POST STROKE INTERPERSONAL COMMUNICATION: AN INTIMATE EXPLORATION OF STROKE SURVIVORS' LIVED EXPERIENCES

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A

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Abstract

This qualitative study explores the personal and intimate lived experiences of stroke survivors who suffer the comorbid emotional sequelae of Post Stroke Depression (PSD) and how it affects their rehabilitation and interpersonal relationships post stroke. By using Uncertainty Reduction Theory (URT), the idea of Social Construction of Identity, the epistemology of Narrative Inquiry (NI), and conversational interviews (CI), with stroke survivors, their spouses/significant others, friends, and other family members, the aim of this body of research has been to take on the difficult task of observing how stroke survivors navigate the difficult and sometimes daunting path that all stroke survivors must travel as they attempt the reconstruction of their *self* post stroke. They face every new day with the knowledge of who they once were and who they are now. The person that they are now has become their reality.

Many stroke survivors regardless of the hemisphere in which the brain lesion occurs, suffer from some degree of the post stroke emotional sequelae, or a condition following and resulting from a disease, of post stroke depression (PSD). With the comorbid occurrence of PSD comes yet another challenge to their reconstruction process. The findings of this research study have remained consistent with the current research data and literature on stroke, stroke recovery, PSD, and aphasia.

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Chapter 1

Introduction

1.1 Context Statement

Stroke is a dangerous and potentially fatal incident. According to the American Heart Association (AHA), each year approximately 795,000 people experience new or recurrent stroke incidents. Of that number, it is estimated that 610,000 are new incidents, while the remaining 185,000 represent recurrent incidents. Approximately every 25 seconds an American will have a stroke incident (American Heart Association, 2010).

According to the Centers for Disease Control (CDC), approximately every four minutes one American will die from a stroke incident. Every year stroke incidents cost the U.S. an average of 34 billion dollars. The estimated costs of a stroke incident per patient are between \$59,800.00 and \$230,000.00 (Feigin, Lawes, Bennett, & Anderson, 2003). In the year 2010, one of every 18 deaths was due to a fatal stroke incident. The total death rate for that year was 128.978 that resulted from a stroke incident; making it the 5th leading cause of death in America (American Heart Association, 2010).

By the year 2020, it is estimated that both stroke and coronary-artery disease will be the number one leading cause of death. Stroke is a medical emergency and should not be ignored. The best way to prevent higher medical costs due to disability or death post stroke is to get treatment fast (Centers for Disease Control, 2015). In a qualitative research study by Thompson and Ryan (2009) observed the impact of stroke incidents on spousal relationships and found that:

Survivors of stroke experience profound, complex, and multi-faceted difficulties in many areas of their spousal relationships, which are distressing to both them and their spouses

These have a significant impact on each individual's quality of life particularly in the long term. (p. 1809)

1.2 Statement of Problem

The effects of stroke reach deeper into the heart and soul of the person affected much more so than the advances in modern medicine have been able to follow completely. *Stroke victims* as they are referred to, are affected both psychologically and physiologically. Even if one is familiar with the physiology of a cerebral vascular accident (CVA) it does not provide adequate preparation for the manifestations that can occur long after the stroke incident has passed.

After the magnetic resonance images (MRIs), the blood tests, the medications, the occupational, physical, or speech therapy, and the neuropsychological testing, there remains the reality of who the person is now. That fact is the truest side-affect. What is now left is the real person. Never mind who or what they used to be they are not that person anymore. The harsh reality of it is that they may never ever be that person again. Consequently, the stroke victim must renegotiate the path to *self* and learn to accept who this new *self* is, and take an active role in reconstructing that *self* each day.

The cognitive processes and interpersonal styles of communication could have been affected by the CVA and the stroke survivor must adjust. Also, there might be *physical* manifestations of the CVA. The stroke survivor might be left with a physical disability. Not only the stroke survivor, but those around them who knew them before must understand and take into account the stroke incident. It is not a matter of stupidity, as some stroke survivors have perceived; but rather an anatomical and physiological alteration to their brain.

When brain tissue dies, it does not regenerate or heal itself like other tissue in the body. Where the stroke occurred, regardless of whether the damage is ischemic (blockage) or hemorrhagic (bleeding), that area is dead (Bonita, 1992). Yes, the brain has the amazing ability to reroute and find a new path to travel around the dead area(s) but it will never have access to

that area again. What was there can no longer be accessed.

The reason for this is simply because there are no fibroblasts in the brain, therefore, no scar tissue can form, as the presence of scar tissue would actually cause more damage. Fibroblasts are a type of cell found in the extracellular matrix (ECM) and collagen, these both play a critical role in wound healing because they provide the structural framework (stroma) for the regeneration of damaged cells. The ECM is composed of extracellular molecules that provide structural and biochemical support to the surrounding cells. Collagen is a structural protein in the extracellular space, in connective tissues, and many other cells in the body (The Naked Scientists, 2013).

While the brain attempts to find new pathways, the stroke survivor who has to deal with this change in their brain anatomy and physiology faces many challenges. The journey they must now undergo is fraught with uncertainty, self-doubt, loss of respect and dignity, and fear; gut-wrenching fear. There are days when that person would wish that they could be *back in Nam* fighting a physical enemy instead of the ever-changing silent one. There are no bullets, no bombs, nor weapons to dodge, just the uncertain future to face. Nothing can rid the stroke survivor of the devastation wrought by a stroke incident. Once a person has experienced a stroke incident, they are never the same (Ellis-Hill & Horn, 2000).

1.3 Background

Approximately seven years ago I had a beautiful home in Florida, was married to an amazing retired Army Lt. Col., and had a beautiful life. No, it was not perfect, nothing is. My husband and I enjoyed that rare ability to have fun wherever we were. We also had the maturity level to pursue our own personal interests. I was a nursing student at the time. One evening after watching *Masterpiece Theatre* my husband and I were unloading the dishwasher and just chatting away like we usually did and one of his responses made absolutely no sense. He shook his head and

said, "No, I mean what about the tissue?" He shook his head again, tried to finish the sentence and again failed. His speech was slightly slurred and I first thought that maybe he just had a little too much wine after dinner.

However, after about five attempts at this I got an overwhelming awful feeling in the pit of my stomach and made the *time-out* sign with my hands. I then proceeded to ask him a series of *yes* and *no* questions. My reason for doing this was I remembered that during a stroke the individual could not speak or answer in complete sentences, but could answer *yes* or *no*.

He answered *no* to each question but in my heart of hearts I knew what was going on. I told him to continue unloading the dishwasher but I stressed that he *must* use both his left and right hands (de Jager, 2012). I went to the back of the house where my office was, closed the door, and called the nurse helpline at our local civilian hospital. An ambulance crew arrived and hooked him up to a 9-lead EKG unit. They were very skilled and also were very kind to me. I followed them in my car and stayed at the hospital with him for two and a half days.

1.4 Rationale for Study

The series of events that occurred for the next two years our life after that point is what compelled me to pursue this area of research. It is with great sadness and yet a great desire to help educate anyone who might have to travel this path. Healthcare professionals and even the general public need to be made aware regarding the complex, frustrating, and treacherous path to recovery that stroke survivors are forced to travel. Stroke incidents do not merely affect the stroke victim, but also everyone around them. Thompson and Ryan (2009) address this in their article, "healthcare professionals and service providers need to understand and recognize the subjective experience of stroke and the complex difficulties that stroke survivors experience within their spousal relationships" (p. 1803).

My lived experiences post stroke have led me down this path that I now travel and travel alone. The obstacles that my husband and I faced as a couple and individually, the support that was available, the general knowledge of the doctors who managed my husband, plus the information that was readily available to us was lacking in practicality and usefulness (Thompson & Ryan, 2009, p. 1810).

Another area of this lack in knowledge was in regards to the attitudes and overall knowledge base exhibited by friends, relatives, and people in general to, the stroke survivor. From my personal experience and the experience of others I know, the need for updated information on stroke rehabilitation options, support services, and more practical advice post stroke is vital. This is evident in that a large body of the stroke information has been commissioned by the National Institutes of Health. The aim of this body of research is to provide a more expanded knowledge base upon which stroke survivors and their families can draw upon that will serve to facilitate them in the post stroke recovery process.

Chapter 2

Review of Literature

2.1 Purpose of Study

This qualitative study explores the personal and intimate lived experiences of stroke survivors who suffer the comorbid emotional sequelae of post stroke depression (PSD) and how it affects their rehabilitation and interpersonal relationships post stroke. The approach to this study is derived from the theoretical milieu of uncertainty reduction theory (URT), the epistemology of social construction of self, interpersonal communication and its psychological aspects, the methodology of narrative inquiry, and employing the method of conversational interviews with stroke survivors, their spouses/significant others, friends, and other family members; and finally, the researcher as a subject.

This body of research has taken on the difficult task of navigating through the difficult and sometimes daunting path that all stroke survivors must travel as they attempt to reconstruct their *self* post stroke. They face every new day with the knowledge of who they once were and who they are now. The person that they are now has become their reality (Ellis-Hill, Payne, & Ward, 2000; Ellis-Hill & Horn, 2000; Kvigne, Kirkevold, & Gjengedal, 2002).

Many stroke survivors, regardless of the hemisphere in which the brain lesion occurs, suffer from some degree of one of the post stroke emotional sequelae, or conditions following and resulting from a disease, PSD. With its occurrence comes yet another challenge to their reconstruction process. At this point it is necessary to make the reader aware that there are myriad ways to spell *post stroke* and *pre stroke*. For the sake of continuity I have chosen to spell them the way they appear in this body of research.

2.2 Literature on Stroke and Post Stroke Depression (PSD)

There is a rule in anatomy and physiology which stipulates that form determines function. Following this rule, with the occurrence of a stroke incident, or CVA, that resulted in encephalitic necrosis, or death of brain tissue, an anatomical alteration had occurred. Therefore, an alteration of the physiological function of the affected area had also occurred.

Encephalous tissue or brain tissue does not have the ability to regenerate after sustaining damage for a long period of time. The damage sustained during a stroke is permanent if the tissue has suffered necrosis, or death; as necrotic brain tissue does not regenerate. What remains is referred to as a brain lesion. Therefore, the function(s) controlled by that specific area of the brain are lost. The long term prognosis for individuals who have suffered a stroke incident are based largely upon three criteria: what hemisphere the lesion occurred, the specific location in that hemisphere, and to what extent the brain was damaged.

Stroke survivors' recovery processes are fraught with difficulty and a great deal of frustration is experienced. There are many reasons for this. Initially there are the obstacles faced with gaining back lost function. A right hemisphere lesion will have its own implications as well as a left hemisphere lesion. The left hemisphere is unique in that it deals with the cognitive abilities of an individual (Nussbaum, 2003). The rehabilitation processes that stroke survivors undergo are dependent upon the type of stroke that occurred. However, whether occupational therapy, physical therapy, or speech therapy is needed for some form of aphasia, or a dysfunction in the ability to form and comprehend language due to stroke, illness, or injury, frustration is experienced frequently.

In some cases, stroke survivors gain back a great deal of function but resentment and bitterness start to become a part of their person. Stroke is not like a broken leg or a cut. It is

possible to recover function after a stroke incident, but the complete restoration of the individual is not possible as their anatomical form has been altered and also, therefore, their physiological function.

The need to include PSD in this research is vital. According to research it is the most prevalent emotional sequelae concomitant with the aftereffects of a stroke incident. It hinders the rehabilitation process, hinders the overall process of the individual post stroke, changes the way the individual interacts interpersonally, and has been found to increase the mortality rate of this unique population of people (Brown, Hasson, Thyselius, & Almborg, 2012; Ellis, Zhao, & Egede, 2010; Morris, Robinson, Andrejeweski, Samuels, & Price, 1993; Nelson et al., 1993; Whyte & Mulsant, 2002).

The current literature regarding stroke incidents and PSD suggests that it is the most common emotional sequelae of stroke regardless of the hemisphere in which the stroke occurred resulting in a stroke lesion (Nelson et al., 1993). What makes PSD especially dangerous is that it has been found to lead to an increase in the mortality rate post stroke even after ten years (Brown et al., 2012; Joubert et al., 2006; Nakao et al., 2010; Robinson-Smith, Johnston, & Allen, 2000).

Research has indicated a few reasons for the increase in the post stroke mortality rate due to PSD (Brown et al., 2012; Joubert et al., 2006; Nakao et al., 2010; Robinson-Smith et al., 2000). Firstly, it interferes with the stroke survivor's quality of life (QoL) (Williams et al., 2006) in that their functional independence and the ability to perform their activities of daily living (ADLs), had been diminished. This one aspect remained the same throughout each study and one longitudinal study and amongst individuals from various ethnic groups.

Another reason for the mortality rate increase post stroke was thought to do with the sex of the stroke survivor, whether men or women experienced PSD to a greater degree. Women were found to suffer an increased rate of depression sooner post stroke as well as the younger stroke survivors; this changed three years post stroke to indicate an increase among male stroke survivors (Brown et al., 2012; Joubert et al., 2006; Nakao et al., 2010; Robinson-Smith et al., 2000).

A third factor believed to contribute to the increased mortality rate post stroke was that stroke survivors with PSD who did not have a strong post stroke support group, or were not encouraged to pursue their rehabilitation, counseling, or have a doctor monitor their medication, had a worse prognosis than those that did (Joubert et al., 2006; Nakao et al., 2010; Whyte & Mulsant, 2002). In one longitudinal study, it had been found that after 10 years post stroke, out of the 103 stroke survivors with PSD, 53% of them had died (Morris et al., 1993).

2.2.1 Communication literature on aphasia. Lastly, those stroke survivors with some form of aphasia had been traditionally left out of research due to their inability to speak or speak clearly. Newer studies have found that this concomitant sequelae can deepen PSD (Davidson, Howe, Worrall, Hickson, & Togher, 2008).

Research on aphasia is vital both to the rehabilitation process and the long-term prognosis of the stroke survivor. Corsten, Konradi, Schimpf, Hardering, and Keilmann, (2014) report that:

People with aphasia experience a pronounced decrease in quality of life (QoL). Beyond that identity negotiation is hindered which is crucial for QoL. In sociocultural theories, it is postulated that identity is created through social interaction with others. In telling stories, people build meaning and affirm identity. (p. 4)

Strokes are disruptive to a life. Styles of communication as well as the opportunity for communicative interactions are limited post stroke. The stroke survivor is apprehensive

about engaging in social communication.

Another hindrance that the stroke survivor can face comes in the form of *saving face*. One study by Carlsson, Hartelius, and Saldert (2014) indicated that at times, the spouse of the stroke survivor did *not* pursue providing additional information to aid in the understanding of the stroke survivor with aphasia because they did not want to, "expose a person's linguistic incompetence and thus to save face" (p. 733).

The practices that the communication partners use to aid in the conversations of those with aphasia are termed as *repair work*. If the communication partner does not practice *repair work*, it has a significant effect on the amount or the quality of the information transferred. Avoidance of repair may help a person save face, but stroke survivors with aphasia, "are often dependent on the cooperation of their conversation partners to make themselves understood" (p. 733).

The use of such *repair work* is beneficial and valid as the spouses are more familiar with the speech traits and incidents of their partners. A researcher or someone that is not known personally to the stroke survivor might not be able to understand fully what the aphasic person is trying to communicate. Even so, it is still an intrinsic part of who the stroke survivor is to be able to contribute to conversations, ask for directions in a public place, or just communicate with people. The use of a communication partner is how the stroke survivor is able to continue to make contributions and to express themselves despite the presence of aphasia.

Observation of personal and environmental determinants to the participation of stroke survivors with aphasia in communication interactions was researched and surprisingly found there are more facilitators to communication than hindrances. Le Dorze, Sallios-Bellerose,

Alepins, Croteau, and Hallé (2014) found after interviewing seventeen stroke survivors with aphasia that only limited services, poorly adjusted speakers, pride, and fear were the only real hindrances to communication.

