviews, each caregiver discussed how they became aware that the situation changed and that aphasia and its impact moved forward over time. This is illustrated in the excerpt below.

Example 4.153 (Appendix D, DRC Interview, Lines 192-195)

192 Right she she (.) she grew her confidence to go out to the public she somewhat
193 avoided having to speak to people (.) and that gradually changed she got more
194 of a command of her words ehmm (.) she became confident in asking you
195 know for like something in the supermarket now and ehmm sometimes those

In this example, DRC discussed how DR moved forward through her interaction with other people “to go out with the public” (Line 192). DRC believed that DR progressively moved forward; that she “gradually changed” (Line 193). That is, DR moved from avoiding to speak toward speaking with other individuals in that she “got more of a command of her words” (Lines 193-194). DRC provided an example of DR’s positive change in which DR started to ask questions regarding articles at the supermarket (Line 195).

Change as recovery also emerged and was established in other language skills including understanding spoken language and literacy. Two participants in the Caregiver Group (KNC, DRC) talked about recovery in these language skills. These are presented in the following example.

Example 4.154 (Appendix F, KNC Interview, Lines 512-519)

512 With it but I think it’s my problem I have a big problem with it ehmm the first
513 time he walked up there and read I was (.) embarrassed because I was looking
514 at the way he was reading instead of that he got up and read (.) and after mass
515 two three four people came up to me and said how impressed they were that
516 KN had the courage to get up there and read and one mother said her son asked
517 “why is that man reading that way?” And she explained to him that he had a
518 stroke and that he had the courage that he got up there to do it (.) well I felt this
519 big and I learned a lesson (.) so it wasn’t how he read is that he read (.) I still

For the first time, KN walked up and read aloud in front of people at the church mass (Lines 513-514). KNC considered how people who attended the mass admired KN “how impressed they were” (Line 515). KNC believed that these individuals appreciated KN’s effort, despite the stroke, to stand up and read in front of everyone “had the courage that he got up there to do it” (Line 518). KNC previously focused on how KN actually read aloud “the way he was reading” (Line 514). However, she realized afterwards that standing up and reading in front of people was in fact remarkable attempt by KN to move forward “so it

wasn't how he read is that he read" (Line 519). The caregiver became aware of KN's effort to address aphasia.

DRC saw a similar kind of change over time when discussing DR and her progressive improvements when focusing on literacy. This change as recovery is illustrated in the excerpt below.

Example 4.155 (Appendix D, DRC Interview, Lines 298-301)

298 Right right and then eventually she would she would write the number first (.)
299 she started doing that and bring it for us and that's kind of and the date she
300 would get the date right but she don't she won't mail anything unless we
301 checked it (.) and then gradually she was able to write the number out and

In this example, DRC discussed how DR gradually moved forward in completing her bills by writing. Initially, DR would approach family members requesting to examine her writing attempts "bring it for us" (Line 299). The caregiver provided an example of DR's positive change in writing numbers "would get the date right" (Line 300). DRC believed that DR moved progressively in writing numbers "she was able to write the number out". That is, the caregiver realized that DR move forward in completing bills by writing.

Based on their living experiences, the caregivers believed that the nature of the recovery in aphasia was not static. Instead, they realized that recovery was gradual and progressive in nature. The caregivers noted these changes not only in the language and communication of the IWA, but in other areas as well. One element of recovery as change involved personal change. That is, the IWA moved from dependence or some degree of reliance on others (e.g., working jointly with other individuals), toward greater independence in which the IWA started to perform certain activities alone with no assistance. One participant in the Caregiver Group (DRC) talked about this type of change. Personal change is illustrated in the following example.

Example 4.156 (Appendix D, DRC Interview, Lines 317-321)

317 So then she was like get more confidence in writing you know these long
318 numbers (.) ehmm but now she's she's able to (.) ehmm she has confidence in
319 herself now that she's doing it right because we've done about six months were
320 I 'm checking them and tell her "DR you have got nothing wrong you can do
321 it" you know

As can be not noted, DRC talked about how DR moved forward in writing numbers. DRC and DR worked jointly on writing numbers for a period of time following the onset (Line 319). DR practiced alone how to write numbers in her bills. DRC examined the performance of DR "I'm checking them". Afterwards, DRC provided positive feedback to DR about her writings and encouraged her in writing bills "got nothing wrong you can do it" (Line 320). DRC believed that DR moved forward in writing numbers alone by herself. DRC described DR's recovery in writing as "get more confidence in writing" (Line 317).

In addition, there was a growing awareness that recovery also involved social change. That is, the caregivers discussed through their interviews how IWA moved from less socialization toward greater interaction with other individuals. The IWA went through change in which the individual could talk with other people and share with them about his or her personal life. This is presented in the excerpt below.

Example 4.157 (Appendix D, DRC Interview, Lines 427-428)

427 Right she's more ehmm (..) she's becoming more social now you know
428 because her speech is you know better (.) I find she's coming out more you

In the current example, DR moved forward through social interaction over time. She changed and moved toward being socially active "becoming more social now" (Line 427). DRC described how DR more often meets and interacts with people "coming out more" (Line 428). DRC attributed this social change to DR's improvement in speech "because her speech" (Line 428)

Incomplete Recovery. The second facet of awareness regarding recovery in aphasia involved the realization that any recovery would be incomplete and it coexisted with residual challenges. The caregivers were aware that recovery evolved in aphasia to some degree and a specific level. That is, the caregivers recognized that although moving forward emerged or established, several challenges and impairment were maintained. Therefore, full recovery has not evolved and the IWA didn't return back how they were prior to the onset. All the participants in the Caregiver Group talked about incomplete recovery. This is illustrated in the following excerpt.

Example 4.158 (Appendix F, KNC Interview, Lines 413-415)

413 Yeah some of that has been his determination and that's the biggest he is
414 determined more than anyone I know to try to beat this thing and I think he has
415 some realization that you know he has some limitations that he constantly try

KNC believed that KN wanted to move forward in aphasia "to try to beat this thing" (Line 414). Nevertheless, she was certain that KN was aware to some extent about the challenges that he came across; "he has some limitations" (Lines 414-415). On one hand, KNC believed that KN wanted to overcome the challenges in aphasia following the onset. On the other hand, KN recognized his limitations that he encountered. That is, complete recovery was not an option to be accomplished and KN, according to the caregiver, was aware of his limitations. Again, incomplete recovery is presented in below.

Example 4.159 (Appendix D, DRC Interview, Lines 460-462, and 464-465)

460 And now she realizes you know even like coming here and all that even with
461 the gains that she made and she made tremendous gains ehmm she realizes also
462 makes her realize how much she's lost
...
464 So ehmm (..) she has said to me that "I don't know that I will ever be the
465 same" she says so I don't know ehmm (.) she hasn't given up hope you know

In this example, DRC discussed how DR was aware of her remarkable recovery “she made tremendous gains” (Line 461). DRC with held the belief that DR also realized the extent of her aphasia and its impact; “how much she’s lost” (Line 462). DR questioned whether at some point she would reach a full recovery “will ever be the same” (Line 464). It seems that DRC believed that DR had some thoughts and even reservations regarding moving forward and reaching how she was prior the onset.

