

The Emotional and Psychosocial Effects of Aphasia: An Autoethnography

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Abstract

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People with Aphasia, who have lost their ability to communicate fluently experience significant emotional and psychosocial effects of Aphasia, including fear, depression, and feelings of marginalization because they have lost their “voice”. They need nurses who understand the emotional and psychosocial effects of Aphasia, and who combine their clinical skills with an intentional focus on practicing the art of nursing to improve the quality of care for people with Aphasia. This research examines what it means to live with chronic Aphasia, a communication impairment that makes speech production and verbal output difficult after a traumatic brain injury (TBI). While stroke is the cause of the impairments, the primary focus of this research is on Aphasia and the toll it has on those living with Aphasia, a condition that affects speech but does NOT affect cognitive function.

This study describes one nurse’s experience with acquired, sudden-onset Aphasia after a left-sided stroke that resulted in Broca’s Aphasia, making speech production and output difficult. It describes the effects of learning to live with the stroke’s aftermath, loss of independence, identity, and professional standing due to chronic Aphasia. Drawing on her personal experiences

of living with Aphasia, this researcher conducted an autoethnography, analytically examining personal experiences, viewing it from a societal and cultural lens, using the framework of medical and social models of disability, and the art and practice of nursing care to explore the following research questions:

1. How can the art of nursing practice, verbal and non-verbal, positively improve the Aphasia patient's experience?
2. If caring is considered an integral part of the nurse's role, what opportunity do nurses have to provide effective Aphasia care?

In reviewing the research literature on aphasia patient experiences, the art and science of nursing care, medical model of disability, and social model of disability, in conjunction with the artifacts of her own life and experiences, the researcher sees correlations between themes of identity loss, social marginalization, isolation from mainstream others, inability to self-advocate, loss of voice, and the positive role that compassionate care and supportive structures can have on aphasic's resilience and persistence.

Implications from this study: In today's technology and data-driven clinical care environment, nurses can play an important role in improving the quality of aphasic patients' health care experiences by offering compassion, empathy, and ways to "listen" despite aphasics' loss of voice. Nurses who practice science with art of care can better develop relationships with the patient and family, promote trust, actively listen, and observe, and understand patients' and families' experiences and concerns.

Keywords: Aphasia, Broca's Aphasia, sudden onset aphasia, disability, right sided hemiplegia, TBI, traumatic brain injury, stroke, communication impairment, autoethnography, art and science of nursing, identity loss, marginalization, loss of voice, speech language pathologists.

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To my parents: Sergei Petrovich Sodbinow and Katherine Dakuginow Sodbinow. You arrived in the United States with my grandmother, me, and my five siblings in search of a better life. You worked for years to ensure that your children (now seven of us) received an education so we would not have to labor as hard as you did. I am grateful you saw your dream come true. We love and miss you.

To my brother, Pierre, you have been our family ‘sherpa’ from the beginning; caring for my parents as they aged and later, providing support for me after my stroke, and serving as my ‘*sherpa*’ throughout my studies. My right side is weak, and my right hand is paralyzed, and you have carried my books and supplies, gotten me safely to my destination wherever I needed to be - to the University of Washington for school or to medical visits in long car drives back and forth. If you had not been there for me, my graduate school would have been over a long time ago.

I also want to thank the Graduate School of Nursing for giving me the time I needed to improve after my stroke before returning to complete the program. I would also like to thank Disability Resources for Students’ staff for providing me the accommodations I needed along the way. To my dissertation committee members, Dr. Doris Boutain and Dr. Eeeseung Byun, Dr. Diane Kendall thank you for sticking with me all these years. Betsy Mau, I appreciate your kindness, compassion, encouragement and help with all the administrative details. Finally, Dr. Anne Hirsch, your guidance and encouragement throughout these years means so much. You are strong, impressive, and inspiring. You helped me find a way to complete this research so my voice could come through. I am profoundly grateful to have had you as my dissertation committee chair.

The Prequel

I thought about my active pre-stroke, the first part of my life. It was poor, amazing, and incredible. I was wrapping up my first full year in nursing, a PhD student. I was a 27-year in nursing, the Air Force nurse, the Certified Registered Nurse Anesthetist (CRNA) issues, work with international projects, and the owner and president of the Diversatility™.

The 2nd cause was my stroke. The stroke happened and the effects of it, in stroke, and aphasia. The loss of the ability to communicate in using spoken, or written language. It is not only the physical speech mechanism that is lost, but fundamental human needs. The's social, psychological, physical aspects, and the whole quality of life in me.

The 3rd one, I am proud of how our family came together to cope with the difficult hand we were dealt. Tosh, my brother, and I managed to provide my parents a quality of life as seniors during their last ten years at home. My father died in 2007 at the age of 90 years. My mother lived until 2011, when she died at the age of 88. Caring for them allowed me to feel useful, helpful, and confidential to others, perhaps, the most powerful factor in my recovery.

2011 to right now: the aphasia that will live for the rest of my life, the University of Washington, and it was tough, difficult, and challenging. But it was worth it.

Contents

Abstract.....	i
Acknowledgements.....	iii
The Prequel.....	iv
CHAPTER 1	1
Statement of the Problem	1
Aphasics are invisible	1
Registered Nurses	4
Research Questions RQ:	5
CHAPTER 2	6
Literature Review.....	6
Aphasia and Language.....	6
Clinical / Empirical Approach to Aphasia Care.....	8
Biomedical Imaging and Plasticity studies	9
Social model of disability and aphasia.....	10
Evidence-Based Medicine and Evidence-Based Practice in Nursing.....	12
Speech and Language Therapy	14
The American Speech-Language-Hearing Association (ASHA)	16
Aphasia	17
CHAPTER 3	19
Methodology: Autoethnography	19
Autoethnographies	20
Autoethnography with disabilities	23
Autoethnography with Aphasia	24
CHAPTER 4	25
Introduction	25
The History of Mongolian Oirats in the Russian Landscape	25
Kalmykia.....	26
Kalmyks and the Russian Empire	27
Kalmyks of the Displaced Person (DP) Camps, Germany 1944-1949	29
United States of America	32
Nursing Career	36
Registered Nursing (RN) and Certified Registered Nurse Anesthetist (CRNA)	36
CRNA Military, and Non-Military Professions Nurse Anesthesia.....	36

My Stroke and Aphasia	40
Dealing with Aphasia.....	43
Collaborative Caregiving for my Elderly Parents.....	44
Writing and Computer Skills Post-Stroke.....	46
My Diary (excerpt) before my stroke and afterwards	46
My Diary Post-Stroke and Aphasia – Excerpts	48
1999-2002	48
2006 – 2007.....	50
2010 - 2011	53
2019 - 2020	56
Graduate Nursing School	58
My post-stroke classes	59
PRE-STROKE EDUCATION – Mathematics: Humboldt State University, Arcata, CA	61
Sonoma State University – Rohnert Park, California	61
Reading Club for Individuals with Aphasia.....	63
My Class Aphasia Survey, June 2013	64
Chapter 5.....	66
Reflective Practice and Reflexivity.....	67
Positionality Statement	68
Themes.....	68
Loss of identity	69
Immigrant.....	69
Professional Identity	70
Identity as Student.....	71
Strengths of this autoethnographic study.....	72
Limitations of this autoethnographic study.....	73
Implications for Clinical Practice	73
Recommendations for Future Research	73
Conclusion.....	74
Addendum	76
California Association of Nurse Anesthetists, Address, 1996	76
Awareness of Aphasia Survey	84
Letter from Valerie Gardner	86
References	87

CHAPTER 1

Statement of the Problem

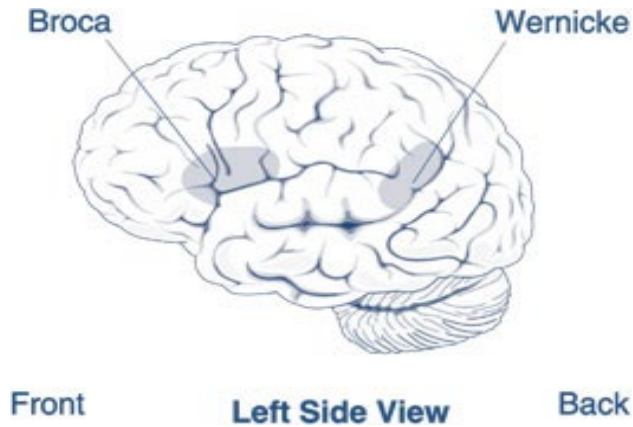
Stroke affects 795,000 people in the United States each year. One-third of them ~225,000 experience a left sided stroke which affects the right side of the brain and its communication center, resulting in sudden onset Aphasia, a communication impairment that disrupts their ability to produce or understand speech, and / or affects their ability to read or write (Aphasia.org). Aphasia often results from traumatic brain injury such as a stroke, and while it may be more prevalent in older individuals, it can affect any aged person due to other types of brain injuries such as head trauma, brain tumors, or infections.

According to a 2016 survey by the National Aphasia Association, there are “at least 2 million people with Aphasia in the United States.” This number is greater than that of other diseases such as “cerebral palsy, multiple sclerosis, Parkinson's disease, or muscular dystrophy” (<https://www.aphasia.org/aphasia-faqs/>).

Aphasics are invisible

Aphasics are often silent. In fact, most people with aphasia remain isolated and inaccessible at home. The loss of speech and inability to communicate, despite a lack of impact to intelligence, leads to higher levels of depression among people who are post-stroke with aphasia, than those who are post-stroke without aphasia (Kauhanen et al., 2000). It is in fact extremely common for people with aphasia to experience anxiety, depression, changes in their close relationships with others, job loss, unemployment, loss of identity, exclusion from social activities, isolation from others, and inability to participate in what were once enjoyable leisure activities (Thompson et al., 2012).

While Aphasia does not affect intelligence, or thinking, it does impair the ability to produce speech and writing (<https://www.nidcd.nih.gov/health/aphasia#what>). Even so, as a chronic disability it has been shown to have the “largest negative impact on quality of life, more than cancer and Alzheimer’s disease.”



Areas of the brain affected by Broca's and Wernicke's

<https://www.nidcd.nih.gov/health/aphasia>

“Aphasia is a disorder that results from damage to portions of the brain that are responsible for the language discourse” (<https://www.nidcd.nih.gov/health/aphasia>). A stroke occurs when a blood clot cuts off a blood flow to part of the brain. The image above shows a left-sided view of a brain and the Broca and Wernicke’s regions. When the brain cells in these regions die, a lesion is formed, resulting in fluent (Wernicke’s) or non-fluent (Broca’s) aphasia. (<https://www.nidcd.nih.gov/health/aphasia>). In Wernicke’s aphasia, speech may be characterized using unnecessary or made-up words or meaningless sentences. Often, people with this type of aphasia are unaware that their words and sentences make no sense.

In contrast, people with Broca's aphasia may have a clear idea of what they want to say, but they are unable to speak without great effort and short phrases are difficult to form. They may also omit the small words that fill out sentences such as, "is," "and," or "the." While many aphasics experience improvement in speech production over months and years, for many speeches may continue to be halting, hesitant and uncertain throughout their lifetime. For aphasics, this ongoing difficulty with speech can be a source of ongoing concern and effect their self-confidence.

Cahana-Amitay, et. al. (2011) explains that "the processes by which emotion interacts with language systems in the aphasic brain are still poorly understood" (p.146). Yet, it is clear, that stroke and aphasia have a negative impact on emotional well-being, with communication as a fundamental component (Code et al., 1999). A chronic condition, aphasia is not well known by the public (Aphasia.org/quiz). In 2020, the National Aphasia Association conducted an Aphasia Awareness Survey of 1,001 individuals, 25 years of age and older. The survey results showed that "86.*% of people have never heard of Aphasia and, only 7% had heard the term and knew that it was language disorder. 41.5% of those surveyed agreed, or were neutral, in their response to the idea that speech difficulties were a sign of intellectual deficiencies (Aphasia.org. 2020).

It is not surprising that those with Aphasia may withdraw from others to avoid being judged as having "intellectual deficiencies," (Aphasia.org, 2016) or draw attention to their impaired communication (Cahana-Amitay et. al., 2011). Others, lack of knowledge, or misconceptions about aphasia, coupled with aphasic withdrawal from social interactions, further erodes the bonds that give life meaning (Thompson et al., 2012). Thus, not receiving the empathy and understanding they need from others adds to the struggle, becoming a constant source of suffering for the aphasic (Liechty et al., 2007).

In today's complex health care systems, communication, and the ability to effectively advocate for oneself, is vitally important to accessing optimal health care. For people with aphasia, communication difficulties present overwhelming obstacles to their ability to fluidly express their needs. Conversation may be halting with words and sentences. Group situations with multiple conversations and / or external noises and sounds occurring at the same time can make it difficult to concentrate, much less be able to express their immediate needs. In stressful situations, such as an emergency or crisis, the ability to communicate worsens for aphasics, becoming practically non-existent, with some not even able to utter their name. This is critically important for medical professionals to know. Not only are aphasics already emotionally vulnerable, but when confronted with a health care situation, they are even more vulnerable and in need of empathy, caring, and understanding (Ganzfried et al., 2019).

Registered Nurses

Nursing has been described as a science and an art. The former refers to the evidence-based practice that is central to nursing while the latter refers to the significant role that nurses play in patients' experiences and perceptions of care as they blend the clinical with the human centered aspects of health care. Skilled nurses who possess the theoretical and technical knowledge blend the two, the human element and science, and make "the art of nursing come alive" (St Scholastica, 2018). They do this through their ability to develop relationships with the patient and family, their ability to promote trust, or actively listen and observe, so they understand the patient's experience and concerns.

Nurses skilled in the art of nursing can clearly explain complicated concepts about a patient's condition or treatment. More importantly, they are empathetic, possess emotional intelligence, and had the ability to read non-verbal cues, picking up on the emotional climate and demonstrating flexibility in their approach with diverse patients. The ability to effectively

communicate with patients is a critical “aspect of the quality of care” (Sundin et al., 2003, p.107).

With aphasic patients for whom communication is already affected, the nurse’s attention to communication, including what patients cannot say, is even more important. Nurses who strive for communication reciprocity will ensure that care is provided in co-operation with the aphasia patient. Their aim is to allow the patient agency, to take charge, and only take command of the communication when the patient is unable. When nurses practice empathy, they are “opening themselves up to receiving and sharing feelings with the patient” (Sundin et al., 2003, p.115) thus, gaining insight to their patient’s fears and concerns and what they need from their health care provider.

Research Questions RQ:

The purpose of this ethnographic research is to answer the following questions:

1. How can the art of nursing practice, verbal and non-verbal, positively improve the aphasia patient’s experience?
2. If caring is considered an integral part of the nurse’s role, what opportunity do nurses have to provide effective aphasia care?

CHAPTER 2

Literature Review

Aphasia and Language

Language, the system by which humans communicate with one another, is “pivotal to everyday life and to human culture” (O’Sullivan et al., 2019, p. 380). It is a complex process that incorporates various inputs, including thoughts, what is seen and heard, and orders them into structured patterns that become written, or spoken output. As such, humans are highly dependent on language as a primary way of expression, enabling the development and maintenance of relationships. Humans rely on the ability to express themselves through language and when language fluency, or the ability to communicate, is lost or impaired due to neurological disease or injury, it has serious psychosocial and emotional consequences for the patient (O’Sullivan et al., 2019).

Yet, it is an everyday occurrence in neurological practice, with language disorders typically arising from the primary injury to the left hemisphere of the brain, as with Aphasia. Aphasia as a language disorder becomes a chronic disability which causes stress for patients, their families and for their caregivers while at the same time making clinicians ability to collect patient data about their case histories, past experiences, and other needed data more difficult. Further, like other language disorders, Aphasia can be difficult to evaluate because “individual deficits often do not fit classical syndrome descriptions” (O’Sullivan et al., 2019, p. 386).

Aphasia has a long history of research behind it, and the field continues to evolve, so much so that it continues to challenge clinicians, and those in training, to keep up with evolving diagnostic methods and therapeutic interventions. A review of the literature shows that there are two approaches used in treating Aphasia.

The first is diagnostic, aimed at understanding the brain, its biomarkers, and the application of neuroscience in determining brain plasticity and its role in improving aphasic language capabilities. The second is to take a humanistic approach, one that factors in the psychosocial needs of the aphasic, understanding that loss of language impedes their ability to self-advocate, while at the same time they are dealing with disability, identity loss, job loss, and social marginalization.