The facilitating factors were helpful family members, aphasia community-based organizations, determination, positive attitudes, finding alternatives, and an overall positive outlook on life post stroke. Also according to Le Dorze et al. (2014), "ownership for success in communication and perseverance to reach that aim were helpful for participation" (p. 427). One participant that stood out from the rest actually felt that having aphasia was very *liberating* as she did not believe that she *had* to speak with others.

Regarding the hindrances, or negative aspects, some of the participants expressed a concern for how others, in general, would perceive them and experienced apprehension at the thought of being judged negatively (p. 428). Withdrawing from certain situations, holding back, or saying that they preferred to be alone, was how some reacted to the presence of aphasia post stroke.

Some of the research was conducted on the premise of the aphasic experiences, attitudes, and rehabilitative strategies. (Hesketh, Long, & Bowen, 2011; Howe et al., 2012; Johansson, Carlsson, & Sonnander, 2012). Hesketh et al. (2011) reviewed existing assessments of the functional communication for people with aphasia post stroke compared to how they were assessed by their care-givers, speech and language therapists, and healthcare providers.

The results revealed discrepancies between the *professional* and the *non professional* assessments. These discrepancies were thought to be attributed to familiarity with the patient. The care-givers spent a great deal more time in the presence of the stroke survivor with aphasia than the speech or language therapists and the healthcare providers. These results

were consistent with previous studies (p. 302).

The object of the study was not to focus on the differences, but to explore reasons for the different perceptions and to work out what those differences meant in terms of intervention. In order for assessments to be practical and be of clinical use for the stroke survivors, they needed to be designed to identify the areas in which aphasic people experience the greatest difficulties and identify ways that serve the aphasic individual's needs best.

Johansson et al. (2012) researched methods that would facilitate stroke survivors with aphasia to be able to increase the participation in communication interactions. They interviewed men and women to see how they handled experiencing difficulties with communication and how they perceived their partners' use of communication strategies helped or hindered them.

One major finding was that communication partner training should be included as an integral part of the rehabilitation of stroke survivors with aphasia (p. 154). The communication partners had not been aware of the use of supportive conversation strategies and had not, therefore, received training in how to use them (p. 153).

Finally, consistent with the findings of Johansson et al., a study by Howe et al. (2012) recognized the need to include the family members of stroke survivors with aphasia in the rehabilitation process. They sought to bring to the attention of the health professionals and the rehabilitation facilities the need to provide a family-centered approach to the rehabilitation process.

Elements of that family-centered plan would include a positive attitude and the ability to provide a hopeful resource, to be able to learn to reestablish or maintain their relationship with the stroke survivor with aphasia, also to be able to have methods to cope with their

struggles and be given ways to support their own well-being. Inclusion in aspects of the speech, language, and physical therapy are suggested (p. 518). This is suggested to give the family members ways to aid the stroke survivor and to strengthen the relationships. Also, to be provided with more in-depth information and receive from the healthcare professionals hope and encouragement (p. 519).

Providing a time for the family members to participate in activities just for them was found to be another important aspect once the stroke survivor was at home (p. 520). Although a family-centered program for rehabilitation of stroke survivors with aphasia is implemented in the field of aphasiology, this study suggests that, from the perspective of the family members, it is not to the extent that is required.

Of all the research on PSD and aphasia, one thing is painfully clear; it is a condition that must be recognized, treated, monitored, and have more longitudinal studies conducted that are more inclusive of all stroke survivors regardless if they suffer from some form of aphasia. Even though those with aphasia may not be able communicate as they once could, new ways of including them have been found so we do not lose the vital information that can be gleaned from their experiences post stroke.

Further reading about stroke lead me to a thesis by Gelinas (2008). She makes a statement, "For committed partners, stroke quickly changes from *his* or *her* stroke to *our* stroke" (p. 3). This statement stuck out and I actually started doubting my own personal commitment to my husband post stroke. In order to best serve my husband I had to lay aside my role as wife and become the career to him. The research indicates that there are many aspects of a stroke survivor's life that change post stroke and this is not uncommon (Thompson & Ryan, 2009). This study addresses those changes and to what extent they

affect the spousal relationship. They quote one of their participants' response to this:

Even yet my biggest struggling problem-in my opinion it's not as if I have had appendicitis or something like that and you'd get better again...It's not going to be like that...(Thompson & Ryan, 2009)

2.3 Literature on the Social Construction of Self

Every stroke survivor faces the reality that they must reconstruct their *self* Regardless the hemisphere the stroke lesion occurred, they are not the same person that they once were.

There are many theories, paradigms, assumptions, and philosophies derived ethnomethodologically that deal with the idea that our *self* is constructed socially. There are many components of social constructionism (SC) that would be too tedious to unpack. Therefore, in an attempt to be concise assumptions within this concept from different disciplines such as social psychology and communication have been included.

From each one was selected aspects that deal with illness, recovery, and how our sense of *self* is created, formed; or rather, negotiated. The academic underpinnings of SC circumnavigate phenomenology, hermeneutics, poststructuralism, symbolic interactionism, as well as some threads of literary criticism, and social psychology.

Going back as early as the 1600s, the idea that we are social beings and social processes are intrinsic in shaping us, the saying, "No man is an island unto himself" (Donne, 1624) is apropos. What happens to us and around us affects us and shapes who we are. It would be very naive to think that our sense or idea of *self* is merely a product of cognitive reasoning and/or parental and familial influence (Teachnology, 2013).

Mead (1982) in a book of his unpublished articles, was quoted, "neither the consciousness, mind, nor the self can be separated from action which involves a relationship between the

organism and the environment' (p. 19). The two of them cannot be separated. They coexist and work together to create that organisms' *self* consciousness.

The theory of SC comes to us from the fields of anthropology, social psychology, sociology and communication. It assumes that a persons' concept of, or understanding of, the world around them is a joint coordination between themselves and others (Berger & Luckmann, 1966). Key elements of this theory assume that, "human beings rationalize their experiences by creating a model of the social world and how it functions and that language is the most essential system through which humans construct reality" (Berger & Luckmann, 1966, p. 23). The social practices used by individuals or groups of individuals to navigate their surroundings, give meaning to, and actually participate in the construction of their perceived social realities is a major focus of this theoretical perspective (Blumer, 2004).

One way this process of navigation was hypothesized to take place was through an early 1950s psychological "notion of persons as scientists who form and test theories about their worlds" (Harré & Gillet, 1994). Harré and Gillet (1994) introduced to the field of psychology a new psychological paradigm in favor of the more modern discursive psychological approach rather than the traditional Cartesian approach. This psychological paradigm is also included under the general term of SC.

In his work regarding social cognition and coping behaviors, Bandura (1997) adds to his previous work with the notion of perceived self-efficacy. Bandura (1997) makes a statement that

I believe will aid in the understanding of the stroke survivor's predicament. He says, "self-belief does not necessarily ensure success, but self-disbelief assuredly spawns failure" (p. 77). Stroke survivors are in a state of confusion, stress, and distress. They can experience a high level of cognitive dissonance on a daily basis. Their perceived self-efficacy has been severely limited.

Bandura (1991) also states that perceived self-efficacy refers to, "people's beliefs about their capabilities to exercise control over their own level of functioning and over events that affect their lives" (p. 257). In his later research (Bandura, 1998), he redefines self-efficacy to include, "people's capabilities to organize and execute the courses of action required to produce given level of attainments" (p. 624).

Mead (1982) approaches the development of *self* from the very earliest stages of childhood. He proposes that a child must be able to see itself as an *object* (p. 58). How the child accomplishes this is through social interaction. It is not clear at this time as to whether this stage of *self development* is repeated by the stroke survivor in his or her quest to reconstruct their *self*

But, there is an aspect of Mead's (1982) scheme that does seem to come into play in this situation. He says that, "other persons, in whose positions one imaginatively places oneself, serve as the points from which one can approach oneself. One makes an object of oneself by addressing oneself from the standpoint of others" (p. 58). At this time, I believe that more research is needed to unpack all the components of Mead's (1982) theory of the construction of the *self* and to what extent it does apply to the stroke survivor.

After a person experiences a CVA they sometimes are not able to organize and execute those courses of action. Their physical or cognitive functions have been altered; sometimes severely. When a person perceives they no longer have control over their environment, they react to this negatively. Peoples' perceptions of their abilities to deal effectively with change or, in the case of a stroke survivor, the new reality of who they have become either adversely or favorably affect their actions from that point onward (Bandura, 1997, p. 21). Another researcher, Ajzen (1985) concurs with the findings of Bandura (1997), but seeks to discover if there are other aspects of social cognition that affect the behavioral outcomes of people.

It is vital that stroke survivors have a strong support system in place to aid them in navigating through the cognitive dissonance that occurs with a feeling of loss of control over their environment. Bandura (1991) reports that in regression studies, "self-efficacy contributes to achievement behavior beyond the effects of cognitive skills" (p. 431).

In a health-related communication study, Richey and Brown (2007) stress that the decision for a patient to become a survivor or a victim ultimately rests with the patient (p. 145). A model of the emergent self was created by Richey (2003a) to help us gain insight into the social processes of construction of self as an emergent self (Appendix F). This can definitely be applied to the stroke survivor. Richey and Brown (2007) stipulate that when a survivor's perception of their condition is negative the only way to turn it to a positive is by way of a change in their self-knowledge. One way this is achieved is through interaction with relational others who assist in the construction of a more *life embracing standpoint* (Richey & Brown, 2003b).

Richey and Brown (2007) concluded that, "advocacy and empowerment, as sociocultural and relational interaction, can ground the individual choices that reconstitute self-with-cancer [substitute *self-post stroke* here] as a self-embracing and/or celebrating life" (p. 159). Part of their conclusion is that from a SC vantage point, the ability for a person to change their health behavior revolves around their social and cultural interactions with those around them and also included is their own personal self-narrations. Both of these aspects aid in the reconstructive course of healthy change (Richey & Brown, 2007, p. 160).

Lastly, are included some thoughts of Gergen (2001a). In regards to mental functioning and dysfunctioning, SC is rarely included. Psychologists tend to explain human action only through mental processes. Gergen asserts that the *psyche* is not the origin of human action, but

rather, it is in the processes of relationships (p. 25). In some of his earlier work, Gergen (1991) posits that our meanings come from our relationships (p. 48). This is particularly true in stroke survivors with some form of aphasia. It is vital for them to be around other people to regain their ability to comprehend language and speak it.

If the stroke occurred in the left hemisphere, then the personality and cognition of the person was affected. Many times the person pulls away from society because they know they do not comprehend as quickly as they used to. They also have a tendency to pull away from their interpersonal relationships. This is due either to bitterness or fear of the unknown.

But as the stroke survivor forces themselves to go past the fear of the person that they are now, and chooses to interact with other people socially, then they are greatly aided in their journey of self reconstruction. All of the assumptions of this theory are the most inclusive that I have found to aid in addressing the process of post stroke reconstruction of self.

Basically, as the stroke survivor was influenced by his or her relationships with other people and became who they were; so it is post stroke. They will have to learn to be comfortable with being uncomfortable socially so they can reconstruct their self and not have that vital process stymied by fear.

2.4 Literature on Interpersonal Communication (IC) and Relationship Stages

If the *self*: is constructed socially, the most important way that is accomplished is through language or communication; it becomes central to discuss interpersonal communication and the stages of interpersonal relationships. Interpersonal interactions are vital to any person, especially a stroke survivor attempting to reconstruct their *self*. As early as childhood a person is exposed to interpersonal relationships in the context of the family. It is within this context they learn to be *social* and *individual* so must the stroke survivor be willing to learn, once again, from their

family or their support system to be *social* and *individual* (Deetz, 1982). Deetz makes a statement that fully conceptualizes what I am trying to get across in this chapter.

A person's sense of reality and/or how they construct it, confirmation, and transformation occur during interpersonal interactions. For instance, people talk to other people they trust about their problems, parents fill the early childhood role of educator, and on a daily basis a person interacts with his or her boss and coworkers. Deetz (1982) goes on to say, "the interpersonal encounter has a special residual capacity to support the individual and maintain identity and meaning" (p. 2).

Due to the intense nature of interpersonal interactions, it would be almost impossible to define a person in terms of institutional roles or generalized categories (Levinas, 1969). Another important aspect of interpersonal communication is that in an interpersonal interaction all of the sense modalities are being used. It would be very difficult to distinguish between which of the sense modalities is most responsible for making sense of the total message; thus making the interpersonal interaction a culmination of all essential inputs (Deetz, 1982, p. 3).

Gergen (2001b) addresses therapeutic communication and its ability to create reality. He says, "there is something about the nature of communicative interchange that engenders change" (p. 1). Within our interpersonal interactions, we can express ourselves to each other and then, in turn, have our expressions validated or critiqued. It is within this process that a person actually gains more insight into who he or she is as their *self*. They are able to explore different aspects of their personality and cognitive processes and make decisions in a safe and non-threatening environment whether to change a part of themselves or not. Also, let us understand that a person's expressions of thought, remarks, declarations, or statements have no meaning unless shared with another. They begin to gain any kind of meaning when accompanied by

another person's response (p. 5).

Gergen (2001b) goes on to emphasize that a single person cannot create meaning or reality, they must have another person to coordinate with them. Only then can it be said that communication was achieved. They must be "granted by others a privilege of meaning" (p. 5). If a person is not willing to acknowledge another person's words, then they are reduced to nonsense (p. 5).

Why is this concept so important? It is what helps a person to remove any repression of their *self*, an opportunity to gain insight, an alteration in cognitive interpretations or depictions, can aid in improvement of self-acceptance, and most important to the stroke survivor it is a process of catharsis. The stroke survivor has undergone an intense time of emotional and physical change and the emotional tension that has built up can be released (p. 9).

In any of these instances, a change has taken place. The stroke survivor is left with self-doubt, a lack of self-acceptance, and is repressed. They are only concentrating on the negative and need to gain the valuable insight that comes from an interpersonal interaction. The context by which a person participates in an interpersonal interaction is within the elements of an interpersonal relationship.

Interpersonal relationships are not fixed in any time or place. They are subject to time and events. Knapp and Vangelisti (1996) attempt to give us a perspective on relationship stages and that movement through them is fairly certain. They pose that there are four generalizations that exist within the maintenance of interpersonal relationships. They are: (a) movement through stages is generally systematic and sequential, (b) movement may be forward, (c) movement be backward, and (d) movement is always to a new place (p. 126) (Appendix E).

To add clarity to the stages of relationships, I believe it is important here to include Knapp

and Vangelisti's stages *coming together* and *coming apart*. When people meet for the first time there are five stages they work through to determine the direction of the relationship, they are: (a) initiating, (b) experimenting, (c) intensifying, (d) integrating, and (e) bonding. When the relationship is in its final stages, they go through: (a) differentiating, (b) circumscribing, (c) stagnating, (d) avoiding, and finally, (e) terminating (p. 127).

Stroke survivors find themselves in the uncomfortable position of having to renegotiate their way through an existing interpersonal relationship. As they have been changed by the stroke experience, their relationship with others will also experience change. Some relationships will not be able to sustain the change and they will move into the termination stage. In turn, other relationships that may not have been as developed will suddenly move to the intensifying, integrating, and bonding stages of the relationship (p. 127).

Josselson (1996) examines the elements of human relationships, she studied Buber's (1958) work and expounded upon his concept of *I and Thou*. Our connections to others adds to the richness of our own personalities. As each of us are a separate being, the only way to become *joined* to another physical human being is through relationships; this is the only "means of overcoming the space between us" (p. 4).

In our efforts to reach across the chasm that separates people, we reach out to another person and attempt to relate to them. In this context, we not only experience the other person, but it also serves for the experience of our *self* (p. 5). Again, this is a vital need for the stroke survivor. Their sense of *self* has been shattered. They sometimes feel as though some alien being has taken over their body leaving behind someone that they do not know nor like.