Acceptance: Bipolar Person. Acceptance is another sub ordinate theme that fit under the theme of awareness and involved how recovery needed to be eventually viewed by the caregivers. The caregivers made basic interpretations of the recovery in aphasia. That is, perception was considered as how the caregivers interpreted moving forward in aphasia based on their lived experiences. These interpretations regarding recovery in aphasia were manifested through language. Perception involved similes representing the core of what the caregivers went through and their understanding of recovery by using other terms. In the excerpt below, MNC responded to a question asked by the interviewer: “Do you think that MN believed she has improved over time with her speech and communication?”

Example 4.160 (Appendix F, KNC Interview, Lines 202, and 204)

202 Sometimes I think it’s like a person with bipolar

...

204 When you stop taking your medicine

As noted in this example, MNC made a comparison between the recovery of MN and the bipolar disorder “like a person with bipolar” (Line 202). It is common for a person with bipolar disorder to experience high period of mood changes. That is, the individual moves from feeling extremely high to feeling very low. MNC believed that the recovery of MN was constantly changing and even swinging frequently. MNC considered her recovery as the mood frequently changes of people with bipolar disorder when they discontinue consuming

the relevant medicine “stop taking your medicine” (Line 204). He believed that that recovery of MN was systemically changing in which sometimes aphasia was moving forward and sometimes it was static as not moving forward.

Contextual Influence

The fourth super ordinate theme in the data set of the caregivers addresses the context in which the state of aphasia and its recovery occurs within. As we know, the caregivers attempted to make sense of their experiences regarding recovery based on the meanings of specific experiences and events. However, their interpretations are reliant to some degree on the settings in which these experiences are interpreted. This theme involves less direct experience with aphasia but is centered on providing the setting from which those experiences are interpreted. That is, rather than focusing on the way that the caregivers organize their lived experiences as they describe them, this super ordinate theme provides the true nature regarding how and why the living experiences were interpreted as they were. According to the interviews with the caregivers, there were two tangible themes that emerged and served as contextual influences with several subordinate themes employed within each of these themes. These involve the perspectives and the expectations of the caregivers.

Perspectives

The first theme that fit under the super ordinate theme Contextual Influence involves the perspectives that each caregiver brought with him or her into the state of aphasia. As previously discussed in an earlier section of Chapter Four, perspective can be considered as a mental outlook in which an interpretive filter was used to organize the caregiver’s experience with aphasia. As a result, the perspective of each caregiver provides the emotional/affective environment regarding the IWA during recovery. For instance, the nature and the extent of

the motivation and the persistence of the IWA during recovery are based upon this mental outlook. There were two primary sub ordinate themes that created the IWA perspectives, Identity prior to the stroke and locus of control.

Prior Identity. The first contextual sub ordinate theme categorized under perspectives involved how the caregivers considered who the IWA to be before the onset of the aphasia. Since caregiver's outlook is structured by the image or identity of the IWA as it was considered pre-onset, the crucial questions were: who the IWA was, what were the individual's competencies, what were his or her strengths and weaknesses, and how have these changed since the onset of aphasia. These all influence how the caregiver viewed the current state of the IWA and their prognosis for the future. Certainly, there are a number of elements that make up one's social identity and not all of these facets can be described. However, according to the analysis of the caregiver interviews, each IWA's identity before onset seems to be greatly influenced by four facets: communicative proficiency, faith, education, and occupation.

The first facet of prior identity viewed by the caregivers seems to be each IWA's *expertise and proficiency with communication*. That is, how proficient a speaker and/or social actor the IWA was considered before the onset of aphasia. This aspect is significant since the caregivers interact with the IWA and tend to compare these individuals communicatively before and after their stroke. Throughout the interviews, each caregiver talked about the communicative facet of the IWA's identity prior to the onset. This is illustrated in the following excerpt in which KNC discussed KN's previous communicative expertise as a social actor and set this premorbid effectiveness against what he is now capable of doing.

Example 4.161 (Appendix F, KNC Interview, Lines 184-188)

184 KN been very social and he loves people he loves to talk with people and
185 I think he's finding out more people (.) they've been polite (.) but the time take
186 him to say something ehmm (.) people lose interest KN has a way of fluffing
187 around things instead of getting straight to the point he goes all the way around
188 and he tells you the point he had to make

As can be noted, KNC believed that KN was sociable in terms to interact with people “been very social” (Line 184). KNC described how KN enjoyed interacting with other individuals “he loves to talk with people” (Line 184). According to KNC, KN attempted to interact and to make contacts with these individuals “finding out more people” (Line 185). That is, KN was considered as a speaker who interacted with other individuals. However, KNC believed that “people lose interest” (Line 186) due to his way of talking around the topic as “not straight to the point” (Line 187). Similarly, the IWA was identified as a speaker is illustrated in the excerpt below.

Example 4.162 (Appendix E, MNC Interview, Lines 158-159, and 161)

158 She'll stop and they you know they'll talk but ehmm sometime she talks non
159 stop
...
161 Oh she always liked to talk

In this example, MNC talked about how MN spoke sometimes without stopping. The interviewer asked MNC if the speech of MN had changed compared with before the onset. MNC believed that MN as a speaker enjoyed talking before the onset “always liked to talk” (Line 161).

In a similar manner, DRC discussed the effectiveness of DR in reading prior to the onset of the stroke and aphasia.

Example 4.163 (Appendix D, DRC Interview, Lines 414-416)

414 Things that were important for her (.) now her goal is we were talking about in
415 our way coming (.) ehmm which she'd like to be able to do is to read again she
416 was always a happy reader (.) and her goal is to be able to read fluently again

DRC talked about the important issues for DR in her recovery “were important for her” (Line 414). She believed that DR enjoyed reading prior to the onset. DRC described how DR used to read before the onset of the aphasia as a “was always a happy reader”. She also considered DR prior the onset as a “fluent reader” (Line 416). That is, DR as a reader was part of her identity before the onset.

Faith was another facet that contributed to constructing the identity of the IWA. Based upon the interviews with the caregivers, all three of the participants in this group value the faith and the power of prayer regarding the IWA as a sustaining influence from their premorbid state. According to the caregivers, faith for each IWA was based on the religious values of Christianity by which all three IWA were Roman Catholic and various facets of each one’s faith was discussed. The caregivers highlighted the importance of faith of the IWA by talking about using their faith to sustain them through prayer or by engaging in church activities for religious and social reasons. For instance, KNC discussed the sustaining value of KN’s faith as well as her own and the social values that her belief placed upon her in these circumstances. This is illustrated below.

Example 4.164 (Appendix F, KNC Interview, Lines 237-241)

237 And I always had a strong faith catholic background ehmm (.) that was one of
238 the things that we tried to make KN and I teach each other because KN was
239 always catholic but he was away from the church for twenty years or so (.)
240 came back to the church a couple of years before we met so that was one of the
241 things that brought us together was our faith

In the current example, KNC talked about KN and her own catholic faith. KN and KNC shared the same faith and it was common between them. KNC and KN talked with each other about their faith “teach each other” (Line 238). She believed that religion contributed to their marital relationship “brought us together” (Line 241). Again, faith is presented in the following example.

Example 4.165 (Appendix E, MNC Interview, Lines 298-299, and 301)

298 She's very religious and she'll go to she belongs to the catholic society and do
299 the whole thing (.) I mean she really is more religious minded than I'm

...