Nurses are most often at the forefront of aphasic patients care whether in the hospital ICU, or in a doctor's office, playing a role in the treatment of aphasics in a variety of settings. Because aphasics are vulnerable, they need empathy, compassion, and willingness to communicate from nurses. Yet, in today's environment with the growing complexity of the nursing field, rapidly advancing technological innovations, and a growing shortfall of talent (<https://www.ncbi.nlm.nih.gov/books/NBK493175/>), registered nurses are finding less time to focus on delivering "care, compassion, and communication" that is at the heart of the art of nursing (Vega et al., 2019, p.62).

People with aphasia, in addition to losing speech capabilities, also find that their "sense of self" and the relationship-building skills are equally essential to well-being are also at risk" (Thompson et al., 2012, p.417). Therefore, it becomes even more important for nurses to focus on the patient as a whole person, whose "biopsychosocial needs, cultural preferences, and spiritual needs" must be met (Vega et al., 2019, p.62).

As stated earlier, communication is one component of the art of nursing practice and for aphasia, it is the most critical area needing consideration. The importance of communication in health care is already clear, with effective communication known to lead to the best outcomes (Ratna, 2019). Patients expect their care providers to prioritize clear communication. According

to Thompson et al., (2012), “when verbal communication is absent or unclear from severe aphasics, nurses are expected to use alternative strategies to communicate with their patients” (p.410). When nurses fail to seek and deploy alternative methods of communicating with those who have lost their skills, the quality of the nurse-patient relationship erodes (Thompson et al., 2014).

Findings from this ethnographic research study will fill a gap in nurses’ knowledge of Aphasia through the account of one career Registered Nurse / Certified Registered Nurse Anesthetist (RN/CRNA) who experienced sudden onset Aphasia and has lived with the condition for over two decades. It does so by offering the perspective of aphasics as patients whose emotional needs are uniquely felt related to their loss of identity and displaced status, in society, due to loss of language fluency. It is hoped that greater awareness of aphasia and its effect on aphasic patients’ emotional well-being, combined with a greater emphasis on practicing the art of nursing care, may lead to improved patient / nurse communication and treatment outcomes.

The following sections of this literature review describe two healthcare approaches, the Clinical/Empirical approach, and the Social Model as they relate to Aphasia and aphasia patient care.

Clinical / Empirical Approach to Aphasia Care

While measurable indicators for neurological diseases used to be rare, innovations in technology continue to improve the processes by which researchers track brain health, which results in less invasive testing and the ability to diagnose diseases sooner. Such clinical approaches to understanding aphasia and its effects include biomarker tracking and plasticity studies. In fact, Biomedical imaging of aphasia in the brain has “increased in the last five to ten years” (Smith 2017, p.1341). The aim is to better understand the functioning of the human brain

to determine how the lesion and resultant structural damage affects aphasia language and their prognosis for recovery, while at the same time, conducting pharmaceutical research that may aid in speeding up drug development, resulting in treatments that are more effective (Smith, 2017).

Biomedical Imaging and Plasticity studies

MRI (Magnetic Resonance Imaging) is often used to determine the effect of stroke and other injuries on the brain. MRI provides information about the brain's function (i.e., blood flow) and structure (lesion size, weight, gray and white matter effects). Smith (2017) describes this as the “functional and weighted structural characteristics in the brain” (p.1341). Ulm et al., (2018) described recent studies using various methods to investigate “recovery and treatment-induced neural reorganization in aphasia” (p.742) stating that while the field is new, such techniques will over time increase our knowledge of the “neural mechanisms underlying aphasia recovery” (p.759). They described such advances as critically important to the enhancement of projected outcomes and treatment effectiveness for aphasics, emphasizing that improved patient care “should be at the heart of what drives aphasia imaging research” (Ulm et al., 2018, p.759).

According to Eliassen et. al. (2008) neuroimaging has been used to study post stroke recovery by assessing brain function at three points: the beginning of a study, at the end, or by comparing before and after images to see changes over time. There is evidence of growing research focused on predicting aphasia recovery through the identification of neuroimaging biomarkers that could lead to new treatment plans. Yet, while Shuster (2018) advocated for the clinical implementation of neuroimaging biomarkers for recovery from aphasia, “there has been little discussion” (Shuster 2018, p.291) of how they will be used to determine patient outcomes. This is a critical issue because the most efficient way to develop treatments for aphasia is to

perform laboratory research. Yet, despite the promise of the research findings “research into this arena is, in its infancy” (Kiran et al., 2019, p.10).

Klein et al., (2008) says that neuroplasticity principles show that early intervention in aphasia capitalizes on spontaneous recovery, in the immediate post stroke period, with brain biomarker assessment being integrated with other methods known to influence aphasia recovery. For example, Klein, et. al., discuss the “essential principles of experience.” The idea is that you “use it or lose it” or “use it and improve it.” In general (Kiran et al., 2019, p.3), large left hemisphere lesions are typically associated with poorer recovery, whereas smaller lesions suggest better language recovery. It would be Plasticity studies support the “use it or lose it” principle showing that “beneficial behavioral and neural changes can be affected through intense and repetitive practice” (Kiran et al., 2019, p.8). Studies also show that intensive aphasia treatment therapy for short periods can be more effective than a similar number of therapy sessions over longer periods. Yet for many aphasics, there are few opportunities practice improvement of language skills when they are socially isolated (Shuster 2018, p.300–301).

Social model of disability and aphasia

Because a medical approach to aphasia care has its limits, a growing awareness of the need for a social model of disability approach to aphasia therapy has emerged (Tippett, et. al., 2014). To understand what is meant by the term Social Model of Disability as it relates to chronic conditions like Aphasia, it is first important to understand what it is not. It is not as laypeople, and many in the medical community, may understand as disability and there is a problem that needs fixing in the body of the person with the disability (Goering, 2015, p.134). The belief is that patients need to return to normal, or barring that, learn to adjust to the disability despite what is broken.

To clarify, when viewed from the medical model of disability, one's impairments are the bottom-line source of their difficulties, and the disability is the individual's problem. As such, the attitude is that the individual must seek to mitigate the effects of their disability through ongoing or continued therapy aimed at curing their condition (Goering, 2015). This perspective situates the person with the impairment (e.g., chronic Aphasia) as being less than, imperfect, flawed, subject to others' pity. It also suggests that every disadvantage they have is a result of their disability.

Conversely, the Social Model of Disability as advanced by disability scholars, activists and those living with chronic conditions, distinguishes between "impairment and disability" (Goering, 2015, p.135). For example, in the social model, Aphasia is the impairment, while disability is imposed by the external environment which encourages conformity to specific norms of what is acceptable to the larger society, promoting negative attitudes about impairment (and those with impairments) and make navigating public spaces, or engaging with others difficult. Thus, as Goering (2015) suggests, the problem is not with the person, or their physical body which has been disabled, the problem is with "their unwelcome reception in the world" (p.134). Thus, how we, as a society, think about people with a disability, combined with the physical spaces and structures they must navigate, along with societal and institutional norms and attitudes that result in circumstances that "exclude and/or denigrate them" (p. 134).

Consequently, registered nurses and other service providers who understand the distinction between the medical and social models of disability may uncover beliefs, attitudes, and behaviors that affect their relationships with patients with chronic impairments. By viewing disability as a social construct, care providers can seek to co-create authentic and engaging experiences with aphasics, seeking to provide the treatment they need, in order, to comprehend

what living with aphasia means to them, to improve their quality of life, finding ways to improve their communication capabilities and/or compensate for their impaired language. Some may want to focus on broader goals, to craft new identities or find new and different activities that add satisfaction and enhancement to their lives.

As care providers, nurses and others can support aphasics by helping them practice their communication skills, actively listening and engaging in two-way conversations, utilizing creative, visual, and technology enabled means to change and promote communication. Therapists and others who embrace the social model incorporate such means to provide aphasics with options that can be changed as needed because ultimately, the principle of the social model “is fundamentally about the relationship between healthcare provider and healthcare user” (Stark et al., 2005, p.919).

While there is increasing awareness within the health care community about the principles of the social model and its positive implications for health care, research shows that within the aphasiology community the approach is still considered as an alternate form of care as compared with the medical model. Consequently, aphasia clinicians and researchers are advocating for legislation in support of social model principles to ensure that they are not “left out of the healthcare delivery agenda” (Byng et al., 2010, p.921). This perspective may also be useful for nurses increasingly reliant on technology, data and evidence-based approaches that reduce focus on the nurse-patient relationship.

Evidence-Based Medicine and Evidence-Based Practice in Nursing

Evidence-Based Practice in Nursing has its roots in Evidence-Based Medicine (EBM) a concept that was first described as “the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients” (Sackett, Rosenberg, Gray,

Haynes, & Richardson, 1996, p.71). Shortly after, the notion of Evidence-Based Practice gained traction in the nursing field and, with the 1999 article published in *Nursing Management*. In that article, the benefits of implementing evidence-based practices in nursing were described with the suggestion that it (evidence-based practice) “defines and documents quality nursing practice and then practitioners ensure that the staff delivers quality patient care based on evidence rather than tradition” (McMenamin, Sun, Prufeta, & Raso, 2019, p.56).

The idea was that practice based on fact and statistics was better than practice solely based on intuition. Yet not everyone agreed. Loewy (2007) in his discussion of Evidence-Based Medicine (EBM) argued from an ethical perspective that EBM has become a “straight jacket” that based on institutional cost and profit concerns may tie physicians to dependence on use of algorithms and data even when the use of such data may not apply across patient demographics. Loewy (2007) provides such an example stating, “evidence gathered in 20- to 30-year-old athletes cannot be transposed to 50- to 60-year-old women who lead sedentary lives” (p.30).

McMenamin, et. al. (2019) state “in the 2000s, EBP was high on political and professional agendas, and nursing literature was abuzz with the term” (p. 16) and today, evidence-based practice (EBP) has become the gold standard in nursing with nurses having moved even further from the service role they had previously been known for, to that of “innovators, scientists, and scholars” (p.16).

Carper (1978) defined four ways of nurses’ knowing; the empirical, ethical, personal, and esthetic. In this new paradigm, only empirical knowing seems to be given primacy, with alternative modes of inquiry leading to practice given only passing reference in current nursing curricula. The emphasis on the nurse, generalist, or advance practice nurse, arriving at treatment strategies based on self-understanding and their relationship with, and in context with the patient,

seems all but forgotten with the nurse–patient relationship, as a model for practice now deemed less desirable with the scholarship that supports such an approach marginalized from mainstream nursing education. Today’s nursing education at most institutions is largely structured around standards and protocols.

McCarthy et al., (2019) provide an illustrative example of a recent doctoral candidate at a prominent Midwestern university whose study of nurse’s affinity with nursing identity and adherence to nursing theory–driven practice included interviews of graduating senior BSN students about their role identification and ability to define nursing. The researcher found that at the time, over 90% identified with their role and with nurse driven practice.

A year after graduation, the researcher interviewed the same cohort and found that only 5% identified any remnants of nursing paradigms as guiding their practice. The other 95% now identified with a medical model wherein their practice was driven by medical protocols. For them, “nursing no longer had a distinct identity or occupied any autonomous domain” (McCarthy et al., 2019, p.106). Despite such findings, Vega et al., (2019) believe that the best way for nurses to provide optimum care is through an approach that leads with compassion and sensitivity and draws on technical skills and clinical knowledge. In this way, nurses can provide the care that patients and their families need and expect.

Speech and Language Therapy

The pressures for nurses to stay current on, and use, emerging technologies to employ empirically grounded data and manage the administrative aspects of patient care, are just a few of the demands on their time, making it more difficult to confidently address their aphasic patients’ psychological needs.

Despite the challenges faced by Speech Language Pathologists (SLP’s) there is evidence that speech and language therapy after a stroke (as compared to no therapy) is effective for

aphasics. Therapy helps them improve their ability to communicate basic needs and they can improve reading, writing, and other forms of communication (Brady et al., 2016). Beyond the basics however there are numerous other factors to consider when developing treatment options for aphasics.

Speech Language Pathologists (SLPs) have long had to navigate the same issues in their care of aphasia patients. To illustrate, a recent survey of Speech Language Pathologists in the United Kingdom (n = 124) found that only “42% felt confident” in addressing their patients’ psychological needs (Northcott, et. al, 2017, p. 366). 72% cited “time and caseload pressure, 64% felt they lacked skills and training, and 61% felt they lacked “ongoing support” (p.366).

In another recent journal, Persson et al., says that “in Sweden, SLPs experience a lack of resources of various kinds to be able to fully comply with the *Best practice recommendations for aphasia* (BPRA) in 2021.

Foster et al (2015) said “an evidence practice gap has been identified in current acute aphasia management practice, with the provision of services to people with aphasia in the acute hospital widely considered in the literature to be inconsistent with best-practice recommendations.” Their engagement with the research is limited, in part because it is perceived to lack clinical utility. A sense of professional dissonance arises from the conflict between a desire to provide best practice and the perceived barriers to implementing evidence-based recommendations clinically, resulting in evidence-based practice becoming a disempowering concept for some. Recommendations from this study include revising how evidence-based practice is taught at both a conceptual and practical level; strengthening relationships between aphasia researchers and acute clinicians; and organizational change to promote evidence-based approaches to acute aphasia management to empower speech pathology clinicians.

Sarno (1998) states this most “eloquently”: “...For most individuals, aphasia therapy must be intensive, comprehensive and of long duration, but the cost of private therapy is prohibitive, and the availability of public funds is severely limited.” Limited reimbursement for services makes aphasia rehabilitation unattainable for most people. A second, no less important, obstacle is the “inadequate number of speech-language pathologists who possess the interest and expertise to work with aphasia” (Sarno 1998, p.90).

Without further studies demonstrating the effectiveness, the need for long-term treatment, and that document the psychosocial effects of the condition, things will not markedly improve in aphasia treatment. According to Sarno, the field of medicine’s focus on high tech acute care issues coupled with the chronic nature of aphasia (and its lack of visibility in acute care settings) reduces awareness and focus on aphasia.

The lack of awareness about aphasia is problematic. There is a prevailing misconception that recovery for the person with aphasia takes place only in the first six months post-stroke. Consequently, many aphasics are disqualified from receiving services after the early post-acute period (Sife 1998).

The American Speech-Language-Hearing Association (ASHA)

The American Speech-Language Hearing Association (ASHA) is a national association for “218,000” members whose work centers on audiology, speech, and language disorders. These include practitioners, scientists, support staff, faculty, and students. The association’s stated vision is “making effective communication, a human right, accessible and achievable for all” (<https://www.asha.org/>). To understand the magnitude of that vision one must know the broad range of communication disorders they must deal with, thus it is useful to refer to their Practice Portal (<https://www.asha.org/practice-portal/>) which provides audiologists and speech language

pathologists (SLPs) information on over 70 clinical topics, professional issues, client/patient resources and other practice related resources. Within the clinical topics area, aphasia is just one of over 40 topics related to speech, hearing, language, swallowing, and other related conditions. Given this broad range of patient related issues, it is understandable that in clinical and professional practice settings, SLP's might have minimal experience working with patients who have sudden onset aphasia.

Even in the Pacific Northwest region of the United States where I live, The University of Washington, a top-ranked research university with a dedicated Speech & Hearing Sciences department, it is clear their focus is broad. According to their web site they “address the fundamental aspects of communication—hearing, speech, and language—as well as the causes and treatment of disorders such as childhood speech sound disorders, aphasia, stuttering, voice disorders, and hearing loss” (<https://sphsc.washington.edu/>). Thus, for the practice, and for individual centers (like at UW) there are other competing communication disorders that SLP's must address. As a result, the number of SLPs and nurse's familiar with aphasia and with the effects of aphasia on patients is smaller than their overall practitioner numbers.

Aphasia

Worrall (2016) said “let's call aphasia” and “eliminate the term dysphasia.” But most of the people know it as communication disorders. They may not understand that “He can't talk” or “She's had a stroke” or “His speech is gone,” means that the person is struggling with word and/or name retrieval although their intelligence is intact. For people with aphasia, the ability to access ideas and thoughts through language are disrupted, not the ideas and thoughts themselves.

About 91% of people do not know anything about aphasia. If aphasia is over two million in America, why are few nurses in the care of them. In statistics, less than 10% know of aphasia.

There is a lot of people who have a communicative disorder, but aphasia is unknown. Elman (2000) says that while the word '*aphasia*' is sometimes used, it is often used out of context or in association with many different etiologies. These data substantiate the notion that "aphasia" has been inadequately described and may explain why so few people have heard of it.