Relating to others and being an individual are not dichotomous. They serve to compliment each other in that the *self* is realized through others (p. 15). Within the context of a

relationship a person can maintain their autonomy and competence but also glean from another person within this interpersonal sphere insight that could not come from within ourselves alone. Within this sphere exist the "realm of the subjective and affective, the symbolic and the transcendent" (p. 15). Most of what is vital and necessary here is not found in words.

While it is true that people bring to any relationship aspects of themselves, however, while in a relationship that person might find that their own characteristics are indelibly altered (p. 17). We find that the development of our *self* comes from the primitive synthesis or merging with others (p. 18). A different vantage point of this synthesis might be explained in the theory that the *self* is inherent and to envisage the infant born separate and alone; disconnected and helpless. Development of their *self* then becomes a matter of learning to attach, connect, and to find ways of meeting the complex needs for contact with other human beings (p. 18). This is precisely how it is for the stroke survivor.

They must find a way to make it past the confusion and resentment that can occur post stroke of not being who they were and press on to re-develop or reconstruct their *self* If they do not have someone there to encourage them to do this, their progress of self reconstruction is thwarted and they will retreat deeper and deeper into themselves and merely exist and not learn to live life with others, once again.

In one very different study on IC, Heath and Blonder (2003) observed videotaped interviews of stroke victims and their significant other and the interviewer. Humor was found to be a way that the stroke survivor was able to re-assert "autonomy and self-esteem and maneuvering social distance by pointing to boundaries and creating, confirming, or denying allegiance" (p. 91).

The recovering stroke survivor who has had any form of cognitive or motor impairment can sometimes experience a longer recovery. Research shows that "many stroke survivors

experience stress in the negotiation of acute post stroke changes such as an altered appearance or loss of independence" (p. 92). It has been found that humor has a positive influence on physiological and psychological health (p. 91). There have been previous studies conducted focusing on humor as a modulator of social relationships. With the presence of humor, awkward moments in day-to-day interactions were alleviated (p. 92).

However, when cognitive deficits sustained by stroke survivors lead to a reduced ability to engage in humor, both their social and interpersonal coping skills suffered (p. 93). In this case, their relationships suffered. It is in this time that stroke survivors most need emotional stamina and a strong social support network or system, but are unable to exercise the needed cognitive means to support an optimal recovery (p. 93). To reiterate, the reduction in the QoL of a stroke survivor jeopardizes their sense of *self*, thus increasing their levels of stress, anxiety, and deepening the PSD.

2.5 Literature on Uncertainty Reduction Theory (URT)

Everyday life seems to be unpredictable. Even without the consequences of a stroke incident, everyday life has aspects of uncertainty (Knobloch, 2008; Knobloch & McAninch, 2014). Take it to the next step: communicating in circumstances of uncertainty. IC is fraught with uncertainty; add to that a stroke incident. Everyday life and the IC that are a part of it become more uncertain. Stroke survivors are now even more apprehensive to engage in IC as well as seek out new interpersonal relationships.

To address the complexities of this fact, Knobloch and McAninch (2014) expound upon URT to help explain this. This theory seeks to explain how we communicate under conditions of ambiguity. In other words, how do people manage or reduce their level of uncertainty when uncertainty is a certainty? Berger (2011) gives us the premise for and the application of URT:

The main supposition underlying the theory is that when strangers meet, they are faced with myriad uncertainties about each other's attitudes, beliefs values, and potential actions. In the service of predicating, and in some cases explaining, each other's beliefs and actions so that communicative choices can be made, individuals seek to reduce their uncertainties by acquiring information about each other. Initial interactions are highly saturated with questions during their initial few minutes... and individuals may employ a variety of strategies to acquire uncertainty-reducing information. (p. 215)

URT places communication in dual roles: (a) communication is a vehicle for uncertainty reduction and (b) communication is affected by uncertainty reduction (p. 298). People experience both behavioral uncertainty as well as cognitive uncertainty (dissonance). There are three basic connects in which people seek to reduce uncertainty: (a) a partner deviates from the expected, (b) they expect to communicate with the partner in the future, and/or (c) their rewards and costs are controlled by the partner.

Along with the three contexts, there are seven axioms regarding the connections between uncertainty, social cognition, and communication. These seven axioms are then paired with every other axiom to construe 21 theorems. Other communication theorists have, over time, added to these axioms and theorems (p. 299).

One particular theorist, Gudykunst (1993) has taken the basic concepts of URT and added an intercultural aspect to it to create what is now known as anxiety/uncertainty management theory (AUM). AUM is an intercultural communication theory and deals with encounters between cultural in-groups and strangers (Griffin, 2005, p. 426). I believe that URT is a more appropriate theory as it has to do with communication at the interpersonal level and not at the collective cultural level that AUM concentrates on. Some theorists has thought at one time that

URT had morphed into AUM (Gudykunst, 1993). Until 2014 it definitely looked that way, but Berger published new work under the heading of interpersonal communication and included in the book a chapter on URT.

One important note is that this theory has given the field of communication empirical evidence gleaned from investigations into initial encounters with able-bodied and physically disabled strangers. However, this is not all, URT has also given important insight into and demonstrated substantial heuristic value influencing research on romantic relationships and more. Principles of URT have been imported outside the field of communication to marketing, psychology, business, intercultural episodes, and within the health context (Gudykunst, 1993, p. 300).

There are three information-seeking schemes of URT that are the underpinnings of this theory. It is these three schemes that people engage in to aid in uncertainty reduction. These three schemes are: (a) passive information-seeking strategies, (b) active information-seeking strategies, and (c) interactive information-seeking strategies (p. 298). They are reasonably self-explanatory. Each of these schemes have both a risk and reward to them. These three information-seeking schemes are necessary for the stroke survivor to engage in as his or her world is much more uncertain now as they carry with them the consequences of a stroke incident.

A certain amount of anxiety or cognitive dissonance can be experienced each time the stroke survivor is required to engage in any form of interpersonal communication. They are not as confident as they were pre stroke. Looking at a different element of uncertainty, Zaider, Heimberg, and Iida (2010) explore the daily processes of couples attempting to deal with anxiety disorders. They found that, "intimate relationships are the primary context in which

express and manage personal distress" (p. 163). Stroke survivors are called upon more so than the average person to reduce uncertainty due to the after effects of a stroke incident. With the presence of PSD some of them can develop anxiety, as well.

Empirical data obtained through the longitudinal study conducted by Zaider et al. (2010) it was found that if one partner had an anxiety disorder then both of them tended to report low marital quality. It was also reported that over a 2-year period, the low marital quality was a strong predictor of the onset of an anxiety disorder (p. 163).

Within the partnership, the wives/females tend to be more sensitive to the moods of their intimate partners in that they asserted their partners played some part in causing, exacerbating, or alleviating their anxiety (p. 174). This finding supports the necessity for the stroke survivor to have a strong support system in place and also within their intimate relationships the ability for the unaffected partner to be able to encourage the stroke survivor.

In summary, the research demonstrates that there is a very real and present danger for the stroke survivor as PSD is the most common emotional sequelae post stroke. One specific danger is that, undiagnosed and untreated, it can lead to death. Not only that, but PSD can prolong the recovery process of the stroke survivor. As the stroke survivor must reconstruct their *self*, research on SC has shown to think the *self*, is not a product of your social environment is naïve.

IC is one of the aspects of SC and is severely, at times, affected post stroke. Within IC is the aspect of relationship stages. These stages occur naturally within each new and developing as well as terminating relationships. Stroke survivors must renegotiate their way through their interpersonal relationships and some may not survive. URT has shown to be an effective tool for reducing the stress or uncertainty that plagues the life of a stroke survivor. We all experience stress or uncertainty at times, but for the stroke survivor, they face each and every new day with

a heightened amount of uncertainty.

To reiterate, the purpose of this study, and the use of recorded audio interviews of the lived experiences of stroke survivors to observe how they navigated through their rehabilitative processes while having the comorbid occurrence of PSD and how it affected that process but also how it affected their interpersonal communication within their interpersonal relationships is the goal of this body of research.

2.6 Research Question

What are the lived experiences of stroke survivors with or without PSD and how has the stroke incident affected their interpersonal communication?

Chapter 3

Methodology

3.1 Content

Any person's life story will contain within it some context of how their *self* was constructed. Therefore, the retelling of that person's story has a vital place in the research of human lives. Brinkmann and Kvale (2015) point out that if you want to know and understand how people understand their world, lives, and the events around them; you need to *ask* them. They go on to stress that "conversation is a basic mode of human interaction" (p. 1). It is important at this time to stress that that interviewing is a craft. Kvale (1996) states:

It does not follow content-and context-free rules of method, but rests on the judgments of a qualified researcher. For the therapeutic as well as the research interview, the interviewer is the instrument. The outcome depends on the knowledge, sensitivity, and empathy of the interviewer. (p. 105)

An emphasis is placed on the crucial role of the *person* of the researcher, but does not excuse the neglecting of techniques and a wide knowledge base. Just as an artist masters the use of oils, acrylics, watercolors, or charcoal, so does the conversational interviewer attempt to *master* his or her use of their knowledge, sensitivity, empathy, and skill with words. The journey of mastering the art of conversational interviews leads from a rule-guided *knowing that* to an experience-based *knowing how* (p. 106).

In our interpersonal interactions, or conversations with other people we have the ability to see life from another perspective. We also can understand how they make sense of their attitudes, their experiences, and their emotions. Conversational interviews are just that. In order to better understand a phenomenon, it is crucial to observe it from many different angles or perspectives.

The use of conversational interviews allows the researcher to look at the phenomenon in an objective way to see how each individual person deals with it (p. 4). The use of conversational interviews is a way to bring to light the *evocative* narratives that make up peoples' lives. The use of the word *evocative* is intentional. It implies intimacy as well as being personal (Ellis & Bochner, 2007).

How this is done is by a series of steps designed to aid in the conversational interview and get the best data from it. While creating the initial research proposal, there needs to be a thorough process to determine two things: (a) what methodologies and methods will I employ in the research and (b) how am I going to logically justify my choice?

This process to answer the two questions puts into perspective the "assumptions of reality that we bring to our work" (Crotty, 1998, p. 2). At this point in time, my initial questions have morphed into four questions: (a) what *methods* do I propose to use? (b) what *methodology* regulates my choice and use of methods? (c) what *theoretical perspective* am I basing my assumptions of reality upon?, and (d) what *epistemology* elucidates this theoretical perspective? (p. 2).

One thing that needs to be avoided is the mistaken viewpoint that these different process elements or questions get intertwined as if they were synonymous terms for each other (p. 3). Each question or element is a step in the whole process and each one builds upon the other to explain the entire research process.

3.2 Methods for Conversational or Narrative Interviews

3.2.1 Participants. I interviewed eight people with ages ranging from 18 and older. The emphasis of research in the human sciences is to find a commonality within a given population. According to Brinkmann and Kvale (2015) when conducting conversational

interviews, the number of participants that you interview is solely based on your research question (p. 199). By using a smaller sample size you are able to get a more personal look into the lives of the people you are interviewing, thus gleaning from them a deeply personal, honest, and therefore, reliable account. For this study, eight people; some within a relationship and some family members of a stroke survivor were interviewed.

As mentioned in research by Heath and Blonder (1993) the presence of aphasia was overcome by having the stroke survivor's significant other, spouse, family member, or intimate friend attending the interview and, as needed, speaking for the stroke survivor. Per the recommendation of the University of Alaska Fairbanks' Internal Review Board (IRB), I had to create two different Informed Consent forms (p. 93). One was for the unaffected interviewee to sign and the other was for the affected interviewee to designate in a manner that was obvious, that they understood the nature of the research and willingly participated (Appendix A, B, & D).

3.2.2 Procedure. To recruit people to interview I used a combination of the snowball method and people I had met in my personal journey of post stroke recovery with my husband. Due to the confidentiality issue of releasing names, medical information, etc., I was not able gain access to patient records. Also, as my research was not being funded directly by any of the local health organizations, therefore, I was not able to post flyers. I was, however, able to place my flyers in libraries, the University of Alaska Fairbanks (UAF), coffee shops, pharmaceutical supply companies, and restaurants.

One more method of gaining potential interviewees was to go to the other departments at UAF and ask if they could pass on the flyer for me to anyone who could be a potential interviewee. Finally, I was able to contact local organizations that provided counseling or

support to members of the community, such as Access Alaska, Fairbanks Resource Agency, Love Inc., Parish Health Ministries, and the local Veteran's Administration office both at UAF and in Fairbanks to inquire if they could assist me in my recruitment.

When I was initially contacted by a potential recruit I told them who I was and why I was conducting this research. I explained that I was seeking stroke survivors that had been affected with PSD and wanted to spend approximately an hour or so with me recording an interview with them on their personal experiences post stroke. I stressed that I wanted to include in the conversation the person that had known them pre stroke as they could also give me vital information regarding the process.

Most importantly was the fact that even if the stroke survivor had a form of aphasia, they would not be excluded as their partner could speak for them. One thing that I found effective was to share with them that another reason for my research was because I was also the partner of a stroke survivor. In order to make sure that they knew exactly what they were up against, I made sure to tell them the very personal nature of the questions that I was going to ask them. I included with the informed consent forms a list of local organizations that could provide psychological counseling in the event that they were upset by any aspect of the interview (Brinkmann & Kvale, 2015, pp. 95-96).

In order to insure the confidentiality of the interviewees, once I had recorded the interview with them on a Sony mini digital audio recorder I transferred the information to a thumb drive that was kept in a locked and secured location in the Department of Communication at UAF.

To further protect their identity, a pseudonym was assigned to each individual.

In the attempt to stay true to Polkinghorne (1998) and Brinkmann and Kvale's (2015) concepts for conducting conversational interviews, there was a list of open-ended questions to

reassure them that this was just having a conversation with them and not to focus on the fact that it was being recorded (Appendix C).

I kept a journal at each interview for the purpose of clarification and to keep the process fresh for analysis at a later time. Another record was of any nonverbal cues that I observed during the interview process, such as their facial expressions, extended pauses, frustrated gesticulations, sighs, or laughter. This is an important step in the process of analyzing the data as it serves to help me, as the researcher, to gain understanding from the interviewee in regards to their *intended* meaning.

3.2.3 Methods of analysis. After each interview I was careful to make sure that I did not let a great deal of time pass before I transcribed it. In doing so I wanted to make sure I kept the essence of the interview fresh in my mind. It is also important to note here that, due to circumstances that could not be overcome, the interview was conducted via telephone (p. 174). Nonverbal cues are not always missed on a telephone as sarcasm, tone, inflection, extended pauses, and laughter can be heard, even if they are not seen in a face-to-face interview.

I elected to type out my own transcriptions to suffuse myself with what was actually said by the interviewee during the interview and to be able to discover any commonality, or emergent theme. Each transcription took approximately four hours to create based on a one hour interview. The pseudonyms were used in place of the real names in the transcriptions. The notes that were taken added to the transcriptions of the interviews was the source of my data that was used in the narrative analysis.

Brinkmann and Kvale (2015) use six steps to analyze interview data: (a) the first step is during the actual interview when the interviewee describes their lived experiences, (b) next,

the subjects themselves find new relationships during the interview and are able to see new or emergent meanings in what they experienced, (c) during the interview, the interviewer has the opportunity to clarify *meanings* rather than relying on what the researcher *thought* or *assumed* the interviewee meant, (d) the recorded interview is transcribed and analyzed by the researcher, (e) here, it is suggested that a reinterview could be used, and lastly, (f) the sixth step is also a suggestion if the interviewees has actually started to act upon the knowledge they gained during the interview and discuss it (pp. 221-222).

Creswell (2007) also has an approach used in interview data analysis: (a) taking notes, (b) summarizing field notes, (c) identify codes, (d) reduce codes to themes, (e) relating categories, and (f) displaying the data and discussing emergent themes (p. 149). These are both different approaches to narrative analysis and serve to provide a coherent and structured format to discuss in depth an understanding of the lived experiences of stroke survivors.