301 No no her faith you know has not (.) has always been the same

MNC believed that MN had founded faith “very religious” (Line 298). MN was a member of a catholic society and participated in their events; “do the whole thing” (Line 299). MNC compared between MN’s faith and his own faith. He believed that she was more oriented toward religion compared with him “more religious minded than I’m” (Line 299). MNC viewed that MN’s faith hasn’t changed over time “has always been the same” (Line 301) and this acted to contextualize her recovery process

In addition to language capacity and religion, *prior education* was another element that contributed to shape the identity of the IWA. The caregivers reported the educational background of the IWA and how it shaped them. Based upon the interviews with the caregivers, each IWA had a college degree and was employed in his or her career as to get and hold jobs in their professions. The importance of being educated and how this formed the identities of the IWA prior to the onset of aphasia can be seen in how it was discussed by the caregivers. This is presented in the following excerpt below.

Example 4.166 (Appendix D, DRC Interview, Lines 67-71)

67 Yes oh yes yeah because DR DR was ehmm (.) an LSU undergraduate you
68 know and she always prided herself on ehmm even in high school she was she
69 wasn't valedictorian but she was third fourth or fifth somewhere right up
70 there so she was always very studious ehmm (.) so at first you know pride has
71 a lot to do with it and it was (.) DR's sharing experience

In the current example, DRC discussed the educational background of DR. The caregiver described how DR was proud of her education; “always prided herself” (Line 68). DR completed a bachelor’s degree in an academic institution in Louisiana (Line 67). DR

graduated from a high school. DRC considered DR's educational achievements at school as one of the top ranks "third fourth or fifth ... right up there" (Line 69). The caregiver believed that DR was very serious about her education "she was always very studious" (Line (70). This suggested both her intellectual ability as well as her work ethic. Again, prior education is illustrated in the extract taken from the interview with MNC.

Example 4.167 (Appendix E, MNC Interview, Lines 50-54)

50 Yes she does and she is a college graduate (.) she finished college in secretary
51 science nineteen fifty six or seven in UL (.) I finished in fifty five she finished
52 in fifty six or fifty seven I don't remember exactly (.) and all the three kids
53 went over there and graduated (.) so her background her knowledge is there (.)
54 but sometimes (.) and she also started speaking very softly

MNC talked about how MN graduated from an academic institution in Louisiana. MNC described MN as a "college graduate" (Line 50). MN graduated from the secretary sciences program at the University of Louisiana at Lafayette. MNC believed that MN had an educational background that was available and intact following the onset of the aphasia; "her knowledge is there" (Line 53).

Relevant to education, *occupation* was the fourth facet that most appeared to help construct the identity of the IWA. In all three cases, the focus was on the occupations of the IWA just before the onset of aphasia. All the participants in the Caregiver Group talked about the occupational background of the IWA. This is presented below.

Example 4.168 (Appendix D, DRC Interview, Lines 260-263)

260 I think for her life her profession ehmm DR was ehmm (.) ehmm she worked
261 in an ICU for about fifteen years so her daily life was regimented to ehmm (.)
262 being unguard you know watching out for someone making decisions splitting
263 decisions ehmm people relying on her

In this example, DRC talked about how DR worked as a nurse in an intensive care unit at the hospital for a long period of time (Line 261). DRC believed that the nursing

profession contributed to DR's life style "her daily life was regimented". According to DRC, the career of DR as a highly ranked nurse involved supervising and making professional judgments about the patients "splitting decisions" (Line 262). DRC described how people at the hospital were dependent on DR "relying on her" (Line 263).

Locus of Control. The other sub ordinate theme that helped the caregivers to contribute to shape their perspectives about the IWA was locus of control. That is, the caregivers considered whom or what was responsible for addressing and modifying the state of aphasia if recovery is to occur. Locus of control seems to be compromised of two primary types: internal locus of control, and external locus of control. However, internal locus of control was primarily dominant. Each of the three participants in the Caregiver Group believed that the IWA took on primary and personal responsibility for moving forward in recovery from aphasia and that this made a great difference. These caregivers expressed a belief in the IWA's self determination and sufficient willpower to address aphasia.

Determination of the IWA to move forward is illustrated in the following example.

Example 4.169 (Appendix E, MNC Interview, Lines 322-324)

322 At short period of time she was more determined in (.) focusing on what the
323 word she wanted to use she could tell that she was really wanted to decide the
324 word that she wanted

As it can be noted, MNC believed that MN was responsible to address her aphasia during a particular period of time; "she was more determined (Line 322). MN decided to focus on the targeted word during talking. MNC believed that MN actually chose the relevant word that she intended to say "really wanted to decide the word that she wanted (Line 323). That is, MN wanted to say the targeted words, and therefore her determination was considered as internal locus of control. Again, the determination of the IWA is presented in the following excerpt.

Example 4.170 (Appendix F, KNC Interview, Lines 413-416)

413 Yeah some of that has been his determination and that's the biggest he is
414 determined more than anyone I know to try to beat this thing and I think he has
415 some realization that you know he has some limitations that he constantly try
416 with it because he really believes that he's going to get a job (.) and

In this example, KNC talked about the willpower of KN that played an important role in his recovery, that his determination has made the biggest difference (Line 413). She believed that KN was “determined” (Line 414) to address his aphasia. KNC described how KN really wanted to overcome the challenges “to try to beat this thing” (Line 414). Again, KN’s determination to address aphasia was considered as internal locus of control.

On the other hand, external locus of control involved social parties who were responsible for moving forward. Members of the family were considered by the caregivers as a social party who contributed to recovery. One participant in the Caregiver Group talked about how family members contributed to address aphasia. This is illustrated in the excerpt below.

Example 4.171 (Appendix D, DRC Interview, Lines 364-367, and 369)

364 She was somewhat withdrawn but we realized that the children ehmm ehmm
365 David is eight now and that's a grandchild well David and Steve ehmm Steve
366 is three now they were able to draw her out in a lot of times and ways that that
367 we want
...
369 So we used the children a lot to motivate her you know and ehmm

In the current example, DRC believed that her grandchildren were used to address the aphasia of DR “to motivate her” (Line 369). DRC believed that these children contributed to move DR forward through her social interaction with other individuals “they were able to draw her out” (Line 366). That is, these children who addressed the aphasia of DR and are viewed as external locus of control

In addition, social parties also included clinicians who provided therapy to the IWA. Clinicians were also considered by the caregivers as social party who contributed to moving forward in aphasia. That is, since the clinicians were involved in recovery, they were viewed as external locus of control regarding moving forward. This is illustrated in the extract taken from the interview with DRC.

Example 4.172 (Appendix D, DRC Interview, Lines 394-399)

394 And ehmm and one of the confidence builders early in the beginning was due
395 to her speech therapist was ehmmm she asked DR in one of the sessions if she
396 was driving and she took this “well no” and she said “well why aren’t you?” (.)
397 And she said “well I didn’t know that I could” and she says “DR you don’t
398 need to speak to drive” (.) so probably that was one of the milestones of her
399 confidence so she got in her car and she drove around the block (.) and she just

DRC talked about how the clinician contributed to DR independence. The caregiver described the clinician as a “one of the confidence builders” (Line 394). In one clinical session, the clinician talked with DR about driving. DR wasn’t aware that she actually can drive “I didn’t know that I could” (Line 397). The clinician made it clear to DR that there was no relation between talking and driving “you don’t need to speak to drive” (Lines 397-398). Afterward, DR started to drive in her surrounding area “she drove around the block” (Line 399). DRC described the contribution of the clinician as “one of the milestones of her confidence” (Lines 398-399). According to the caregiver, the clinician contributed to the independence of DR. As we can see, this clinical contribution to moving forward was considered as external locus of control.

