The SOCIAL ORGANIZATION OF SECONDARY STROKE PREVENTION

by

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Abstract

The early writings of Dorothy Smith (1990) and the tools of institutional ethnography were used to explicate the social organization of stroke prevention care in Ontario, Canada. This study was undertaken to understand how social determinants of health that set the context for patients’ lives and health are rendered invisible by the lens of health care professionals. This is despite the fact that there is substantial evidence that lower socioeconomic status is associated with higher incidence of stroke, stroke risk factors, and mortality after stroke. Data collection included observations of direct clinical care in a secondary stroke prevention clinic, interviews with patients, health care professionals, and extra-local informants, as well as the analysis of texts that were encountered in the setting. The entry point for data collection was through observations and interviews with patients who attended a secondary stroke prevention clinic. This local setting was connected through texts to the larger administrative and governing organizations, including the Ministry of Health and the Heart and Stroke Foundation.

Data analysis made visible a new interventionist paradigm in stroke care. This paradigm relies on a pharmaceutical innovation, provincial data circulation, as well as on visual imagery of vascular disease through brain scans. Secondary stroke prevention was found to be based on statistical risk formulas which act as a proxy for certainty. Rather than prevention, secondary stroke prevention constitutes last minute ‘damage minimization’ in patients with serious vascular disease. A significant finding was that patients did not know what secondary prevention was, yet actively participated in the related work, seemingly driven by the fear of disability. Biomedical
risk ideology locates disability and ‘risk factors’ in the body, thus social determinants of health are invisible. The complexity of health warrants the application of social as well as biomedical knowledge.
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Dedicated to Oliver Edmond and Julia Beatrix

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Be True to Yourselves!

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Chapter 1: Background

Jeffrey Simpson’s (2012) recent book, *Chronic Condition* resonated with me. In his analysis of the current state of Medicare in Canada, Simpson highlights Canadians’ dedication and commitment to our health care system. Growing up in Canada, I was socialized to brag about, believe in and trust our health care system and the decisions made by those responsible for our health. I, as Simpson (2012), believe that the story of Tommy Douglas, his childhood illness, and his successful quest for a universal, accessible, free system of health care is the story of a hero. Simpson is correct in identifying that Canadians rely on our system of family doctors and specialists, and on the larger health care system, hospitals, for when we are more seriously ill or injured. The acute care system holds a special place in the hearts of Canadians, as that system is there for us in our crisis, performing what we perceive as lifesaving operations or interventions.

As a nurse, I too have had my share of beliefs and perceptions about health, and the health care system. Originally trained at the College level, I did the duties I was trained to do, fulfilling the needs of my patients to the best of my abilities. Over the years, advancing my education, I continued to work with patients, but started to wonder about the way we as nurses and doctors were meeting these needs. We seemed focused on solving the problem in front of us, but did not seem to notice context. The system seemed reactive, rather than proactive.

When Simpson (2012) identifies problems with the system, and Canada’s need to “dehospitalize” (p. 328), I again found myself in agreement. But it is when he notes, “every study confirms, that despite all the pressures to spend even more money on the health care system per se, a dollar spent on reducing inequality would do more for the system’s sustainability over the long term than another machine, nurse, doctor or hospital bed” (p. 48), that he really hits home.
Ten years earlier, curious about health and health care in a broader perspective, I had attended a conference at York University called *Social Determinants of Health across the Lifespan*. At this 2002 conference, health was related to key determinants in the social context, such as income and inclusion, rather than an outcome of an intervention in the hospital. Concepts and ideas about health policy, the role of nurses and doctors, the role of hospitals, acute care and prevention swirled in my head.

About that same time I had begun work as a newly graduated nurse practitioner on a stroke team, just as the Ontario Stroke Strategy was being launched in Ontario. I was part of a team of neurologists, research nurses, and stroke prevention nurses whose goal it was to create an infrastructure for stroke care in that particular hospital, but also a continuum for stroke care within the region. My role included teaching nurses the anatomy and physiology of a stroke and the subsequent consequences they were seeing in their patients, building infrastructure within the hospital to accommodate new stroke care processes, and building an interdisciplinary team as part of a larger goal to build a stroke unit. I also had direct patient involvement. I conducted assessments that, depending on timing, either involved participating in the decision to administer a new ‘clot-busting’ medication in the Emergency department, or to ascertain the impact of the stroke and related rehabilitation goals. As part of follow up before discharge, I would discuss risk factors for stroke with patients and their families, and leave literature on lifestyle or behavior changes that could be considered.

This was not my first nursing role. I had previously worked on a general medicine ward, as a critical care nurse, as an Emergency room nurse. I had completed a Master’s in Education in counselling psychology and had worked as a therapist for people who had experienced trauma. This new role as a nurse practitioner with the stroke team brought all of this prior experience
together, yet I approached this differently, with different questions. I witnessed people having a stroke before my eyes, their physical abilities changed, possibly forever, with their roles and livelihoods jeopardized by the stroke. I watched the distress of their families. While I was pleased that we had some options for people during an acute crisis, I sometimes wondered if the bigger picture of the person’s circumstances played more of a role than we considered in the hospital. When I would speak with patients after their stroke about what might have happened, and how to, based on our best knowledge, prevent another stroke in the future, at times the advice or knowledge I was sharing didn’t resonate with my concerns and musings about their underlying health. Our answers seemed too simple, or too late.

One patient whose story remains with me, and whose story led me to pursue this doctoral study, was a woman I will call Dot. Dot was a 73 year old retired housekeeper. She had been living alone and independently. She experienced a stroke that left her with paralysis on the right side of her body, and substantial facial weakness that left her with a drooping mouth. Without the use of her arm and leg, Dot could not get out of bed, she could not eat without help, and she could not get dressed. Completely dependent on the nurses, she relied on others to ensure her needs were met. When I met Dot, she was already in her hospital room, having been admitted to the hospital during the night. Two adolescents were sitting, appearing quite overwhelmed, on chairs at the foot of Dot’s bed. I learned that Dot had a daughter, and these were her daughter’s children, her grandchildren. The change they were facing in their lives was apparent in their eyes. I learned that Dot raised her daughter on her own, and evidently the bond they shared extended to the grandchildren.

It became apparent to me during our interview that Dot had lived a hard life. As a single mother with little education, she worked very long hours for minimal pay. Social values during
the years Dot was raising her daughter alone were conservative and Dot faced social exclusion. During our interview Dot and I reviewed what my stroke team colloquially termed the ‘four horsemen of the apocalypse,’ (a term popularized by Dr. D.J. Sahlas) that is, the stroke risk factors: high blood pressure, high cholesterol, diabetes and smoking. Dot had them all. When we started to speak about smoking, Dot confided her ‘chain smoking’ addiction to cigarettes, looked at her grandchildren, and exclaimed, “DON’T SMOKE!” I could not help but reflect on Dot’s socioeconomic circumstances and the social exclusion as contributors to her health.

The illustration of Dot and her stroke brings forward complex issues of personal and family loss, social circumstance, biomedical risk factors, disability, medical care, source of stroke, prevention of stroke, chronic conditions and the acute care environment. There is substantial literature surrounding each of these topics. Each topic stands independently as a field of research, a body of knowledge within the disciplines of medicine or sociology. However, I was not aware of any studies that bring forward these issues together.

In an effort to explore and understand health and health care more deeply, to make visible how the health care system works, and to explore how decisions that impact Canadian patients are made, I decided to pursue this doctoral study. As a nurse, my values draw me to the patient, and I decided to design the study using stroke patients attending a stroke prevention appointment as the entry point into the stroke system. Smith’s (1987, 1990) writings, as the theoretical and methodological approach, provided an empirical way to investigate the local hospital clinic setting with the patients, as well as the larger administrative governing system.
This dissertation has eight chapters, including this introductory note. The next chapter, Chapter Two, situates the study in the literature. Stroke is a complex condition, and when one looks beyond the biomedical view, the connecting bodies of knowledge are vast. The literature review therefore encompasses sociological, medical, nursing, economic, and policy documents.

Chapter Three presents the theory and methods of institutional ethnography as developed by sociologist Dorothy Smith and explicates the research design. The vital role of texts as the empirical link between settings, a distinctive feature of institutional ethnography, is presented. The administration of the study is described, including the recruitment criteria and recruitment method. A table of informants (Table 1) provides an ‘at a glance’ look at the men and women who allowed me to accompany them into their medical appointment. The data drawn from the entry point these people provided into their lives and the Ontario Stroke System are analyzed in Chapters Four, Five and Six.

Chapter Four presents the analytical material starting from the external or extra-local environment, in order to contextualize the encounter the patient has with the system in the later chapters. Consequently, this chapter draws upon several significant texts. These texts include a speech that facilitated the provincial emergence of the Ontario Stroke System (OSS), publications that further contextualize the origins of the OSS, a diagram that highlights the various activities that occur in a stroke prevention clinic, data collection documents which illustrate the circulation of patient information and its use in the larger system and snapshots from a World Health Organization (WHO) *Atlas* which connects stroke to the concept of economic burden.

In Chapter Five I introduce informants who noticed something different in their body (a symptom) that led them to the stroke prevention clinic. The impact of social marketing products
in symptom recognition will be detailed. In the second part of the chapter the privileged knowledge and risk logic of the clinic emerge. I argue that secondary stroke prevention is potential ‘damage minimization’.