In today's health care environment, this lack of awareness of the need for, as well as access to ongoing treatment for a chronic condition becomes even more urgent. According to Sife (1998), the number of people in the United States who need speech pathology services "far exceeds the number who are receiving treatment". He describes this conundrum as a "moral challenge" and reminds us that the current medical system's focus on high-tech acute care interventions ignores the need to improve the quality of life for those with chronic conditions.

And finally, for patients with Aphasia who feel they are judged for their slow speech and distorted expressions, the empathetic understanding that comes with this kind of nursing care can be significant. When "rare nurses" pay more attention to aphasia nonverbal cues and their patients' feelings, they open communication channels, allowing silence to the aphasia anxieties, worries and concerns so that nurses can better understand their emotional needs.

CHAPTER 3

Methodology: Autoethnography

“An autoethnographic study through the understanding of self, other, and culture” (Chang 2008 P. 3). The research method used in this dissertation and ethnography is a qualitative research method rooted in the social sciences. The study topics where researchers seek to understand patients’ experiences of health and illness, in ways that may not be easily understood through purely objective means (Peterson, 2015). It has been described as “one of the oldest” (Streubert, et. al., 2011, p.167) of qualitative methodologies, long providing nurse researchers with a personal perspective from patients, their family, and others, as to how they make sense of their health, their interactions with providers, their families and caregiver dynamics, and what it means to experience and manage various health issues.

Through ethnographic research, nurses can learn from patients what it means to experience illness or care from their providers within a social context. It can illuminate the patient’s “voice” in order to get at the “meaning of human behaviors within the context of culture and from a personal perspective” (Robinson, 2013, p. 14). Savage (2000) described the usefulness of ethnography to understand how patients perceive their illness or the way service providers deliver care. In fact, researchers’ interest in understanding patients’ personal experiences has led to increased use of a type of ethnography called autoethnography. Grbich (1999, in Streubert et al., 2011) states, “using this approach, the self is overtly and centrally positioned” (p.170). As such, this methodology has wider acceptance as a “legitimate research method in health science” (Chang 2016, p. 443) because it allows researchers to examine their own lived experience within a cultural context.

Autoethnographies

In the decades since Ellis (1999) first sought to promote autoethnography as a form of ethnography that “celebrates concrete experience and intimate detail (p.669), the methodology has grown and gained more acceptance in the social sciences. Autoethnography allows nurses to “access a realm of private experience that may otherwise never be made public, offering the potential to raise awareness, empower others and enter uncharted territory” (Peterson, 2014, p. 231). The benefits of the methodology are its ability to use what Sparkes (2020) describes as “highly personalized accounts that draw upon the experience of the author/researcher for the purposes of extending sociological understanding” (p.21). Nurse, and qualitative researcher, Sarah Wall (2008) describes the usefulness of autoethnography to write about her experience of internationally adopting a child thus “giving voice to personal experience” (p.38).

Grant (2019) states that to understand autoethnography one must first understand the meaning of its component parts, that of the self (auto), culture (ethno), and the written style (graphy) explaining that they are interdependent, and together, are used to develop a critical analysis of the social context in which the individuals find themselves. It is an “approach which values relationships, revelations and other powerful experiences as acceptable research data” (p.88). Best (2020) states that this viewpoint is supported by others who note the role of autoethnography in researchers’ self-reflection through an examination of personal experiences as data from which social experiences may be explored.

Yet while autoethnography has been recognized as a viable qualitative research method, it remains in its infancy within the nursing profession. Some reasons for this may be due to questions about the reliability of the data, the focus on self, and other methodological issues related to shifting the researcher’s objective stance to that of subjective participant posing ethical

challenges which result in the approach being “understudied and underused” (Peterson 2015, p.227). Other concerns are focused on perceived lack of rigor and the focus on one’s own life and experiences as being narcissistic and self-indulgent (Hamood, 2016; Roulston, 2018). Winkler (2017) cautions autoethnography, to remain focused on “learning about culture” (p.237).

To assure that autoethnographies succeed in providing the “thick description” of experiences that is characteristic of qualitative research while also serving as a “sociocultural interpretation” of those experiences, Chang (2016, p.448) recommends that autoethnographic researchers ask themselves some guiding questions:

- (a) Is the researcher-self the central figure of the study?
- (b) Are the rights of others in autoethnographic narratives protected?
- (c) Is the sociocultural meaning drawn from the researcher’s personal experiences?

Authentic and Trustworthy Data:	Does the autoethnography use authentic and trustworthy data?
Accountable Research Process:	Does the autoethnography follow a reliable research process and show the process clearly?
Ethics Toward Others and Self:	Does the autoethnography follow ethical steps to protect the rights of self and others presented and implicated in the autoethnography?
Sociocultural Analysis and Interpretation:	Does the autoethnography analyze and interpret the sociocultural meaning of the author’s personal experiences?
Scholarly Contribution:	Does the autoethnography attempt to make a scholarly contribution with its conclusion and engagement of the existing literature?

Despite resistance to autoethnography as an acceptable research methodology in nursing, the tide may be turning as greater emphasis is placed on the role of reflective practice in nursing. Ricker (2020) emphasized the importance of teaching reflexivity methods “at every level of nursing education not just as a research method but as part of a nursing approach and a method

for analyzing nurses' and patients' experiences in healthcare" (p.185). This idea may be gaining traction. Reflective practice is embedded in the Nursing and Midwifery Council (NMC) standards for the profession, with inclusion of documented accounts of reflection mandatory in revalidation submissions.

Interest in and the use of autoethnography in health care research continues to grow, especially during these uncertain and volatile times. Recent events such as the 2020 Covid-19 pandemic with its uncertainty and the need for social distancing further highlights the importance of reflective practice. Best (2020) suggests that nurses have a singular opportunity to explore their Covid-19 experience "within the cultural, social and political paradigms that exist, not only within the NHS, but the healthcare sector as a whole" (p.2). Thus, they can "gain greater insight into their personal and professional experiences and in so doing help to secure new ways of working" (p.1). In fact, recent published research includes one nurse's experience of providing mental health care during the 2019/2020 Australian Bushfire Season (Hayward, 2020) and Pruulmann-Vengerfeldt's (2020) account of using prompted writing as a form of autoethnography to make sense of the Covid-19 pandemic.

Such examples illustrate the effectiveness of autoethnography to help researchers gain the personal knowledge that Carper (1978) described as "knowing, encountering and actualizing the concrete, individual self" (p.28). As an approach to research, autoethnography allows one to describe and systematically analyze personal and emotional experience, challenging traditional objectively focused ways of doing research, it does so by treating research "as a political, socially just and socially conscious act." Thus, as a method, autoethnography is both process and product (Ellis, et al, 2011).

For this researcher, a former actively practicing RN/CRNA, the experience of suffering a stroke and living with chronic aphasia for over two decades can prove uniquely valuable in advancing the nursing profession and nurses' knowledge and understanding of what those with aphasia experience daily and the type of care they need from health providers. Through an examination, of my own experiences I may develop a narrative that Ellis (1999) describes as follows:

"...That includes researchers' vulnerable selves, emotions, bodies, and spirits; produces evocative stories that create the effect of reality; celebrates concrete experience and intimate detail; examines how human experience is endowed with meaning; is concerned with moral, ethical, and political consequences; encourages compassion and empathy" (p.669).

Autoethnography with disabilities

Narrative forms such as autoethnography have been used in recent years to describe diagnosis of illness and experience with disability. Lewis (2007) uses autoethnography to chronicle her intersectionality experience as an African American woman whose spinal-cord injury changes her identities and transforms her, from being able, to becoming a disabled person. For Schenk (2017), autoethnography allowed an examination of what it means to have multiple disabilities as developmental, deafness, and speech.

A narrative approach was employed by Schwartz (2008) to describe her diagnosis of Huntington's Disease while Harmon (2010) sought to understand her cancer diagnosis of non-Hodgkin's Lymphoma. Both sought to fill a gap in the health care literature about their respective diseases, in order, to allow vulnerable people a voice.

More recently in her dissertation about a registered nurse living with "chronic undiagnosed illness," Ricker (2020), credits autoethnography for helping to "transform a significant traumatic personal experience into a formal academic study" (p. iii). Key themes that

emerged from her study of undiagnosed illness were “not knowing, loss, and hidden self,” themes that are understandable for those whose lives are changed by illness and disability. More important and most relevant to my experience as an aphasic however is what Ricker describes as the “most important clinical implication” of her study: “to identify and develop nursing’s role in caring for patients living with chronic undiagnosed illness” (p.169).

Autoethnography with Aphasia

This autoethnography will describe my researcher’s experience as a career RN/CRNA after a stroke and living with aphasia, but it will *also* address the lack of knowledge, lack of information, and lack of education about aphasia that is common among health care professionals, as well as lay people. When lay people say it is a “communication disorder” and nurses say “aphasia,” those two things are not the same. Aphasia is the professional term. But in either case, people who lack education about aphasia advance negative psychosocial outcomes.

What this story exemplifies to me, so many years later, is the attribute in nursing to provide something, so seemingly small, and genuinely human. That of listening, not to provide solutions, not to give answers, and not even to provide direction but to allow human expressions of sadness, frustration, grief, and of emotional pain and to be there when another human being needs us. To listen and to show care is such a natural extension of nurses as professionals, but such an easily overlooked part of who we are, in what we do, that we may easily minimize this aspect of our work.

However, this small but significant act, continues to have great meaning during the chaos, glamour, and, yes, science of health care. It is still what emotional aphasia people reach for in their most vulnerable, helpless, and individual moments. Most of the moderate and serious aphasias are staying at home, so that they are invisible to the public.

CHAPTER 4

Introduction

Growing up in a family impacted by Soviet Communism, I developed an avid interest in the region. My grandmother, born in Elista, West Russia, in 1887, was a young woman when the Russian revolution erupted in 1917-1919. Illiterate and able to speak only the local dialect – Kalmyk – she succeeded in fleeing with her husband to Bulgaria where, under poor conditions in 1924, she gave birth to my mother. In late 1943, when Allied forces bombed Bulgaria, the family fled again to Germany.

My father was born on the *other side* of Elista and grew up fluent in both Russian and Kalmyk. He was a soldier in the Red Army when, on August 26, 1942, Nazi forces captured Kalmykia in Elista, Russia. As the Red Army pushed the German forces back, he eventually found himself in Germany. Along with fellow Kalmyk soldiers, he found his way to a displaced persons camp that housed their community. His sister and mother, sadly, were left behind in the USSR, the Soviet Union.

The History of Mongolian Oirats in the Russian Landscape

The Kalmyks as a distinct people trace their ancestry back to the early 1600s. At that time, the Oirats, one of the western confederations of the post-Mongol Empire, were decentralized and embattled in continuous back-and-forth struggles for the regions of Dzungaria and Mongolia. Our tribal unit migrated 2,000 miles farther west to the lower Volga region, where they settled and acquired the name Kalmyks between 1607 – 1630.



<https://www.nationsonline.org/oneworld/map/russia-political-map.htm>

Kalmykia

Kalmykia is the official name of the republic within Russia. The literature is ambiguous on the origin of the term “Kalmyk.” What our parents and elder kinfolk routinely told us children was that our people were the last vestiges of a larger collection of tribes that eventually returned to their Western Mongol homes some 150 years after settling in Russia. To me, the most satisfying account of the name’s origin is that provided by Michael Khodarkovsky as derived “from the Turkish verb *kalmak*-to stay, to remain.” The term differs from our understanding of our ancestors as nomadic pastoralists. However, growing up we understood ourselves as

remnants, removed from Mongolia proper yet not fully embraced by Russia, and later in the 20th century, exiled and displaced (Khodarkovsky, 2018).

Russian Imperial hegemony during the subsequent decades of the 17th and 18th centuries imposed political pressure upon the Kalmyk Khans to capitulate to the Tsarist authority. In addition, Russian settlements, as well as those of other outside peoples, encroached upon the Kalmyk's territory and pastures. Simply put, Russia's eastward and southern expansion coincided with the Kalmyk's arrival in the lower Volga regions.

By 1771, almost 80% of the dispirited Kalmyks in Southern Russia decided to return to their original homelands of Dzungaria and Mongolia. Between 170,000 and 200,000 Kalmyk people left on January 4, 1771, of whom it is believed almost 100,000 perished during the exodus. Fewer than one-third of the group, 66,073, reached Dzungaria, and in wretched condition. They returned to a decimated Dzungaria, the place where hundreds of thousands of their Oirat ancestors had been killed by the Qing Dynasty.

On October 19, 1771, the Kalmyks remaining in Russia were subjected to the imperial system of governing foreigners, which abolished all titles of the Kalmyk khan and thus ended any official recognition of a single Kalmyk ruler. All authority was transferred to Astrakhan governors.

Kalmyks and the Russian Empire

The Kalmyks, now subjects of the Russian Empire, continued their existence as semi-pastoralists. One celebrated group of Kalmyk men was accepted into the Tsar's Imperial guards. Another group was the Kalmyk men whose horsemanship merited inclusion in the neighboring

Cossack troops. By and large, Kalmyks had settled into a peaceful co-existence – until the Russian revolution.

The revolution and civil war created great anxiety in the Kalmyk population, especially among those who were prosperous and people of means (owning thousands of sheep, for example). This included my maternal grandparents. They recounted that several hundred families fled their homelands ahead of the Communists in 1919 and 1920.

As noted above, my maternal grandparents were successful in their flight, crossing the Black Sea into Turkey and eventually settling in Bulgaria with about two dozen fellow Kalmyk emigrees. My paternal grandmother and my young father, then only a toddler, were stopped by the Reds between their home and the Black Sea port of Novorossiysk. They were sent home to face the great agricultural disruption and attendant widespread famine that decimated large swaths of Russia in the early 1930s, having been preceded by the famine of the lower Volga basin in 1921-1922. My siblings and I often heard how our grandmother and father's sister kept a cow hidden inside their home during this time.

In Bulgaria after the revolution, the Kalmyk families remained in contact with other emigrees in Yugoslavia and France. These connections eventually enabled the families to find one another during the chaos of the Nazi retreat and Allied offensive push.

In the USSR, as the tide turned toward Nazi retreat, the Kalmyk population was deported in masse to isolated villages and camps scattered throughout northern, eastern, and southern Russia. The Kalmyk ASSR administrative unit was abolished after the Kalmyk population was accused of collaborating with the enemy.

As noted above, my father deserted at this time and found his way to a Displaced Persons (DP) camp in Germany. The total number of Kalmyks in the DP camp was estimated to be about 800. The Kalmyks in the DP camps, “believed that they may be the only remaining Kalmyks in the world” (Johnson, 2003). The tragic events of the first half of the twentieth century, the Russian Civil War of 1917, World War II, repressions against the clergy, and the deportation (via cattle wagons) of Kalmyks in 1943 led to the decline of traditional Kalmyk people.



Cattle wagons were used for the Soviet deportations of Kalmyks in 1943; Source: Wikipedia

Kalmyks of the Displaced Person (DP) Camps, Germany 1944-1949

The Kalmyks’ arrival to the DP camp near the end of World War II constituted a social gathering as well as an escape from the clutches of the Eastern Bloc of socialist states. Many were reunited after displacement by the revolution. Both sets of my grandparents had known of each other before the onset of revolution. It was in the camp that my parents met and married. More than a few nuptials occurred at the DP camp and of those, many of which were a matter

more of necessity than of love. This is a picture of my parents on their wedding day outside of the door of the main building at the DP camp where official rites were held.

For several grim years, the Kalmyks declined in the camp near Munich, while their spokesmen, working through the Tolstoy Foundation and the Church World Service, advocated for their resettlement. Their Mongolian background proved a liability, for it summoned up prejudicial stereotypes about Mongols and Orientals in general. The USA had an Asian exclusion policy in place at the time.



In 1951, however, the United States Attorney General's office was petitioned to admit the Kalmyks. The winning argument was that Mongolian was a Ural-Altaic language and that the Kalmyks had occupied European Russia for greater than three hundred fifty years. Thus, they were not "oriental" and could be granted entry into the US as Europeans. The first wave of Kalmyks arrived in the US between December 1951 and April 1952 – approximately 700 people.

In 1949, before the first of these Kalmyks had made it to the US, my parents followed my mother's sister and brother-in-law to France, where they found work, a hard laborer outside Strasbourg. There my mother gave birth to me, her third child, my two brothers were born earlier.



(My parents, two older brothers, and me in Dachstein, France)



*My grandmother, who fled Elista, Russia in 1919, and made her way to Bulgaria in early 1920s.
Here, she is in Philadelphia (1967) preparing a Mongolian fried dough called bortsuk.*

United States of America

My parents arrived in America on May 24, 1956, as part of the second wave of Kalmyks, aided by the Tolstoy foundation and the Church World Service. My mother, father, and six children sailed, along with my grandmother, across the Atlantic on the boat, SS America.