On the other hand, divine power involved the faith based on religious values of the individual. The caregivers believed that faith was responsible for the recovery in aphasia. Faith contributed to shape external locus of control regarding recovery. Two of the

participants in the Caregiver Group talked about divine intervention in recovery. This presented in the excerpt below.

Example 4.173 (Appendix F, KNC Interview, Lines 423-426)

423 His faith has played an important role I really believe that and I believe that he
424 become ehmm more grounded and stronger in his faith since this because he
425 had no one to rely on (.) he's nice to himself but knowing that there is someone
426 a yeah a higher power and daunt to

In the current example, KNC believed that the faith of KN significantly contributed to his recovery “faith has played an important role” (Line 423). KNC compared between the faith of KN before and after the onset. She believed that KN was further oriented toward religion compared before the onset “more grounded and stronger in his faith since this” (Line 424). KNC believed that KN cannot depend on any individuals to KN “no one to rely on” (Line 425). According to the caregiver, KN considered faith as a superior and overwhelming power “a higher power and daunt to” (Line 426).

Internal locus of control could coexist with external locus of control. These two primary types of locus of control don't have to be separated and independent from each other. That is, internal locus of control and external locus of control could actually be combined together. Therefore, a compromise can be reached between these two types. The combination between these two elements can shape the nature of locus of control regarding recovery in aphasia. This is demonstrated in the following example.

Example 4.174 (Appendix F, KNC Interview, Lines 429-432)

429 Yeah you can't really expect him you know I think he realized that you can't
430 expect to lie on the road and expect a car to hit you (.) you have to be realistic
431 in that way and you have to do your part (.) but I think ultimately he knows
432 ehmm (.) god has helped him tremendously through this

Clearly, KNC believed that KN should not be expected not to make any effort to address aphasia “to lie on the road and expect a car to hit you” (Line 430). According to the

caregiver, KN should be committed to respond to aphasia “you have to do your part” (Line 431). However, the caregiver also believed that the divine power has remarkably contributed to his progress “god has helped him tremendously” (Line 432). As we can see, internal locus of control was combined with external locus of control.

Expectations

The second theme included under the super ordinate theme of Contextual Influence involves the expectations that the caregivers bring to the interpretative process. Expectations are essential since they often provide the evaluative measure regarding moving forward when recovery is addressed. While the theme of perspective provided the substance underlying emotion and affect, expectations supply a basis for the evaluative measure that is used when describing and rating the recovery in aphasia. When the caregivers considered what has happened or would happen during recovery over time, expectations served as contextual setting. Two sub ordinate themes were identified as accounting for most of the expectations that were discussed: time and reality.

Time. As it was discussed previously, each caregiver employed the expectation that recovery occurred over time. Skills and abilities of the IWA were constantly described using a “then-and-now” framework and through the constant use of past and future considerations when discussing recovery. This was most often manifested in how the caregiver contrasted between the difficulties that the IWA encountered in the acute stages of recovery with the difficulties that were reduced over time. As it seems, time served as an operational contextual influence. Indeed, each caregiver considered the recovery of the IWA as moving forward over time and the states of change in recovery were distinguished through this temporal framework. The use of time as the background for change was necessary for the caregivers in

order to allow making these comparisons available (then-now; past-present-future change).

The caregivers viewed time as a sequential constituent that contributed to shape the movement in aphasia. This tendency to construe recovery as a constant moving forward over time is presented in the following excerpt.

Example 4.175 (Appendix D, DRC Interview, Lines 243-246)

243 Yes about a year and a half now but it's and in the beginning you know ehmm
244 her personality (.) I found that she ehmm there was a sadness about her and
245 you know I could I knew my sister and I could see that in her and now I'm
246 seeing more ehmm little more like hardiness

In the current example, DRC talked about how DR changed over time. She described DR as unhappy in the early stage following the onset “in the beginning” (Line 243). DRC believed that DR became recently more resilient “now I’m seeing more hardiness” (Line 246). That is, DRC believed that DR moved forward over time by making a comparison regarding her personality between how DR was sad in the early stage following the onset and her resilience now.

Example 4.176 (Appendix F, KNC Interview, Lines 354-358)

354 Well dependency on everything at the beginning because it was just I know
355 what are you thinking he knew (.) he didn't know what to do you know in any
356 situation almost and now its ehmm try to cover his mistakes or just ehmm he
357 always ask me or say “I have to ask my wife” to be sure that's correct so I find
358 more I wouldn't call it collaborating it's more dependency

KNC believed that in the early stage following the onset KN was not aware about his performance in various situations “at the beginning” (Line 354). Recently KN attempts to address his condition “now” (Line 356). KN approached KNC seeking assistance and clarification “I have to ask my wife” (Line 357). That is, KNC believed that KN moved forward over time by which she made a comparison between the early stage following the onset when KN didn't seek collaboration and recently when he approached KNC to ask for

assistance.

Reality. The second variable to influence the expectations of the caregivers was based on the realities of illness and deficit. That is, the caregivers recognized that the state of aphasia has consequences and that these consequences are tend to remain, despite the recovery that they experienced over time. The projection of each caregiver regarding recovery was pragmatic in which moving forward was expected but only to a certain level and extent. That is, complete recovery based on the identity of the IWA was not projected forward; the caregiver didn't expect the IWA to return to her/his premorbid state. Indeed, each caregiver used this reality to reach a compromise between his or her projections regarding moving forward to recovery and his acceptance of the aphasia. That is, the caregivers attempted to find a common ground between expecting recovery and the acceptance of residual challenges that may remain over time. This is demonstrated in the extract taken from the interview with KNC.

Example 4.177 (Appendix F, KNC Interview, Lines 413-420)

413 Yeah some of that has been his determination and that's the biggest he is
414 determined more than anyone I know to try to beat this thing and I think he has
415 some realization that you know he has some limitations that he constantly try
416 with it because he really believes that he's going to get a job (.) and
417 particularly with ground postorium and I don't find that realistic and I don't
418 see that but that something I'm not taking away his striving for that but I don't
419 see that but he's determined and that's what is going to happen now how much
420 of that is determination are being realistic I don't know

In this example, KNC discussed KN's determination about having a job in the future "he's going to get a job" (Line 416). He expected to have a job in a certain agency (Line 417). However, the caregiver was reluctant about the potential job. She had reservations about his expectations "I don't find that realistic" (Line 417). On the other hand, KNC was not seeking to minimize his determination to find a job "not taking away his striving" (Line

418). KNC was not certain whether KN's determination was pragmatic (Lines 419-420).

That is, the focus of KNC was on how realistic are the expectations regarding KN's career in the future.

Summary of the Caregiver Group Data

The analysis of the data set of the Caregiver Group, based upon what they witnessed from what the IWA went through, can provide interesting suggestions regarding the recovery in aphasia. These IWA as well as the caregivers seem to be fully engaged and committed to the recovery of the IWA. While the aphasia actually changed several aspects of the lives of the IWA as well the caregivers own lives, it seems they consider recovery as novel and unexpected journey that they go through in which they need to assist the IWA in going back to how the person was before the onset to some degree. That is, since there are negative effects from aphasia in the lives of the IWA as well the lives of the caregivers who interact with them on regular basis, it is natural that recovery revolved around the IWA; however, aphasia and its recovery does involve the caregivers, and other elements and mechanisms to some degree.