I make the case that patients with complex social and medical lives encounter a clinical experience in which their bodies are mined for precise exclusive data in Chapter Six. Initially, through textual analysis of the documents that enter and are encountered in the clinical flow of the stroke prevention appointment (such as referral and triage forms), I show the knowledge that is privileged in the clinic, and the logic that directs clinical decision making. I then shift the analysis to a direct patient-health professional interview that occurs behind the closed clinic examination room doors. I will show that the person who enters the appointment is encountered as a patient by the stroke team. By that I mean her lived reality is subjugated to the predetermined required data collection and assessment. The health work of the patient is also made evident in this chapter.

In Chapter Seven, I discuss the risk ideology that becomes apparent through the analysis of the work of the health professionals and patients and textual links to external informants. ‘Risk’ as a taken-for-granted concept that obscures the complexity of the patient, the broader contextual issues, and justifies the status quo is discussed in the conclusion, Chapter Eight. The implications of “hidden complexity” bring us back to Dot. With the workings of the Ontario Stroke System made visible, I argue that the “power of the concerted activities” (Smith, 1990, p. 80) of the privileged biomedical knowledge and governing risk ideology excluded other perspectives in the secondary prevention stroke clinic.

Chapter 8 concludes the dissertation and offers three recommendations for future research.
Chapter 2: Locating the study in the literature

Researchers using institutional ethnography (IE) recognize published literature as the authorized version of the way a topic is known (Campbell & Gregor, 2002). In IE, the literature is reviewed both to grasp the scope of the knowledge that is available, but also to understand the lens or perspective of the particular author researching or writing within a particular discipline or field. In this chapter, I introduce the literature to present the different epistemological perspectives of stroke and stroke prevention as seen in the fields connected to the study area, in this case, biomedical and sociological research. In advance of the fieldwork, the literature was reviewed to understand the work of patients who experience stroke, to understand the relationship between social variables and stroke, and to review the concept of risk that is pervasive within biomedical stroke literature. Following data collection, findings from the study that informed the extra-local social organization generated a supplemental literature review to examine social marketing, the economics of stroke and a deeper review of the concept of risk. Access to research and theoretical articles was gained through scholarly databases, including Medline, Web of knowledge, Web of science, and Google Scholar as well as the grey literature which included Ontario Government documents, local evaluative reports, Best Practice Guidelines (BPGs), federal government documents, as well as World Health Organization (WHO) reports. Reference lists and bibliographies from reviewed documents were also searched.

Stroke is complex. It is not just a medical phenomenon, but an event that brings forward multiple issues. Stroke is personal, yet impacts family members or significant others directly. Indirectly, the greater community is impacted as stroke is a health care expense. A stroke event that creates a visible disability (such as a facial droop or limb paralysis) brings forward responses to disability that are again highly personal but also social and economic. The event of stroke is biomedically linked to underlying risk factors. Risk factors are not just objective variables, but
manifest themselves as comorbid conditions that people are self-managing, such as high blood pressure, or may include personal habits that are longstanding and embedded, such as smoking. The constellation of predisposing risk factors also provides an opportunity to reflect on social determinants of health.

The complex nature of stroke requires a literature review that covers these multiple territories. The literature review is presented in sections. The first section includes the knowledge gained from patients and their families regarding the experience of stroke in the acute phase, through recovery, as well as the management of comorbidities. This literature is important as it points to the rationale for stroke prevention from the patients’ perspective. The biomedical context of stroke care is then presented as section two, as well as the areas in which the biomedical perspective is challenged: the area of disability and of risk. Third, I highlight the literature that surrounds stroke as a healthcare cost linked to disability, and the related literature of stroke as a consequence of social economic status. Finally, I review the literature regarding categories in the disease prevention-health promotion continuum and the studies directed towards understanding public knowledge of stroke symptoms.

*The stroke experience*

Poirier and Derouesné (1993) tell us that in the West, stroke was first described as apoplexy, a term from the Greek word *apoplexia*, meaning struck down with violence. This term implied the shock of being struck by lightning or a thunderbolt, and the terror experienced by such a calamity. This historical information that Poirier and Derouesné (1993) report aptly depicts the predominant view of how stroke survivors and their family describe their experience of stroke in research published in biomedical nursing and medical journals. Hafsteinsdottir and Grypdonck (1997) describe patients’ initial experience of the stroke as “extreme shock and fear” (p. 583). The stroke onset was described as overwhelming by stroke survivors interviewed by
Burton (2000). Individuals felt unprepared for the stroke and were afraid they were going to die. The perspective of tragedy and rejection is also reported in the literature regarding health care professionals’ view of stroke patients. Historically, stroke patients have not been a sought-after group to work with clinically (Wade, 1989). An early Canadian ethnographic study conducted by Eakin-Hoffman (1974) over six months on a neurological ward explored the care of stroke patients. Eakin-Hoffman (1974) revealed a ‘nothing can be done’ perspective from health care professionals. Professional groups working with stroke patients spoke about the patients as ‘frustrating’, ‘depressing’, ‘vegetables’ and ‘gorks’ (Eakin-Hoffman, 1974). Hamrin (1982) has suggested that negative attitudes of staff towards this patient group are impacted by attitudes towards disability and the elderly. In interviews, physicians often expressed a sense of hopelessness about stroke patients. They equated a patient’s severe stroke with a living death, and viewed stroke as a profound disaster (Becker & Kaufman, 1995).

Stroke survivors continue to struggle after the acute event, as they move into their recovery. Becker (1993) interviewed 100 stroke survivors three times over the course of a year to understand their feelings about disability, recovery, loss and disruption. Research participants unanimously viewed the stroke event as a profound disruption to their lives. Becker (1993) commented that, for the stroke survivors, the stroke “destroyed the fabric of predictable, everyday life” (p. 152). Doolittle (1994) describes one patient as “deeply stunned and distraught over the stroke” (p. 13) and notes that recovery for the patient included reconciling their social identity, not just physical function. Backe, Larsson and Fridlund (1996) noted that stroke patients’ conception of their bodily changes led to physical and psychological trauma and crisis. Sembi, Tarrier, O’Neill, Burns, and Faragher (1998) in the United Kingdom observed that some acute stroke inpatients experienced flashbacks, ruminated about the stroke event, and displayed
active denial or high anxiety. Sembi et al., (1998) then investigated whether post-traumatic stress disorder (PTSD) occurred after a first transient ischemic attack and stroke. A PTSD prevalence rate of 9.8% was found in the population with stroke and transient ischemic attack (TIA), suggesting that the event of stroke is traumatic.

The period of recovery from stroke is described by patients as “an intensely personal experience” (Burton, 2000, p. 307) that requires restructuring of one’s emotional, physical and social life. Two researchers referred to stroke as ‘foreign’. Doolittle (1992) used the words “foreign body” (p. 125) to describe her ethnographic observations of stroke patient’s recovery. She argued that “there was no longer a bodily sense of wholeness; bodily integration was missing” (p. 122). Ellis-Hill, Payne and Ward (2000a) used a life narrative approach to interview eight male/female couples whose life had been impacted by stroke. Interviews occurred at six months and one year. The researchers theorized a separation of self and body, and described patients as “entering a foreign world” (p. 727). In a further study, Ellis-Hill and Horn (2000b) found that stroke patients saw themselves as less interested, capable and independent, less in control, less active and less satisfied after the stroke, but also as friendly, calm, caring, hopeful and talkative (Ellis-Hill & Horn, 2000b). Clarke and Black (2005) interviewed eight middle-class white stroke survivors regarding quality of life after stroke. Survivors reported that reduced participation in previous activities (driving, running, skiing) made them feel they could no longer be the person they used to be before the stroke. They pointed to social exclusion, as their neighborhood friends had ‘dropped them’ and others were afraid of them (Clarke & Black, 2005). Later, Clarke (2009) described a retired professor’s severe depression post-stroke as the stroke thwarted his plans to write his memoirs.
Loss after stroke is a prevalent theme. Doolittle (1988) reviewed the neuro-medical literature between 1970 and 1987 to explore patient experience of stroke. She reported that the experience of patients included loss of dignity, financial difficulties, and role alterations. She noted one study in which 51 patients with hemiplegia were interviewed about leisure activities that they engaged in before and after their stroke. Patients commented that they felt inferior post-stroke. They expressed the belief that they could never live a full life again (Doolittle, 1988). In 1997, Hafsteinsdottir and Grypdonck’s review of the literature on the patient’s experience of stroke noted that patients spoke about loss of activities, abilities, and independence, mobility and travel. McKevitt, Redfern, Mold and Wolfe (2004) found that the impact of stroke on survivors was repeatedly described as loss in their systematic review of qualitative studies of stroke using literature databases from their time of origin until 2002. Conversely, Gillen (2005) explicitly asked stroke survivors during their rehabilitation about any positive benefit after surviving a stroke. Ten of 15 patients stated that their social relationships were strengthened, their health awareness was increased, and they were more engaged in spiritual practices. The respondents felt that they had grown personally, with an enhanced awareness and concern for others.