Brinkmann and Kvale (2015) stress that despite the six suggested steps of narrative analysis:

With no specific mode of analysis planned, there are no particular requirements for interviewing and transcription. The general requirement of providing rich descriptions and well-controlled information still pertains. (p. 269)

Lindlof (1995) adds to the understanding of reporting on narrative interviews:

the notion that meanings are continually constructed lies at the center of interpretive approaches in communication...how we describe the world constitutes what we describe... the researcher must decide what kind of author he or she will be, and what sort of story to construct of the facts of the case. (p. 24)

The researchers role in narrative research is to serve as an interpreter of conversational

interviews in order to come to a deeper knowledge of and understanding of interpreted meanings (p. 25).

3.2.4 Emergent themes. A major component of the analysis is to synthesize emergence from the data. Emergent themes are just that; themes that have arisen during the process of reviewing the transcripts to see what has been repeated or what ideas or concepts that have surfaced in the process of reviewing the conversational interviews (Brinkmann & Kvale, 2015).

It is important to reiterate there that I am not looking for a theory to generalize, but rather to understand what ideas, concepts, or *themes* emerged and were strictly unique to the conversations of the lived experiences of the interviewees at that time (van Manen, 1990). The use of *thick descriptions* is employed rather than trying to interpret the experiences in my own words.

In doing so a subjective and/or intersubjective experience of someone is being objectified. (Ryle, 1968). By doing so, in effect, the tactics of Geertz (1973) are being employed. Also, the, "explication...construing social expressions on their surface enigmatical" (p. 1). In other words, an objective attempt to analyze or explain this conversational interview has been made. And also an attempt to intricately and in a particular way analyze it, despite its apparent mysterious or unknown qualities; because how can I see *inside* the interviewees mind to *know?* So, I let it *speak* to me and compare it to other conversations to arrive at a commonality to interpret that lived experience accurately (p. 2).

3.3 Narrative Inquiry (NI)

The logic behind the methodology of NI is embedded within the epistemological perspective of constructionism. This particular research paradigm is employed to enable the qualitative

researcher to recognize *emergent* themes that arise through the processes of interaction. The paradigm of objectivism, constructionism's supposed polar opposite, follows the traditional *a priori* viewpoint that a phenomenon exists as it is without any subjective or interpretive aspect to it to form an idea or theory that can be generalized to apply to a certain population or culture. Objectivism's orientation toward research with humans is often considered a false assumption (Deetz, 1982; Gergen, 2001a). Therefore, Social Constructionism (SC) has been utilized as an alternative to the more traditional viewpoint of the construction of the *self*. The use of SC is vital as an element that is embedded within SC is interpersonal communication. By using NI it is possible to observe and enables the commonalities or themes to emerge from the interviews.

A part of how we construct our *self* is through our interactions or communicating with others and, within that, finding shared meanings. Those shared meanings aid us in our journey of who we are. Having said that, I use NI as the methodology behind my method of conversational interviews in my research.

In order to understand more about NI, it is important for me to expound upon it. Research and the corresponding data regarding stroke survivors relied solely upon quantitative methods until about 1993 with a study conducted by Nelson et al. (1993) with humor being used amongst stroke survivors to negotiate through stroke recovery in a qualitative approach to researching stroke survivors.

This research project opened the door to be able to study an entire group of people that had been left out previously. It is somewhat common following a stroke incident that the stroke survivor is affected with a form of aphasia, or the inability or impairment to communicate through speech, writing, or signs. Because the stroke survivor could not fill out a survey, they

were not able to participate in the much-needed research of life post stroke.

In the Nelson et al. (1993) study, the stroke survivor was coupled with their significant other and a video recording of an interview between them and the interviewer was used to observe any humor events and record the findings to be compared with other couples. Since then, more qualitative research has been conducted to give us the much-needed insight into the lives of stroke survivors and also included a population of stroke survivors that has traditionally been left out of stroke research.

Due to the lack of knowledge or misunderstanding of the knowledge available, I will discuss the benefits of using narrative inquiry as a form of valid research. Alasurutari (1997) expounds on the discursive approach to studying data obtained by life stories. Gone is the assumption that "each person possesses an authentic self that could be captured in a text where the person honestly tells his or her life story" (Alasurutari, 1997). Instead, life stories are situational and serve a purpose. I do not mean to say that people cannot be trusted to be honest. What was meant by this is that in a certain circumstance or context, the storyteller will craft their story to meet a need at the moment. Where the stroke survivor is at in their personal development at the time they are telling a story will have a direct influence on the content or style of their story (Rosenwald & Ochberg, 1992).

Siebers (2001) takes a different approach and looks at SC and applies it to the disabled body. Some stroke survivors are left with physical evidence of the stroke incident and must be able to look at their body in a healthy way and put their thoughts into a healthy and functional perspective. It is being discovered that the "idea that representation governs the body, of course, has had enormous influence on cultural and critical theory" (p. 738).

Studies conducted and the research gleaned from them use these theories because they

provide the researchers as the individuals observed with a viable and convincing alternative to the medical model of disability. This is vital as within the medical model the patient is ostracized and viewed as diseased, flawed, and even substandard. SC allows disability to be realized as the product of an environment that is hostile to these *imperfect* or *flawed* bodies and welcoming to those that are socially accepted (p. 738).

With that being said, I will attempt to explain the premise for narrative inquiry, (NI). Clandinin and Connelly (2000) introduce their book with the question, "why narrative?" (p. 1). They give an in depth history of NI and provide the theoretical as well as practical underpinnings of this research approach. The fields of higher education, anthropology, communication, psychology, psychotherapy, and organizational theory have used this form of research very affectively either just in recent years or in years past (p. 2).

One statement made on the place for NI in modern research was made, "our questions, our research puzzles, have focused around the broad questions of how individuals teach and learn, of how temporality (placing things in context of time) connects with change and learning, and of how institutions frame our lives" (p. 3). In other words, personal stories help us see into aspects of the lives of people affected by such things and have to negotiate their way through such things that a strict quantitative method could not.

The reason for this is simply that it is relatively impossible to *quantify* emotions or feelings. Nor is there a need to generalize qualitative findings as is the scope of a more positivistic style. Lived experiences are a subjective as well as intersubjective research process (van Manen, 1990).

Dewey (1916) who is in the field of education, is referenced in this section. One overarching concept pertaining to NI is that experience is *continuity* (p. 2). To clarify,

experiences form out of further experiences and this process keeps repeating and building upon itself. The end product is experiential. Each of us go through this process, thereby adding to the overall experience. But, in order to find a specific answer to one part of that entire experience, one must look at an individual story. Dewey's massive contribution to the field of education is simplified with his view of NI with this thought:

We tried to hold all these matters in mind as we reflected on the educational puzzles and problems in our inquiry lives. We learned to go back and forth between the personal and the social, simultaneously thinking about the past, present, and future, and to do so in ever-expanding social milieus. (p. 2)

Within these social milieus, or social circles, we operate adding to the experiential aspects of the broader theory experience (p. 2).

Clandinin and Connelly (2000) are wise to include the narrative accounts of theorists in other fields of study. As I mentioned earlier, they have reached into the fields of psychology and anthropology to gain valuable insight into NI (p. 6). One theorist that they borrowed thoughts from in the field of anthropology is Geertz (1995):

What we can construct, if we keep notes and survive, are hindsight accounts of the connectedness of things that seem to have happened: pieced-together patternings, after the fact... It calls for showing how particular event and unique occasions, an encounter here, a development there, can be woven together to produce a sense of how things go, have gone, and are likely to go. (p. 6)

That is one of the best descriptions of NI that I have found to date. It exemplifies the whole idea behind and expected outcome of my research into interpersonal communication post stroke, with PSD using NI.

3.4 Theoretical Framework Supporting NI

Next, in an attempt to be faithful to the outline given by Crotty (1998) it is necessary to expound upon the theoretical perspective that I have chosen. With this it is my intention to stipulate the context for the course of action that I use which, in turn, gives credence to its logic and criteria (p. 7).

3.4.1 Interpretivism. In this body of research it is the goal to find emergent themes intertwined within the stories of stroke survivors; by investigating *social reality* and not *natural reality*. Interpretivism which is in direct contradistinction to positivism is the approach I am employing (Crotty, 1998). Interpretivism shifted its data analysis from empiricism to hermeneutics, phenomenology, and symbolic interactionism (p. 68).

Crotty (1998) expounds on the theoretical differences between the two theoretical approaches. He also gives us insight into the theorists that have supported these two differing approaches. In using the positivistic approach, therefore dictating the research style to be quantitative: one is studying nature and looking for "consistencies, regularities, the 'law', that obtains, *nomos*" (p. 68). However, by taking the interpretivistic approach and thereby dictating that the research will be qualitative; one is looking at the social sciences or human affairs and "concerned with the individual case, *idios*" (p. 68).

In conducting this qualitative research, it is vital to the researcher to strive to be consistently objective; following that as I strive to remain objective I am able to describe or illustrate scientific knowledge from subjective meanings. These meanings that people incorporate into their everyday lives can *reflect* or *mirror* objective meanings (p. 15). There is the danger that the qualitative method of discerning these objective meanings can or will be viewed as scientifically inferior (p. 16).

However, if we can interpret or place these objective meanings along with scientific data all on the same foundational perspective we find that they are all constructions. Both scientific data and the objective meanings gleaned from qualitative research become equal in that none are "objective or absolute or truly generalizable. Scientific knowledge is just a particular form of constructed knowledge designed to serve particular purposes—and yes, it serves them well" (p. 16). Weber (2004) reiterates this point in his editorial and states that:

I believe deep similarities rather than deep differences underlie...I hope this editorial will inspire both positivist and interpretive colleagues to respond—to engage with me and with others to either support my arguments or to refute them. (p. 3)

Interpretivism demands that I, as the researcher, will take the standpoint of *others* as they are the actors I am studying. To achieve this, an attempt to discipline my own viewpoint, opinion, or experience on the situation and communicate the standpoint of who I am studying patently and precisely (p. 17). Along with this, a careful attempt not to be ethnocentric in my discussion or analysis has to be made. To observe the phenomenon as "closely as possible... to take the place of those within the culture, search out the insider perspective" (p. 18).

Weber (2004) gives us a practical explanation of interpretivism. He asserts that NI from the theoretical perspective of interpretivism implies that the researchers themselves in essence are developed into quantitative instruments. As the researchers interpret, or in other words, measure the phenomena they observe, they are mindful that this is process is affected by and affects their real-life worlds. They also realize that their research processes affect the objects they are observing. Lastly, they also realize that the research objects are, in turn, affected themselves; thus the researcher and object observed are interdependent (p. 7).

Lastly, based on the information regarding interpretivism that I have provided thus far, it is important to also understand that as human beings we react towards things, people, and situations, based on the meanings that these are developed from. How this is accomplished is through the social interactions with other human beings. So, in keeping with the idea behind my research, stroke survivors are having to re-negotiate this process of social interaction based on the limitations that they face post stroke. Crotty (1998) goes on to state that, "we owe society our very being as conscious and self-conscious entities, for that being arises from a process…interaction, by way of significant gestures (p. 74).

Denzin and Lincoln (1998) define the role of an interpretivistic perspective in employing the narrative interviewing method as one that attempts to bring into focus "the constitutive nature of consciousness and interaction... focusing on the ways that the life world... every person *takes for granted*—is produced and experienced by *members*" (p. 138). By doing this, narrative interview researchers endeavor to construct an in-depth understanding and gain valuable knowledge of a particular phenomenon. Their goal is not to reveal an indisputable human or social *truth*.

Taking this information into account as I analyze the data, I can attempt to find the emergent themes that came from me seeking *the insider perspective* of the stories of the lived experiences of stroke survivors. Having done this, I can obtain the *mirror* that reflects the everyday objective meanings.

3.5 Phenomenological Foundation of NI

Another element in the research process is the phenomenological methodology of NI. Denzin and Lincoln (2000) explain that:

The scientific observer deals with how the social world is made meaningful. The

observer's focus is on *how* members of the social world apprehend and act upon the objects of their experience as if they are things separate and distinct from themselves (p. 489). This is a fundamental divergence from the assumptions underlying the natural or accepted attitude that the world is principally *out there* and in a different class than acts of perception or interpretation. In other words, the *life world* existed before any members were present and will continue that way after they are gone. Narrative interview researchers attempt to observe the members' attention to this *life world* in order to find an order or a commonality within the members' life experiences (p. 489).

Crotty (1998) explains that what the researcher hopes to achieve is to surrender any preexisting understandings of the phenomena that we are observing. When this is achieved it opens up to the researcher the ability to discover the emergent themes or meanings to record and discuss having built upon former findings (p. 22).

In other words, the researcher lays aside their frames of reference that they use to explain the phenomena observed and simply lets the phenomena speak for themselves. In doing so, we are explaining the true observation of the phenomena before we started thinking about them, interpreting them, or assigning meaning to them (p. 24). There are four key points to remember when observing the phenomena: (a) suspend assumptions, (b) be suspicious of culture, (c) break free, and (d) open your mind (p. 25).

The old system of taking everyday meanings as we have always known them and saying we are building upon them based upon the assumptions that constructed them is counterproductive and should be viewed as counterintuitive to the research of phenomena. Instead, researchers must learn to open up their minds to the phenomena and observe, record, analyze, and discuss it as it *is* (p. 26).

The advantage of phenomenology is that it is: (a) objective and (b) it is critical. The claim of objectivity is backed by the very idea that became the definition of the research of phenomena in that the researcher views the experience as the object as opposed to a description of the experiencing subject. It is critical in that it forces the researcher to question the things that are taken for granted (p. 83). Crotty (1998) ends this chapter with a brilliant quote:

The problem with [taking the place of the other] in modern phenomenology research is that it is not phenomenology, each of us must explore our own experience, not the experience of others, for no one can take that step back to the things themselves on our behalf. (p. 85)

In order to clarify the use of phenomena research or the phenomena observed, let me put it in two words; *lived meanings*. The phenomena that I am attempting to observe objectively is the *lived meanings* or *experiences* of stroke survivors. I will observe through their conversations what they *experienced* post stroke (van Manen, 1990).

Polkinghorne (1988) proposes to us a conceptual context that explains the place of narrative research in the study of human beings. He helps us to understand the function of narrative is to understand the events of an individual's life and, therefore, by achieving that to be competent to plan for the future. By providing us with this conceptual context, narrative research converts to a paradigm used as a methodological approach (p. 11).

Not to belabor the point by unpacking all the elements used to form this paradigm; instead the inclusion of a brief description of the basic elements that form the foundation for NI will be used. Firstly, the realm of human existence is so vast and complex that no one system for the construction of meaning can fully explain it. Attempting to define *meaning* as a thing would not do it justice. It is, rather, an *activity*. Within this activity is the interpersonal interactions with

other human beings. Therefore, narrative meaning serves to bring together human actions and human events that ultimately affect human beings. It is not the observance of the relationships between inanimate objects (p. 1).

Secondly, having established that, the definition of *narrative* is simply any spoken or written presentation. This comes in the form of *stories*, *tales*, or *histories*. Therefore, it is necessary for to insert here that Polkinghorne (1988) refers to narrative as both the *process* and the *results* (p. 2). Having said that, it is also important to add that Polkinghorne (1988) does not subscribe to the *paradigmatic mode* that dictates the search for *universal truths*. Rather, he used the term *narrative mode* that implies the search for *connections* between *events* (p. 3).

3.6 Reliability and Validity in Qualitative Research

Qualitative research tends to be placed under scrutiny when it comes to reliability and validity. To have research that is valid and reliable, it must have gone through a process to meet the criterion of validity and reliability. Kvale (1996) stresses that "validity comes to depend on the quality of craftsmanship during investigation, continually checking, questioning, and theoretically interpreting the findings" (p. 241). Therefore, the craftsmanship and credibility [reliability and validity] of the researcher now plays a vital part in the research process.

There is another element of validity that needs to be discussed. Validity is not merely concerned with the methodology, but also the *person* of the researcher including his or her moral integrity. That is an essential attribute for evaluation of the quality of scientific knowledge produced.