Source: Sodbinow family archives: May 1956 to United States to America, SS America



By this time, my father had about six years of schooling. My mother attended high school but did not graduate. She did have knowledge of Kalmyk, Russian, Bulgarian, French, and spoke some passable German. She learned English quickly upon their arrival in the US. At home, in Philadelphia, my mother was hard on her six children. Soon there was a seventh baby. All the while she was a stern, strict, and a loving mother. She always held a job of sewing at a construction building, or working at Korvette's Department store, or sterilizing equipment in the hospital. She was intent on educating in her children for a better life. I was the oldest of two

daughters that used to help mom out. Young ages: I can help put on the flame in the morning; assistance to the store, and visit and purchase bread; put everyone into the bath; and get everyone into the house the four of us, etc. etc. etc.

In 1990, while Gorbachev was in power, a gathering of about 50 families was planned in Elista, Russia. My father still feared the Russians, but he and my mother went away to Russia, afraid and worried. They went with Lisa (me), their daughter, and Viviane, the younger daughter. The four of us went to Kalmykia and they enjoyed the trip and now, they returned to Russia again the following year, resuming contact with many aunts, uncles, and cousins. Growing up I heard, read, and learned a good deal about my ancestral history, but that first trip to Kalmykia was a real awakening. From that trip, I learned much about the Cold War impacts and influence still in existence. Still, more importantly, I learned about the consequences of Communism on large populations of the people, and on a small number of the Communism leaders.

Overall, my parents led a poor, rugged, but resilient life. As remnants, not yet fully embraced by Russia, around 350 years, the deportation of Kalmyks in 1943, and in the 20th century, Displaced Person Camps, exiled and displaced. As shown in the Ship Manifest for my family's voyage to the United States in 1956 (see page 43) we were "stateless" people, arriving via ship to New York in the footsteps of so many poor immigrants before us. Emma Lazarus (1883) poem, *The New Colossus* (see page 44) eloquently describes what coming to the United States meant to my parents. About fifty years after arriving in the US, all seven of their children had earned a bachelor's degree, four held master's degrees, and one held a doctorate in Education. I am completing my own journey to the Ph.D. in Nursing. My family and I realize the good fortunes we have had living in the United States. My parents felt they had found a new home, which promised freedom, opportunity, and the hope of prosperity for their children.

MANIFEST OF IN-BOUND PASSENGERS (ALIENS) (PERM)

Class TOURIST from Le Havre, France May 17, 1956

(Port of embarkation)

PREPARED BY:

L.W. Gustafson - Jr. Purser

on S. S. A M E R I C A arriving at port of New York, May 23, 1956

(Name of vessel)

(1)

(2)

(3)

(4)

LINE No.	FAMILY NAME-GIVEN NAME	TRAVEL Doc. No. NATIONALITY	NUMBER AND DESCRIPTION OF PIECES OF BAGGAGE	THIS COLUMN FOR USE OF MASTER, SURGEON, AND U. S. OFFICERS
1	ACW CBEJNAROWICZ, Konstanty 47 Billerica Street, Boston, Massachusetts	I-786569 Stateless	1	73
2	DAKUGINOV, Nadischda c/o Mr. S. Sodinow Church Road Farm, Medford, N.J.	I-786600 Stateless	SEE LINE #8	
3	MCBRIDE, Donald 914 East 38th Street, Brooklyn, New York	U.S.C. 4516 New York	13	
4	MCBRIDE, Ann-Marie -As above-	W I-378534 France	-	
5	SODBINOW, Elizabeth Church Road Farm, Medford, New Jersey	I-786591 Stateless	-	
6	SODBINOW, Emmanuel -As above-	I-786592 Stateless	-	
7	SODBINOW, Andre -As above-	I-786603 Stateless	-	
8	SODBINOW, Serge -A above-	I-786587 Stateless	9	
9	SODBINOW, Katherine -As above-	I-786588 Stateless	-	
10	SODBINOW, Badma -As above-	I-786589 Stateless	-	
11	SODBINOW, Lidscha -As above-	I-786590 Stateless	-	
12	SODBINOW, Pierre -As above-	I-786586 Stateless	-	
13	NOWC ZEBERTAUVICIUS, Gediminas 167 Atkins Ave, Brooklyn, New York	I-786028 Stateless	3	
14	CW5 WELBICKI, Peter 148 West Frambes Ave., Columbus, Ohio	I-786038 Stateless	1	
15				
16				
17				
18				
19				
20				
21				
22				
23				
24				
25	U.S.C. 1	ALIENS 13	TOTAL 14	

Df Henry
 5/23/56
 10:40 AM

“The New Colossus”

*Not like the brazen giant of Greek fame,
With conquering limbs astride from land to land;
Here at our sea-washed, sunset gates shall stand
A mighty woman with a torch, whose flame
Is the imprisoned lightning, and her name
Mother of Exiles. From her beacon-hand
Glow's worldwide welcome; her mild eyes command
The air-bridged harbor that twin cities frame.
"Keep, ancient lands, your storied pomp!" cries she
With silent lips. **"Give me your tired, your poor,
Your huddled masses yearning to breathe free,
The wretched refuse of your teeming shore.
Send these, the homeless, tempest-tost to me,
I lift my lamp beside the golden door!"***

Emma Lazarus

November 2, 1883

<https://www.nps.gov/stli/learn/historyculture/colossus.htm>



Nursing Career

Registered Nursing (RN) and Certified Registered Nurse Anesthetist (CRNA)

Over my career, I accrued 27 years as a full-time nurse and nurse anesthetist. I worked initially as a staff nurse at St Peter's Hospital in New Jersey (1972-1973), then full time as a US Air Force Nurse (1973-1975), and then I was an Air Force Reserve Nurse. I moved to California and worked in ICU at Stanford Hospitals, went on to the Arcata and Eureka hospitals, and then moved to Houston, Texas and worked at Memorial Hermann Hospital. When I had ten years of nursing under my belt, I earned my Master of Science in Nursing and became a nurse anesthetist. In 1984, I was awarded the Agatha Hodgins Award for Outstanding Accomplishment for the anesthesia student.

The education of nurse anesthesia in Kaiser Permanente in Southern California for three years. Then, I moved on to Kaiser Permanente Northern California, the CRNA at the Redwood City, San Rafael, and Santa Rosa. I worked at the clinical anesthesia, instructing nurse anesthesia, and educating CRNAs at the Kaiser Permanente. I lectured on the corporate Nellcor Pulse Oximeter at clinical UC Davis, Sacramento, and at Group Health Cooperative in Seattle, WA. All the while, I worked on the one hand in clinical hospitals, lecturing on Best Practices and anesthesia, and on the other hand in leadership as an officer in the Air Force military reserves.

CRNA Military, and Non-Military Professions Nurse Anesthesia

The two trips to Russia, with my family, in 1990 and 1991, and the communism to the people of the Soviet Russia. All that I had heard and read about took on a distinctly different feel with my first trip to Russia in 1990. I learned much about cold war behaviors and activities still in existence but, more importantly, I learned about the consequences of

communism on large populations of people. Both my family and I, realize the good fortunes we have had living in the United States.

Two years later in 1993 I traveled to Western Mongolia, without the military, one year after communism had collapsed, and in 1994 to Paris, France. I commanded 35 persons in Air Force in Korea in 1995 and was sent to Armenia for 3 weeks, and Uzbekistan, seven weeks, in 1996 and 1997, respectively. Throughout my travels to South America, Mongolia, and Russia, I found the American presence to be quite formidable. I saw how American travelers, whether military or civilian, must be culturally attuned to the place they are visiting and aware of how they present to others. All experiences allowed an in-country immersion that combined work activities with cultural exposure and integration

I participated as an Air Force Reservist and clinical team member with Operation Provide Hope (OPH), a program directed by the State Department that provided humanitarian assistance to the republics of the former Soviet Union by donating surplus Department of Defense medical equipment and supplies. Clinical team members were responsible for providing clinical education and hands-on teaching for equipment and supplies that had been delivered by OPH's joint military force.

I gave local and national lectures as a member of the American Association of Nurse Anesthetists program committee; I served as chairperson of Health Volunteers Overseas in Guyana, South America, in 1995 and 1996; and as the California Association of Nurse Anesthetists (CANA) president, chairperson, and lead lecturer. I published an article, "Advanced scientific concepts: update for nurse anesthetists -- pulmonary pharmacology: bronchodilators" in the *AANA Journal* in 1988.

Appropriate preparation for an international role not only helps military personnel represent the United States favorably but also helps in the interaction, cultivation, and development of successful partnerships. Even basic language skills can help enormously. In the work setting, I felt a greater sense of ease from the local people we were working with and an appreciation of my feeble attempts to communicate in the local language, even if far from perfectly.

In 1998, I began my studies as a Ph.D. student in the Nursing Program at the University of Washington in Seattle. My pre-doctoral nursing dissertation plan, *Prenatal Women of Mongolia*, won a National Institute of Nursing Research, NINR, in August 1999 to March 2000. I had also been invited to lecture the American Association of Nurse Anesthetists (AANA) in Boston. The owner and president, I was an entrepreneur, with Diversatility™, is an active trademark, which represented a concept I had introduced in my final message, as President of the California Association of Nurse Anesthetists (CANA). See page 79 of this document.

After 22 years in the military, I became a Colonel in the Air Force in June 1999. I have been able to increase my participation in military missions in a way that I had never thought possible. These experiences allowed me to go to countries that I had previously only read or heard about, to represent the United States, and to use my professional skills as a nurse to complete directed missions. These kinds of global and cultural experiences, in my view, can never be learned from readings, books, videos, or tapes.

October 1998, I developed a mild headache. It was a lower left-sided pain, without auras. No matter what I took – Advil, Motrin, Tylenol, or aspirin – the low headache was there. I had an MRI of the brain, in December 1998, and it was normal. Except for the headache, I was still healthy – a strong hiker and an avid walker. So, I continued my studies, and part-time teaching,

and lecturing. By August of 1999, I was wrapping up my first full year in doctoral nursing. In sum, I was a leader, lecturer, military colonel, trailblazer, and an expert in RN and CRNA issues. In summation, as an expert I was on top of my experience in professional nursing.

My Stroke and Aphasia

On August 4th, as a member of the CRNA Programs Committee, I had flown six hours from Seattle to Boston to attend and deliver a lecture at the annual meeting. On August 5th, after the Programs meeting, I joined my brother and his wife for dinner at their home, which was located about an hour from the conference venue. The plan was that I would stay at their house while putting the finishing touches on my lecture. They both left for work early the next morning. On August 6, 1999, my full and accomplished life came crashing down in pieces.

My stroke occurred while I was alone in my brother's house. When my brother and his wife arrived home from work that evening, they found me delirious and vomiting, many hours post-stroke, and immediately called 911. The paramedics lifted me onto a stretcher and took me straight to the hospital in Franklin, Massachusetts. I have a few random memories from that time. The clock in my room read 8:20 AM. I glimpsed my brother's daughters as I was carried downstairs via the stretcher. I would cry when I wanted to say something, but verbally, I had no words.

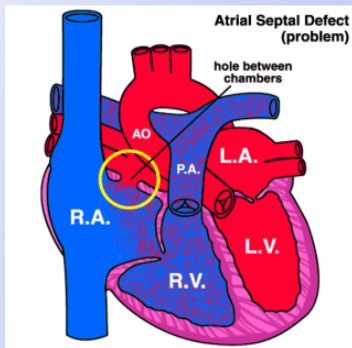
In the days that followed, many tests were performed, including a scan of my carotid arteries, blood work, and all kinds of ultrasounds and X-rays. All appeared normal *except* for the echocardiogram. It revealed an atrial septal defect (ASD) of which I had never been aware: an opening of 6mm at the site of a patent foramen ovale (PFO). Certain ASDs may occur on a genetic basis, but 40% do not. The ASDs were present from birth. These ASDs are termed spontaneous, especially in cases with small or isolated defects. They generally remain asymptomatic throughout the first four decades of life. Physical signs are subtle – headache or fatigue. By age 40 to 50 years, some untreated patients experience symptoms, such as dyspnea, fatigue, palpitation, arrhythmia – or a stroke. More than 70% of patients become impaired by

their 50s or 60s. Following the discovery of my defect, my five brothers and one sister all underwent ultrasounds for their PFOs. The results were negative in all cases.

Doctors also conducted full hypercoagulability and genetics testing, with all avenues turning out negative. In November of 2000, a 'Cardio SEAL' was implanted, and six months later, the ASD hole was closed. The low headache had stopped. However, my whole life had been devastated by the stroke. In March of 2000, I had to turn down the NIH predoctoral award. Conducting research in Mongolia or anywhere was now out of the question. My UW doctoral education was put on hold.

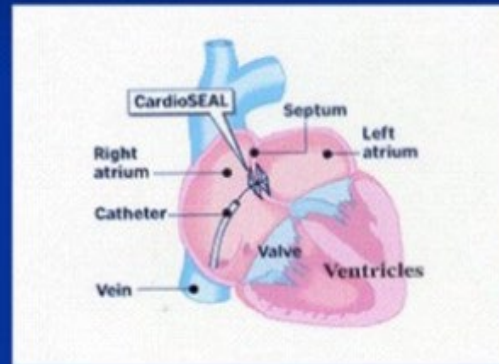
Hole in the heart 8/1999

Hole Between The Upper Chambers



Closure of hole 11/2000

DEPLOYED CARDIOSEAL DEVICE



Aphasia means the loss of the ability to communicate using spoken or written language, often the result of a stroke in the left side of the brain. About one-third of the 750,000 strokes occurring annually in the US result in aphasia (225,000).¹ As an aphasic, you may be able to comprehend what is being said to you, and you know perfectly well what you want to say back,

¹ <https://www.aphasia.org/aphasia-resources/aphasia-factsheet/>

but you can't get the words out. The person is fully aware of their deficit, and many isolated in their homes rather than risk traumatic feelings of anxiety, humiliation, and helplessness.

When aphasia occurs, it is not only the physical speech mechanism that is lost, but fundamental human needs, the social, psychological, physical aspects, and the whole quality of life for the patient. Emotional needs are uniquely felt related to their loss of identity and displaced status, in society, a two and half million persons in America due to loss of language fluency. But most of the people know it as communication disorders, then aphasia.

Public knowledge of aphasia is lacking in every country, including the US. Name recognition is imperative for understanding of a condition (Klissner of the American Parkinson's Disease Association.) 'If the disorder doesn't have a name, how will it ever be understood?' (Klissner, personal communication, July 1998).

The lack of knowledge, lack of information, and lack of education about aphasia is common among health care professionals, as well as lay people. When lay people and nurses say, it is a "communication disorder," its wide open. When other nurses and Speech and Language Pathologists (SLP) say "aphasia," those two things are not the same. Aphasia is the professional term. But in either case, people who lack education about aphasia advance negative psychosocial outcomes.

The public is sorely lacking an understanding of aphasia. Aphasia masks an individual's competency, aptitudes, and intelligence because the individual has no voice through which to convey them. Many assume that if a person has problems with speech, they must similarly be deficient in intellect. People will wrongly judge a person with aphasia to be mentally ill or suffering from mental retardation. Most people with aphasia can't secure employment. They feel isolated and marginalized. Aphasia is hidden away, viewed as fragile, emotional, and needing

care. The decades of work required to progress toward any degree of recovery are frustrating, laborious, and tedious. In general (Kiran et al., 2019, p.3), large left hemisphere lesions are typically associated with poorer recovery, whereas smaller lesions suggest better language recovery.

Dealing with Aphasia

While I was in Massachusetts during the first week of my stroke, I felt wrapped in silence. Sitting in a wheelchair in my hospital room, I could see the turmoil in my parents' faces. They had acquaintances who suffered strokes, and those people had all died. My parents knew virtually nothing about what happens during, or because of a stroke. My mother asked, "Is she going to die?" My brother told her no. Greater relief came to my parents when they heard 'no' from the doctors, but even so, they had no idea how long my medical treatment would last. After a week, my parents went home. I followed them to Colorado Springs after I was discharged from the hospital.

I was severely aphasic in the beginning. For the first two years, I went regularly to speech and occupational therapy. My right-side was weak with hemiplegia. I was in 'robotic' form for the first few years. I would still cry over my loss when I wanted to say something, unable to call forth the words. How long would it be, I wondered constantly, before I could move my right arm and right leg and produce speech? One of the most devastating results of the aphasia, is the inability to share experiences, or emotions with others. I stopped asking this question about five years post-stroke.