Bendz (2003) explored the experience of stroke using a phenomenological approach and noted that stroke survivors engaged in reflection on how the stroke happened. She concluded that unique personal factors were involved in people’s perceptions of the cause of stroke. Examples of unique factors included painkillers that they had taken, getting going too early in the morning, carelessness about food choices and leading a stressful life (Bendz, 2003). In rural Indonesia, stroke was known as “mati badan sebelah” which translates as “half dead body”. Stroke was understood as a plug in the blood flow in the affected area (Norris, Allotey, &
Barrett, 2010). Participants interviewed by Kamera and Singh (2012) linked their longstanding medical problems as contributing to their warning signs of stroke (transient ischemic attack, TIA). High blood pressure was commonly understood to be related, but atrial fibrillation and smoking were not. Most participants felt that having a TIA in the past increased their risk of future TIA and stroke and were fearful of having a severe stroke that would end their lives or leave them severely disabled (Kamera & Singh, 2012). Townend, Tinson, Kwan and Sharpe (2006) similarly found that participants interviewed about their beliefs about the cause of their stroke identified causes of stroke as: old age, family history, high blood pressure, cholesterol, diabetes, smoking, under-exercise, being overweight, reckless lifestyle in youth, bereavement, worry, overdoing it, and/or the result of a hard life.

For some stroke survivors, the stroke provided an impetus for lifestyle change, for others who felt their lifestyle had been good there was a sense of unfairness about having the stroke (Rhoda, Evans, Kilbride, & Campbell, 2008). Participants reported challenges to making lifestyle changes, including feeling too old to make changes, sustaining any changes, and navigating conflicting information about healthy options from health care professionals (Rhoda, et al., 2008). In Townend et al.,’s (2006) study, people expressed the belief that nothing could stop a recurrence. Almost three quarters of the participants reported fear of another stroke, as well as the fear of acquiring more severe disabilities, such as being wheelchair-bound or unable to communicate. A few expressed the view that death would be preferable to severe stroke, partly due to concerns for loved ones’ welfare (Townend, et al., 2006).

These findings of fear, doubt, and ambiguity regarding the cause of stroke, utility of lifestyle changes, and possibility of prevention in the stroke literature are echoed in the area of heart disease (Bergman & Bertero, 2003; Jensen & Petersson, 2003). Focus group participants in
a study by Angus, Evans, Lapum, Rukholm, St. Onge et al., (2005) discussed heart disease as a “sneaky, silent” hidden disease. Participants in all groups noted that it was difficult to commit to risk modification measures when there was no way of determining personal candidacy for heart disease. Participants weighed their own risk based on family history, personal health habits, and their understanding of the doctor’s reports. The most credible evidence of risk was the experience of a myocardial infarction. The shock of the heart attack was a powerful source of motivation to change, but for a limited time. Angus et al., (2005) found that socioeconomic status played a role in the health knowledge of participants. In Wheatley’s (2005) ethnography at a heart center in the United States, one couple coined the term “cardiophobia” (p. 18) in reference to their preoccupation with their heart disease and concern over what might happen next.

Being ‘at risk’ has been explored in the field of cancer and genetics testing. Robertson (2001) interviewed 20 women who attended a breast health clinic at a Canadian hospital, and who had not been diagnosed with breast cancer, in order to understand women’s accounts of breast cancer risks. Robertson (2001) reports that women referred to their breasts as flawed (using terms like ‘time bomb,’ for example) which Robertson termed “breast worry.” Scott, Prior, Wood and Gray (2005) described a liminal state for those identified at risk after genetic testing for cancer in a UK study conducted with 58 people referred to a regional cancer genetics service. This intermediate state lay between two worlds where they waited to develop a disease and be treated accordingly, or to be reassured from screening results that they were in good health. This study found that those found to be at high risk perceived their outcome to be fortunate as it appeared to create feelings of safety, reassurance and trust in the power of medical knowledge. Participants were interested in being monitored, cared for, looked out for, and
supervised, which the authors interpreted as a desire for surveillance, engagement and access to resources. Participants deemed to be normal or low risk seemed to be dissatisfied and experienced the most challenge to self-identity, as perhaps their own sense of risk was not validated by the testing. They felt they were unfairly denied access to resources, and were not reassured by the test result. Some strove to re-position themselves into a higher risk category.

Patient work to manage conditions such as diabetes and atrial fibrillation that predispose patients to stroke is substantial. A grounded theory study in Vancouver (Paterson, 2002) investigated how people with long-standing type 1 diabetes mellitus manage self-care decision-making and relationships with health care practitioners. Participants described their experiential knowledge being discounted in favor of laboratory results, being blamed for high blood glucose concentrations, and being excessively monitored. Long wait times at appointments, child care and parking challenges at appointment times, and pace and length of appointment times were also found to influence participatory decision making (Paterson, 2002). Xuereb, Shaw and Lane’s (2012) meta-synthesis of studies undertaken with patients receiving oral anticoagulant therapy found information provision to the patients to be problematic. Different communication styles of doctors meant that some patients were provided with statistics about risk to inform decisions. In other cases, doctors made the treatment decision for the patient (Xuereb, et al., 2012). Patients commented that for the doctor it was ‘business as usual’ to give medical advice, but that is was difficult for them to absorb what the doctor told them. One example was information about what they could not eat anymore due to interactions with their medication. Patients felt that their eating habits and preferences were well-established and not easily changed.
The context of stroke care: the biomedical model

In order to understand the context of the Ontario Stroke System and the work of patients uncovered in my study, it is important to understand the overall organizing biomedical theory of disease, and specific biomedical infrastructure in the field of stroke. In the case of stroke specifically, this includes a pivotal new pharmaceutical innovation from stroke research, the organization of biomedical stroke knowledge and the source of data the Ontario Stroke System uses to circulate new knowledge about stroke and the stroke system. Tensions exist in the literature in these areas: the site or location of disability, the role of risk management and the role of finances in stroke. Where tensions exist, this literature is also presented.

Baranov (2008) informs us that biomedical values, beliefs and practices are derived from empirical, objective procedures and investigative tools such as measurement, observation, and experimentation of the body. Historically this scientific logic led to the mapping and classification of distinct diseases and their causes. This “doctrine of specific etiology” (p. 242) located disease in the body’s tissues, organs and cells. Disease arising in the tissues, organs or cells was understood to impact physiological function. In relation to the field of neurology and stroke, this perspective locates stroke in the body, organs and cells. Biomedically, stroke is defined as the sudden onset of a focal neurologic deficit due to a disturbance in the blood supply to the brain (Dombovy, Burton, Sandok, & Basford, 1986).

Dawes, Summerskill, Glasziou, Cartabellotta, Martin et al., (2005) tell us that biomedicine organizes knowledge using evidenced based practices and guidelines. In the field of stroke, Webster (2009) tells us that the “positivist discourse of evidence-based medicine assumes that research produces knowledge that is neutral and can be translated into treatment that is in the patient’s best interest. Yet these assumptions remain empirically unexamined, despite social science critiques of these processes” (p. ii). Examples of guidelines in stroke include Sacco,
Adams, Albers, Alberts, Benavente et al.’s (2006) *Patients with Ischemic Stroke or TIA*, and Lindsay, Bayley, McDonald, Graham, Warner and Philip’s (2008) *Canadian Best Practice Recommendations for Stroke Care. Early Management of Patients with Acute Ischemic Stroke* was published by Jauch, Saver, Adams, Bruno, Connors et al., in 2013. Recommendations in these guidelines include management of risk factors, diagnostic methods and treatment recommendations. The goal of these guidelines is to limit the morbidity and mortality associated with stroke (Jauch et al., 2013). Language and terminology in the guidelines depicts predominant interest in body function and physiology. Loss or lack in function is noted as an impairment or disability that is located in the body. Here I use the term location as defined by Lorenz-Meyer, “locations are positionings in time and space which have specific effects and consequences, or ‘politics’, that need to be analyzed and historicized” (n.d., p. 2). In other words, there is recognition of the power of naming the ‘source’ of disability or impairment. The term impairment is defined in the glossary of terms from Lindsay, Gubitz, Bayley, Hill, Davies-Schinkel, Singh and Phillips’ (2010) *Update* as “a problem in the structure of the body (e.g., loss of a limb) or the way the body of a body part functions (e.g., hemiplegia)” (p. 227). Disability is defined in the stroke literature as “a defect in performing a normal activity or action (e.g., inability to dress or walk)” (p. 220).

There are autobiographical accounts in stroke literature regarding the experience of stroke that challenge the mainstream medical perspective of stroke. As well, scholarly arguments arising from critical disability studies challenge the biomedical belief that disability is a problem within a person and maintain that disability is better understood within the social model of disability. Shakespeare (2013) informs us that the social model of disability emerged from the intellectual and political argument of the Union of Physically Impaired against Segregation (UPIAS). A key element of the thinking of this union was the distinction between
disability (considered social exclusion) and impairment (considered physical limitation). The union group argued that society disabled physically impaired people through exclusion (Shakespeare, 2013), an argument now understood as the ‘social model’ of disability.