Kvale (1996) gives us three aspects of validation that act as a guide to the conversational interviewing process: (a) checking, (b) questioning, and (c) theorizing. Each of these three aspects are a critical part of the entire research project. They will be continuously made use of

and the results considered and re-considered (pp. 241-244).

In researching an area that has multiple, or changing realities, reliability would not be relevant. When a phenomenon changes, then the understanding of it also undergoes a change. This does not make it unreliable, necessarily, it simply means there are aspects about it that are not static. The properties of the phenomenon are dynamic and change. It has been said that, "if a measurement is composed of a single, non-repeated operation, there can be no measure of reliability" (Anderson, 1987, p. 126).

In the narrative interview, there are no repeated operations. The interview is conducted one time. There is no need to repeat the interview. The outcome of the interview is not based upon how many times it is conducted, rather, it depends upon how the interviewee experienced the event in question. The information that is needed is *subjective* in nature and the narrative researcher *objectifies* it. Repetition is not needed for that, what is required is an objective analysis of it. There are times when an interview will be conducted again, but not for the purpose of repetition. Interviews are conducted again in the case of longitudinal studies to indicate any change.

That is not to say that validity does not matter or can be evaluated in qualitative research. Lindlof and Taylor (2002) discuss validity in their textbook. Validity in research traditionally indicates the *truth value* of the observations:

Whether a research instrument is accurately reporting the nature of the object of study and variations in its behavior. Validity is often characterized by its internal, conceptual, and external dimensions. In objectivist terms, an internally valid study is one in which the instrument makes the distinctions that are intended. (p. 239)

They discuss further conceptual validity and also external validity. It is rather difficult to expect

the qualitative researcher to employ these aspects to qualitative research. In researching the social sciences, one single representation of a phenomenon cannot serve as an adequate and precise measurement (p. 240).

Another aspect of qualitative research that adds to the difficulty is that the qualitative researcher takes on the role of a *reflexive agent* in the field. In other words, the actions of others are observed, but also the researchers' reactions to those actions. One last element to look at is that the subject matter of qualitative research is *historically* and *culturally* positioned and therefore, not easily generalized to the entire population of the earth (p. 240).

It is the goal of all qualitative researchers to attempt to deliver data that is credible and to be able to establish its validity. Attaining the right interpretation of the data serves to be a source of inspiration to the reader as well as the researcher. The best process to attain this is to examine and re-examine the method of evaluating and interpreting the data as well as the interpretation (p. 240). One method that is suggested is *member validation*. That brings me to my next area of discussion.

3.6.1 Participants as co-researchers. Within social-scientific research it has not been the usual practice to consult with those outside of academia. Social-scientific knowledge has always been considered to be superior. Recently, however, interpretive social science has adopted the practice of considering the participants as co-researchers in the research study. The participants, for example, in conversational interviews would be considered highly knowledgeable regarding the phenomenon that is being observed as they, themselves, experience the phenomenon (Murray & Harrison, 2004, p. 808). It is also presumed that the participants are able to assess and critique the written descriptions that the researchers produce to portray and support the observations of their practices, routines, experiences, and

beliefs (p. 242).

Towards the end of the research project the main researcher will meet with the coresearchers to discuss the interpretations of them. Not only at the end of the project can these meetings take place, but also at many different points along the way. This also serves to ensure the accuracy of the interpretive findings before the work is published. The researcher will ask questions such as, "Did I get anything wrong? Is there anything you particularly like about this?" and "Have I been fair?" Again, this is done to ensure the *truth value* of the results (p. 243). Member validations can be sources of authoritative verification processes. The researcher must approach them, however, with the attitude in mind of the possible influences on what is said by the participation (p. 244).

There are benefits to the participant as well as the obvious benefit to the researcher in using the participants as co-researchers. One benefit that can be derived is that during the course of the conversational interview, the interviewee can actually come to a new understanding of that experience and therefore come away from it with a new *lived meaning* (van Manen, 1990) or lived experience. Consequently, van Manen (1990) explains that within the qualitative study of lived meaning an attempt has been made to represent "the way that a person experiences and understands his or her world as real and meaningful... describing those aspects of a situation as experienced by the person in it" (p. 183).

Another viewpoint is that as these conversational interviews are taking place, these casual conversations serve as venues for the construction of significance in our lived experiences.

Ochs and Capps (2009) articulate that actuality poignantly:

The difference between telling a story *to* another person and telling a story *with* another... of incidents, especially those that happened recently and those half-forgotten or

repressed, often look like rough drafts rather than finished products. Narrators have something to tell, but the details and the perspective are relatively inchoate; they are still in the middle of sorting out an experience...Narrative activity becomes a tool for collaboratively reflecting upon specific situations...the content and direction that narrative framings take are contingent upon the narrative input of other interlocutors, who provide, elicit, criticize, refute, and draw inferences from facets of the unfolding account.

In these exchanges, narrative becomes an interactional achievement and interlocutors become co-authors. (pp. 2-3)

3.6.2 Reflexivity and researcher as a subject in qualitative research. Reflexivity in qualitative research can be a perilous issue. Finlay (2002) tackled it and has this to say about reflexivity:

Reflexivity can be defined as thoughtful, conscious self-awareness. Reflexive analysis in research encompasses continual evaluation of subjective responses, intersubjective dynamics, and the research process itself. It involves a shift in our understanding of data collection from something objective that is accomplished through detached scrutiny of what I know and how I know it to recognizing how we actively construct our knowledge. The reflexive ethnographer does not simply report facts or truths but actively constructs interpretations of his or her experiences in the field and then questions how those interpretations came about. (p. 531)

As a qualitative researcher, I am ever mindful of the fact that I am a central figure who can influence the collection, selection, and interpretation of data. Meanings, therefore, can be viewed as a negotiation between the researcher and the researched. This being so, the social context that the research was conducted within will differ for another researcher that is

researching the same thing. Reflexivity demands that the researcher participate in a frank, self-aware, meta-analysis of the research process. By making this a priority and attempting to master it, the problem of *subjectivity* is transformed into an opportunity (pp. 531-532).

The process of engaging in reflexive analysis is challenging, at best. There is the possibility that the researcher would be faced with external criticism and they could possibly fall prey to *over-purifying* the results. There is the chance that the whole process would be avoided all together. That would not serve the researcher well. There is a tendency to use *reflexivity* and *reflection* interchangeably. A useful differentiating concept could be that both are each very important stages on a continuum. Reflexivity is used at the beginning stages of the research project and often used as a check-and-balance system during the research process. Reflection is used at the end of the project to look back at it. I will conclude this discussion with Finlay's thoughts:

Having come to understand that the researcher, the world, and the researcher's experience of the world are intertwined, the challenge is to identify that lived experience that resides in the space between the subject and object. The researcher strives to capture some of the connections by which subject and object influence and constitute each other. (p. 533)

Chapter 4

Narrative Co-Constructions

4.1 Lived Meanings

The lived meanings or lived experiences of people serve as a way to examine personal events, feelings, and experiences. Narrative inquiry is the methodology that accomplishes this and the method is conversational interviews. Up to this point I have discussed the rationale for every step in my research process. When I transcribed the conversational interviews I intentionally included any sounds or non-verbal cues. The use of non-verbal cues or behaviors is the vehicle through which the verbal is represented. The inclusion of the non-verbal gestures is intentional as they serve to bring clarity, reinforce, or contradict what has been verbalized.

Each transcription is a co-construction of both my knowledge and understanding of the stroke process as well as my co-researchers'. I have included any consultations between myself and my co-researchers in the process of analyzing the content of the interview.

4.1.1 Andrew's conversational interview. Andrew is my first interview. I arrive at his home to find him and his wife in the process of feeding their three adopted children dinner and trying to get them to be quiet. He is a teacher at one of the local schools and is going to be telling me about his grandmother, Angela. Angela suffered a stroke incident almost one year ago. She has lived in Washington State almost all her life and now lives with her sister in another part of the state.

Andrew begins to describe his grandmother to me. He has big smile on his face as he tells me that her and his grandfather were "towering people. My grandfather was 6'6" and my grandmother was 6'4". I have lots of happy memories of her. "We have a very close family and since we lived in a small town, we saw a lot of each other." "She was the librarian at our

church and was very loving. Grandma was a workhorse." "Grandma was always very active.

She loved to garden." We have to pause the recording here so that Andrew can settle a dispute between his children.

I turn back on the recorder and Andrew goes on to tell me that his grandfather had also had a bilateral stroke about 20 years ago. He says it was very debilitating. He remembers that "he just sort of gave up. I guess back then depression after a stroke was not really discussed." He then tells me he had a second stroke and passed away six months after it.

We pick back up with Angela and the events that transpired shortly before her stroke incident. Her family was starting to get concerned about her health as she was now 83 years old. She had had six children and "clearly, she can no longer live alone." Her sister volunteered to let her come and live with them. Angela's sister had experience working with special needs children, so was used to having to take care of someone with disabilities.

One evening they found Angela in her bedroom on the floor and unresponsive. The next morning was when Andrew had gotten the call. Andrew has lived now in Alaska for close to 10 years so had not been there when the stroke incident occurred. He recalls that Angela had the "best of circumstances" as their cousin lived next door and was a nurse. She got prompt medical attention. However, she suffered severely from aphasia. For several weeks she had "very little language skills." Their family members were with her a lot during the rehabilitative stage. When I asked him about post stroke depression, he said "he didn't notice any." One speculation of his regarding this is that the family spent a great deal of time with her post stroke. They were encouraging her and helping her to "speak" to others by translating her body and hand gestures. It took about two months of speech therapy for her to start to be able to communicate better.

Just this past summer Andrew and his family were able to visit Angela. He recalls his

first impression of her and I see much sadness in his eyes. "She was curled up on her bed, she just looked so small." They were able to communicate "reasonably well". There were other family members present to help them understand what she was trying to say if she started to struggle with the right words. Sometime when she could not think of the right word "she would just laugh it off." Behind the laughter Andrew said "I could see the frustration at not being able to articulate the way she used to."

When I asked him what was the most frustrating thing that occurred post stroke; he said "The inability for her to speak." "At first we tried calling her on the phone. That did not work well. Then we thought of Facetime. That seemed to work better, but it was never just my grandma, there always had to be other people there to help her." The best thing about the Facetime, Andrew stresses is that "even though she could not articulate, she was present...and not solely inside of herself." "I think in the beginning she really thought that she was never going to be able to talk again."

At this time I ask Andrew if there is anything else he would like to share about his grandmother and he pauses and thinks for a moment and then says "no." I thank him for his time and he adds "Thanks for your patience with the children."

4.1.2 Angela's conversational interview. I get the call from the sister of Angela and we discuss the informed consent form. We agree that it would be acceptable for me to make a note on the informed consent form (A) that Angela has agreed to participate. She agreed via phone to participate with her sister as a witness. We are on speaker phone so that I can record the conversation and she also has agreed to this. The interview is very short, but I was glad for the opportunity to get to talk to her.

Since I had spoken with her grandson, Andrew, there was not a need to get the

personal details from her. I started right in with asking her about the aphasia. She tells me very slowly that "I am learning to live with it." I ask her if she gets angry or sad about it at times since the stroke incident. This is the most crucial part of our conversation. She does reveal to me that "there were times that I thought about my husband and how debilitated he was after his stroke and I was a little afraid." I ask her "why?" She responds, again slowly "I was afraid that I was not going to get my speech back." "I was afraid that I would just wither up and die."

She goes on to tell me that "my family members were a great help to me to not feel so "isolated" from the world or my friends." "I think that it was a miracle of God that I have a close family and that they were so near when it happened." "I don't think that I would be this far along today without the help and understanding of my family and friends."

I reveal to her that her grandson said that he didn't think that she had any down times or sadness after the stroke because she always sounded so positive. She laughs. "Because I never wanted him or his family to see me down." "He lives all the way up there in Alaska and it would not do him any good to be worrying about me down here." "He has plenty of worrying for himself and those great-grandbabies of mine." "I bought this little outfit and told him and his wife to put it up where they could see it every day." "They were having some trouble getting pregnant." "Well, it must have done some good, 'cause they got three kids now!" I have to chuckle out loud. I hear the aunt in the background laughing, too.

I ask her if there was anything else she wanted to say and she says "I am tired and need a nap." I thank her very much for taking the time and energy to talk with me. She says to me '"Good luck on your thesis." And then we hang up.

4.1.3 Carlotta's conversational interview. I had been asking around UAF if anyone knew someone who has suffered a stroke incident. One of the employees has someone in their

family that has. I asked her if I could interview her and she agreed. Her aunt is now 77 years old and suffered a stroke incident about 10 years ago. We went into the conference room and I had her sign the consent form and then I turned on the recorder.

I open up the conversation by asking her to tell me about her aunt before the stroke incident. She smiles and laughs, "Aunt Turtle, that's what she has always been called. She is very southern and very slow." "Oh! She is amazingly talented." "She does arts and crafts. Painting; she used to sew, and needle-point." Her eyes cloud over now and her voice catches in her throat. "Her left hand is always curled up now, she can't use it." She wipes her eyes with her fingertips. "But she has always been somewhat of a homebody." She tells me, "She used to go out once a month with her lady friends to celebrate their birthdays." "She rarely does that now." I asked why that was so. She told me that, "It takes her so long to get ready to leave the house because she only has the use of one hand. By the time she gets ready, two-three hours could have passed." "To tell you the truth, I think she uses the stroke as an excuse to be at home." "She still does, however, still come over for Christmas dinner." "I go over a few hours earlier and help her get ready."

She now starts to talk about how her aunt has been physically affected by the stroke. "When she gets really tired, she starts slurring her speech, also when she has had to go out shopping. Her balance is a big issue much so now than before." I ask her about any other health issues and she mentions, "My aunt also has some issues with her heart and has a pacemaker." "I think the depression has stopped her from getting it serviced." "Her arts and crafts are still very important to her," Carlotta adds. "But I think they are more of a job now than a pleasure."

All of the sudden Carlotta starts laughing. I look at her and she explains why. "I told you

that her left hand does not work. I was talking with her one day and she says to me that she can no longer buy whole chickens. I ask her why. She tells me that she had the hardest time cutting up the chicken with just one hand." "My aunt says, "I chased that damn chicken all around the damn kitchen! Wherever it landed I had to disinfect." We laugh more.

I ask if there are any more funny stories or anything else she wants to share and she says, "No." I thank her very much and say good bye.

4.1.4 Agnes' conversational interview. I had attempted to call her one day but she was in the middle of cracking open crabs to make crab cakes. I could hear her slurred speech. I told her it would be no problem to call her the next day.

I call Agnes on the phone and at first she could not hear me and hung up the phone thinking it was the wrong number. I called again and spoke louder and slower and she understood me. Immediately I can hear the slurred speech. We talk a little about my project and I tell her I interviewed her niece and that it is very kind of her to let me interview her. She tells me that it is her pleasure to be able to help me out.

I asked her first how she felt after the stroke. I go on to explain that some people are angry, some are bitter, and some are depressed. She tells me that, "I was just exhausted." "I would get aggravated at times because I couldn't use my left hand, you see." "I have lost the feeling in it." "Let's say if I put my keys in my left hand and I start to walk down the hall (I live in a condo), if I couldn't hear them fall, I wouldn't have known I dropped them." "The main thing is I can't pick up anything with that hand. I am just grateful that the hand therapy worked and it isn't curled-up anymore." "I had a good doctor." "I really enjoy to cook. But sometimes I have to ask people to do things like cut up and onion." "I mean, I could do it, it would just take too long and I would get too tired."

I am not doing much talking, and I just sit back and let her tell me her story. "It's kind of hard to put on lipstick. One side of my face has no feeling." I ask her what side and she tells me, "It is on my left side. "Everything is on the left side." "It takes me so long to get ready to leave the house. If I know I am going out the next day I always take a shower or bathe the day before." "Taking a shower is exhausting." "I can do most everything I used to. I paint, I draw." I tell her that I draw, too. She asks me, "What do you use?" I tell her mostly charcoal. "I just finished a painting. I bought this little print at Neiman Marcus in 1962, *The Peaceable Kingdom*, I am going to give it to Carlotta when I am done." "I will take a picture of it so Carlotta can bring it in and show it to you." I thank her for that and tell her that I have seen that painting in my art books.