By that point, speaking was hard, laborious, and awkward. Calling forth and speaking words was still difficult, and the silences caused me embarrassment. The individual with aphasia must intentionally choose words, and then develop a sense of how to form, arrange, and speak to

them. My pauses were long, the words I would speak came with great effort and were sometimes pronounced abnormally. I recall, for example, attempting a simple order at a deli counter where the server could not understand me, so my brother had to step in and repeat my request for me. After a few such experiences, I felt relegated to the margins of aphasia.

Ten years post-stroke, my speech was clumsy and cautious. I didn't like to talk around friends or acquaintances. The main reason people with aphasia lose friends is a shortage of commonality through communication. People with aphasia often experience a major identity change in life, becoming a 'receiver' rather than a 'doer.' That's why post-stroke aphasia brings higher levels of depression (60%) than post-stroke without aphasia (30%). Persons with aphasia are prone to psychosocial problems such as anxiety, depression, threatened identity, and loss of leisure activities. I had no depression because of my mother and my pop, with whom I was living there with. I wanted them to feel as if every day were like normal. IE: I would put out everything to be in salad. Then pop would chop up in small pieces the salad, cut up the cucumber, and sliced up tomato. Then I would get it. To be caring for them allowed me to feel useful to others.

Collaborative Caregiving for my Elderly Parents

While my brother served as the main facilitator of care for both my parents and me, "upwards of 80% of Medical Bills Contain Errors"...."One cause behind the frequency of medical billing errors is the complex billing system we have in the U.S. healthcare system". "Billing errors may incorrectly code outpatient care as inpatient, driving up the cost of a medical bill" 80%. Every time, tosh looks at, **any** medical bills, he is 3 out of 4 billings is wrong.

(<https://www.lblgroup.com/how-common-are-medical-billing-errors/>)

The Colorado Springs, Colorado, my most important mission, was to lower the depressive and anxiety of the parents. And this is what we did. Tosh was driving us to medical appointments and seeing to our daily needs. I also contributed significant service to the household. I managed

much of the housekeeping and food preparation. I also backed up my brother in keeping our parents engaged with events, finding audiobooks, and setting up the cassette or MP3 player for them to listen. Also, we received one of the Russian newspapers 4 times a week. We made sure that they both stayed up to date with their medications. We also saw to their hygiene, bathing, and essential daily routines. Maintaining routine is crucial to managing stress and anxiety. Tosh would give showers to our father, and I would do the same for our mother.

We would do for them whatever they could not do for themselves. When my mother and father went out places, we would bring their transport chair to physically move about them which entailed a good deal of exercise. Whenever we went on trips with them, we would serve as their attendants. I recall once asking my mother whether she would like me to line up caregiving from some other organization. She replied “no.” My brother and I collaborated as live-in caregivers.

During his last six months, my father needed oxygen and breathing treatment in addition to medication. The hospice provided an RN to go to the pharmacy, but I served as the dispenser, doing everything a hired caregiver would do from sunup to sundown. As they grew increasingly frail and vulnerable, I focused on providing a safe environment for them by setting up their chairs strategically and providing physical support whenever they walked from one room to another, ensuring that they wouldn't fall. My father died in 2007 at the age of 90 years. My mother – weak, delicate, and fragile – lived until 2011, when she died at the age of 88.

I am proud of how our family came together to cope with the difficult hand we were dealt. Tosh and I managed to provide my parents a quality life as seniors during their last ten years. Caring for them allowed me to feel and be useful to others – perhaps the most powerful factor in my recovery.

Writing and Computer Skills Post-Stroke

My computer skills soon after my stroke were less than basic. Fortunately, I could still read in short stints from day one following the stroke, but my diary reads like that of a first grader. The combination of the stroke and the isolation at home weakened all computer skills in my brain, so I made the effort, the long endeavor of working at it, from home, for many years.

Pre-stroke, I loved reading books, journals, and everything in the newspapers. Post stroke, 1999 to current, I read very little. My writing has improved markedly from the low point of 1999. Basic reading is intact but reading at length still proves difficult. Thus, I am grateful for UW's disability program for students, as the audio reading is a lifesaver. Starting around March of 2017, I noticed my verbal expressions growing smoother, and my spontaneous speech improving. Not excellent but improving.

My Diary (excerpt) before my stroke and afterwards

I have kept a personal diary from 1977 until now. Excerpts are included in the following pages. I would write freely on whatever came to mind. Original writing, no editing involved. The pre-stroke writings in the diary of the Guyana, Armenia, Uzbekistan, Mongolia. etc. was easy. My post-stroke aphasia writings are harder, nevertheless I wrote, still original writing, no editing involved. The last five years writing has been for school and the UW dissertation.

10/24/81

Am in Houston. Left Sonoma 14 Oct & arrived
~ 2^{pm} 18 Oct. Stayed in Mojave, CA, Phoenix, AZ,
Las Cruces, N.M & Junction, Tx. Put over
2000 miles on the car & in transit had to
A the fan belt & alternator. A bit tiring
trip, possibly because I'm getting too old
for stuff like this. Worked 4 nights at
Stanford 4 Oct → 7 Oct. to make clear
\$500 for this trip. This week went to
NSI, St Lukes, Hermann & SW Memorial
hospitals & settled on St. Lukes & will
start there on Monday. Mom & Pop are
still on their Taiwan trip & probably
will be back 2 or 3 Nov. They sound
like they're having a good time. Not need
to say at this point. Am looking forward
to not being poor anymore. Would like
to buy Mangad a color TV for his birth-
day.

9 Mar 82

It's been a very long time since I've written & I want
to write all that has happened. First I took the job
with St Lukes & has that turned out to be a fiasco.
It's such a large reputable medical center but nursing
is so far behind. Staffing is so poor that they use
many, many ancillary personnel in the ICU's.
Overtime is rampant, but one does not get paid
overtime. The quality of care & continuity is almost
non-existent. It's really difficult for someone like
me not to feel an immense frustration & sense of
anger. I walk a tightrope everytime I go to work.

My Diary Post-Stroke and Aphasia – Excerpts

1999-2002

1999-2000

I just took a while before I let in nih. I does seem aware, now moreso than ever, that I can let go this folder and let come in the next folder. I am stroke. My parents are fine as are my brothers and sisters. I did see on a second theater, since the stroke, that my heart is has atrial-septal defect and a large hole in my heart. Prior to this time there was not a murmer to my portfolio or to slap reserve.

August 2001

my parents are fine. He is 85 and she is 77. They both have a glaucoma and some aches and pains but do not have any cardiac, or lung or stomach problems. I probably have greater than 40 years left, if not more.

1/16/2002

I stayed all alone, today, after my parents went to the cxr and mri at penrad hospital via Tosh. The cxr was because pop coughs a moderate amount. And the mri was because of the dizziness for my mother. Before the parents came home I had put the leftovers in the oven. We had macaroni and stuffed potatoes. And that was it. It was snowing in the morning.

June 20, 2002

in August 4 of 1999 i went to boston from seattle, nonstop. my head has been hurting since October 98, but not enough to do anything that i want to. I have motrin 2 or 3 x a day.

I had a Thursday morning program meeting and then we be free until Saturday. I hopped the train to franklin about 50 minutes from my boston hotel. We had dinner with my brothers family and he told me that his wife and him would be working and they would be leaving 6;00am the next day. they plan to see me in the early evening. My lecture alone on Friday and that would be good so i can finish it up. Then Friday came, there was no warning signs i seem to have seen it on 8;20 am. i had a stroke, alone.

My head and my mind was delirious, conscious and unconscious. I don't know when i had to get up, my arm and my leg, it went down,,,,,,,,, i didnt even know when my head thought or if it ever thought at all. I knew i had had to have bathroom but if i made i don't know

My brother came at around 6;00pm. He said liz and I nodded yes. Are you all right, nodded yes,,,,,,,, and he called his doctor when he saw my bruises. he told him that i did not speak and then he called 911. The long story is The milton-whitenville hospital said that i had a large and serious stroke. But what had given this to me, at this time i do not know. My blood pressure in the hospital 120/80, it was fine. My blood pressure in the house 160/90 and this was my highest number. They listened to my heart and it was fine. They did blood studies and too was fine. The blood cholesterol was 160 and it was fine. So they did an echo..... and they did bubble studies. It was Asd with a pfo.....hole in my heart. i did not know it.

December 24, 2002

It is almost Christmas. Yesterday it snowed and I couldn't even get the mail. But we are lucky..... and Ezan, he got the mail. The license was easy, in Colorado Springs. And I didn't have to take the test. The renewal is 10 years from now. Can you believe that my license is to be renewed again in 2012!!!!!!!!!! I can't believe that!

Beba and me got to Burbank. The weather was cool (not as cool as Colorado Springs) and hazy. Badma picked us up and we went to lunch at a small little chinese place. It was good. Two days at Badma's house, the little girl, and robin, her mother. 2 days at Joyce's house and attending a CRNA conference, and finally 2 days at the Malibu inn, somewhere at Malibu. This hotel was on hwy 1 and it was all right but when you got in to the hotel, the third floor, it was an ocean view. We can't even look over anyone. Its just views in the ocean.

2006 – 2007

January 21, 2006

I don't know where my writings are for 2005 and 2006 because I write the plain paper, Microsoft word or notepad. Anyway I must have just lost them.

Today is the 21st of January 2007. Pop has cancer. we all saw the doctors in may and that's we knew of it. Pop said no to chemotherapy or radiation in front of the cancer doctors. And this was when he became a Hospice patient in june. The months that he was sick and not so sick. was now.

May 7, 2007

On Monday 16 April 2007, pop was confused and not so confused. He knew us but he did not know when he ate. But Tuesday, he was feverish about 100.6 rectal. He did not want anything to eat. When he was sitting on his bed he looked down to the floor and said he did not want to broken pieces of things. My brother and I, we didn't see anything. I did not know what they were broken pieces. (He has a urinary catheter times 2 months)

By Tuesday late afternoon, there was an ambulance and some paramedics. I heard him say to mom, 'I am going to the hospital, the last time.' He was in the hospice room when he gave mom a smile on Thursday. The last one, because after this he was in a coma.

Pop breathed his last respirations on 24 April 2007 at 12:20 am. I was so glad I was there in the hospice inpatient room and I was holding his hand. His breathing was 10 – 12 per minute and comatose since Thursday night. I was holding his hand about 2 minutes when I noticed he did not breathe. He went the 10 respirations to none. I noticed his last breath was 1-2 minutes and that was that. I did get the nurse to come in. My pop officially died at 12:30 in the morning. My mom and Pierrie had to come back in at 1 am.

Pierrie had the phone all day. He had to call all the siblings. He had to call Rova Farms, call the hotels, and he had to call the rental cars. The funeral home in Colorado springs had to transport his remains to Newark, NJ. The snow had fallen that morning. All in all, we did it. Pop died in Tuesday morning, the burial on Friday (rain, hardest rain) and we got back home on Sunday.

July 4, 2007

I plan on going out to Seattle the last of August and seeing the dean. I have not emailed the dean, yet, because I've got to make the plans in my head. There are some things I've got to do.

- 1) I've got to be back in school full time 3 years from now.
 - A) Physician record, school record, nrsa
 - B) moving, selling the house, mom and tosh would say yes
 - C) would you NIH predoctoral disability apply the first year or after the 2nd year
 - D) would your nrsa be counted or the NIH will be all new

3) phd vs dnp. Dissertation in both or one. Dissertation in China and the ASD with a stroke?

- A) My goal is to teach, which one would be better

August 11, 2007

I just got back from Seattle yesterday. It was a 4 days rapid trip. So let me start.

One to two months ago, I was thinking about the school, again. If my hold is to be deleted, say months ago, I would not worry about the school, now. But it was not deleted. It was on hold. If my speech is better, than say, 2 years ago, I want to say to the dean, now, I want to go back to school...BUT in 3 years. This 3 years would make it 11 years on hold. The nursing format would make the phd holds deleted the first 10 years.

Questions for the dean.

Can I have the extension of my hold?

2) The 'domain of theory nursing classes' would be nearly finished. The NMeth classes (18 units) would be next. Is there a distance class?

3) I got the NRSA in 2000 and I had to give it back to the NIH. Is UW a participant in a 'NIH predoctoral fellowship award for students with disabilities?' These were 3 important things I had to tell the dean. I am pleased my appointment with her went so well.

Do you know what? I am glad I went to see the dean even if I'd never met her before.

August 23, 2007

My plans would be to finish up the phd nursing. I know that I can do it!!!

I didn't know - 2 years ago, but now, I feel I can do it. It is going to be hard. My reading Nmeth is slow. My rapidity in reading and writing would be slow. my getting the words out would be slow.....But I know, I know, I know my phd would be finished, 5 or 10 years from now.

2010 - 2011

April 26, 2010

We brought the bed for mom with the 'head up' and the 'leg up' several month's ago. I think this was good, because before the bed, her legs would ache for an 2 to 4 hours. After the bed, she was good and her legs would not ache.

June 29, 2010

I can't believe the bed. The two things was 1) mom's legs would not ache with feet up. She has not feet and legs were not aching. 2) The right leg was edematous, that is why mom used to take a lasix once a week. The bed with leg up, she has normal legs, not any edema.

Mom's overall pain is way, way down. She push's the wheelchair around to the kitchen and back to her room. Mom was in vancouver this month. She was worse when we got her into vacouver and worse when we got her home. And the middle was fine.

I had a dream the day before. Tosh and I went to north seattle and we went to the seaplanes. Tosh got on it and I was left behind

February 19, 2011

The last 4 months has been a lot of activity.

1. tosh has been to vancouver, bc and seattle, 7 to 9 days from home. When he came, he had a new house in redmond for a year. So, mom, me and tosh had gone to seattle, 2 weeks later, and had seen the house. We spent 5 days in redmond and said yes we want it.
2. Tosh, mom, and me had everything packed up by the united van lines was out to see us. They went and moved everything and we went on the road.

March 30, 2011

Mom had a strange pain in her left neck, just under her ear a week ago. She'd said her neck was hurting with movement. She had a strange nodule, about a soft penny. She also said her hand was numb. The numbness and the penny had disappeared. She'd say it was 2 to 3 minutes.

Today, in the morning her both hands to her elbows suffered severe pain. And she could not feel anything in her hands. She took two tylenol and it relieved itself.

September 2011

From April – August 2011

About March or April, mom had an 'angina' episode. She had never had a heart episode before. Her left arm had sporadic pain and tightening of her neck like a noose around her neck. If left alone her episode would last ~20 minutes. Nitroglycerine sub lingual, had angina relief by the end of the month after she had taken this med. But she had taken her SL nitro increase that

Dr. W. had her take Carvedilol 3.5 times 2. She'd take Carvedilol in addition to her nitro.

Her angina would last once a day or twice a day. Her eating is normal. She'd get around by pushing wheelchair moderately. She'd read the wall street journal in the morning. She would see the Phillies in the afternoon. All the while, her angina would increase

She was constipated, did not eat vegetables, and her food was the bread and butter. She would eat ham from the deli but more and more she'd shy away from deli. Once a week or two weeks we would go to the restaurant. She would only eat what birds would eat.

She had a hard time with her artificial teeth. I would take her teeth, clean them and then she'd have the cushion grip on the teeth. I felt the hospice was good for her because father had hospice for a year before he died. She needed the nurses, the medications was increasing, and what pharmaceuticals were important for her and what meds are the least important for her. She did not enter hospice. She would need a doctor to get her in.

Dr M---- from hospice was here 8-26. Mom was in the recliner in the den, reading the WSJ and she was 'in between' the angina. She was very good when the DR came in. Dr M---- did her physical and her mental notes and said Mom was very attentive and very good. 'I don't feel there is any need for hospice.'

We told them about angiogram and maybe the angiogram may be good. And so, when she left we made a call to Dr W---- and the angiogram was set for Monday. She said her angiogram was the weekend if her pain got even worse.

Yes, her angina got worse. She had angiogram on Saturday. She had two coronary major vessels blocked and she had collaterals that made her alive. The hospital said no she would have to wait till Monday. Mom said no! We came home that Sunday because mom insisted. Rural metro ambulance. Once she came home on Sunday, the hospice would not be around until Monday. That evening she had an angina pain, she got it worse. Even giving her nitroglycerine did not help her. I tried to give NTG 4 times it does not help. Tosh is out getting the MS out at pharmacies. When he finally arrived, I gave her MS. She went to sleep for 4 hours. The next morning, I tried to give some tea. She ate a little bit of farina and she vomited. And 2 hours went by, she ate Jello and she threw up again. She is not eating and very little water. Mom sat on the green chair in her bedroom. The hospice came by, but mom was in and out, does not even talk. I would just give her MS with a valium, but it's not that, every 3 hours around the clock. On Wednesday, her hands would go up and down, whenever. On Thursday morning around 2am she raised her hand up and down the last time. I thought she was not there anymore. She died of a myocardial infarction that led to her death at 11:00 am, Thursday September 1, 2011. She died at home.