Robert MacKay (2003) a sociologist at the University of Toronto experienced a stroke and subsequent aphasia. He writes about the contrasting ideology of the medical model and the social model toward disability as detailed by Shakespeare above (2013). His paper is an excellent example of the complexity of stroke and the tensions between two contrasting views of the disability that stroke can produce. MacKay experienced a stroke and subsequent aphasia, and studied people with aphasia, including himself, “and I am one myself” (MacKay, 2003, p. 811). MacKay illustrates that people with aphasia have to “operate between two ideologies” (MacKay, 2003, p. 811). MacKay claims that “the medical ideology is built on the idea of personal tragedy, which rests upon the individual who has the disability” (MacKay, 2003, p. 812) and contrasts the medical model with the social model. MacKay illustrates the differences between the medical and social model using his own personal experience in the hospital after his stroke. He describes an interaction between himself and the attending physician and himself and a visitor. He shows how, from the medical view, he was considered incompetent as he could not speak using words, and how, from the social model perspective he had agency in making sense, despite the lack of words.

Kelley and Betsalel (2004) used ethnographic photo essay to explore the ‘culture of stroke’ after Kelley experienced a stroke. They describe the struggle of being in culture and against culture, and Kelley’s wish to be ‘normal’ after her stroke. They state that this desire can be understood as the internalization of the “dominant ablest” (Davis, 1995, p. 5) culture and the fetish with normality (Davis, 1995). Both of these personal accounts stand apart from the dominant reports of stroke survivors experiences. In each case the researchers are well educated
critical scholars offering a perspective that show how they struggle with their environment and their experience.

Other social researchers challenge the medical model of disability as well. Medicine explains disability as a “departure from normalcy, a loss of a way of being in the world” (Titchkosky, 2007, p. 134). Davis (1995) argued that categories such as ‘disability’, ‘handicapped’ and ‘impaired’ arise from a society invested in denying the variability of the body, part of a politics of power and fear. He contended that disability is socially organized (Davis, 1995). Stiker (1997) confronted not just the negativity of words as *mal-formation, dis-ability, im-potence* (author’s italics) but the fearful, visceral reaction to the disruption and disorganization that occurs socially and individually when disability occurs. He claimed that the world is socially organized for the person designated ‘normal’ and our expectations are situated accordingly. Stiker (1997/1999) argued that society engages with strategies of rejection towards disabled people, rather than recognizing, accepting and valuing nature’s physical and cognitive differences. Patston (2007) reflects upon Constructive Functional Diversity as a ‘box in which all human beings sit, stand or otherwise exist’, pointing out we do not label someone disabled if they cannot sing, act, cook or swim. He stated that ‘dysfunctionphobia,’ our own fear of losing function, is the reason we label some, and not others with medical terminology. Mitra (2006) argued that disability is not the attribute of the individual, but is created by the social environment and requires social change.

In Ontario, data collection and analysis of stroke care, with related evaluative reports and generation of stroke care guidelines, occurs through the Institute for Evaluative Studies. The data source for stroke care is the Registry of the Canadian Stroke Network. When this Registry began, there were challenges in receiving consent from patients to collect their data. Tu,
Willison, Silver, Fang, Richards et al. (2004) conducted a study to explore the feasibility of obtaining written informed consent from patients for this Registry. The study found that the clinical challenge in obtaining consent was echoed in the research study. Reasons for the challenges included patient death or discharge before consent, language barriers, no substitute decision-maker available, or patient refusal. Findings from Tu et al.,’s study led Registry administration to decide that de-identified data would be collected without consent, arguing that in a publicly funded system, patients have a “social obligation to permit data to be used without consent so that the health care system can be monitored and improved for the benefit of all” (Tu, et al., 2004). Patient data is valued, and collection is privileged over privacy.

The application of risk knowledge generated from epidemiological population statistics to individual patients is apparent in stroke prevention guidelines, documents generated from the analysis of data from the Registry. Under the heading Stroke Prevention in the Canadian Best Practice Guidelines (Lindsay et al., 2008), the first recommendation reads, “Persons at risk of stroke and patients who have had a stroke should be assessed for vascular disease risk factors and lifestyle management issues. They should receive information and counselling about possible strategies to modify their lifestyle and risk factors” (p. S7). The Report of the Joint Stroke Strategy working group divides risk factors into unmodifiable factors which include age, one’s family history, male sex, ethnicity, and socioeconomic status (Ontario Ministry of Health and Long Term Care, 2000). Modifiable risk factors include high blood pressure, sedentary lifestyle, being overweight, smoking, excessive alcohol consumption, high cholesterol, atrial fibrillation, coronary heart disease, diabetes, transient ischemic attack, previous stroke, and asymptomatic carotid stenosis (Ontario Ministry of Health and Long Term Care, 2000, pp. 46-48).
Biomedical treatment for stroke prevention takes a risk logic approach. The Number Needed to Treat (NNT) is the point at which the negative consequences of treatment equal the therapeutic benefit, that is, the number of patients one needs to treat to prevent one patient having the target event (Sinclair, Cook, Guyatt, Pauker, & Cook, 2001). Sinclair et al., (2001a) report the NNT for treating a heart arrhythmia with a blood thinner is 133 patients per year.

Other factors play a role in treatment decisions. Alhusban and Fagan (2011) reviewed the secondary stroke prevention literature to determine treatment modalities for the elderly. The authors recognized the physicians’ fear of prescribing anticoagulants for perceived increased risk of bleeding, as well as the concern of lowering blood pressure. Their review of the research led them to conclude that age alone is not a reason to limit secondary stroke prevention treatments (Alhusban & Fagan, 2011). The complexity of treating the elderly with antihypertensive medication is discussed by Vischer (2012). There is fear of ‘going too low’ with the blood pressure.

Treating risk factors is highly complex as treating one condition may jeopardize another health variable. Haynes, Devereaux, and Gyatt (2002) advocate for clinical decision-making that incorporates research evidence with clinical circumstances and the patient’s preferences. Investigators for stroke prevention in atrial fibrillation (Man-Son-Hing, Laupacis, O’Connor, Biggs, and Drake, 1999) conducted a randomized control trial to determine whether a decision aid affected patients’ decision-making about taking anti-thrombic therapy. Anti-thrombic therapy is a therapy known to create bleeding risks, but also known to prevent stroke. The decision aid included the work the patient would be required to participate in, such as regular blood tests and possible changes to activities that put them at risk for head injury. The study found patients in the decision aid arm to be more knowledgeable about risks.
Devereaux, Anderson, Gardner, Putnam and Flowerdew (2001) conducted an observational study to determine differences between perspectives of physicians and patients in the trade-offs between risk of stroke and risk of bleeding using an anti-thrombic with patients who had a risk of developing atrial fibrillation, but were not currently considering actual treatment. A pictorial information chart depicting risks of bleeding and possible consequences of a minor or major stroke was used during discussions of possible clinical scenarios. In scenarios using either aspirin or warfarin, patients had a higher tolerance to accept the risk of bleeding internally or after a fall versus the risk of stroke than the physicians would accept for their patients. The authors advocate the inclusion of patient perspective in treatment considerations.

The biomedical view of using risk formulas to determine treatment strategies has been critiqued by sociologists. In the USA, Crawford (1977) described victim blaming, that is, blaming individuals for their illness. He argued that personal behavior was seen as the problem and that changing life-style or taking more responsibility for one’s health, was the proposed solution. Crawford (1980) later coined the term ‘healthism,’ the preoccupation with personal health. He suggested there was a new role, a ‘potential sick role,’ that was created by the notion of preventing illness and argued that “to be health-conscious today is to come into an understanding that one’s health is in continuous jeopardy” (Crawford, 2006, p. 403). Crawford (1980) points out that prevention of illness has become a standard by which everyday behaviors such as eating, drinking, working and leisure activities are judged. “We become deviants in our everyday lives – when we light up a cigarette, when we consume eggs at breakfast” (p. 380).

Castel (1991), using the example of psychiatry, noted that ‘danger’ has been shifted to ‘risk’. “Risk does not arise from the presence of a particular precise danger embodied in a concrete individual or group, it is the effect of a combination of abstract factors which render
more or less probable the occurrence of undesirable mode of behavior” (p. 287). He notes that risk promotes a new mode of surveillance, anticipating and preventing the emergence of some undesirable event such as illness, abnormality, or deviant behavior.

Armstrong (1995) described the rise of surveillance medicine through a mapping of medical frameworks. He claims that initially, physicians treated the illness that the patient described, their symptom, for example abdominal pain. Later, the illness was linked with the findings of the clinical exam, known as “the sign” which indicated the presence of a hidden pathological lesion, for example, the symptom of abdominal pain linked with the sign of abdominal tenderness. The symptom linked to a sign made visible the pathology to be treated, rather than the symptom itself. Armstrong provided an analysis of surveillance medicine as the next framework. He argued that surveillance medicine opens up a new space, problematizing the normal through screening. Symptoms and signs are re-read as risk factors that point to a future illness, an “at-risk” state. Applying the logic of surveillance medicine to the population targets everyone, “no one is truly healthy” (p. 397).