"You see, I can only copy things. My sister, she could just sit there and paint things from her head. I can't do that. I have painted that picture on so many things now, I am about sick of it." She asks me, again, what this is for and I re-explain to her it is for my thesis. She says, "I will have to ask Carlotta how you do on your thesis, then darlin'." I thank her, again. She says it was, "so nice to talk to you darlin'. I hope you do well. Bye now."

I tell her goodbye and it was a pleasure talking to her.

4.1.5 Robert's conversational interview. I called Robert on my mobile phone as he lives in another state. He was not in agreement for me to record our interview. I said that would be okay. I told him I was very grateful to him for allowing me to interview him and he said that it was not a problem. I faxed the informed consent form and he faxed it back signed.

I asked Robert about his post stroke depression and he was not very open about it. "Oh, it's not a problem. I didn't have any kind of problems like that." So, I asked him what kind of medications he was prescribed post stroke. I commented that one of them was an

antidepressant. I asked him about the stroke incident and what had happened afterwards. He said that he could "remember everything that was going on. I remember that I was mad that you called an ambulance." "I couldn't talk right, it made me feel like I was stupid or something." "It was awful, very bad." He goes on to tell me "I couldn't even read the damn newspaper." "The next day everything looked like *x's* and *o's*." "It was very scary, I didn't know if it was going to be permanent." "I couldn't even hold a decent conversation for weeks."

I then asked him if he thought the care he received immediately after the stroke was adequate or not. "No, I think the doctor was excellent." "The doctors were hesitant at first to tell me what they thought the prognosis was going to be." "I some neuro-psychological testing done and I was only performing at an eight grade level." He stresses again, "I had excellent doctors; I had this woman neurologist and I think she was excellent."

I asked him next how his interpersonal communication had changed. He said "You know, it was the lack of the ability to hold a conversation that made me feel very stupid." "I think that my friends were pretty understanding, you know, after I had explained to them what had happened." I then asked about his family, if he thought they understood. "No, they didn't have a clue. They did not understand to what a significant degree that the stroke had affected me."

I try gently to approach the subject of depression again. "No, no that is not a problem." He said "I was angry and bitter for a long time." When I asked him about rehabilitation he stated that "The doctors had me doing these mental exercises." Later, in the conversation, I asked about how his wife had helped. He now said "She had me doing these mental exercises; crossword puzzles, daily reading, I was reading constantly, and journaling. I hated

the journaling. I mean, what the hell was I supposed to write about?" He did give his wife the credit for the exercises that he was doing to recover. He shared with me that he "was mostly angry with himself." "I had to have even the cupboards and drawers labeled to know what was in them." "I was just angry at myself because I couldn't remember anything." I finally asked him if he suffers from anything that is noticeable. He denies any such thing. I push the issue a little and ask about slurring of the speech. He says that he does not have a problem with that. Next, I ask him how his *anger* manifested itself. He says that he was, *grumpy* a lot. "Well, I tried to keep the anger inside myself, but it came out sometimes. I was grumpy."

"I remember being short-tempered and frustrated when the people around me thought I was stupid." "But now it is just like nothing happened, I am fine; back to normal." I close the interview by telling him that I am glad that he is doing so well now. I ask him if there is anything else he needs to add and he says no and I hang up my mobile.

4.1.6 Chad's conversational interview. He is going to be talking to me about his maternal grandfather. In 2009, he had his second stroke incident and was severely debilitated. He passed away after the second one. Two years prior to that he had his first stroke incident. He has the year of his grandfather's death tattooed on his back along with his year of birth. He was 83 years old when he passed away.

I now ask Chad to tell me about his grandfather; what he was like before the stroke incidents. Chad begins by telling me that his grandfather was always a, "very stubborn man; a man's man. He hunted, fished, and was a father of six." "He was also a scout leader and did the Cispus program with the kids from the local school. He would take them out and teach them survival skills; taught them what and what not to eat" "He was an elder at his church

and the janitor for the schools." I questioned him about Cispus and what it stood for and we Googled it. It is the name of a local river in that area. "He was a World War II veteran and fought on the Eastern front." He goes on to tell me that his grandfather was, "not shy at all, he had this air of confidence about him. He was friendly, out-going."

I ask about his first stroke. He tells me, "I got the call in the morning hours. The stroke had happened the night before. He was in the hospital about three weeks." He said that he, "couldn't read, couldn't see the other half of the page. His left side was limp." There is a very long silence. I watch many emotions pass over his face. He tries at least four times to speak. Tears come to his eyes and every time he tries to go on, he chokes up. I sit there and decide to just wait. After a while he can continue. "The second stroke was very debilitating. He was actually bedridden for a long time." "He shuffled when he walked." He stops for a moment and smiles, "He was always a very strong man. He always provided for his family." "I remember seeing the inward struggle when he had to call upon other people to help him."

He starts to chuckle a bit and tells me, "He was somewhat persnickety and obstinate afterwards; not like his usual self at all." "He kicked a cat once. He had these stray cats that he would feed and one day he was out there feeding them and this cat that was not the usual cat that came by." "That fucking cat! If he comes back I am gonna stomp its head." "There was no reasoning with him at these times, he was completely unreasonable." "He was a lot less patient and more critical of people; life." He snickers. "Yeah, he had a lot less patience, even hugs could bother him if you hugged him too long."

I ask him now about his interpersonal communication style and if it had changed.

"Conversations were a lot shorter. He didn't have the patience anymore for long ones." At

this point in time Chad leans forward in his chair and there are tears forming in his eyes. "The confidence was gone. I saw just resignation. He was afraid, I can see it at times." "There was talk staring in the family about putting him in a home. After he was placed in the home, he couldn't remember things anymore, they were gone." "About six months after he was there, he passed away." "I remember this one conversation I had had with him in particular, he told me that he was "studying for a test". There was this big test he had to take and he had to pass it." I wait a few seconds and then ask if there was anything else he would like to tell me. I thank him for his time and shut off the recorder.

4.1.7 Victoria's conversational interview. Her best friend had had a stroke and she very much wanted to take part in the research. I had her sign the informed consent form and turned on the recorder.

I ask her to tell me about her friend, Phillipe such as what he was like and how she met him. She tells me that he is "my best friend." "Well, I had originally met Phillipe at another university in Alaska in 2003 when I started working there as an assistant professor and he was a brand-new assistant professor." "We immediately bonded, at a barbeque. He was sitting by himself and I am always awkward at those kind of situations and so I walked over to him and sat down next to him. This is kind of a personal thing, but I figured, uh, from what he looked like that he was gay. And so I started up a conversation and I asked him if he was gay, I said, you know, I am. And maybe we could become friends and we talked and before I knew it a couple hours had passed." "... we were talking about metaphysics and he was knowledgeable. And for me that is hard to come by. People can't talk intelligently about it. He could. And we bonded over that." "We started talking research together. I even co-taught a research class with him... we just had wonderful conversations about research and metaphysics."

"I would spend the summers in Fairbanks and would go down to Juneau to find a place to live. I was always running behind financially and I would show up in August not having enough money to rent a place so I stayed with Phillipe, oh, the first time I stayed with him for a month. I lived in his studio apartment. The two of us. I was on the floor with a pad and he was on the floor with a pad, a thick pad and he; Phillipe was a Buddhist by choice and he did his chanting; his Buddhist prayers every day. He lived a very, what do you call it? what's the word?" I insert *minimalistic* here and she continues on. "Yeah, he had hardly any furniture in his apartment. I had to bring a *chair*, a fold-out chair because I needed to have it to sit in because I had a bad hip at the time."

"But we had such wonderful times talking. And he was a vegetarian for a while and then he switched over to eating meat. But he would cook all sorts of what I would call Asian-type foods and a lot of brown rice...he was very health-minded." "He was concerned a lot about diabetes because his mother had diabetes, so he made sure he didn't eat a lot of sugar. He knew I had those tendencies, I hadn't been diagnosed yet, but he knew I had tendencies for diabetes." "As it turned-out we just became very tight friends." "It's hard to explain the progression of it, but we just became close and he had had other close people he had gathered over the years."

I ask her what else she can tell me about Phillipe. "He had a Ph.D from the Hawaiian University... and his focus was diversity." "When he taught his graduate course in education he had a focus on diversity... that's what I had a focus on because I teach a lot on gender and diversity." "He had a friend named, Theresa. She had a master's degree and they taught together." 'When he moved to Juneau she wanted to move with him. But she couldn't find a job. So he master-minded a way for her to join him at Juneau in a part-time position that

worked its way into a full-time position." 'So she's there now in Juneau, so she did move there eventually." "I got to know her, too. She as a little bit jealous of the relationship I had with Phillipe." "She kinda felt that *she* was Phillipe's *girl*."

Now she starts talking about Phillipe's partner, Jacques. "Well, Phillipe was a gay man and his partner, Jacques, he met him in Bali; Java; I guess that's where." "He had never had a long-term relationship and he got involved with Jacques. And he was committed to him. Phillipe built him a house, it is very cheap to build in Indonesia. Phillipe spent a lot of time there. He spent all his summers in Bali with Jacques." "They're married now. And this is one of the problems, I don't know if you want to ask me some questions."

I tell her I do, and ask her if she knew anything about strokes. I start to ask her about the post stroke Phillipe. I had remembered she had said that he could not speak. "Speak, he lost his recognition of language; I mean letters, he could not remember them." I interject here that he is completely aphasic now. "From what he has told me, because I had a long conversation with him over the phone about six months ago, he called me. Which was a surprise..." "He knew everything that he did and what had happened to him. But he just couldn't articulate anything. His sister did not want him in Bali. She had him come to her house and had him doing speech, occupational, and physical therapy in a rehabilitation facility. So now at this time his sister and Theresa are the main contacts and Theresa has remained the main contact to this day. She had promised to keep me updated with Phillipe, but that didn't happen." "So, he was telling me that all of the sudden a light went on and he could now articulate again." We now switch back to Victoria's phone conversation with Phillipe. "It was good. But when I would ask him a question, he wouldn't answer. He would stutter and then count out loud; one, two, three, four, five, six, seven, eight, nine, ten,..."

"That was a mechanism that helped him concentrate and re-center him when he got frustrated. But he still wouldn't answer the question. He would start to randomly talk about what he wanted to talk about and then he would get angry. It took me a while to realize this."

So now I ask her about the obvious changes in his style of interpersonal communication. She reiterates that he, "couldn't carry on an interpersonal conversation, he would get very frustrated." I ask her now about post stroke depression and what role it played. She said that he had told her that the frustration level had gotten so high that at one time, "He actually thought about killing himself." "He was very depressed." "I mean, his plans, everything he had wanted to do with his life was never going to happen. He had always talked about when he retired that he was going to just spend his time with Jacques on the beach." "That is exactly what he is doing now that he went back to Bali. It's just not in the way he planned it." "Phillipe does everything for him, so he is regressing." "I lost my best friend in every way, intellectually, spiritually..."

We end the interview with her telling me that Phillipe had cast a birth chart for the year 2017 and is determined to spend it here, in Fairbanks, with Victoria. I smile and say that I hope it really does happen and stop the recorder. I thank her for participating and just as I am about to leave, she asks me about a story that had surfaced a few years ago about a man that had lost everything, he had no arms, legs, and even most of his face was gone. But he had an attentive nurse and she figured out that he was, "still there and could communicate by blinking." She says that some stroke survivors are like this man. They are still, "in there." "We need to be sensitive enough to be able to find a way to communicate with them." 4.1.8 Martha's conversational interview. I had heard about Martha through one of the students here, at UAF. When I asked if I could interview her I was told that she was suffering

from such severe PSD that she had to be flown to the states for treatment. I thought about it for a while and realized I *must* speak with this woman. I ask my friend if she could call her and ask her if I could have a brief conversation with her over the phone. A few days passed and I got word that I could. I call her at the facility she is at in Seattle, Washington and tell her that I am indebted to her for letting me talk to her.

We start out with me asking about herself. She told me that she is a 50 year old woman of Athabascan heritage. She had a hemorrhagic bilateral stroke one and a half years ago. Her speech was severely affected and so was her hands. She said, "I was very confused. I wasn't sure exactly what was going on. I felt so strange." "But, when I did *finally* realize what was going on, it sunk in that this is how I am going to be. I just...I don't know, I just didn't want to accept that." "My husband and I had been divorced for a little over two years. We hadn't had any children. I had been alienated from my family for so long due to the marriage, I didn't have anyone I could talk to or turn to about this." "One major thing is that my damn hands shake so bad it is hard for me to do my beadwork.

I ask her about the PSD and she is very open about it. "The medicine that my doctor has given me for the depression is not working." "There are some days that I don't even get out of bed and get dressed, I mean; why? What's the use?" "I kept telling my doctor that I didn't feel right and he kept telling me to give the medicine a little more time to start working. Well, we can see how well that worked out." "There were so many tests run afterwards. If I have one more damn test run, that's it. I mean, you know, what are people who live alone supposed to do?" I ask her if she thinks that this facility is going to help her. She says, "I think it is." "It's better, I mean, I feel better here." As I had promised her I would not keep her long, I wish her the best and thank her very much for her frankness in the interview. We

say good-bye.

Chapter 5

Interpretive Analysis

After reviewing the transcriptions and re-reviewing them to see what emerged from them as far as common phrases, words, relationships, or a common theme, four overarching themes emerged. A very important aspect of data analysis is to let the interviews have their own voice and listen to it. Upon studying the transcriptions I let myself delve into each experience and search for patterns that are interrelated. I believe I have crafted these emergent themes to accurately represent the experiences of my co-researchers.

5.1 Theme 1: I Can Do This! I Have To; I Have Too Much To Live For

The first theme that emerged was this staunch resolute determination to go on and to be successful as the post stroke self. Even though there exists the memory of who they were pre stroke, they have made a determination to accept and be the best self they can be. Amidst the daily struggles that a physical disability could present and the uncertainty that a new day can bring, they are adamant about being successful. Looking at the ones who epitomize this there is a depiction of a tough, competent, and sometimes stubborn stroke survivor with this need to keep persevering despite this setback.

This reminded me of one of my co-researchers, Angela, Andrew's grandmother. I asked Angela about her aphasia and she responds, "I am learning to live with it." This is a woman who is very strong and independent. Even with her post stroke limitations she has tried to continue to live her life. She has a large family and they are very important to her and she is to them. The thought of giving up has entered her mind, but she has made a determination to go on. In fact, if she had given up, the outfit for the baby would never have been bought and given to her grandson and his wife to, "keep for that little one." Well, they have been blessed with *three* little

ones via adoption.

Agnes, a co-researcher of mine is also one of the stroke survivors that helped me see this theme. In her words "I can do most everything I used to. I paint, I draw." She has not let the fact that she has extremely limited use of her left hand stop her from the things she loves to do, and has adapted strategies to help her do them. "If I know I am going to go out the next day I always take a shower or bathe the day before."

Robert, another one of my co-researchers had been able to go back to work and worked until this year and plans on retiring. I recall him speaking about the severe frustration he experienced immediately post stroke at not being able to talk correctly, remember things, and perform basic math calculations in his head. He overcame that and went on to retire from a position in a financing company. I would say that he was, indeed, a survivor that had a lot to live for.

There are ways that these survivors stay survivors. They employ mechanisms to alleviate the uncertainty, the stress, and frustration that every new day brings to them. One of these mechanisms is the use of humor (Heath & Blonder, 2003) or laughter. It is interesting to point out here that "historically humor has been approached from such multiple angles as evolution, physiology, and interpersonal relationships" (p. 93). Also interesting to discover is that those research findings in my review of the post stroke literature also hold true in my research. Heath and Blonder (2003) tell us that:

Many stroke survivors experience stress in the negotiation of acute post stroke changes such as an altered appearance and the loss of independence... Chronic illness is a time of increased reliance on social support systems and a time when coping skills translate into health-promoting behavior. (p. 92)

And, again, an interview with my co-researchers' grandmother, Angela, comes to mind. She uses laughter or humor as a mechanism to alleviate the frustration that can come when she cannot think of the right word. A certain amount of cognitive dissonance can be the result when a stroke survivor is in an important conversation with someone and cannot articulate.