2019 - 2020

June 9, 2019

Finland, Sweden, Norway

The north bend house, at 9AM and got into the red car. Beba drove us till seatac airport and said we will see her later, 12 days. We got into the business/first class into the ticket and we went into the Lufthansa lounge. Afterwards into the Lufthansa plane, 1330 clock, and we went up into the 2nd floor; 2 seater at 86. The seater is last because it is right there in the downstairs flight. Plane was normal; eaten x 2; drinks was free rum and coke; and overall the flight was 9:10. Frankfurt, Germany. I got to the wheeled cart, put our luggage in them and went to walk to Hilton (45 minute walk). It was tiring for me.

June 11, 2019: Helsinki, Finland to Turku, Finland by train from 1137 and got to Turku at 1335 pm. VR train about 2 and half. Man came over by the track 19, and said you are going to Turku? We said yes. The man said you are going to Turku by the track 24. Where in the world did he come from? We did not see him again. The Safe Taxi to the Radisson hotel.

12-20-2020

26 or 27 of November 2021, Badma and his friends went to a dinner in restaurant in new jersey, no masks. By the 30th of November he is really sick. When asked by Manny over the telephone, he said no to the hospital, he said I want to go to South Carolina as soon as possible. Talk to Manny on Monday, tosh would almost a week, no hospital. When he stand up, on December 4 or 5, he will fall down. He could not even talk.

By the time the paramedics called, he was in the home for 7 days. Badma was in the hospital, in Trenton, NJ, (Helen Fuld Hospital.) a new name (a capital health). He went to the ambulance hospital, the 5th of December with a covid 19 a positive. He was a severe SOB and stayed in the emergency room X 24 hours. When he went to the ICU, he was in cardiac arrest or some kind cardiac arrhythmia.

Endotracheal tube and all kinds of iv fluids did not work. Remdesivir. Badma died in the afternoon at 5PM, 12-21-2020.

Graduate Nursing School

After twelve years on hold, I returned to graduate school in 2011, taking one class at a time toward my PhD in Nursing. My command of language, communication, and mathematical calculation were all impacted by the same left-brain lesions, so the difficulty level of my classes overall was moderate to high. I think for me to maintain caregiving while going to school while the parents were alive, would have proven too much. It seemed just a natural progression after both parents passed away.

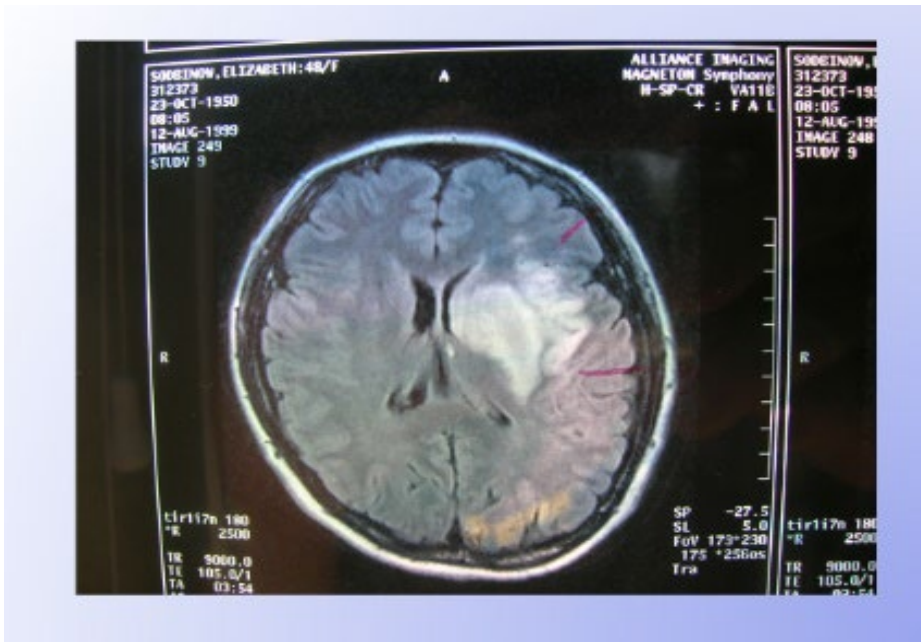
My courage pushed me beyond whatever and social or physical concerns I had, so I attended programs with in-person learning, despite my aphasic pauses. I offered PowerPoint presentations in my courses *slowly*. Before each class, I approached the faculty to make sure they were aware of my condition and disability status. I took up challenge after challenge, even though my aphasia persisted at a moderate level, resulting in pauses and difficulties with pronunciation.

My word retrieval is not fast enough to permit me to respond rapidly to spontaneous talk. Nevertheless, I kept my goals in the forefront of my mind: I want to foster inclusion of aphasia and promote diversity through the knowledge gained through nursing research on aphasia. As someone living with this chronic disability, I am an expert on the aphasic experience. I represent thousands of aphasic people who remain unseen, unheard of, and marginalized by those who misunderstand their condition – the aphasic disabled majority trapped in silence.

As of 2021, I have decreased the severity of my aphasia to moderate to mild – from almost total in 1999. From three months post-stroke until today, I have never given up on my exercises. I work constantly toward improving my energy, increasing my sleep, reducing my anxiety and stress. I will continue to press forward with these exertions for the rest of my life,

and I believe that my abilities will continue to improve. I will direct them toward educating others about the nature of the aphasic experience and accomplishing whatever can be done to increase future awareness of – and perhaps even treatment for – this devastating injury.

My post-stroke classes



All the blood tests and EKG were normal. The stroke was cryptogenic because no cause was determined.

The CVA brain lesion can be seen on the left side – where mathematical skills naturally reside. My MRI showed a left-sided middle cerebral artery infarction and a large stroke. All the impairments to my body’s motor skills and my command of language regarding speaking, reading, and writing resulted from this injury, the left lesion was dead. The hemiparesis was moderate to mild. In addition, an examination and consultation with a neurologist (2014) and a neuropsychologist (2015) have confirmed that the disruption to the left cerebral hemisphere has

had a significant impact on executive functioning, making sustained concentration especially difficult.

EDPSY 490 Basic Educational Statistics, 3 units. This course was difficult, requiring 30 – 40 hours per week. I Passed.

EDPSY 593 Exp. Design & Analysis, 5 units, withdrawn. I felt overwhelmed after 5 weeks.

BIOST 511 Med Biometry I, 4 units. Though I gave my all to pass this, devoting 30 – 40 hours per week, I was unable to pass the two exams. (Neuropsychologist 2015), said that the disruption to the left cerebral hemisphere has had a significant impact on executive functioning, making sustained concentration especially difficult. I did, however, succeed with the Data Analysis Plan and Report class component, which amounted to 35% of the grade. Passed.

SOC 504 Applied Social Statistics, 3 units. I Passed.

Overall, the statistics was very hard, and the ten required units are, passed:

Autumn 2011	EDPSY 490	Basic educational statistics	3 units pass
Autumn 2016	BIOST 511	Medical Biometry	4 units Pass
Autumn 2018	SOC 504	Social Statistics	3 units Pass

The UW school was in the post-stroke time, 2011 - 2021 and it was tough and difficult. Aphasia could have silenced me permanently if my school and the grades in the Humboldt State University in 1979, Sonoma State University in 1993, and the Master of Science in Nursing, the California State University in 1984, it was not there. The classes would be deleted.

But I had it! The full time in the September 1979 to June 1981, I loved the school. I enrolled at the Humboldt State University (HSU) in Arcata, CA, studying toward a Geology major. I had previously worked as a Registered Nurse on weekends. I made use of my Bachelor of Science in Nursing by working at Mad River Community Hospital. I enjoyed math, and statistics, which came to me easily. HSU and SSU, these grades had been uncomplicated and was

straightforward. The classes, I had been taking, from the winter 1988, to the pre-stroke mathematics was comfortable.

PRE-STROKE EDUCATION – Mathematics: Humboldt State University, Arcata, CA

Winter 1980	Math	Algebra and Elementary Functions	5 units B+
	Ph. Science	Meteorology	4 units B
Spring 1980	Math	Calculus I	4 units A-
	Physics	Physics I	4 units A-
Fall 1980	Math	Calculus II	4 units B
Winter 1981	Math	Calculus III	4 units B
	Math	Statistics	5 units A-
	Physics	Physics II	4 units B+
Spring 1981	Math	Calculus IV	4 units B
	Physics	Physics III	4 units B

Sonoma State University – Rohnert Park, California

Spring Semester 1990	Math	Statistics	4 units B
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I completed two years at the Humboldt State University, at which point if I had wanted to go into Geology field, I would have to commit to many years of study. I elected instead to venture into the nurse anesthesia field. I applied to and was accepted by California State University Long Beach / Kaiser Permanente Nurse Anesthesia School 1982-1984 and, having already devoted ten years to nursing.

I became a nurse anesthetist with my Master of Science in Nursing. As I pursued these goals, administering anesthesia in clinical hospitals and giving lectures to nursing organizations,

I was simultaneously active as an officer in Air Force leadership positions. Lastly, I undertook graduate nursing studies as a PhD student 1998 at the University of Washington. My pre-stroke classes, while challenging, were relatively easy to master (45 CEU), but my post-stroke courses have proven highly difficult, particularly, post-stroke statistics.

Reading Club for Individuals with Aphasia

I set up a meeting at the library for people with aphasia. This is what the flyer looked like.

a•pha•sia (uh-fay'-zhuh) n. - *“an impairment of the ability to use or comprehend words, usually acquired as a result of a stroke or other brain injury.”* (National Aphasia Association, NAA)

**Reading Place: Meeting room #1 or #2
East library
5550 North Union Boulevard
Colorado Springs, CO 80918**

Will begin on September 26, 2004.

Readings (times 6) will take place on Sunday at 1 PM – 3 PM

If you have any questions, please email me at

es@emailctr.com or telephone 1-719-310-7239

My Class Aphasia Survey, June 2013

See Appendix Page 89

What is Aphasia?

	YES (F)	YES (M)	NO (F)	NO (M)
4TH FL (21)	8	4	3	6
RED SQ (20)	1	3	11	5
STORE (21)	0	1	10	10
TOTAL (62)	9	8	24	21
	17 total YES 27%		45 total NO 73%	

I designed an aphasia survey to administer at the University of Washington. Two stores in the local area (Redmond, Washington) provided a space for face-to-face administration among random samples in a public area. Thus, I gathered 21 samples from Home Depot and Fred Meyer locations in Redmond, Washington. From among the community of 50,000 students on the Seattle campus, I gathered samples as follows: 21 samples from outside the 4th floor, 20 samples from outside Odegaard, Undergraduate library at the University of Washington. I contacted many individuals but about 90% would evade the surveyor. Men would avoid taking the survey more often than women. Of those taking the survey, approximately 75% would get as far as the 2nd sheet, which referenced “trouble speaking after the stroke.” As the survey was independent and informal, it is not necessary to know the mean, variance, or shape of the sample.

Summary of results:

Because of the locale selected, many of the respondents were medical and nursing students going to and from classes, with the hospital next door. Asked whether “aphasia” is a known word, most would answer, I don’t know. If we told the samples that “aphasia” means trouble speaking, many reacted anecdotally: “My grandmother had it;” “my friend’s father had it,” etc.

Elman (2000) says that while the word ‘*aphasia*’ is sometimes used, it is often used out of context or in association with many different etiologies. These data substantiate the notion that “aphasia” has been inadequately described and may explain why so few people have heard of it. “If a person has difficulties with speech, they also have intellectual deficiencies” (<https://www.aphasia.org/2020-aphasia-awareness-survey/>). This false assumption is widespread, but not true. Without public awareness, less funding is available for research, aphasia centers, and an aphasia clinic.

Prior to my stroke, I too, knew very little about the nature of aphasia, despite decades in the medical field. It is up to people like me and others, whose lives have been changed in ways our society fails to understand, to **educate** people about aphasia. I was a leader, lecturer, military colonel, trailblazer I was a leader, lecturer, military colonel, trailblazer What I face today is, the slow speech, pauses while internally large left hemisphere lesions are typically associated with poorer recovery,

Chapter 5

The purpose of this study was to examine the emotional and psychosocial effects of living with Aphasia and determine how the art of nursing practice can improve aphasia patients' experiences. I will determine what opportunity nurses must provide more effective care for aphasic patients. I am very clear on what my life was like pre-stroke. I was a leader, lecturer, military colonel, trailblazer, and an expert in RN and CRNA issues. I was on top of my experience in professional nursing. And my full and accomplished life came crashing down in pieces.

What I face today is, the slow speech, pauses while internally I search for a word, right side is weak, none of it socially acceptable. I know how it feels to be categorially marginalized. Aphasics often comply with society's dismissal in silence, and too many of us simply stay home. I choose to be active, to participate fully in my life and my schooling. I want to give PowerPoint lectures, slowly, on aphasia to share my journey with others. I will finish my Ph.D. in Nursing, if possible.

The study was conducted as an Autoethnography, from the lens of an almost thirty-year career as a former career Registered Nurse / Certified Registered Nurse Anesthetist (RN/CRNA) who has now been living (for over 22 years) as an Aphasic. Thus, I have a perspective as both caregiver and patient.

Because this research is an autoethnography of a career RN with first-hand experience as an aphasic, it authentically describes what it feels like to experience loss of personal and professional identities, and diminished status in society because of disability and loss of language fluency. Findings from this autoethnography will help fill a gap in nurses' knowledge about the unique needs of patients with aphasia. My experiences as a nurse and aphasic will help

underscore the importance of practicing the “art of nursing” care to promote improved patient / nurse communication and treatment outcomes and the emotional well-being of aphasic patients.

This chapter includes discussion of the factors that affect the emotional and psychological well-being of those who experience sudden-onset Aphasia (i.e., marginalization, loss of identity) and the connection to those factors as informed by my own experience as an Aphasic (Chapter 4). It also describes common themes of resilience and persistence that have enabled me to get to this point in my PhD journey. There is also a discussion of the study findings as they relate to the research questions and the implications they hold for nurses and nursing practice. The chapter will conclude with a discussion of the study’s limitations and possible areas for future research.

The research questions that guided this study were:

RQ 1: How can the art of nursing practice, verbal and non-verbal, positively improve the aphasia patient’s experience?

RQ 2: If caring is considered an integral part of the nurse’s role, what opportunity do nurses have to provide effective aphasia care?

Reflective Practice and Reflexivity

Reflective practice has long been a staple in nurses’ education and their ongoing professional development (Dodgson, 2019; Patel & Metersky, 2021; Timmins, 2006). Benefits include the creation of new knowledge as nurses combine theory with their practical experiences. While reflection is often thought of as a look back and examination of what has already happened, reflexivity is about focusing on one’s thoughts, actions, and feelings in the moment, as events are occurring. At the same time, one confronts one’s own thinking, including beliefs, assumptions, values, and role in the larger systems in which they are practicing care. According to Peddle (2021) reflexivity involves critical self-examination during the research process while

Roulston (2010) describes reflexivity as “the researcher’s ability to be able to self-consciously refer to him or herself in relation to the production of knowledge about research topics” (p. 116).

Koopman, Watling and LaDonna (2020) suggest that autoethnography, which promotes examination of personal experiences can allow researchers to “facilitate engagement in deep reflexivity” (p.2). In qualitative studies, such as this autoethnography, reflexivity, identification, and examination of my “assumptions, values, biases and prejudices” (Northway, 2000, p.391) is critical to ensuring rigor, trustworthiness, and credibility of findings (Dodgson, 2019).

Positionality Statement

In examining the emotional and psychosocial effects of Aphasia through the lens of my own experiences as a nurse and aphasic, it is important for me to describe my own positionality as it relates to this research. I acknowledge my status as an aphasic. As someone who has experienced being marginalized and ignored. Thus, my experiences with aphasia will be a bias and my advocacy will be in favor of the aphasic.

Themes

In reviewing the artifacts of my own life and experiences as presented in Chapter 4 of this autoethnography and comparing them to social emotional effects of Aphasia as described in Chapter 2, I see correlations as they relate to identity loss, social marginalization, isolation from mainstream others, depression, inability to self-advocate, and loss of support structures. I describe these as they relate to my own experiences below.