Recovery as a journey seems to involve three segments that shape three of the super ordinate themes: 1) encountering aphasia, 2) reacting to aphasia, and 3) coping with aphasia. These domains reflect on how the aphasia disrupted the daily lives of the IWA and the caregivers; and how the participants need to move forward over time seeking to return toward a state of recovery as similar to performance before the onset of the stroke and the aphasia. Certainly, the most dominant theme involved how the IWA (and caregivers) made the effort to cope with the state of aphasia in which the focus was on the tools (mechanisms) employed seeking to address aphasia. Apparently, the final super ordinate theme (Contextual

Influences) was not discussed openly by the caregivers, rather it emerged as how they relate the IWA to recovery. All these super ordinate themes will be discussed more in-depth as follows.

The experience of recovery was first described by relating to the *emergence of the stroke and its impact*. However, each caregiver did not actually relate to the stroke and the aphasia, rather it was mainly used as a starting point indicating the medical emergency (as they remember it) that resulted in a trip to the emergency room. That is, the caregivers focused on the onset of the physical aspect of the condition. Once the medical emergency was over, each caregiver witnessed how the IWA encountered several kinds of difficulties in their daily lives that focused on the functional aspect regarding their performance; how these individuals were engaged in communicating, socializing, shopping, and changes in occupational status.

Interestingly, the caregivers considered how aphasia affected the IWA as well as the caregivers themselves. That is, these caregivers discussed the impact of aphasia on them as well as on the IWA. These individuals related to the emotional impact of aphasia by which they witnessed how aphasia emotionally affected the IWA and at the same time how aphasia had an emotional impact on the caregivers themselves.

The third phase involved how the caregivers were coping with aphasia in order to move toward recovery. There were two themes that were systemically discussed by the caregivers as major categories of coping: developing awareness and employing mechanisms to try and overcome the aphasia. That is, this segment revolved around the recognition of the need for change and how that could occur. Initially, the IWA (and the caregivers) employed certain tools to move forward over time; only later did the caregivers recognize that these

mechanisms and tools were actually how the IWA and they themselves actually coped with aphasia. All three caregivers considered recovery as change to individual's current levels of performance but appeared to also recognize that recovery would never get the IWA to the levels as they were before the onset of aphasia. Certainly, the last aspect of their coping awareness was that the aphasia and its recovery would likely represent something new. There were five general categories of coping mechanisms that they each discussed. First, familial support, followed by clinical intervention which involved professional assistance, and then various independent compensations as coping. These three along with social affiliation (commonality between the IWA and family members), and personalized practice by which the IWA perform certain activities seeking to move forward over time were the additional tools to their coping mechanisms. There was a pattern that suggested that once the IWA started trying to cope with their states of aphasia, the emotional reactions and avoidance tended to be reduced. This was true in all three cases.

It is important to note that the explanation of these three segments of recovery was influenced by several elements that appear to “prepare the ground” or to provide a *context for the experiences* of recovery. According to the comments of the caregivers and how they witnessed the experiences of the IWA, their perspectives were influenced by the prior identities of the IWA before the stroke and on the tendency to believe that the determination and effort by the IWA (intrinsic locus of control), or social parties, including the family and/or the clinicians, or faith (extrinsic locus of control) that were all partially responsible for any recovery that happens; their expectations for how much time the IWA would require to continue moving forward influenced by the reality of aphasia as a dynamic state help point to their awareness of progress and need for more improvement.

Comparisons Between the Individuals with Aphasia and the Caregivers

Once the super ordinate themes and their subsequent components (themes and subordinate themes) were derived from the interviews in both groups (Individuals with aphasia and the Caregivers), these results were compared across the two groups to determine what kinds of similarities and differences could be discerned. Since both groups were basically discussing the same general experiences – the lived experiences involved in an individual's recovery from aphasia – it would be expected that there were a number of similarities between the two groups. This was the case. However, there were also various differences. Each category and the reasons for them will be discussed in this section.

Similarities

The most noticeable similarity between the IWA and their caregivers were that the reports of recovery from aphasia yielded, in general, *parallel experiences*. These were manifested by the four major super ordinate themes that each group discussed. In both groups (and all six participants) there was a *phase-like orientation* that described a *gradual change* from the abrupt occurrence of stroke and its resultant aphasia to an *eventual form of acceptance* in terms of awareness that aphasia was permanent and a *determination to find some mechanisms* to reduce the impact of the aphasia.

With regard to the temporal trajectory of recovery, both groups discussed *encountering aphasia* and that phase was followed by *reactions to the aphasia*. This reaction phase was short in duration and eventually transformed into a more active phase where both groups recognized that there were some ways to more effectively *cope with aphasia*. The similarities across the groups for these three phases are primarily due to the fact that each

participant did share a host of like experiences that were guided over time by the responses of the IWA. Although their perspectives were a bit different (see next section), both groups had corresponding experiences and discussed them in similar ways. Of course, since the participants were invited in this study to “tell their stories” about their experiences with aphasia and the recovery process, the uniformity of narratives also helped shape these interviews and the resultant themes. Each of the participants was similar enough in terms of culture and education (General American and college educated) that the kinds of narrative structures and stylistics they employed in their interviews were equivalent. Consequently, the stories were well formed and shared a “general American commonality”.

Within these three phases of recovery there were also some content similarities. When *reactions to aphasia* were discussed as a phase, both groups recognized that there were comparable types of reactions. They responded emotionally to the circumstances of the state of aphasia, they realized both abruptly and then verified over time that the aphasia was truly life-changing, they both recognized that the avoidance reaction experienced by each of the IWA was not very adaptive, and both groups shared a tendency to use metaphorical description to try and understand and transmit the experiences. Similarly, when describing the ways that the IWA (and even the caregiver) *coped with aphasia* each group used five different types of mechanisms to assist recovery. While these five categories (clinical intervention, support mechanisms, compensatory strategies, social affiliation as motivation and opportunity, and independent practice) were valued and described somewhat differently (see next section) they were correspondent ways that both groups felt that coping occurred.

There was a fourth super ordinate theme (*Contextual Influences*) that was not a phase or a description of the recovery process but, rather, a set of variables that were instrumental

in formulating the behaviors and perceptions of the recovery process. While the two groups were different in terms of their lived experiences (and this will be evident when more specific differences are discussed), both tended to be influenced by the same overall variables (prior identity of the IWA, an extrinsic orientation to locus of control, and the impact of temporal considerations and real world practicality on each participants expectations). Overall, then both groups shared a number of similarities.

Differences

As mentioned previously, even though there were general similarities across the two groups, there were also a number of differences. Very often the participants in the two groups recounted many of the same experiences – especially problems and reactions or solutions to the problems – but they did so from different perspectives. That is, the individuals with aphasia directly experienced the physical, cognitive, and emotional impact of neurological deficit so their lived experiences were more organic or salient. The caregivers, while being very concerned and also lived a version of the recovery experience, did so only indirectly for the most part. Consequently, their perspectives were different and so some of the foci and specific content within the super ordinate themes that made up the organization of the lived experiences were understandably different. It is at the level of the specifics that the differences primarily exist and these differences are manifestations of the differences in perspective.