Petersen (1996) critiques health promotion as a method of targeting the individual who is expected to manage his or her relationship to risk and obliged to consult with numerous experts. Individuals must discriminate between available competing risk messages, and be able to make decisions about appropriate courses of preventive action, “as though some absolute truth about risk can be established” (p. 56). He states that being healthy has come to mean adherence to strict codes of conduct and close self-scrutiny, and that the distinction between healthy and unhealthy populations dissolves since everyone is “at risk”. Descriptors such as ‘healthy’ and ‘unhealthy’ have become signifiers of normal and abnormal identity, or of one’s moral worth.
Wheatley (2005) describes the risk and surveillance technologies she observes in an ethnographic study conducted at an American cardiac rehabilitation centre. She claims that fitness is defined by bodily risks such as percentage of fat and blood pressure, which are treated as reasons for medical intervention. She describes how epidemiological knowledge of population risk is translated to individual cases through risk profiling, although epidemiological knowledge cannot predict which individuals are at risk within that population. Wheatley (2005) identifies that social structural risks such as housing and insurance are not taken into account. She claims that lifestyle behavior changes will not improve the health of those whose risks are reproduced by social relations and forces they cannot control (Wheatley, 2005).

O’Byrne (2008) provides a conceptual analysis of risk within the field of nursing. He argues that the term ‘risk’ implies agreement about a preferred positive outcome. He claims that this assumption reveals the social-regulatory component of risk. The concept of risk, O’Byrne (2008) states, is a naïve technique implemented by altruistic health care providers engaged in risk management on the grounds of patient safety, yet dually engaged in social control.

Galvin (2002) argues that the emergence of neo-liberal social and economic order shifted circumstances such as illness, poverty, unemployment, and racism from the failure of the state, a matter of social responsibility, to individual responsibility. Risk management as a neoliberal characteristic is both a source of personal power and a tool for blaming those who fail in the face of choice. Galvin (2002) states that in the “commodification of health”, the church has been replaced by the gymnasium as the edifice which represents the kind of moral perfection that individuals are to aspire to. She points out that the chronically ill are burdened with moral blame, and, as many who are chronically ill are often reduced to poverty, they do not have access to the quest for health.
Anderson (1990) argues that the move towards ‘self-care’ (self-management) in Canada is an economic decision. She claims that there is a social attitude that people ought to assume responsibility for their health, regardless of the realities of their lives, such as access to resources. An individual’s day to day management of health can be both an economic and emotional struggle, while the magnitude of the issues people face in their daily lives seeming go unrecognized by those who are responsible for the allocation of health resources.

In the early 1990’s, Beck opened up public and academic discussion about industrial risk. He (1992) noted that hazards connected to industry were no longer confined to institutional walls but transcended spatial and temporal boundaries. Beck argued that the feudal age had become an industrial society with a wealth-production logic and that as “productive forces lost their innocence” (Beck, 1992, p.12), a new society based on risk-production logic emerged. Beck claimed that citizens engaged in reflection to determine how much risk was tolerable, however Lupton (2013) challenges reflexivity as a social norm, arguing that reflexivity not a skill all members of society have. Giddens (1990), Beck’s peer, also described a risk society, and drew in the element of trust that is required between community members to co-exist.

These critiques of risk all point to the economic and social systems that underlie the health care system. Galvin (2002) points to neoliberal strategies of risk management, Anderson (1990) notes the fiscal tone of self-management strategies and Wheatley (2005) points out the omission of social risks from the risk factor profile. In the case of stroke, the event of stroke is both a health care expense, and a consequence of socially determined factors.

*Stroke as known economically*

Twenty-eight articles were reviewed. Direct care costs included early critical care after tissue plasminogen activator (t-PA) therapy, medical-surgical services, radiology, rehabilitation therapies, pharmacy, laboratory costs and long term care (defined as care after 30 days) costs. Indirect costs were determined as a calculation of premature mortality, reduced productivity and lost earnings of stroke survivors. Total direct and indirect costs resulting from stroke were reported to be more than $65 billion for 2008 in the United States. Stroke was ranked among the most expensive chronic diseases. Cancer costs were reported as $219.2 billion in 2007, diabetes as $174 billion in 2007, and depression as $83.1 billion in 2000. The authors noted that “direct and indirect costs associated with stroke can be reduced by wider utilization of improved strategies for stroke care, such as t-PA, the only Federal Drug Administration approved drug indicated for improving neurologic recovery and reducing the incidence of disability in adults with acute ischemic stroke” (Demaerschalk, Hwang, & Leung, 2010, p. 532).

Saka, McGuire and Wolfe (2009) used data from the South London Stroke Register and a number of other national sources to quantify the annual cost of illness of stroke to the UK economy. Direct care costs included diagnosis, inpatient care and outpatient care. Income loss and social benefit payments to stroke patients are accounted for in the indirect cost calculations. The treatment of stroke and productivity loss arising from stroke was £8.9 billion per year ($14b US).

In Canada, Sinclair, Frighetto, Loewen, Sunderji, and Teal et al. (2001b) compared clinical and economic outcomes of IV t-PA therapy using total acute stroke and post-stroke treatment costs and cumulative quality-adjusted life-years (QALY). Using a hypothetical cohort of 1000 patients, estimated lifetime stroke costs were over $103 million Canadian dollars in the t-PA arm, versus over $106 million in the non-t-PA arm, translating into a lifetime cost
difference of almost $4 million, deeming treatment of acute stroke with t-PA an attractive cost saving strategy.

In Ontario, financial estimates of direct and indirect costs for stroke care were studied by Waterhouse Management Consultants (Chan & Hayes, 1998). Direct costs were calculated from Canadian Institute for Health Information (CIHI) data housed in the Discharge Abstract Database, pharmaceutical costs were captured through the Intercontinental Medical Statistics and itemized hospital expenditures through the Public Accounts of Ontario (Chan & Hayes, 1998). Indirect costs were derived using a human capital approach (Chan & Hayes, 1998). Disability from stroke was linked to the individual’s economic productivity. The estimate of total cost of stroke for the year 1994/5 was $857 million, and stroke accounted for 2.7% of total direct health care expenditures in Ontario. The costs related to premature death were $229 million and disability costs were $99 million.

Statistics from the World Health Organization’s (WHO) *Atlas of Heart Disease and Stroke* state that 15 million people per year worldwide suffer a stroke, five million per year die and another five million are left permanently disabled (Mackay & Mensah, 2004). The World Health Organization discusses death and disability using a population measure called the Disability-Adjusted Life Years (DALY). The DALY was created in 1992 through a partnership between the WHO, the World Bank and the Harvard School of Public Health as a measure intended to quantify the burden of disease and injury for the Global Burden of Disease Project. “DALY lost” is a mathematical determination, the “sum of years of life lost due to premature death and years of healthy life lost due to disability” (Hong, 2011, p. 110).

In 1996, Murray and Lopez, researchers at the World Health Organization who studied global burden of disease, published a significant epidemiological study in which they assessed global mortality and projected mortality through to 2020. The authors describe the use of the
DALY. They note that individual countries used the QALY (Quality Adjusted Life Year). The Disability Adjusted Life Year (DALY) is an internationally standardized form of the QALY. The DALY expresses years of life lost to premature death and years lived with a disability of specified severity and duration. One DALY is one lost year of healthy life. Murray and Lopez (1996) note in their report that quantifying disease burden may appear as a neutral exercise, but in fact value choices are made because “a society’s values are explicitly built into its measures of health status” (p. 7). The cost of stroke is the cost of loss.

Yet, economically, there is another picture of stroke. Researchers in Canada and the United States studied the direct impact of poverty and lower socioeconomic status on health. Poverty is linked to a variety of behaviors which impact health and are known to be risk factors for stroke in the biomedical field. Poor people in Western countries are less likely than those who are economically well-off to eat a good diet, are more likely to have a sedentary lifestyle, more likely to be obese, more likely to be regularly drunk, and use legal and illegal drugs (Jarvis & Wardle, 2006). Cigarette smoking, a risk factor for stroke, shows a strong association with indicators of social disadvantage (Jarvis & Wardle, 2006). Jarvis and Wardle (2006) found emerging evidence that the level of nicotine dependence increases with deprivation, they noted that the poor smoke more cigarettes and smoke each cigarette more intensively. Lightman, Mitchell and Wilson (2008) found that the poorest one-fifth of Canadians, when compared to the richest twenty percent, have more than double the rate of diabetes and heart disease (including high blood pressure), both risk factors for stroke.

Mikkonen and Raphael (2010) describe a theoretical formulation that Canadians who live in adverse social or material conditions experience high levels of physiological and psychological stress. This chronic stress weakens the body’s resistance, making people more
vulnerable to cardiovascular disease and adult-onset diabetes. This stress leads to use of alcohol, cigarettes or high-carbohydrate food as coping mechanisms (Mikkonen & Raphael, 2010). Stressful experiences arise from attempting to cope with conditions of low income, poor quality housing, food insecurity, inadequate working conditions, insecure employment, and various forms of discrimination based on Aboriginal status, disability, gender, sexuality or race (Mikkonen & Raphael, 2010). Canadians of colour, recent immigrants, women and people with disabilities are likely to experience social exclusion (Mikkonen & Raphael, 2010). The correlation in Toronto between poverty rates, diabetes and visible minority status has been well documented (Mikkonen & Raphael, 2010).