Loss of identity

Immigrant

In chapter 4, I shared the history of the Kalmyk people, whose stories have shaped a large part of my identity. As nomadic peoples who settled in Russia in the late 1600's the Kalmyks experienced oppression, loss of language, loss of culture, loss of homes, and were forced to give up their Kalmyk names under Russian rule. The story of the Kalmyk people is the story of my grandparents and my parents who eventually fled Russia, traveling to Yugoslavia, Bulgaria and eventually Germany and France before and during World War II, searching for work and a way to provide stability and a home for their children, ultimately making their way by ship to the United States where my parents and grandmother eventually settled with me and my 5 siblings.

Thus, my first and enduring sense of my identity comes from my nomadic ancestry. Along with that strong connection to my Mongol ancestors is the identity as a displaced person, as an immigrant, as someone for whom English was NOT my first language, thus my knowledge that my family and I were outsiders because we were poor, we were “different,” did not speak English, and thus not part of the mainstream society. Like my Kalmyk ancestors in Russia, we also had to conform, to fit in, or be marginalized.

While my family's experience came from a place of being different throughout our lives, this experience of feeling different, marginalized, and isolated is also what people with sudden onset Aphasia feel. While they may have been a part of their personal and professional networks, fitting in with others, and contributing to relationships, the sudden loss of communication skills for an aphasic throws them out of the worlds where they were accepted and understood into a place where they no longer fit.

Professional Identity

Shadden (2005) describes identity as having both personal and social components that must be acknowledged by others and by society as a whole. Identity sets the stage for how we engage with others and through ongoing communication relationships with others, our identity is affirmed and continues to evolve over time. For aphasics however, the loss of communication abilities (a primary way of developing and maintaining relationships) and a diminished role in society results in loss of “confidence and identity” (p.212). As a result, the biggest hurdle for aphasics is the task of renegotiating identity (Shadden & Agan, 2004).

In reflecting on my journey post-stroke, I can see how this played out for me in terms of my professional identity. After stroke, the who I *am* was lost because my identities as a RN, CRNA, military officer (Colonel), global traveler, entrepreneur, and public speaker had altered drastically simply due to having lost the ability to communicate, to participate in the back and forth of dialogue that keeps relationships alive. How I communicated was no longer acceptable or understood by others. As a result, I lost my identity as someone who was perceived as a competent and contributing member of society. I also lost my place as part of the collective “us” that is often characterized by membership in social groups and professional organizations.

Shadden (2005) states, “conversation is one medium through which our valuation occurs”, describing use of language as conveyer of “power and status” (p. 215). In society and for aphasics, this is all too true. Aphasia is only an issue in the context of one’s relationship with others and from the perspective of how society views someone whose language skills are compromised.

To illustrate, early on, within the first year after my stroke and aphasia, I thought I could continue to participate in activities such as professional conferences, after all my cognitive abilities were very much intact. Yet, over time, I came to know that the difficulty and slowness of my speech seemed to make others uncomfortable. This is very much as described in Parr, Duchan, and Pound (2003) where Christopher (an aphasic) shares his experience of being visited by a friend but feeling uncomfortable because of his friend's unwillingness to "wait for him to contribute to the conversation" (p. 135). The number of people that voluntarily engaged with me diminished and eventually my participation in such gatherings, conferences, etc. came to a halt. As described by Thompson et. al. (2012) lack of understanding about aphasia and discomfort with aphasics' inability to fluidly communicate is one factor in why aphasics withdraw from others, to avoid feeling judged, to avoid making others uncomfortable and as a result, their meaningful social bonds are further eroded.

Identity as Student

Another change was my identity as a student. Prior to my stroke, I had completed the first year of my PhD in the UW Nursing program. I had decided I would study maternal health in Mongolia (home of my ancestors) and had sent off a grant request to the National Institutes of Health. Later, after my stroke, I found the letter that said the grant had been approved. I had to turn it down. This was one proof that my school had to be "on hold," but not over, because I still believed I would go back.

Chapter 4 includes an excerpt from my online journal entry (July 4, 2007) showing the list I made to plan to go back. My father had just died, I had spent the years since my stroke, taking care of him and my mom, and I knew that it would soon be time to return to Seattle.

When I finally was able to return in 2011, after 12 years “on hold”, it was hard. In chapter 4, I describe my return to Graduate Nursing School and how hard it was to focus, especially on mathematics. In that same chapter, I include an image of my brain MRI showing the lesion and the region of the brain affected. Both a neurologist (2014) and a neuropsychologist (2015) confirmed the disruption to the left cerebral hemisphere, its significant impact on my executive functioning and ability to sustain concentration. This was proven to me when I took statistics courses in 2011, 2016, and 2018. This was another loss of identity and sense of self because before the stroke I had excelled and enjoyed solving problems in the many statistics and math courses throughout my undergraduate and graduate school. I was good at logic and problem solving. Yet now, I could no longer concentrate the way I used to, and no matter how many hours I spent on homework, the courses did not become easier. Instead, my brain just got more tired. After one especially difficult course, I ended up getting very sick after the quarter was over.

Strengths of this autoethnographic study

This study brings to light the importance of aphasia awareness outside of the SLP field. It combines theory with practice, allowing for reflexivity and the creation of new knowledge (by combining theory with practical experiences). It underscores the distinction between the type of care required in acute settings where interventions are highly clinical, and the type needed by aphasic patients in an outpatient setting who need nurses to focus on their whole person, with biopsychosocial, cultural, and emotional needs (Vega et al., 2019).

Researcher has a unique lens from her years of experience as RN/CRNA, as teacher, scholar lecturer and as aphasic for over 20 years. Autoethnographic approach overcomes restrictions of more powerful, dominant forms of research that inhibit representation of

marginalized, aphasic voice. My story has the potential to transform others' lives through the power of sharing my experience.

Limitations of this autoethnographic study

The study draws on only one aphasic's experience, and it does not benefit from having included other aphasics' stories. There is possible bias due to researcher's lens of experience as RN/CRNA and over 20 years living with aphasia. Researcher's life experiences of being an outsider due to poverty, immigrant status, non-native English speaker, woman, etc. might have more positively prepared her for challenges of aphasia.

Implications for Clinical Practice

Nurses with greater insight about aphasic's emotional and psychosocial needs can improve the patient experience through a more human centered approach (as opposed to clinical). Nurses with knowledge about aphasia can provide information during the acute care phase that can help alleviate aphasics' and their families' concerns about the unknown.

For outpatients, nurses' knowledge of aphasia can instill greater trust in the health care process and empower aphasics and their families to ask questions so they can make better informed decisions moving forward. Nurses can partner with Speech Language Pathologists to provide more holistic care to aphasics.

Recommendations for Future Research

Future aphasia related research should include, but expand beyond nursing, healthcare and SLP fields. Because of aphasia's impact on the whole person, related studies should also explore all areas of aphasics' lives. Examples include aphasics and employment, aphasia effects on relational communication, etc. Future research should explore impacts of aphasia on individuals in underserved communities, domestically or internationally. Future research should

further explore the identity /intersectionality aspects and implications of what it means to live with aphasia.

Conclusion

Today, as I look back on my experiences, I can see how themes of resilience and persistence are present throughout my life. Resilience has been described as the quality or ability that helps individuals to adapt and recover from setbacks, challenges, and to continue moving forward despite + (Ovan, 2015, psychologytoday.com). Along with resilience is persistence, which Merriam-Webster.com defines as “continuing to do something or to try to do something even though it is difficult or other people want you to stop.” This has certainly been true for me. While it would have been easy and well-accepted by others for me to have abandoned my dream of completing my PhD in the face of loss of language abilities, and after having put school on hold for so many years, I persisted in my dream. In the 22 years since my stroke and aphasia onset, despite having lost use of my dominant writing and typing hand, and with compromised verbal and written communication abilities, with help from my family I was able to find workarounds. For example, I was no longer able to handle printed materials easily or to write, so I had to learn to use my computer better and became more adept at using only digital files. I also had to learn to type with my non-dominant hand. These are things that for others would be simple, but for me, each thing took a long time to improve, and it was very hard. I needed to not only persist, but I needed to be resilient and not allow the setbacks keep me from moving forward.

Now I am here, at the final phase of this dissertation draft and for me the opportunity to be completing my PhD is huge. I have been told by prominent speech language pathologists both here in the United States and abroad that there has been no one with aphasia that has completed

their PhD. While my goal for this research has been to shine some light on what nurses must know about aphasics who might be in their care, and the importance of practicing the art of nursing care to improve the aphasic experience, it has also been to advocate for their inclusion in mainstream society, to mitigate the feelings of marginalization.

For me, this journey to completion of my PhD has also been about demonstrating for other aphasics that your life pursuits do not have to be abandoned in the presence of aphasia. If my work here can help nurses see their aphasic patients in a different light and to look beyond the slow words, halting speech, and long silent pauses, they will see the person who is still there behind the aphasia symptoms. I also believe my work can serve as a beacon of hope for someone like me whose dreams seem to be shattered because they experienced a traumatic brain injury resulting from stroke, if they feel they have lost their identity, who they are, and their place in the world, with hope, persistence, and a resilient attitude, they can move beyond the setbacks and find fulfillment in new endeavors.

Addendum

California Association of Nurse Anesthetists, Address, 1996

President's Message

Elizabeth Sodbinow, CRNA

I have just returned from the annual meeting of the AANA in Philadelphia. It was the last national meeting where I represented the California membership as CANA's president. This was a wonderful opportunity to gather the latest in educational and professional information, and to meet with our national leaders, other state representatives, students, and colleagues from around the country about our changing practice and profession. Many CRNAs are being affected by these changes and are rising up to meet the various challenges that are presented to them. Overall, we have a long way to go before the transitions and changes settle into comfortable reality, if there is such a thing. Nevertheless, a transformation has begun that will continue on into the next century (*more on this later*).

CANA'S BOOTH IN PHILADELPHIA WAS A HIT!!!

CANA had a wonderfully decorated promotional booth in Philadelphia. Decorating designs were developed by Debbie Dach, Marta Hammond, and Celeste Villanueva. This booth was an opportunity for California to be visible at this year's annual meeting and to promote the annual meeting to be held in San Francisco next August. Administrative assistance and staffing coordination was managed by Celeste and Sandra Even. California CRNAs and students helped to staff the booth and answered questions about San Francisco and the meeting

to be held next year.

CALIFORNIA HAD WINNERS AT THE ANNUAL MEETING!

The results of the annual AANA election are in and California had winners. Dr. Scot Foster, director of the Nurse Anesthesia Program at Samuel Merritt College in Oakland, was elected to the office of AANA President-Elect. Brent Sommer, assistant director of the Samuel Merritt program was elected to the AANA's Resolution Committee.

Jan Mannino, 1987-88 president of the AANA, won the Agatha Hodgins Award for her many years of dedicated service to the profession of nurse anesthesia. Congratulations to all three of these active and involved CANA members. We're proud of you!!

STATE ASSEMBLY BILL 595

Very little has changed regarding the status of CANA's activity related to the implementation of AB 595. The law went into effect July 1996 and impacts office practices where anesthetics are provided. With the help of CANA's legal counsel, CANA requested a clarification of this bill and its potential impact on CRNAs involved in office practices. We are still awaiting a response from the appropriate agencies who would be accrediting these office practices.

Continued on page 6

President's Message

Continued from page 5

Cathy Kay, CANA's legal counsel has left CANA to work with a State of California government office. Trina Bruener has now taken over the position as CANA legal counsel. Trina is a nurse as well as an attorney, and has worked previously with Phil Recht on various CANA projects. CANA's Board of Directors wishes Cathy much success in her new position and welcomes Trina as CANA's new legal counsel. We look forward to a long and successful relationship with Trina.

UPCOMING CANA PROGRAMS

CANA's Program Committee is in the final stages of developing the program for our annual state meeting in Monterey, California. This meeting will take place at the Monterey Plaza Hotel on October 11 - 13, 1996. Some of the features of the program will include computer technology in anesthesia care (with a hands-on workshop with some of our corporate sponsors), and a Friday evening panel discussion about changes in the practice of nurse anesthesia. Several panelists will offer their perspectives on anesthesia — past, present, and future. I look forward to seeing many of you at this October meeting.

CANA's Program Committee has also begun work on the Spring 1997 CANA meeting to be held in San Diego in May. This will be a joint endeavor between CANA and the

Association of Veteran's Administration Nurse Anesthetists (AVANA). Carol Mann, from CANA, and Dan Meyer, from AVANA, will be co-chairing the development of this program. We look forward to an exciting and informative agenda.

THANK YOU TO CANA'S STUDENT REPRESENTATIVE!

Jeanne Senn, from The Nurse Anesthesia Program at Samuel Merritt College, served as the student representative to the CANA board during my presidency and has been our liaison to California's student nurse anesthetist population. I thank Jeanne for taking on the role of student representative at a time when California health care is in the throes of change, when the face of anesthesia care is being re-engineered in some environments, when the job market looks tenuous at times, and the demands of nurse anesthesia education continue to increase. Jeanne has been a quiet but informed voice at our CANA board meetings. Her patience as a board member, her perspectives on the future of her new profession, and her energy at CANA meetings in providing program assistance has been greatly appreciated. I thank Jeanne for her participation and for her insightful *CANA, Inc.* articles. Finally, I wish Jeanne and all of California's new graduates great success as future certified registered nurse anesthetists.

CANA AND ITS MANY COMMITTEE MEMBERS

An organization such as CANA, Inc. is only as effective, dedicated, and responsive as its volunteer commit-

President's Message

tee members, committee chairs, and Board of Directors. There is no stipend or payment for spending hours on the telephone with committee or board members; or for obtaining speakers and sponsors for CANA programs; or for sitting down and developing agendas for programs or board meetings; or for giving professional presentations about your organization and work to those who may or may not know the work of CRNAs. These are only a few of the many activities that your board and committee members are involved in throughout the year as they volunteer their time and serve CANA's CRNAs. They also educate and speak to state and national legislative representatives; or listen to and try to help our members who have concerns about our practice and our profession; attend meetings with other healthcare professionals; monitor the quarterly meetings of the Board of Registered Nursing, no matter where in the state of California, to stay abreast of issues that may ultimately impact CRNA practice; and sift and sort out various archival and historical materials that document our past but may give clues to our future.

For me this year, as president, could not have been so easily accomplished without the dedication, assistance and work of the many individuals who take time away from their families, friends, and jobs and make CANA's committees function. I acknowledge their sacrifices and am greatly indebted to all of the committees and their chairs for their energy and efforts. Please refer to the slate on page 17 of this journal, for a listing of these dedicated volunteers.

I would like to give a special thank you to Camille Ranker, *CANA Inc.*'s editor, for producing one of the finest CRNA news bulletins in the country. I have spoken to many CRNA leaders around the country who have expressed their compliments about our publication. They have been pleased with the organization and format of the journal, its diverse content, and the quality of materials that are presented. I now pass these compliments on to Camille and her staff at Mendocino Graphics and thank her for a job well done. In addition, I would like to personally thank Camille for giving me a forum for my thoughts, impressions, and comments as CANA and our profession move toward a new century.

Finally I would like to thank Sandra Even, CANA, Inc.'s association manager for keeping me on schedule, keeping me informed and tuned in, and for assisting me with the many, many details and tasks of CANA's daily business activities. I am most appreciative that Sandra has taken care of many of these tasks at the CANA office and has made my overall job as president that much easier.

Thank you all very much!!!

THE SILENT MAJORITY

I cannot end my presidency without acknowledging the fact that those of us who are in elected positions cannot do what we do as CANA representatives without the support of those who elected us AND who stay behind to

carry on the work of nurse anesthesia when we travel to take care of the organization's business. In most cases, someone else is doing the job when we are not there; we trade shifts or days off, or we bargain with our peers and co-workers to make the appropriate adjustments so that we can have the time off to carry out our elected duties. Whatever arrangements we eventually make, those of us in office know whom we serve and in whose best interests we make the decisions that we make. Sometimes the decision-making process is not an easy one and sometimes it is fraught with great discussions and opposing views, but in every case we hope that we have made wise and thoughtful choices.

In this last *CANA, Inc.* message as President, I would like to express my thanks to the California CRNA members who are the silent majority. These are the CRNAs who ultimately make it possible for our association to exist and succeed through their membership, who have come through in a pinch when we have needed additional financial resources, who have sometimes given me advice when I needed it, and who have given me the opportunity to serve as CANA's state president. I hope that I have represented and served all of the membership well and I look forward to continuing to work with many of you in the future.