The differences at the levels of specificity – the specific ways that the super ordinate themes were perceived and manifested and the specific ways that the participants in the two groups valued the various categories and strategies employed – were fairly numerous. For example, when describing the phase designated *encountering aphasia*, the **IWA were very**

detailed and emotional about the onset of the stroke and aphasia. They tended to make this a sizable component in their recovery narratives and employed five subordinate themes (patterned experiences). They fixated on what might have caused the stroke, talked about various facets of its emergence and then described very detailed symptoms and behaviors that enabled them to realize the impact of their aphasia. The caregivers, however, merely described the medical emergency that resulted in a trip to the emergency room and *did not provide detailed descriptions* and only *focused on the alarming physical symptoms*. That is, both groups recounted some of the same symptomology but whereas the IWA saw them as aphasia emerging, the caregivers saw them as indicators of a medical emergency. Similarly, the caregivers were not nearly as descriptive when discussing the impact of aphasia. They did describe several kinds of difficulties that the IWA were having but these were viewed from the functional perspectives of communicating, socializing, shopping, and changes in occupational status.

The differences in the phase *reacting to aphasia* also had to do with specificity and empathy for the other person. The IWA discussed numerous emotional reactions and behavioral changes but they only focus on their problems and experiences. The *caregivers, however, not only described their emotions but they also empathized with their loved one with aphasia*. Of course, these differences may be due to the fact that the caregivers were not the individuals who had aphasia and its resulting impairments. Consequently, while they did experience various emotional and life style changes, they also needed to focus on the needs and reactions of the IWA. To do this, they discussed emotional reactions from their own perspectives and from the perspective of the IWA. The IWA did not focus on any problems that their caregiver might have had adjusting to the various facets of their aphasia.

In terms of *coping with aphasia*, there were several interesting differences. First, the caregivers focused more on *familial support* for the IWA while the IWA focused more on their independent efforts and those of a professional clinician. For example, the IWA primarily emphasized clinical intervention as the major coping mechanism while the caregivers all considered family support as the primary coping mechanism for the IWA. In discussing various support mechanisms, the creation of compensations, and their eventual reliance on social affiliation, the IWA mentioned the professionals, their friends, other IWA, and their families. The caregivers overwhelmingly discussed the role that family played in of the coping mechanisms. It seems that the caregivers didn't cast a wide enough net when discussing collaborators with the IWA while the impaired individuals tended to take family assistance for granted. This difference in perspective between the two groups appeared especially strong when intervention was discussed by both groups. The IWA spent a great deal of time talking about therapy and what they did within those clinical activities while the caregivers hardly mentioned clinical intervention at all. As previously stated, they focused on the activities and support provided to the IWA by the family.

Over all, therefore, there are a number of similarities across the two groups in terms of their lived experiences with aphasia. As a life experience, they lived through comparable events and could recount these with accuracy and perception. However, how these events were experienced and the saliency of these events was different between the two groups so there were significant differences as well. These were manifested in the value assigned to different experiences, the specificity of the events, actions, and content of the narratives and the different interpretations based on dissimilar perspectives.

This chapter has provided a detailed analysis of the lived experiences of two groups of individuals who jointly have been involved in the state of aphasia and its recovery process. A number of complex results have been described and discussed. The final chapter (Chapter Five) of this dissertation presents a summary of these findings and the results. It also provides some implications for what has been learned here about living through the recovery process after the onset of aphasia.

100CHAPTER FIVE

CONCLUSIONS

The current investigation attempted to explore the experiences of the IWA and their caregivers regarding the recovery in aphasia. This study considered the perspectives of three IWA and three caregivers on the nature of the recovery process based on their lived experiences. Through a qualitative research analysis the investigator was able to scrutinize the stories of the two groups including their similarities and differences regarding recovery. In general, the current investigation has been successful in exploring this topic and highlighting the factors that contribute to shaping the nature of recovery based on the perspectives of the two groups. Indeed, the qualitative method of phenomenological research captured two rich data sets that allowed for detailed and thick description of the everyday life of these individuals.

This final chapter incorporates the conclusions of the investigation and a discussion of the initial research questions. Further, the limitations of the study are provided and possible implications for the clinical practice are considered. The current investigation can allow the clinicians to understand and to take under consideration – within their clinical practices – the personal accounts and the experiences of the IWA and their caregivers concerning recovery in aphasia.

In general, the results of this investigation suggest that recovery in aphasia is a complex process that appears, at least from the perspectives of the two groups studied here, to be systematic and somewhat predictable. Both groups viewed recovery from a temporal perspective involving several phases or stages, *encountering aphasia*, *reacting to aphasia*, and *coping with aphasia*. Within each of these phases of recovery there were a number of

components that effectively enriched the lived experiences of the recovery process. The initial encounter with aphasia could be seen as involving emergence of the malady and its impact and this led to the second phase of the participants' reactions to aphasia. These reactions were emotional and well as behavioral and were often described using figurative descriptions and metaphors that had great power to relate the experiences. In every case that was investigated in this study, one of the reactions to aphasia was an initial avoidance strategy that was not particularly effective. Consequently, the IWA tended to establish enhanced awareness and to create a series of mechanisms to cope with the state of aphasia. In general, the lived experiences of the individuals with aphasia were shared with their caregivers, who due to a difference in perspective, did view some aspects of the recovery process differently.

In this phenomenological investigation the research also determined that there were a set of contextual influences that helped shape the lived experiences of the participants. Even with different perspectives, these contextual variables influenced both groups.

Responses to the Research Questions

The focus of this investigation was to seek to address the following main question: ***What are the perspectives of IWA involving the nature of recovery in aphasia, as compared with their caregivers?*** Chapter Four presented a detailed account of the lived experiences of the IWA and their caregivers regarding the recovery in aphasia. Through a comparison of these two data sets (IWA and caregivers), elements that differentiated these two groups to some extent were identified and discussed in the previous chapter. In addition, these results are reviewed as part of the conclusions of this investigation.

These data suggest that the IWA group's perspective was essentially *self-oriented* and focused on their need to *personally address their own recovery*. The IWA directly experienced the aphasia with its physical, cognitive, and emotional impact so their experiences were more organic and salient. The caregivers, however, experienced the aphasia in a more indirect manner and, while they had the direct experience observing their IWA during recovery and had to directly deal with some concomitant issues, their primary experiences with the aphasia and the recovery process were more vicarious and less salient. These led the caregivers to have a perspective that was *other-oriented* and focused on the *various ways that family could and did assist* the IWA during recovery.

These primary differences in perspectives are based upon an interpretation of the specific differences between the two groups. This allows us to determine differences in perspective. As discussed in Chapter Four, while there were many general similarities between the two groups in their narratives about recovery, there were differences with regard to specific content and orientation. When discussing the emergence of aphasia, the IWA were more detailed and emotional, they were focused on their own experiences when discussing their reactions to aphasia and they oriented their discussions to the clinical intervention variable as the primary way to cope with aphasia and tended to down-play family support as when compared with the caregivers.

This *self versus other orientation* is understandable since the two groups' experiences are somewhat different (both in terms of what was experienced and how it was valued and interpreted). This forces a first person versus third person orientation that colors other aspects of the experiences with recovery and how these experiences are structured and prioritized.

These experiential differences are not easily overcome. In *Home Burial* (1968) the poet Robert Frost wrote,

“.....The nearest friends can go
with anyone to death, comes so far short
They might as well not try to go at all.
No, from the time when one is sick to death,
One is alone, and he dies more alone.”

While aphasia and its recovery is not as extreme an experience as being sick to death, the actual experience can only be vicariously experienced by the caregiver and this (apparently) makes all the difference.