Researchers at the Institute for Clinical Evaluative Sciences (ICES) in Toronto looked at 39,545 stroke admissions to Ontario hospitals from 1994 to 1997 and found that the number of stroke patients was higher in the lower-income levels, reflecting the higher burden of disease with lower socioeconomic status. Physiotherapy, occupational therapy and speech therapy were more often given to patients in the higher-income levels (Taggart, 2001). In an ICES investigation into diagnostic services in Ontario, socioeconomic disparities favouring affluent neighbourhoods were noted in MRI investigations (You, 2007). Reasons suggested for this disparity included variations in health-seeking behaviors, access to specialists, physician decision-making, or clinical differences. Differences in socioeconomic disparities are not just about income, but about class connections, access, and ability to navigate the health care system.

A Canada-wide study looked at hospital ischemic stroke admissions from 2003-2004 to examine differences in socioeconomic status, hospital volume and stroke fatality (Saposnik, Jeerakathil, Selchen, Baibergenova, Hachinski, et al., 2008). The study concluded that patients from low-income areas presenting with acute stroke are more likely to be seen in low-volume
facilities and suffer a higher fatality than those from high-income areas seen at high-volume facilities (Saposnik et al., 2008).

Van den Bos, Smits, Westert, and van Straten (2002) showed that lower socioeconomic status is associated with higher risk of stroke. Kleindorfer, Lindsell, Broderick, Flaherty, and Woo et al., (2006) and Thrift, Dewey, and Sturm, (2006) published findings connecting lower socioeconomic status to stroke within the biomedical field, in the journals Stroke and the Annals of Neurology. An updated review of socioeconomic status (SES) and stroke was conducted by Addo, Ayerbe, Mohan, Crichton, and Sheldenkar (2012) and published in Stroke. Nine studies on SES and stroke incidence between 2006 and 2011 were found, originating in Australia, Italy, Sweden, the US and the UK. An increased incidence of stroke, higher rate of stroke risk factors and higher mortality from stroke were reported among those of lower SES (Addo et al., 2012).

Because low socioeconomic status has been associated with a higher mortality after stroke in Europe and the United States, and Afro-Americans have a higher stroke incidence and lower socioeconomic status than whites, researchers in Kentucky, USA sought to determine how much of the excess stroke incidence was due to socioeconomic status. Within the biracial population, they found that 39% of the racial disparity in stroke incidence for blacks was associated with poorer socioeconomic status (Kleindorfer et al., 2006). These findings were replicated in Melbourne, Australia (Thrift et al., 2006). In Texas, the Brain Attack Surveillance in Corpus Christi (BASIC) project found Mexican-Americans to have a greater burden of stroke then White Americans (Morgenstern, 2004) as well as a higher risk for recurrent stroke (Lisabeth, Smith, Brown, Moye, Risser, & Morgenstern, 2006). The same project examined socioeconomic status and found that low neighborhood socioeconomic status may influence stroke risk, especially among men and persons under age 75 (Lisabeth, Diez Roux, Escobar,
Smith & Morgenstern, 2007). Data from 465 stroke patients in the Netherlands suggested that patients with a lower socioeconomic status experienced a stroke with a worse clinical profile, and seemed to have significantly worse health outcomes in terms of disability and handicap after stroke (Van den Bos et al., 2002).

Huang, Khan, Kwan, Fang, Yun and Kapral, (2013) investigated possible reasons that death after stroke is higher in those with a lower socioeconomic status. Using data from the Ontario Registry of the stroke network, the researchers evaluated post stroke care and medication adherence in patients who received care at Regional Stroke Centres in Ontario. Income was the marker for socioeconomic status. Huang et al., (2013) found no differences in the amount of home care provided by nursing, physiotherapy, occupational therapy, or speech language pathology, and no differences in 1-year adherence to antihypertensive, lipid-lowering, or anticoagulant medications by income group. The group did find that individuals from lower income areas were less likely than those from high income areas to present within 3 hours of stroke onset and thus were less likely to receive thrombolysis, were less likely to be cared for on a stroke unit or by a neurologist, less likely to be referred to a stroke secondary prevention clinic at discharge, and less likely to have physician visits within 3 months of discharge, and suggested targeted messages at this group. The reasons for lower stroke survival in lower socioeconomic group individuals were not clear from this study.

The prevention paradox

The socioeconomic location of stroke does not enter into the discussions of stroke prevention. There is one isolated paper from 1985 that argues for a focus on deeper levels of health such as quality of life and social change, rather than solely the current focus on the eradication of health risk through primary health promotion. In this paper, Brown (1985) regales
a tale of two villages by a river, a story told to represent the differences between health promotion and disease prevention. The story goes that villagers from the village downstream noticed people in trouble floating down the river and they rescued these people. This pattern continued. After much time spent rescuing the villagers, some downstream villagers left the work of rescue, and explained to their angry co-villagers that they decided to go upstream to determine how to stop people from falling in. Brown (1985) proposes an epidemiology of health rather than an epidemiology that is predominantly focused on the distribution of a disease phenomenon. She states that ‘epidemiology’ is not committed to either health or illness by the origin of the word, yet ‘epidemiology’ is applied primarily to disease.

The concept of prevention was defined and categorized by the 1957 Commission on Chronic Illness in the United States. This group differentiated health promotion from disease prevention and categorized prevention into primary and secondary prevention (Mayo, Hamilton, Colman & Klumpp, 1957; Gordon, 1983). Health promotion was seen to be in the domain of public health and was a counselling activity. Primary prevention included actions which averted the occurrence of disease, such as the control of communicable diseases through immunization. The Commission maintained that secondary prevention involved physicians who could halt the progression of disease and preventing complications (Mayo et al., 1957), such as treating diabetes as a preventive measure against blindness and gangrene.

In Canada, Health Minister Marc Lalonde’s (1974) A New Perspective on Health report “changed the orientation of federal health policy by giving birth to health promotion” (McKay, 2000, p. 3). Lalonde’s (1974) new perspective on health provided a Health Field Concept framework intended to shift thinking away health as solely under the domain of hospitals. “Until now, most of society’s efforts to improve health, and the bulk of direct health expenditures, have been focused on the health care organization. Yet, when we identify the
present main causes of sickness and death in Canada, we find that they are rooted in the other three elements, human biology, environment and lifestyle. It is apparent, therefore, that vast sums are being spent treating diseases that could have been prevented in the first place” (Lalonde 1974, p. 32).

The human biology element of Lalonde’s framework was essentially the biomedical perspective of the body, that is, the aspects of genetics, processes of aging, and the internal systems such as the skeletal, nervous, muscular, cardiovascular systems of the body. The element of the environment included matters related to health which are external to the human body and over which the individual has little or no control. This element includes food and drug safety, safety of the air and water, communicable disease, sanitation. Lifestyle was identified as personal risk that could be changed (McKay, 2000), such as smoking (Lalonde, 1974, p. 15). At the core of the framework was the body, factors that a person can’t control (termed environment), factors a person was deemed to be able to control (termed lifestyle), and the delivery of health care.

Epp (1986), the Canadian Minister of Health at the time, advocated for health promotion through a framework that included self-care, mutual aid, and healthy environments. Examples of self-care included an older person using a cane when the sidewalks are icy or a person choosing a balanced diet. Mutual aid included social support that may arise in the context of the family, neighbourhood, voluntary organizations or the self-help groups such as Alcoholics Anonymous, Block Parents, and rape crisis centers. Creation of health environments included housing, air quality, employment, education, transportation and health systems.

In 2009, the World Health Organization published a manuscript entitled *Milestones in Health Promotion: Statements from Global Conferences*. This manuscript summarizes
International Health Promotion Conferences, beginning with the first International Conference on Health Promotion that met in Ottawa, Canada in 1986. During the First International Conference in Ottawa in 1986, a framework for health promotion action was created. The framework identifies five actions required for health promotion. These actions include the need to build healthy public policy, to create supportive environments, to strengthen community actions, develop personal skills, and reorient health services (WHO, 2009). The Second International Conference on Health Promotion, in Adelaide, Australia in 1988, focused on the first action, building healthy public policy, and provided recommendations on health public policy. Health was described as a fundamental human right and a sound social investment. The Third International Conference in Sweden, 1991, met to formalize a statement on Supportive Environments, the second action in the Health Promotion framework. A widening gap in health between poor and rich countries was noted. The conference highlighted aspects of supportive environments, including the social, political, and the economic dimensions (WHO, 2009). The Fourth International Conference was held in Jakarta, Indonesia in 1997. The conference was called “New Players for a New Era” as it was the first time that the conference was held in a developing country, and also the first to involve the private sector in supporting health promotion. The conference in 2000 in Mexico had no significant differences. The conference in Bangkok in 2005 noted that the global context for health promotion had changed markedly since the development of the Ottawa Charter, due to increasing inequalities within and between countries, new patterns of consumption and communication, global environmental change, and growing urbanization.

In North America, business marketing strategies entered into the health promotion methodology used to inform the public about health issues and to promote self-management. Social marketing is a technique used to promote a health behavior or behavior change in the
public. Recently the public health department in Toronto employed this strategy to change the way Torontonians sneezed. Posters covered the city and subway trains advocating a sneeze in the sleeve instead of in the hands. Social marketing has been used to encourage vaccination (Kunze & Kunze, 2003), hand hygiene (Seto, Yuen, Cheung, Ching, & Cowling et al., 2013), and Human Papilloma Virus (HPV) vaccination among men (Newman, Logie, Doukas, & Asakura, 2013). Social marketing provides the ‘psychological technology’ to persuade (Erben, Franzkowiak, & Wenzel, 2000). The audience is intended to listen to these messages and adopt them and change the related aspects of their lives accordingly.