PREPARE FOR A NEW MILLENNIUM

The arrival of a new millennium, or a new century, is generally considered an event of global significance. In that context, it may seem that we overstate matters when we refer to the recent events within the healthcare sector as a "revolution." Rather, what we have been witnessing has been a series of small shifts in the healthcare management paradigm. In the view of some, it is still an upheaval, to others a reactive turmoil, and to yet others, these are small proactive steps intended to move forward from the status quo. But whatever we call it, it is true that it has brought about changes greater than any we have previously experienced.

It is also true that these changes represent an opportunity for CRNAs to move in directions we have never envisioned, let alone seriously contemplated. In the time I have been a CRNA, and particularly during this presidency, I have repeatedly marveled at the resiliency, creativity, and strength of will of the CRNAs whom I have been privileged to meet, observe, work with, and most of all, to teach. It is the resiliency of the CRNA student who has persevered in his/her studies and clinical work and who, despite the political debates, now stands at the threshold of a profession that itself promises to transform and be transformed during his/her career. It is the creativity of the CRNA manager who, shrugging off the corporate downsizing that so often comes in the name of cost efficiency and reengineering, still manages to oversee the duties and responsibilities within his/her purview. It is the strength of will of the CRNA who, throwing off the objections of nurses and physicians that he does not belong in his specialty despite his credentials and successes, nevertheless has found professional satisfaction in acute and chronic pain management.

Credit for these successes goes to numerous individ-

Continued on page 8

President's Message

Continued from page 7

uals and institutions. It goes to the educational programs that act on their vision of reinventing themselves and their students so that their graduates may present a portfolio of clinical competencies that take them beyond anesthesia management. It goes to the educators who embrace and pursue significant and serious qualitative and quantitative research, so that they can establish, unequivocally and irreversibly, that nurse anesthesia is a major profession and presence in the healthcare sector. It goes to CRNA leaders, who work diligently to reach a consensus on the true definition and mission of an anesthesia care team, but who also try to remain responsive to changes within the professions.

Credit also goes to individual CRNAs, who have gained the respect of their medical and nursing colleagues by the dedicated and consistent work that they perform. It goes to the rural CRNA who, in circumstances and conditions that are often much less than ideal, continues to make difficult decisions on a daily basis. It goes to the groups of CRNAs who, having aggregated, analyzed, compared, and correlated clinical performance and financial data, make a convincing case for the value of nurse anesthesia as their CEO and CFO approach a merger or acquisition. It goes to the CRNAs who recognize that technology, informatics, and distance learning are an integral part of future CRNA education and practice. It goes, in short, to all CRNAs, who bring to bear all their skills and talents simply for the benefit and care of the patient.

But just as the credit for these successes goes to all these individuals and groups, so must the continued burden for ensuring that the new millennium brings more of the same. As CRNAs, and as the proper stewards of our profession, we must look ahead to see how we can continue the transformation of the profession to be better, stronger, and even more contributive than it is now. This means maintaining constant communication with our customers and our patients to determine if we are meeting their needs and addressing their concerns. It means measuring and evaluating our work and outcomes. It means continuing to forge collaborative relationships to ensure the highest level of contribution from everyone involved in patient care. It means being willing to share information — and to receive it, as well.

This may be a tall order and it will require a certain courage, but it will force us to be receptive to new ideas, to learn and master new skills, to develop new curricula and programs, to become comfortable in new settings, and to look at challenges from new perspectives. It may force us to consolidate educational systems to optimize the use of resources, facilities, and educators. It most certainly will stimulate the development of leaders who understand the importance of a long-term collective vision and who can strategically and wisely move the profession toward that vision. It will, inevitably, force all of us to become more versatile.

As we move toward the new millennium our goal and our responsibility should be to develop within ourselves

and our profession a diversity and richness of clinical experiences, educational tools, business and management aptitudes, and leadership skills. But we should do so within a framework that recognizes and embraces the diversity and richness of backgrounds, lifestyles, opinions, ideas, and approaches that we all bring to the profession. To a degree unprecedented in human history, we are irreversibly connected to a global community of patients, clients, customers, companies, and organizations.

Corporate America has understood for some time that in the new millennium success will be ensured not only by what we know, but by how well we acknowledge, adapt to, and incorporate the differences that constitute such a rich part of our country's heritage. Their efforts, now driven by competitive concerns, generally go by such names as diversity management, cultural sensitivity, or some combination of these, or similar, terms. As a management watchword, then, "diversity" has been a part of the business community for more than a decade. From this perspective, the healthcare sector is somewhat behind.

The business sector has also recently discovered that the focus on diversity has been far too narrow. It had concentrated on making sure that employees of different backgrounds understood their differences and kept those differences from interfering with the tasks at hand. Or it had concentrated on information delivery about multiculturalism, or on optimizing some level of racial and gender equality. Lately, however, businesses are learning that effective diversity management is so much more, that diversity is not something to be worked around and that differences are not obstacles to be overcome. Rather, diversity enriches the mix, introduces fresh ideas, and increases the versatility of the work force. An emerging requirement, then, is for a work force that can use its diversity to enhance its versatility. For want of a better term, we may think of this convergence as *Diversatility*SM. Future efforts in diversity management must be directed toward using a work force's diversity as a tool for strengthening its innate and inherent capabilities. Our ultimate success will be determined by how well we use this attribute in all of our professional relationships, communications, and activities.

As the healthcare sector continues to re-invent itself in the years to come, challenges will also continue to present themselves to CRNAs. The onus will be on us to recognize and utilize the essence of *diversatility*SM and to develop truly collaborative relationships with our colleagues to find or create reasonable and practical solutions. As I reflect on my term in this office, I am ever-confident that, as CRNAs, we can meet all of these challenges and achieve unprecedented new heights and success in the process.

¹The concept of *Diversatility*SM is the subject of a forthcoming article; the developers of the concept have applied for a service mark on the term, denoting its use within a diversity-training context.

MILFORD-WHITINSVILLE REGIONAL
HOSPITAL
14 PROSPECT STREET
MILFORD MA 01757
(508) 473-1190

DISCHARGE SUMMARY

NAME: SODBINOW, ELIZABETH

DOB: 10/23/50

ATTENDING: C. Peter Le, MD

UNIT#: 312373

ACCT#: 9059563

LOC: GAN

DATE OF ADMISSION:

08/06/99

DATE OF DISCHARGE:

Dictated by: JURGEN HOLLECK, MD

Please refer to history and physical for details.

HOSPITAL COURSE: The patient was admitted to the Intensive Care Unit upon admission. Initial CT scan showed a left basal ganglia, acute infarct without hemorrhage, hypodense left MCA sign concerning for an area of incipient larger stroke. Followup CT scan was done on August 7, 1999. This showed a better defined area of infarction, relatively acute, in the left basal ganglia with extension to the left internal capsular white matter without hemorrhagic transformation. It did not involve the distal MCA branches. The patient and family initially refused an MRI, so the decision of whether or not to anticoagulate was postponed and the MRI was rescheduled now for 8/12/99. The patient was started on subcutaneous heparin 5,000 units b.i.d.

She underwent a thoracic echocardiogram which showed an atrioseptal defect. A bubble study showed bubbles crossing bilaterally through the atrial septal defect.

The patient remained stable and was transferred to the regular floor. She was evaluated by speech pathology and a modified barium swallow was completed. This showed moderate-to-severe oral phase with mild-to-moderate pharyngeal phase dysphagia. They recommended advancing the diet to ground meats, puree and all other foods with thin liquids. This was done. The patient tolerated this diet well. Physical therapy and occupational therapy continued to work with the patient throughout his hospitalization.

The patient continued to do well and was scheduled for discharge to an acute hospital in Colorado for rehabilitation on 8/13/99.

A workup for hypercoagulability was done. The lupus anticoagulant profile was negative with DRVVT of 32 and no lupus-like anticoagulant. Cardiolipin antibodies IgG was less than 10, IgM was less than 10, factor V Leiden is still pending, protein S was 112, protein C was 114, antithrombin III and 112.

Carotid duplex done on 8/7/99 had shown no significant

MILFORD-WHITINSVILLE REGIONAL HOSPITAL

DISCHARGE SUMMARY

NAME: SODBINOW, ELIZABETH

UNIT#: 312373

ATTENDING: C Peter Le, MD

accident without hemorrhage.

1. Atrioseptal defect with patent foramen ovale.

PROBLEMS AND DISCHARGE INSTRUCTIONS:

1. NEUROLOGIC: The patient has had a significant left middle cerebral artery territory ischemic cerebrovascular accident. She remains with significant right-sided weakness and paralysis and will need long term rehabilitation and physical and occupational therapy. An MRI is scheduled for today and assuming that it does not show hemorrhage as is expected due to CT scan findings, the patient will need anticoagulation to prevent future occurrences of DVT and embolus. Given the patient's atrioseptal defect, it is very possible that the patient had formed a DVT on her long flight from Seattle which may have been a paradoxical embolus causing her CVA. Coumadin will be initiated and coags must be followed to adjust the patient's INR keeping it inbetween 2 and 3 as the patient's hypercoagulability workup has been negative so far.

PLAN: Physical therapy, occupational therapy and rehabilitation in Colorado. Anticoagulation with subcutaneous heparin 5,000 units subcu b.i.d. Initiation of Coumadin starting at 5 mg q.d. for the first three days with close monitoring of her PT, PTT and INR.

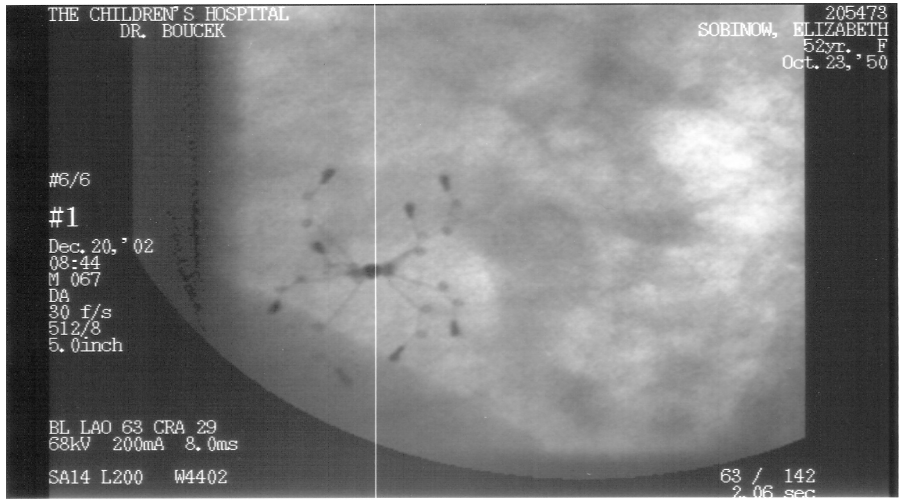
2. CARDIOVASCULAR: Atrioseptal defect: The patient should be anticoagulated given her recent ischemic CVA. However, the patient should followup with her cardiologist to assess and discuss the possibilities of a surgical repair of her atrioseptal defect as outcome may be better with surgical repair than pure anticoagulation. There is no need for urgent intervention at this point, but this issue must be addressed in the future.

3. FLUIDS/ELECTROLYTES/NUTRITION: The patient has moderate-to-severe oral phase and mild-to-moderate pharyngeal phase dysphagia. She is at risk for aspiration and should be on a: diet of pureed and ground foods with liquids. Attention must also be given to her lung exam. The patient has been afebrile during this hospitalization and chest x-rays have not shown an aspiration pneumonia up to this point.

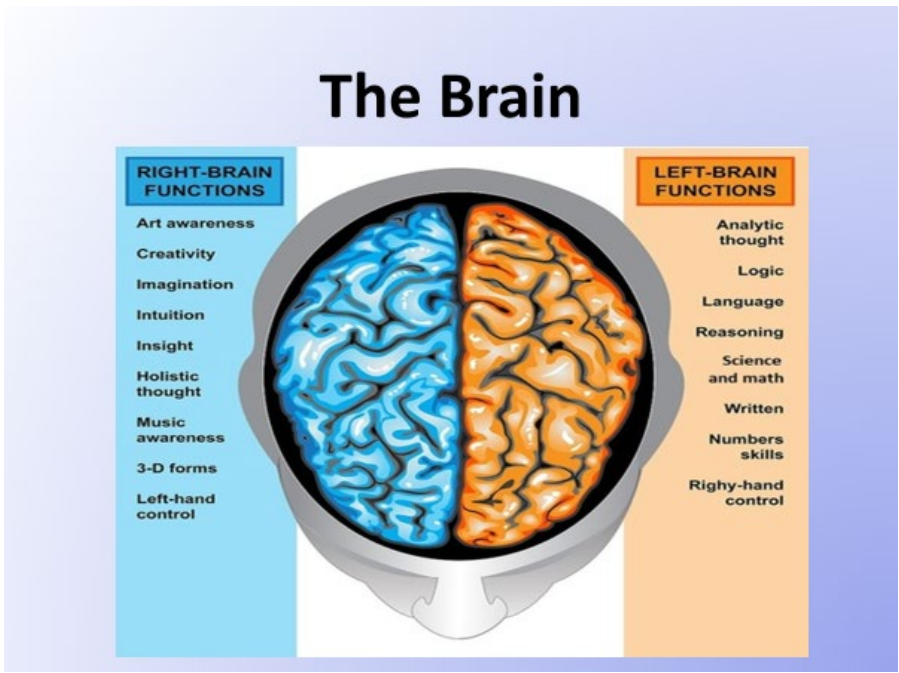
4. HEMATOLOGIC: As mentioned above, the patient should be anticoagulated given her history of recent CVA. She should continue on subcutaneous heparin 5,000 units subcu b.i.d. For the time being she should also be started on Coumadin, assuming that the MRI today does not show any hemorrhagic transformation. She will be started on 5 mg of Coumadin q.d. for the first three days; INRs and PTs must be closely followed.

ACTIVITY LIMITATIONS: None.

DIET: Ground meats and pureed foods⁸¹with liquids, as mentioned



***Atrial Septal Defect Repair – the Cardio Seal is left in the body,
'SPIDER'***



***The left side of the
brain is
responsible
for controlling the
right side of the***

body. It also performs tasks that have to do with logic, science, mathematics, and speech output.

Awareness of Aphasia Survey

Date of survey _____ Place of survey _____

Age of respondent _____ Gender _____ Occupation _____

Have you heard of aphasia? Yes ___ No ___ Not sure _____

If NO, stop here. If yes, or not sure, continue

Tell me in your own words

What is aphasia?

Would you say that people with aphasia:

- A. Have trouble with pronunciation or speech?
- B. Have trouble with language or putting their ideas into words?
- C. Have problems understanding what people say to them?
- D. Have problems with thinking or general intelligence?
- E. Have “mental” health problems?
- F. Have reading problems?
- G. Have writing problems?
- H. Have communication problems?
- I. Other _____

Is aphasia caused by?

- A. Brain damage
- B. Emotional problems
- C. Impaired intelligence
- D. Mental problems
- E. Stroke
- F. Other _____

Where did you hear of aphasia? (In what context did you hear about aphasia?)

Relative/friend has/had aphasia _____ On TV/radio _____

Newspapers/magazine _____ Through my work _____

Social networks _____

Other _____

Letter from Valerie Gardner

November 20, 2007

Nancy Fugate Woods, PhD, RN, FAAN

Dean, School of Nursing

University of Washington

Dean Woods,

I am writing in reference to Elizabeth Sodbinow, a Ph.D student in the nursing program at the University of Washington. She is currently on "hold" status due to a large stroke, which occurred in August 1999. Since September 1999, I have provided speech therapy services to Elizabeth on an intermittent basis for speech/language problems resulting from her stroke. Elizabeth told me that she spoke with you in August 2007 about her eventual return to the graduate program. She is interested in completing her degree in Nursing Education.

Elizabeth underwent extensive speech/language testing at the 6-week Residential Aphasia Program at the University of Michigan in 2001 and 2006. **Elizabeth's primary problem now is with motor speech and not with memory, judgment, problem solving, or concomitant behavior.** Aphasia test batteries she has been given describe her language functioning very well. She is currently attending speech therapy sessions here at Memorial Hospital in Colorado Springs and continues to demonstrate improvement in all areas of language.

In my opinion, cognitive assessment and testing would not offer any additional or useful information about her status. If you have any further questions about Elizabeth's language status, please feel free to contact me at (719)-365-1264. Records are also available at the University of Michigan Residential Aphasia Program.

Sincerely,

Valerie E. Gardner, M.S., CCC - Speech Language Pathologist

Cc: Elizabeth Sodbinow

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