In terms of the sub-questions asked in this investigation, each of these address more specific aspects of the recovery process and are consequences of the differences in perspective just discussed. The first sub-questions was, *how do people with aphasia and their caregivers view aphasia?* Both viewed it as a *significance disruption* of their lives and as a *condition that impacted communication, socialization, and occupation*. Of course, it was a more tangible condition to the person directly experiencing it (the IWA) but it still had an impact and was seen as significantly disruptive to the caregivers as well. Their lives – albeit not to the same degree as the IWA – were also forever changed. Interestingly, in the narratives of the six participants, aphasia was often treated as a *state of impairment* rather than a diagnosis. They appeared to treat it as an all-encompassing experiential state that impacted nearly everything that they did as a family. While *neither group appeared to know anything about aphasia before their personal experiences*, they each learned about it based upon the functional barriers that it placed upon them.

The second sub-question asked was, *what are the understandings and the conceptualizations of the recovery process involving the individuals with aphasia and their*

caregivers? Recovery was seen by both groups as *an essential process that could help alleviate some of the problems* that resulted from the onset of the aphasia. This process, however, was a *gradual one that only resulted in a partial recovery and not a return to pre-morbid conditions*. Over time, the six participants started understanding the process of recovery more than they had previously. Importantly, both groups came to the realization that moving forward in recovery was necessary but that this process was not accomplished by attempting to become their old premorbid selves. Rather, *recovery was interpreted as simply returning toward how the IWA was before onset of the aphasia*. In both groups, recovery was described in such a way that different phases of the recovery were recognized. These were encountering aphasia, reacting to aphasia, and coping with aphasia. Within the process *acceptance contributed to construct the notion of recovery*. Once the IWA and the caregivers came to terms with aphasia, the groups made an attempt to deal with the aphasia to some degree. Acceptance based on the perspectives of the IWA involved personal recognition and social disclosure in which the individual shared with other people about his or her aphasia. Also, with acceptance, the groups were able to conceptualize recovery. It was considered as moving forward from one state to the other over time.

The third sub-question asked, *what is the nature and the roles played by the variables involved in shaping the recovery based on the perspectives of the individuals with aphasia and their caregivers?* With this answer some of the primary specific differences between the two groups are especially tangible. The Aphasia Group, being more self-oriented, placed more emphasis and value on those aspects of the recovery process that they perceive as being more beneficial to them. In terms of the mechanisms they applied for coping purposes, they described *clinical intervention* as being primary. This mechanism

tended to give them direction and hope and they employed *much of what they did in therapy as independent practice* as well. The IWA also placed a great deal of emphasis on *support mechanisms* though not nearly as much emphasis on family support as the caregivers did. This group (Aphasia Group) did not ever discuss *the impact of the aphasia and the recovery process on the caregivers* although this was the mechanism that was always discussed as significant from the perspective of the caregivers. Since the caregivers did not really experience anything dealing with clinical intervention, they did not value it nearly as much as the supports and assistance that they and other family members gave to the IWA. In terms of similarities, the coping mechanisms captured the essence of the variables that contributed to construct the nature of the recovery. This set of tools involved social parties who attempted to respond to aphasia through collaboration with family, professionals and others who came into their experience during recovery. Intervention, supports, and interactant scaffolds, compensation strategies and independent practices appeared most salient. Several findings were surprising in what they did not indicate. For example, throughout the discussions on recovery, there was no mention of age or health within the discussions of recovery. The participants saw their current states of aphasia, recognized that they needed to move forward, and did not use old age or poor health as excuses or even contexts for recovery. They focused instead on their need to put in the work and effort and they focused on the coping mechanisms that helped move them to recovery (clinical intervention, support, compensation, social affiliation, and practice).

The fourth sub-question was, *what are the attitudes, expectations, needs, and concerns of the individuals with aphasia and their caregivers regarding recovery?* The attitudes primarily focused on *responsibility for change*. The IWA exhibited an intrinsic

locus of control so that they believed that they were responsible for their recovery; the more work and effort they employed, the more they believed they would progress. The caregivers were split in their assignment of responsibility. Since they recognized that the IWA considered themselves as being responsible for change, the caregivers had more of an extrinsic locus of control. However, the caregivers did not assign the extrinsic responsibility only to the IWA. They also assigned some of the responsibility for change to God. In all three caregivers God was discussed as providing grace or assistance; none of the IWA mentioned the role of a higher power. In addition to the extrinsic locus of control, however, the caregivers also believed that they and the rest of the IWA families also had a crucial role to play in the recovery process. Consequently, their locus of control was a combination of extrinsic and intrinsic. Both groups agreed that *recovery was a strenuous and gradual process* in that there was a trajectory of recovery and this had to be accepted. Finally, both groups agreed that *recovery would only be partial* and both appeared to have accepted this realization.

The last sub-question concerned treatment, ***how is treatment involved in shaping the perspectives of the individuals with aphasia as well as their caregivers regarding recovery?***

This was one of the most striking differences between the two groups. The Aphasia Group considered clinical intervention as *the primary mechanism for change during recovery*. They discussed the process, never questioned the activities in therapy and even used therapy activities as a springboard for independent practice. While family support and other social affiliations were discussed, these mechanisms were in the shadow of clinical intervention. In contrast, the Caregiver Group hardly discussed clinical intervention. When they did, it was sometimes in order to question activities performed in therapy. Since these participants were

all excluded from the therapy sessions and even discussions on what occurred in therapy, they did not see this mechanism as nearly as significant as the effort, assistance, and support that they and other family members provided to the IWA during recovery. They believed that a number of mechanisms and the increased awareness of the IWA required a great deal of work and effort from the family and this support was the primary coping mechanism.

Implications

The current investigation highlighted the importance of recovery to the IWA and the caregivers. This study enabled these two parties to share their views about recovery. That is, the IWA and the caregivers were given access that allowed us to become familiar to some degree with their understandings, concerns, needs, and expectations regarding recovery. Certainly, this study provided the opportunity to explore recovery in depth and to appreciate its complexity based on the authentic experiences of the IWA and the caregivers.

The findings from this study have several clinical implications regarding recovery in aphasia based on the real world of the IWA and the caregivers. These results highlighted certain issues that the clinicians should seriously consider in planning and providing the appropriate and relevant clinical service aiming to establish recovery that can address to some degree the perspectives of the IWA and the caregivers regarding recovery. Some of these clinical implications are presented as follows.

Implication One

Clinical aphasiologists *should view aphasia as a state of existence rather than just a diagnosis*. As discussed previously and as amply demonstrated in this investigation, aphasia and its consequences is a complex condition that changes over time at different rates and according to the different needs of the IWA who is recovering. Further, its impact is

completely life-altering and does not appear to completely resolve itself in most cases. Aphasia impacts all aspects of the IWA's existence and that of his/her family. Consequently, this complex, dynamic and all encompassing condition should be seen as an altered life condition or context within which the IWA and his/her family will have to operate in the future. Such complexity and inclusiveness is better conceptualized as a state of existence than a disorder. This would result in more inclusive therapies, better expectations, more collaboration, and more temporal and spatial saturation when seeking supports to overcome the barriers due to aphasia.