With the advent of t-PA as a treatment for stroke, social marketing campaigns were designed to raise the public’s awareness of stroke and stroke symptoms around the world. The goal was that patients would recognize they were having a stroke and go to the hospital to receive the t-PA (if eligible). The stroke literature in Canada, the United States and the United Kingdom includes studies investigating public knowledge of stroke and stroke symptoms. Samsa, Cohen, Goldsteing, Bonitor, and Duncan, et al., (1997) assessed knowledge of increased stroke risk among patients medically deemed high risk for stroke. Forty-one percent (41%) of respondents were unaware of their increased risk for stroke despite 74% of the patients recalling they were told of increased risk by their physician. In Cincinnati, OH, 1880 telephone interviews were completed to assess the public’s knowledge of stroke risk factors and stroke warning signs. Dizziness, numbness, weakness and headache were the most commonly cited warning signs. Fifty-seven percent (57%) of participants named one correct sign, 28% listed two correctly, and 8 % correctly listed three warning signs of stroke (Pancioli, Broderick, Kathari, Brott, & Tuchfarber et al., 1998). The most commonly cited risk factors were blood pressure (42%), stress (22%), poor eating (22%), and smoking (20%), cholesterol (15%). Fifteen percent (15%)
of participants did not name any risk factors. Respondents named television, newspaper, magazines, and doctors as sources of information (Pancioli et al., 1998).

A qualitative study was conducted in the United Kingdom in an effort to understand why people do or do not contact emergency services following the onset of stroke symptoms (Mackintosh, Murtagh, Rodgers, Thomson, Ford & White, 2012) in an effort to understand the low rates of thrombolytic treatment. The researchers found that patients who had personal experience with others who had a stroke had more knowledge and readily contacted emergency services. Those that did not have prior experience were confused by their symptoms. Some patients who believed they were having a stroke did not call for help because they decided to wait to see if the symptoms resolved, they were afraid of hospitals, or were concerned about taking up the time and resources of the emergency department. Fear of death from the stroke, and fear of becoming disabled or dependent were major concerns. This fear motivated some to call the ER, or else resulted in denial of symptoms and delayed their call for help (Mackintosh et al., 2012). As well, patients often contacted a relation or friend first to seek affirmation from them, for comfort, support and to help in the encounter with the emergency department. Patients preferred to delay immediate help for having someone trusted with them.

Giles, Flossman, and Rothwell (2006) studied patient behavior after TIA in the United Kingdom, using data from the Oxford Vascular Study. Medical attention after TIA was first sought from the family practitioner (86.7%), the emergency department (10%) and from other sources (not named) in 3% of patients. No patients telephoned the national 24-hour advice service. Just under half (44.4%) treated the situation as an emergency. Among those who did seek medical attention after a TIA, 42% identified their symptoms as TIA, 35% did not know the
cause, and 21% identified the symptoms as stress or fatigue, heart attack, migraine and eye problems (Giles et al., 2006).

Researchers in South Carolina examined recognition of the five warning signs of stroke and appropriate action to call 911 in individuals with prior stroke, and compared across racial/ethnic groups (Ellis & Egede, 2008). Twenty-six percent of the total group recognized all five warning signs and would call 911. Hispanics were least likely to recognize all five warning signs, and least likely to call 911, compared with Whites and Blacks.

In Toronto, Silver, Rubini, Black and Hodgson (2003) compared three different mass media strategies intended to educate the public in four different communities in Ontario about the warning signs of stroke. The strategies included a black and white television commercial advertisement naming the warning signs of stroke shown on a continuous high-level basis, the same commercial shown intermittently, a print advertisement, and a public service announcement as the baseline information. Telephone surveys asking participants the warning signs of stroke were conducted prior to the interventions and three months after cessation of all advertising. The ability to name two or more warning signs of stroke increased in the television communities, especially among women as opposed to men, those aged 45-64 as opposed to those older, and those with higher as opposed to lower levels of education.

As research on the relationship between patient knowledge of stroke warning signs through advertising and subsequent “presentation time” at the hospital with symptoms was not clear, a study was conducted in Ontario, similar to the Silver et al., (2003) study above. Using data from the Stroke Registry, the aim was to analyze the total number of ED visits for stroke; presentation within 5 hours of last seen normal; presentation within 2.5 hours of last seen normal; and presentations with a diagnosis of TIA. Two television advertising campaigns on the
warning signs of stroke were conducted for two different nine month periods, October 2003 to June 2004, and between December 2004 and July 2005. Advertising blackout periods occurred prior to, between and after the advertising campaign dates. Telephone surveys were conducted across Ontario. The results showed that the absence of advertising was associated with significant declines in knowledge. Regarding presentation to the hospital, the Ontario data demonstrated that at the population level, mass media had a significant effect on presentation to the Emergency department. The data from the Stroke Registry demonstrated a nine percent (9%) increase in visits to the emergency department for stroke and a thirty percent (30%) increase in visits for TIA during television campaign times. Hodgson, Lindsay, and Rubini (2007) included the results as part of a “growing body of evidence suggesting that mass media campaigns can change awareness, knowledge, and even behavior” (p. 2120), particularly if campaigns concentrate on clear messages and have prolonged exposure.

The National Stroke Foundation of Australia launched a multimedia campaign to deliver stroke symptom knowledge after a 2003 survey had shown 49% of adults could recall a symptom unprompted. Bray, Johnson, Trobbiani, Mosley, and Lalor et al. (2013) conducted a telephone survey of 12,439 respondents over the age of 40 to examine the reach of the campaign during the years 2004-2010. The trend over the years was an increase in symptom recall (one correct) from 69% in 2004 to 81% in 2010. The authors note that there was a parallel increase in calls to the ambulance and increased use of t-PA in the hospitals.

It is not only patients who may misunderstand what is happening to them. Hart (2001) explored the experiences of 13 stroke survivors in the United Kingdom. One finding was that the failure of some professionals to recognize early signs of a stroke meant some people were sent away with a misdiagnosis or an inappropriate intervention.
The work of symptom self-detection and evaluation of public knowledge occurs in other fields as well. Aronowitz (2001) described this work for women to be responsible for detecting breast lumps, not just responding to suspicious signs of cancer as a by-product of the “Do not delay” posters, pamphlets, books and lectures from the American Society for the Control of Cancer. Similar to research in the stroke field which has evaluated symptom knowledge, women’s knowledge of symptoms and risk of breast cancer (Jones, Gregory, Nehill, Barrie, & Luxford, 2010a) and ovarian cancer (Jones, Magee, Francis, Luxford, & Gregory, 2010b) has been evaluated in Australia. The “Steps to a Healthier NY” campaign in New York used social marketing to successfully increase parent’s knowledge of asthma symptoms in their children (Briones, Lustik & Lalonde, 2010).

Conclusion

The literature reviewed provides background information to what is known about stroke and the context in which stroke care is provided. I will draw out the vital points that link the patient and his/her encounter with the health care system in this conclusion section.

First, it is apparent that for patients, the acute event of stroke occurs as a shock (Becker, 1993; Doolittle, 1994; Hafsteinsdottir & Grypdonck, 1997; Burton, 2000). The vast literature describing the impact of stroke on patients can be summarized as loss and limitations. These losses and limitations that are a consequence of a stroke may be disabling.

Disability is considered as a problem located in the body by the medical model and a problem with social structures and attitudes according to the social model (Lindsay, et al., 2010; MacKay, 2003; Striker, 1997; Titchkosky, 2007; Davis, 1995). Kelley and Betsalel (2004) vividly depict the lived tension between the two ways of knowing (the medical model and the
social model) when they describe Kelley’s interest in ‘normal’ and her awareness that ‘normal’
was an ideological concept.

Disability after stroke is a cause of social rejection. Disability scholar Stiker’s (1997)
argument that society enacts strategies of rejection towards the disabled is supported in the stroke
research. Health sociologist Clarke (2005) notes survivors’ experience of social rejection. For
some people interviewed on their perspectives on stroke, death was deemed more preferable than
severe disability from stroke (Townend et al., 2003). Patient fear of stroke is pervasive in the
literature (Townend et al., 2006; Kamera & Singh, 2012).

The dominant perspective in the health care system, biomedicine organizes stroke
knowledge into Best Practice Guidelines based on epidemiological data and formulated for risk
management. Risk as an organizing concept can be noted in OSS documents such as the Report
of the Joint Stroke Strategy, and the substantial details about risk factors and risk formulas (such
as Number Needed to Treat) throughout stroke guidelines and publications (Lindsay et al., 2008;
Sinclair et al., 2001). The lens of risk has been challenged by sociologists, who argue that risk
management is a form of surveillance or social control (O’Byrne, 2001; Armstrong, 2003),
blame (Crawford, 2001), and as a method to transfer responsibility from the state for social
determinants of health to the individual for personal risk management, that is, a fiscal logic
(Anderson, 1990; Galvin, 2002).