Again, my co-researcher, Agnes, is who I think of. She also makes use of humor to alleviate her moments of frustration when her left hand does not function. If she should mistakenly place something in her left and it falls out, she responds with, "Silly me, I don't know why I just did that. I know better than to try and use that hand." I also refer back to the episode in her kitchen with the chicken. She jokingly says at the end of telling the story to her granddaughter, Carlotta, "I chased that damn chicken around the whole kitchen!"

The co-researchers' stories are able to place into our minds a very humorous series of scenes. This works because as Heath and Blonder (2003) explain, "elicits amusement because it creates the incongruent image." (p. 93). The incongruence, sometimes glossed as absurdity, creates an image that can successfully enable you to be able to see the *humor* in the thought of a proper Southern woman chasing a chicken around her kitchen yelling at it and wielding a knife. Continuing to do the things that they enjoy and having the strength to laugh at themselves is a very strong way to get across to the rest of the world that it is possible, post stroke to live a full life.

5.2 Theme 2: Don't Treat Me Like I am Stupid Just Because I Had a Stroke!

This emergent theme was one that I actually could *feel* through the stroke survivors' body language and *hear* coming through in their words. It is unfortunate that we live in a rather *Mecentric* world. This is hard on a stroke survivor. Found within the SC theory is the need as well as the processes of how we are deeply affected by our social environment. How we form a

part of our *selves* and then evolve through more and more interpersonal interactions is found.

Mead (1982) is quoted to say that:

neither the consciousness, mind, nor the self can be separated from action which involves a relationship between the organism and the environment" (p. 19). The two of them cannot be separated. They coexist and work together to create that organisms' *self* consciousness.

(p. 20)

It is unfortunate that the post stroke *self* must be exposed to this *Me-centric* society and find their new and emergent *self* is constantly being either misunderstood or misinterpreted.

The most prevalent misinterpretation is that the stroke survivor is *stupid* because they cannot even answer a simple question or remember what cupboard a pot is in. Family members have the tendency to expect more of the stroke survivor. They knew them previously and when he or she comes home and is around the family for the first time, the family members see a person with no physical alterations, so therefore, they must be just fine. We know this not to be the case. Dependent upon the hemisphere and sometimes what section within the hemisphere the lesion occurs is the type of damage sustained by the stroke incident (Heath & Blonder, 2003). Unfortunately, that damage is all hidden away inside a person's head.

Robert is one of my co-researchers who again comes to mind. I can *hear* the anger and frustration in his voice as he tells me "No, they didn't have a clue. They did not understand to what a significant degree that the stroke had affected me." His friends understood after he had explained to them what had happened. I remember hearing the anger in his voice as he would tell me about instances. "I couldn't talk right, it made me feel like I was stupid or something." "I had to have even the cupboards and drawers labeled to know what was in them." "I was just angry at myself because I couldn't remember anything."

Robert goes on to say that, "You know, it was the lack of the ability to hold a conversation that made me feel very stupid." I discussed earlier an element that is vital to SC is interpersonal communication, or the interpersonal interactions that we have with other individuals that help us form our *self* When that interpersonal communication is hindered, the stroke survivor appears to experience a great deal of cognitive dissonance.

Also, it has been reported that the stroke survivor is hesitant to engage in interpersonal interactions within social situations that pre stroke they were perfectly comfortable. They pull back or retreat from social gatherings and are hesitant to speak to people they do not know now. So, what should have been the fertile ground in what their *new self* was to be constructed, becomes a source of fear, uncertainty, and frustration.

Bandura (1997) has this to say about the *self* "self-belief does not necessarily ensure success, but self-disbelief assuredly spawns failure" (p. 77). Stroke survivors are in a state of confusion, stress, and distress. They can experience a high level of cognitive dissonance on a daily basis. It becomes imperative for the stroke survivor in this situation to learn methods of alleviating that cognitive dissonance in social situations or within their interpersonal relationships.

One method for this is the behaviors that a person exhibits that serve to alleviate that dissonance or stress. Within the theoretical framework of URT lies the rationale for the practice of these behaviors. Knobloch and McAninch (2014) address this in their book. URT places communication in dual roles: (a) communication is a vehicle for uncertainty reduction and (b) communication is affected by uncertainty reduction (p. 298). People experience both behavioral uncertainty as well as cognitive uncertainty (dissonance). There are three basic contexts that drive people to reduce uncertainty: (a) a partner deviates from the expected, (b) they expect to communicate with the partner in the future, and/or (c) their rewards and costs are controlled by

the partner (p. 298). The pulling back from conversations and/or the retreating from social settings due to fear, uncertainty, or anger, is all a part of URT. I have found that of the three foundational relationship strategies of URT, the two that are expressed post stroke are (a) passive strategies and (b) interactive strategies.

High levels of cognitive dissonance are present within the stroke survivor at any given time during their rehabilitation. Due to this fact, stroke survivors can adopt behaviors that will appear foreign to those around them that knew them pre stroke. I am recalling the interview with my co-researcher, Chad, when he was telling me about his grandfather after the second stroke incident. His grandfather could be very unreasonable, at times, for no apparent reason.

Chad remembers the time his grandfather was feeding the cats outside and he heard him fussing about something and came to check on him and his grandfather said, "That fucking cat! If he comes back I am gonna stomp its head." That was not the grandfather that Chad had grown up with that was a steward of the land and took care of the animals of it.

Two longitudinal studies conducted concur that it is difficult post stroke to continue on after this very disruptive incident. The psychosocial consequences of stroke are long term. Teasdale and Engberg (2005) concur with Kvigne et al., (2004) in their findings. It is a struggle to return to life, or a struggle to return to a life that they have renegotiated. Kvigne et al., (2004) followed a group of women to observe how they adjusted to life post stroke. They found that, "a lengthy struggle to continue life and preserve self during the first year and a half following the stroke" was common throughout the research data (p. 384). This is also concurrent with Teasdale and Engberg (2005) in that, "return to employment, social relations and leisure activities were affected" (p. 1049).

Because of the aspects of the post stroke rehabilitation processes and the reconstruction of

their *self* post stroke survivors truly need people around them that are empathetic and supportive. They do not need people to treat them as less if they manifest physical alterations due to a stroke incident or stupid if they happen to suffer cognitive deficits post stroke.

5.3 Theme 3: Support is Important to Alleviate PSD and Aphasia

The tragic fact that stroke survivors that have PSD and did not have a good support system are committing suicide up to ten years post stroke should be alarming enough for action to take place to help put a stop to this (Brown et al., 2012; Joubert et al., 2006; Nakao et al., 2010; Robinson-Smith, Johnston, & Allen, 2000). My co-researcher, Martha, is a sad reality of the danger of being alone post stroke with PSD. She is now in a facility in Seattle, Washington due to the severity of her PSD to receive treatment.

In fact, there were two other co-researchers who I was not able to get in contact with by phone to interview them because they were in a facility in the lower 48 to treat their PSD.

Although they were exactly who I needed for this research because their stories would have been an unfortunate and sobering example of the extremes that can be experienced with PSD, it just was not possible. They were not stable enough psychologically to participate.

Again, I thought of my co-researcher, Chad, here as he had a vital piece of information to share with me regarding this. "I saw just resignation. He was afraid, I can see it at times.

There was talk staring in the family about putting him in a home. After he was placed in the home, he couldn't remember things anymore, they were gone. About six months after he was there, he passed away."

In an article by Howe et al. (2012) families have been very vocal regarding the need to be involved with the stroke survivor's rehabilitation when the stroke survivor has a form of aphasia, they report that, "although the family members reported that they had a number of goals, even

many years after the onset, some participants reported that they were not involved in rehabilitation at all, to the extent that they wanted to be" (p. 519). It is very difficult to deal with the possible disabilities post stroke and having to re-construct their *self* also, but the incidence of aphasia adds a higher level of frustration and difficulty. If the stroke survivor has a good system in place this helps with their attitude towards themselves and that facilitates their rehabilitation (Murray & Harrison, 2004). Family-centered rehabilitation programs available, just not in enough areas of the country (Howe et al., p. 520).

5.4 Theme 4: Aborted or Re-Routed Relationships

Post stroke, the stroke survivor is inundated with change. Some of that change is good for them and some change is painful. I refer to the stroke survivors' interpersonal relationships. If the stroke survivor is one who can accept their new *self* post stroke and learn to modify their interpersonal communication methods or practices, they have a very good chance of maintaining their present interpersonal relationship. They may need to go back and repeat a few processes of the stages of relationships, but their partner is there to help them.

A person's sense of reality and/or how they construct it, confirmation, and transformation occur during interpersonal interactions. For instance, people talk to other people they trust about their problems, parents fill the early childhood role of educator, and on a daily basis a person interacts with his or her boss and coworkers. Deetz (1982) goes on to say, "the interpersonal encounter has a special residual capacity to support the individual and maintain identity and meaning" (p. 2).

That being said, there are those stroke survivors that absolutely cannot accept the fact that they will never be the same persona s they were pre stroke. Instead of revisiting the (b) experimenting, (c) intensifying, (d) integrating, and (e) bonding stages of relationship

developments, they move towards: (a) differentiating, (b) circumscribing, (c) stagnating, (d) avoiding, and finally, (e) terminating (Knapp & Vangelisti, 1996, p. 127). They are not willing to take the time to re-invest themselves into repairing the relationship.

Anger, resentment, or bitterness engulfs them and they give into it. At this point in time, they are not able to see the hurt of their partner in that interpersonal relationship. Anger, resentment, and bitterness turn the person's focus inward instead of outward. They become very *mecentered*. Instead of repairing the broken or damaged relationship, they stubbornly choose to leave it.

Sometimes, however, the stroke survivor is able to re-route the relationship and experience it in a new way. If a marriage has been dissolved, they can remain friends. If they were intimate partners, they can at least remain casual friends. The ties are not completely broken. This helps both the stroke survivor as well as the partner to be able to face the changes post stroke better because they have not experienced another *loss*. In regards to how this relates to the three relationship strategies found within URT, this would be an example of an interaction strategy

Gergen (2001b) addresses therapeutic communication and its ability to create reality. He says, "there is something about the nature of communicative interchange that engenders change" (p. 1). Within our interpersonal interactions, we can express ourselves to each other and then, in turn, have our expressions validated or critiqued.

It is within this process that a person actually gains more insight into who he or she is as their *self*. They are able to explore different aspects of their personality and cognitive processes and make decisions in a safe and non-threatening environment whether to change a part of themselves or not. The last part of that paragraph is where the answer lies to the question of why some stroke survivors can repair their relationships and why some cannot.

Some stroke survivors are just not left with the mental faculties to process and then act upon the intricacies of the stages of interpersonal relationships. Lack of patience as well as a diminished capacity for handling stress has a lot to do with it. Some cannot initiate new ideas, thoughts, or actions from themselves, they must look to others. Some are left with such a strong stubbornness that it hinders completely their ability to put forth the mental as well as emotional effort to save the relationship.

5.5 Conclusion

The emergent themes that manifested themselves to me were through the collaboration of my co-researchers and myself. What was discovered through the analysis process has been consistent with the findings of previous research on the subject. This fact has brought both a sense of hope and expectation to me. I believe this information will be useful to other qualitative researchers interested in the subject of the post stroke experience.

The first three themes have a rather positive tone to them. I find that very encouraging. It helps reinforce my initial thoughts that so much more research done in this manner needs to be conducted. But more than that, it gives the readers of this study an idea of the permanent aspect of the effects of a stroke incident. And, with that, a passionate desire to help better inform the medical community as well as the general public of the irreversible changes that a person goes through as the result of a stroke incident. And lastly, to have a greater sense of empathy for the stroke survivors as well as those in their immediate circle of interpersonal relationships.

Attitude affects a great deal as it has been shown here. We now know that stroke survivors with PSD that did not have a strong post stroke support group, or were not encouraged to pursue their rehabilitation, counseling, or have a doctor monitor their medication had a worse prognosis than those that did (Joubert et al., 2006; Nakao et al., 2010; Whyte & Mulsant, 2002). In one

longitudinal study, it had been found that after 10 years post stroke, out of the 103 stroke survivors with PSD, 53% of them had died (Morris et al., 1993).

I will include now my experience post stroke. My husband was doing well to regain his ability to hold conversations and was feeling better about that. His friends were very supportive. I was very supportive. I was a nursing student at the time of his stroke and soon realized that if I was going to truly help my husband, then I needed to pull away from the *wife* part of me and fully take on the *murse* part of me. In doing so, that alleviated a great deal of frustration I experienced around him on a daily basis. That also allowed me to concentrate on a plan of care that best suited his needs post stroke.

I had noble intentions. However, his family was not supportive. They either were very ignorant of stroke incidents and their implications or they saw a long-awaited opportunity to get their *daddy* or *son* back and seized upon it. They were very critical of me and how I treated my husband post stroke. As I had to talk to him slower and also not give him more than one task at a time to carry out, they felt and voiced that I was treating him like a kindergartener.

My own genetic illness was getting worse and due to certain aspects of it I knew we would have to re-locate to a colder climate. I put the remainder of my courses on hold and planned our move to Alaska. At first my husband was very excited about it and helped me plan the trip. That lasted only as long as the first conversation with one of his daughters. Soon after that, he became petulant and fussy about the plans.

When we first arrived in Fairbanks his mother called him every day and begged him to return home to her. She could not bear her only son living so far away from her. His daughters soon started calling and asking him to return, too. I had noticed a significant change in his behavior. Now, if he got angry about something he was much more demonstrative. His patience was even

shorter and he could get angry very easily.

We also discovered that he suffered from Seasonal Affect Depression Disorder (SADD) and refused to use the lights that helped alleviate it. He and also stopped taking all of his stroke medicine, including the anti-depressant. He went back to smoking again and drinking more. In a short period of time he realized that he could not live in Alaska, so he left me here. However, what happened to my husband and myself is not uncommon post stroke.

Research has shown that support post stroke is vital to the stroke survivor's recovery but also to help alleviate PSD. The presence of PSD hinders the rehabilitation process, hinders the overall process of the individual post stroke, changes the way the individual interacts interpersonally, and has been found to increase the mortality rate of this unique population of people (Brown et al., 2012; Ellis, Zhao, & Egede, 2010; Morris et al., 1993; Nelson et al., 1993; Whyte & Mulsant, 2002).

A strong support system post stroke also enables the stroke survivor to negotiate the difficult course of *self reconstruction*. Interpersonal communication within interpersonal relationships is a large part of that. If the interpersonal relationship is abandoned, a vital part of that course is omitted or avoided. Practicing avoidance takes the stroke survivor down a dangerous path. At the end of that path research has shown there to be death.

A greater display of empathy as well as acceptance and cooperation needs to be shown by the people that are in the stroke survivors' life. They also play a vital part in the recovery and reconstruction processes. If the stroke survivor is confident in his or her support system they have an increased chance for a higher degree of recovery (Teasdale & Engberg, 2005). This is an important aspect of the stroke survivor's recovery processes as they must gain back confidence in themselves (Carlsson et al., 2014; Kvigne et al., 2004).

Family members are sometimes the people in the stroke survivors' life that do the most damage. They are either too impatient for the stroke survivor to make progress or they ask too much of them. More readily available practical information needs to be constructed and distributed to help family members be a source of encouragement and strength to the stroke survivor. If needed, they need to learn how to pull back from their present role in the stroke survivor's life and learn how to be a rehabilitative presence (Carlsson et al., 2014; Howe et al., 2012).