Implication Two

Clinical aphasiologists *should explore the perspectives of the IWA and the caregivers regarding the conceptualizations of recovery* in order for the clinicians to become familiar with the meaning of recovery according to these social parties. Recovery from aphasia is a complex process that has to be confronted during a time of great stress and difficulty by the IWA and their families. If clinicians have a better understanding of the process from their "customers" perspectives, then they will be better able to assist these parties in the recovery process. The finding of differences in perspective, the different values placed on family support and on intervention, the differences in empathy revealed by the two groups in this investigation, and the various contextual influences that shape the responses and expectations of the IWA and their families makes careful attention to the social and interactional dynamics of recovery essential for the practicing clinician. At the very least this understanding of the recovery process from the perspectives of the IWA and caregiver will enable the clinician to anticipate misunderstandings between themselves and the other two parties to recovery.

Implication Three

Clinical aphasiologists *should become familiar with the expectations of the IWA and the caregivers regarding recovery during the clinical treatment*. This will assist in avoiding unrealistic expectations and potential friction between the clinician and these two social parties. Although the IWA and caregivers did come to an understanding of recovery as dynamic, gradual, and partial, this realization was late in coming to some of the participants. The clinician, by being familiar with the expectations of the IWA and caregivers can help them come to these realizations much earlier in the recovery process. Misunderstandings about discharge and the eventual state of recovery can be minimized and even avoided.

Implication Four

Clinical aphasiologists *should ensure that clinical programs are relevant and appropriate to the IWA and the caregivers regarding how to address aphasia*. While the IWA recognized clinical intervention as a primary recovery mechanism, the caregivers did not. It is likely that this difference in assigned value is due to the lack of collaboration between the clinician and the family. Too often clinicians have a conception of therapy as a self contained process and context where they work with aphasia clients to modify damaged brain circuits through drill and other types of therapy activities that are not always relevant to life participation outside of therapy. This more process-oriented approach to aphasia (see Chapter Two) is now being supplemented with an emerging approach to intervention that is more social and should involve more activity outside of the therapy room. For this to occur, the family needs to become more involved. Perhaps clinicians should collaborate more with the family in determining therapy goals, establishing strategies and techniques to accomplish those goals, and ensuring that these activities are relevant outside of the therapy room.

Certainly, family assistance, support, and expectations will be strengthened if the family is more involved in the therapeutic process rather than just being treated as an agent of transportation to therapy or a by-stander. The clinicians should seriously consider members of the family especially the caregivers as an integrated and relevant component of the clinical program.

Implication Five

The clinical aphasiologist *should consider the nature of the coping mechanisms used by the IWA and the caregivers on regular basis in order to address aphasia*. These mechanisms can be used as an authentic element that can contribute to clinical treatment seeking to establish recovery. It is significant that the two groups easily understood that there were actions and strategies to help the IWA to get better. Both groups recognized the importance of the awareness that recovery took time and was an incomplete process (i.e., the IWA did not return to pre-morbid levels) and both groups discussed the importance of coping mechanisms like clinical intervention, familial and other support, the creation of compensations, the motivation created by social affiliation, and the benefit of independent practice. However, this awareness and these mechanisms should be stressed and focused upon by the IWA, the family, and the clinician if optimal usage of these mechanisms is to occur. Especially, the clinician who serves as the key mediator in arranging and suggesting various aspects of recovery through the coping mechanisms should be very involved and should employ the power of collaboration with the other parties to the recovery process.

Implication Six

The clinical aphasiologist *should consider social affiliation as an active mechanism to address aphasia*. As this investigation verified, social affiliation appears to serve both as a

powerful motivator for persisting in one's recovery from aphasia and as an integral context within which to become better in the application of learned and recovered language skills, developed compensations and opportunities to re-establish lost aspects of the IWA's self-identity. Further, social affiliation greatly assists the caregivers who feel that they are isolated due to the state of aphasia. The use of aphasia support groups that can provide outlets for the IWA and the caregivers as couples and as individuals can reduce the emotional burden of aphasia and establish a feeling of community even within this state of aphasia. The caregivers can believe they have various issues in common regarding providing care and assistance and the caregivers can gain from their counterparts who may listen to them and provide them with support and advice that can be relevant.

Implication Seven

The clinical aphasiologist should be aware of the fact that many individuals are unfamiliar with aphasia and *careful informational counseling regarding the nature of aphasia* should accompany every aphasia referral or consult made to them. It was striking in this investigation that none of the participants (who were all professionals including one nurse) really had an understanding of aphasia. In fact all six participants commented that they had never really heard or paid attention to the term before its emergence in their lives. As aphasiologists we often take on the expectations of our rehabilitative community and employ the concepts and terminology of our profession. Since we have trained in neurogenic communicative disorders and work within this area at all times, we forget that others don't share our knowledge base or experiences. Consequently the clinician needs to pay more attention to the knowledge base that clients and their families do bring to the therapeutic

context. By providing them with more information, they will be better able to work within the state of aphasia.

Implication Eight

The final implications concerns the research paradigm employed for this investigation. As can be seen from this dissertation, *the qualitative research paradigm provided an extremely rich and detailed description of the process of recovery from aphasia*. By using phenomenology as the tradition of inquiry, this complex process of recovery could be investigated from the unique perspectives of individuals who had personal experiences with aphasia and their attempts at recovery. It detailed the dynamic and gradual nature of recovery, demonstrated the importance of personal effort in achieving progress, detailed a number of the variables and/or mechanisms that enabled a steady progression, and it detailed the incomplete nature of recovery (i.e., one rarely returns to premorbid levels of functioning). Further, this research methodology revealed the contrasting perspectives between the IWA and their caregivers that might give rise to different values and interpretations. There is great value in the application of such qualitative approaches to the investigation of complex social actions and they should be employed more often within our clinical realms.

Through applying these implications, clinical programs and clinicians can capture and nurture recovery that is possible and realistic. These recommendations are beneficial to not only for the IWA but also for their families. Hence, these recommendations may have implications for designing clinical program as well as providing clinical service. Indeed, the current investigation can contribute to some extent to construct a meaningful clinical practice

in which the clinical service and procedures can address the attitudes, concerns, needs, and the expectations of the IWA and the caregivers regarding recovery.

Limitations

While the current study sought to investigate the lived experiences of the IWA and the caregivers, this study seems to have three potential limitations. First, the data set is a rich one but it is based upon the interviews of six participants (three individuals with aphasia and their three caregivers). This appears to be a small number of participants. Within the qualitative research paradigm, however, the key is not the number of participants but, rather, the richness of the data obtained. While phenomenological studies can be conducted with as few as four or five participants, a larger number is often preferred. However, if the data and the experiences are somewhat homogenous, then a smaller number of participants are sufficient. This appears to be the case with this investigation.

Second, the current investigation was limited to the IWA and their caregivers who lived in Lafayette Parish. This represented a very specific region in the State of Louisiana. This might also limit the applicability of the findings. Especially with regard to cultural values and the reliance on clinician intervention and family support, there may be unique characteristics in this region that are unlike those in other areas. For example, the investigator has conducted work that shows that locus of control and metaphors used to describe aphasia do vary across different cultural groups – even within the same country (Kardosh & Damico, 2006, 2009). The investigator should have considered recruiting participants for the study in a larger area including the Lafayette Parish located in the south east State of Louisiana.

Finally, all the IWA who participated in this study attended the aphasia support group. This was considered as element that contributed to the recovery process based on the

perspectives of the participants. Of course, if IWA do not have access to such groups, their significance would be lacking. Therefore, the investigator should have considered recruiting another aphasia group in which the IWA in this group didn't participate in any aphasia support groups or this particular finding should be interpreted with care. This would allow the investigator to make a comparison between the two aphasia groups and their caregivers regarding the recovery in aphasia.

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