Bandura (1991) also states that perceived self-efficacy refers to "people's beliefs about their capabilities to exercise control over their own level of functioning and over events that affect their lives" (p. 257). In his later research (1998), he redefines self-efficacy to include "people's capabilities to organize and execute the courses of action required to produce given level of attainments" (p. 624). If the stroke survivor does not have that strong support system in place, they will not recover as well. According to Ellis-Hill & Horn (2000), "the stroke respondents reported a negative sense of self, reduced social activity and psychological morbidity despite inpatient and outpatient rehabilitation" (p. 279). These respondents did not have a strong support system.

Recent research has been supporting this concept of *self reconstruction* post stroke. Recovery and rehabilitation following stroke must involve the concept of *self reconstruction* both mentally and sometimes physically (Brashers et al., 1999; Ellis-Hill & Horn, 2000; Ellis-Hill, Payne, & Ward, 2000; Kvigne et al., 2004).

5.5.1 Study limitations. The limitations that I faced in this research were that, at times, I could not conduct the interview in person. This made the interview process shorter. I also did not have the benefit of seeing firsthand their body language. Verbal as well as nonverbal

communication is necessary for the construction of meaning. The person in those interviews were somewhat more difficult to *see* into.

Another limitation was due to the presence of PSD and I lost some of my co-researchers because as they had to be flown to the lower 48 for treatment for their PSD. I was disappointed by losing them as they met the criteria exactly for my research study. I did, however, still benefit from the short phone conversation with one of them.

5.5.2 Recommendations for further study. The recommendations I have for further study would be to have more longitudinal studies done. Also, case studied would be a very appropriate research method. More research needs to be done solely on the subject of PSD. Methods of identification are needed and evaluating the progression of PSD at intervals. Practical information for the family members and the intimate partners of the stroke survivor needs to be researched and put into print in such manner that would not hinder anyone from understanding the information and being able to put it into practice. Something that I did not include in this study is the nurses' as well as the doctors' roles post stroke. They need to be more knowledgeable regarding rehabilitation facilities as well as community support facilities. Their out dated methods of caring for the stroke survivor, especially those with emotional sequlae, needs to be updated with the newest and best information possible.

I also recommend more studies conducted that include a very large number of participants. Since my research study was concurrent with the findings of the current literature, I would like to see at least 30 interviewees in a study. More and more research is being conducted using NI, as the lived experiences of stroke survivors are subjective and personal, however, the validity of these personal stories is being validated by the results of these qualitative studies (Brashers et al., 1999; Corsten et al., 2014; Le Dorze et al., 2014; Johansson et al.,

2012; Kvigne et al., 2004; Murray & Harrison, 2004; Thompson & Ryan, 2009).

The world cannot afford to simply stand by and watch as "Stroke" strikes, maims, and kills more and more people. We need to take a more proactive approach to post stroke care, rehabilitation, and long term recovery (Appendix G).

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Appendix A: Informed Consent Form

IRB#: 647908

Description of the Study:

You are being asked to participate in a research study about post stroke depression and

interpersonal communication. The goal of this study is to learn just how a stroke survivor deals

with having to recreate their identity and learn to communicate in their interpersonal

relationships with the comorbid occurrence of post stroke depression. You are being asked to

take part in this study because you have an interpersonal relationship with a stroke survivor.

Please read this form carefully. We encourage you to ask questions and take the opportunity to

discuss the study before making a decision on whether or not to participate.

If you decide to take part, you will be asked to be interviewed with your partner, spouse, friend,

relative, significant other that has had a stroke incident, for about an hour.

Risks and Benefits of Participating in the Study:

The risks you take if you participate in this study are that you might experience some emotional

discomfort at recalling an especially difficult time in your partners' stroke rehabilitation.

Confidentiality:

Any information obtained about you from the researcher will be kept confidential and destroyed

after the data analysis, if desired. Any information with your name on it will not be shared with

anyone other than the researcher. I will assign to you a pseudo-name to maintain your

anonymity. I will properly dispose of paperwork and securely store the transcripts of our

interview. Your real name will not be used in reports, presentations, and publications

Voluntary Nature of the Study:

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Your decision to participate in this research study is completely voluntary. You are free to choose whether or not to take part in the form of an interview. If you decide to take part in the interview, you can stop at any time or change your mind and ask to be removed from the entire research study. Whether or not you choose to participate, will not affect your grades/services you are receiving/etc.

Contacts and Questions:

If you have any questions now, feel free to ask me. If you have any questions later, you may contact: (Lora L. Hendley-Ilhendley@alaska.edu, 850-218-9098; Dr. Jean Richey-jarichey@alaska.edu, 907-474-7405).

The UAF Institutional Review Board (IRB), is a group that examines research projects involving people. This review is done to protect the people like you involved in the research study. The committee wants to help make the project the best it can be for you and the researchers. If you have any questions or concerns about your rights as a research study participant, you can contact the UAF Office of Research Integrity at 907-474-7800 (local) or 1-866-876-7800 (toll-free outside the local area) or uaf-irb@alaska.edu.

Statement of Consent:

I understand the procedures described above. My questions have been answered to my satisfaction, and I agree to participate in this research study. I am 18 years or older. I have been provided a copy of this form.

Signature of Interviewee & Date

Signature of Researcher (Interviewer) Obtaining Consent & Date

Referral Services:

Behavioral Health Center Turning Point Counseling Services

600 2nd & Spruce 315 5th Avenue

Fort Wainwright, AK Fairbanks, AK 99701

Phone: 907-361-7419 Phone: 907-374-7776

<u>Fairbanks Counseling Center</u>
<u>Veterans Administration Counseling Services</u>

912 Barnette Street 540 4th Avenue, Suite 100

Fairbanks, AK 99701 Fairbanks, AK 99701

Phone: 907-456-4729 Phone: 907-456-4238 or 877-927-8387

Fax: 907-456-0475

Student Health and Counseling Center (UAF)

203 Whitaker Building

Phone; 907-474-7043

Appendix B: Informed Consent Form (A)

IRB#: 647908

Description of the Study:

You are being asked to participate in a research study about post stroke depression and

interpersonal communication. The goal of this study is to learn just how a stroke survivor deals

with having to recreate their identity and learn to communicate in their interpersonal

relationships with the comorbid occurrence of post stroke depression. You are being asked to

take part in this study because you are a stroke survivor. Please read this form carefully. We

encourage you to ask questions and take the opportunity to discuss the study before making a

decision on whether or not to participate.

If you decide to take part, you will be asked to be interviewed with your partner, spouse, friend,

relative, significant other, for about an hour.

If you are suffering from any form of aphasia, please indicate that you understand fully the

reason you are participating in this study in a way that is clear to the interviewer. Also that you

give your co-interviewee permission to speak for you when necessary and/or indicate for you on

the consent from that you agree to be interviewed.

Risks and Benefits of Participating in the Study:

The risks you take if you participate in this study are that you might experience some emotional

discomfort at recalling an especially difficult time in your stroke rehabilitation.

Confidentiality:

Any information obtained about you from the researcher will be kept confidential and destroyed

after the data analysis, if desire. Any information with your name on it will not be shared with

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anyone other than the researcher. I will assign to you a pseudo-name to maintain your anonymity. I will properly dispose of paperwork and securely store the transcripts of our interview. Your real name will not be used in reports, presentations, and publications

Your decision to participate in this research study is completely voluntary. You are free to choose whether or not to take part in the form of an interview. If you decide to take part in the interview, you can stop at any time or change your mind and ask to be removed from the entire research study. Whether or not you choose to participate, will not affect your grades/services you are receiving/etc.

Contacts and Questions:

Voluntary Nature of the Study:

If you have any questions now, feel free to ask me. If you have any questions later, you may contact: (Lora L. Hendley-Ilhendley@alaska.edu, 850-218-9098; Dr. Jean Richey-jarichey@alaska.edu, 907-474-7405)

The UAF Institutional Review Board (IRB), is a group that examines research projects involving people. This review is done to protect the people like you involved in the research study. The committee wants to help make the project the best it can be for you and the researchers. If you have any questions or concerns about your rights as a research study participant, you can contact the UAF Office of Research Integrity at 907-474-7800 (local) or 1-866-876-7800 (toll-free outside the local area) or uaf-irb@alaska.edu.

Statement of Consent:

I understand the procedures described above. My questions have been answered to my satisfaction, and I agree to participate in this research study. I am 18 years or older. I have been provided a copy of this form.

Signature of Interviewee & Date

Signature of Researcher (Interviewer) Obtaining Consent & Date

Referral Services:

Behavioral Health Center Turning Point Counseling Services

600 2nd & Spruce 315 5th Avenue

Fort Wainwright, AK Fairbanks, AK 99701

Phone: 907-361-7419 Phone: 907-374-7776

<u>Fairbanks Counseling Center</u> <u>Veterans Administration Counseling Services</u>

912 Barnette Street 540 4th Avenue, Suite 100

Fairbanks, AK 99701 Fairbanks, AK 99701

Phone: 907-456-4238 or 877-927-8387

Fax: 907-456-0475

Student Health and Counseling Center (UAF)

203 Whitaker Building

Phone; 907-474-7043

Appendix C: Suggested Questions for Conversational Interviews:

Do you feel that you were adequately informed by your healthcare provider regarding CVA's or strokes?

Do you feel that you had adequate information given to you in your rehabilitation process?

Have you found any local community stroke support groups?

Do you find that now your style of interpersonal communication has changed any, if so, how?

What, if any, significant changes have you noticed in your personality or if you suffer from post

stroke depression how has that affected you (PSD)?

How has the presence of PSD impacted your style of interpersonal communication?

Did you find that PSD hampered your post stroke rehabilitation process?

How successful do you feel are in reconstructing your self post stroke?

Do you feel that you have accepted fully your post stroke *self* or do you struggle with that?

What has been the most frustrating aspect of your post stroke life?

Appendix D: IRB Approval Letter

(907) 474-7800



(907) 474-5444 fax uaf-irb@alaska.edu www.uaf.edu/irb

Institutional Review Board

909 N Koyukuk Dr. Suite 212, P.O. Box 757270, Fairbanks,

Alaska 99775-7270

January 14, 2015

To: Jean Richey, PhD

Principal Investigator

From: University of Alaska Fairbanks IRB

Re: [647908-2] Post Stroke Interpersonal Communication: A Study of Survivors

Thank you for submitting the Revision referenced below. The submission was handled by Full Committee Review.

Title: Post Stroke Interpersonal Communication: A Study of Survivors

Received: December 18, 2014

Action: MODIFICATIONS REQUIRED

Effective Date: January 14, 2015

Expiration Date:

Required Information:

Modifications will be returned to Full review.

Dr. Richey and grad student, Lora Hendley, attended the meeting to discuss this project and answer questions.

Protocol:

- 1. Section F: General Objectives: Please provide a lay language version of the project description.
- 2. Section J. Recruitment: Please clarify statement that recruitment won't be restricted by gender, etc.
- 3. K(5). Please provide a "no-cost or sliding scale cost" provider if possible.
- 4. Section L. Consent/Assent Process: Please discuss how you will determine whether the participantsunderstand the project and questions.
- 5. Please clarify that interviews may be conducted in homes or a different location depending theparticipants' perferences. Discuss privacy of interviews.
- 6. O(7). Please provide the responsible party, usually the PI.

7.	Consent/Assent: Please provide separate documents for stroke participants and partners.
	Pleasetaylor the template to fit your project. Please provide a lay language version of the project
	description. Reduce the reading level to an 8th grade reading level.

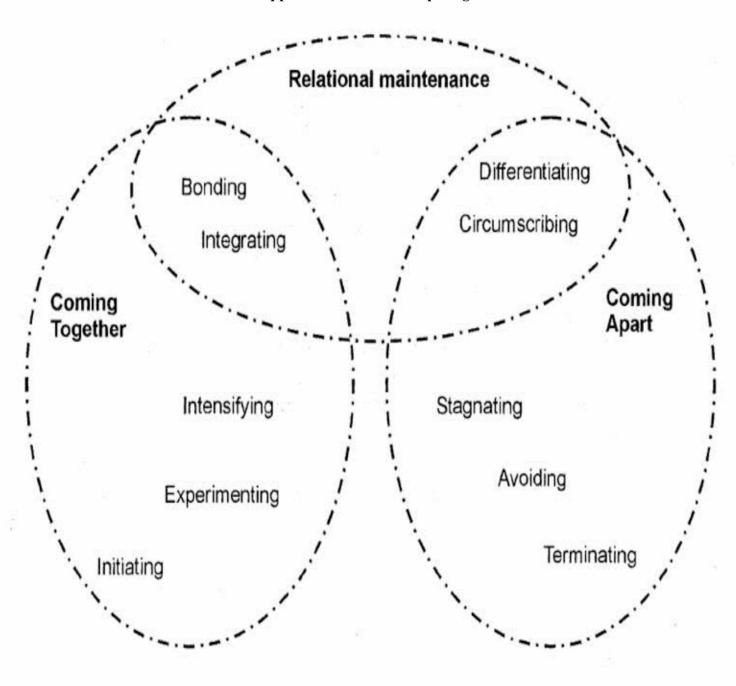
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8. Interview Questions: Please add an explanation about the questions being a guide and not a script.

This action is included on the January 14, 2015 IRB Agenda.

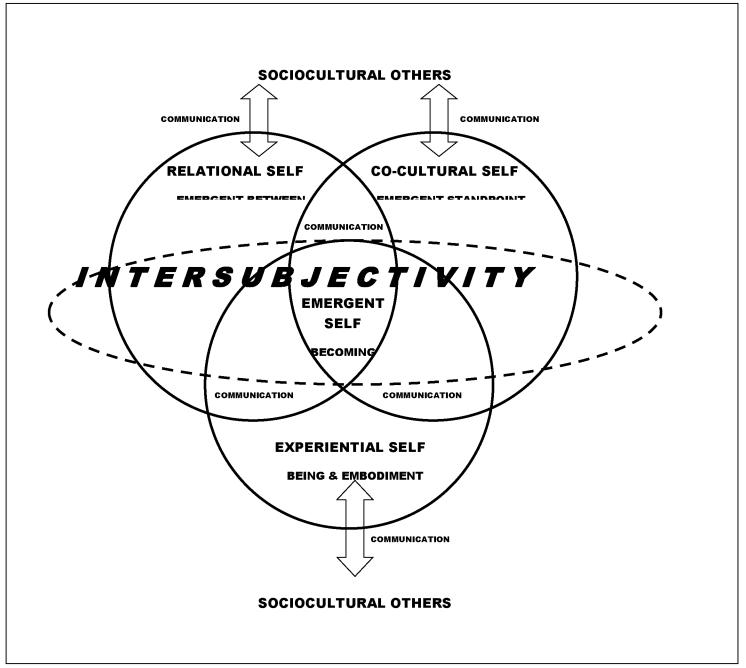
No changes may be made to this project without the prior review and approval of the IRB. This includes, but is not limited to, changes in research scope, research tools, consent documents, personnel, or record storage location.

Appendix E: Relationship Stages



Relational Maintenance Model (Knapp & Vangelisti, 1996).

Appendix F: Emergent Self: Modeling the Social Construction of Self



PHYSICAL ENVIRONMENT

The Emergent Self: Modeling the Social Construction of Identity

(Richey, 2003; Richey & Brown, 2007)

Appendix G: Stroke Narrative

Stroke Narrative

There is a wicked and adulteress woman running rampant in marriages and the lives of men and women all around the world. She travels around silently on her covert mission to maliciously seek out her next victim. Her appetite for 'forbidden fruit' is never satisfied. She is no respecter of class, education level, race, or religious affiliation. She wants all that she can have from her victims. She will never stop destroying or trying to destroy marriages and relationships. No depth is too low for her to stoop to, no trick too cheap, nor distance too far to travel in her need to completely overpower and gain total control over a life. She has no sympathy for the wife or husband left hurting, feeling abandoned and betrayed. Nor does she have any sympathy for the children she leaves fatherless or motherless; she is incapable of sympathy, she has no heart. Who is this wicked, immoral, and heartless creature? I call her 'Stroke'.