There is also more than one way to understand stroke and economics. There is no doubt
that stroke care is an expensive health care cost (Chan & Hayes, 1998; Sinclair et al., 2001b;
Saska et al., 2009; Demaerschalk et al., 2010), conceptualized globally as ‘burden’ (Mackay &
Mensah, 2004). The stroke event is also a cost of impoverishment. There are more strokes
among those with a lower socioeconomic status (Kleindorfer, et al., 2006; Thrift, et al., 2006;
Addo, et al., 2012; Jarvis et al., 2006; Raphael, 2009; Gardner, 2008; Lightman et al., 2008). Stroke is therefore both a major cost to health care services and a consequence of socioeconomic deprivation.

A strategy to reduce health care costs arose with a reconsideration of health as more than health care organizations (hospitals). Lalonde’s (1974) report conceptualized health as not just an outcome of health care, but also as a result of the environment and lifestyle choices. This report, nicknamed the ‘birth of health promotion,’ mobilized the health promotion industry globally, as evidenced by the WHO Milestones report (McKay, 2004). Knowledge about public awareness of stroke symptoms has been an active health promotion and research interest in the field of stroke globally (Silver et al., 2003; Giles et al., 2006; Hodgson et al., 2007; Mackintosh et al., 2012).

Stroke, disability, biomedicine, and risk are all well researched areas. This dissertation draws these literatures together through an exploration of ‘how the stroke system works’ from the standpoint of the patient, filling a gap in the literature.
Chapter 3: The theory and method of IE

Critical scholars argue that the oppressed, or those excluded from power, have a unique vantage point from which to understand aspects of the world that may be invisible to dominant groups (Swidler & Arditi, 1994). Using critical theoretical perspectives, critical scholars challenge systems and methods of power. For example, women’s exclusion from power is analyzed in feminist writings, as are discrimination against disability in critical disability studies, racism in critical racial theories and class in Marxist schools of thought. These approaches share a social perspective. Bannerji (2000) argues that social relations of power, race, class, gender, and sexuality provide the content for difference and oppression. Davis (1995) argues that disability is a social process, “Disability is not an object – a woman with a cane – but a social process that intimately involves everyone who has a body and lives in the world of senses” (p. 2). Similarly hooks (2000) argues that sexism arises from a system of domination and is perpetuated by institutions and social structures. Smith (1990), using a Marxist foundation, links relations of power to relations of knowledge, and argues that knowledge is socially produced (Harrison, 2006).

Campbell and Manicom (1995) claim that government and management are accomplished through work processes that rely on distinctively organized ways of knowing. “Ruling relies on specialized knowledge, as well as the organization and generation of knowledge in a form that is useful for ruling practice” (p. 9). As a scholar within the field of the sociology of knowledge, Smith wrestled with the local, embodied, reflexive knowledge of women in the everyday world and the practices and knowledge of organizing power which erased women’s ways of knowing. Using the writings of Marx, along with those of feminist colleagues of her time, she wrote analyses of sociology as patriarchal from the standpoint of
women, seeking to characterize “just what it is in sociological practices of writing that alienates and occludes the standpoint of experience” (Smith, 1990, p. 4). She went to the heart of sociological methods, challenging formulated concepts. She critiqued ideology as a form of social organization dependent on texts from a ruling standpoint rather than as a mental phenomenon (Smith, 1990; Campbell & Manicom, 1995).

Smith has put forward a method of inquiry that examines relations between power and knowledge using specific and novel ‘Smithian’ concepts. These ideas include ‘standpoint’, ‘work’, ‘ruling relations’, and ‘bifurcated consciousness’. From a power and knowledge perspective, IE takes the approach that in contemporary global capitalist society, the material context of each person is organized by social relations that are put together systematically, but “outside a person’s knowledge and for purposes that may not be theirs” (Campbell & Gregor, 2002, p. 18). Although the relations and process may be outside a person’s knowledge, a theoretical feature of Smith’s method of inquiry is that the operation of power can be discovered in people’s everyday actions, (Campbell & Gregor, 2002) and through translocal relations (Smith, 2006). Smith’s concepts that are used in the method and analysis are outlined below.

**Standpoint**

IE researchers use real people’s local experiences as starting points to identify and analyze how the lives of people have “come to be dominated and shaped by forces outside of them and their purposes” (Campbell & Gregor, 2002, p. 12). Smith uses the term ‘standpoint’ to depict the entry point to the research based on a person’s practices at a particular location. Smith reconceptualized this term from Nancy Hartsock (1983) who had developed the idea of a feminist standpoint. Hartsock’s conception was rooted in the Marxist claim that the proletariat has a distinctive perspective on social relations and that only this perspective reveals the truth.
Hartsock drew an analogy between the industrial labor of the proletariat and the domestic labor of women to argue that women can also have a distinctive standpoint. She claimed that taking a feminist standpoint allowed women to discover the real relationships between people which are mystified by patriarchal ideology (Ramazanoglu, 1989). Smith does not take a “womens’ group” perspective, rather, her use of standpoint is specifically materialist, an ‘actual’ use. Standpoint reflects an entry point to the research inquiry based on actual practices at a particular location. Hartsock’s use would be like a roadmap showing the general direction, Smith’s could be compared to the way a GPS provides the precise location details from which to depart. This study used the standpoint of the patient as the entry into the investigation.

Generous concept of Work

The ‘generous concept of work’ (Smith, 1987) is a concept that embraces everything that people know how to do and that their daily lives require them to do, whether or not people recognize these activities as work (Campbell & Gregor, 2002). Mykhalovskiy (2002, 2008) coined the term ‘health work’ which is used in this study to discuss the work of patients. As an orienting concept, ‘work’ directs the researcher’s attention to the interface between individuals and institutional relations (McCoy, 2006). When viewed from the perspective of work, informants are viewed as active. As Smith (2006) observes, “We can begin to see them as encountering and working with and within institutions that are implicit in their accounts” (p. 7). Directing interviews and observations towards the work of individuals captures the knowledge and skills involved, the difficulties overcome, and the tensions absorbed as part of doing the work (Campbell & Gregor, 2002). These data are analytically located in relation to the institutional processes that evoke and direct their work (McCoy, 2006), showing how knowledge operates as “an active constituent of the social, how knowledge shapes how things get done”
(Weir and Mykhalovskyi, 2010, p. 25). Knowledge can be investigated as the “ongoing coordinated practices of actual people” (Smith, 1990, p. 62).

**Ruling relations**

‘Ruling relations’ is the term that Smith uses for the processes of administration and governance that create a complex field of coordination and control (Smith, 2006) through the social organization of knowledge and power. These ruling (social) relations are made visible through a description of the activities or practices of people in a local setting, an analysis of texts which reach into and out of this local setting, and an analysis of the ways these texts mediate knowledge and power within the local setting. The goal in IE is to reveal how processes are put together, to explicate these ‘ruling relations’ (Campbell, Copeland, and Tate, 1998). Through this explication, IE builds a knowledge of how things work.

**Texts**

Smith treats texts as the central medium of ruling relations. Texts are the bridge between local sites of embodied activity to extra-local ruling relations. They are fundamental to the production and circulation of objectified forms of discourse. As texts are material and their use observable, texts as a data source open up “to empirical investigation aspects of power that otherwise lie hidden and mysterious” (Campbell & Gregor, 2002, p. 32).

In IE, a text can be any kind of document or representation that has a relatively fixed and replicable character which allows them to play a standardizing and mediating role. Examples of texts include words, images and sounds that are set in a material form of some kind from which they can be read, seen and heard, such as documents on paper, on computer screens, in computer files, drawings, photographs, videos or sound recordings, books, bus tokens, airline reservations,
radio, CD’s, e-mail messages (DeVault & McCoy, 2006; Smith, 2006). Understood this way, one can see that ‘texts’ coordinate our social experiences and are linked to larger social organization. The bus token links to the city’s transportation system (and various legislation and policies), the CD links to the music industry, the newspaper to communications, and so on. Quinlan (2009) argues that texts “stabilize and reproduce” (p. 628) institutions, and therefore provide empirical insights into extra-local connections and ruling relations. Data collection in this study included local and extra-local texts which are presented in the analytic chapters.

**Bifurcated consciousness**

Encountering power creates, “potentially, a bifurcation of consciousness” Smith, 1990, p. 17). By this concept, Smith is referring to two modes of knowing. One is a local consciousness, one’s lived actuality in the body, and the other is the conceptual, governing mode of consciousness which passes beyond experience and categorizes it (Smith, 1990). Bifurcation of consciousness occurs when a person moves out of the local experience into the governing mode of knowing, often suppressing their own knowledge in order to participate in the dominant realm.

**Discourse**

In IE, discourse refers to a field of relations that includes not only texts and their inter-textual conversations, but the activities of people in actual sites who produce them and use them and take up the conceptual frames they circulate. This notion of discourse never loses the presence of the subject who activates the text in any moment of its use (DeVault & McCoy, 2006; Campbell & Gregor, 2002). In other words, people participate in discourse. In IE, the analytic interest lies in discovering how the discourse operates in people’s lives and what difference it makes for people to participate or not to participate (McCoy, 2006).
Data collection in IE

Ethnography is one of the oldest forms of qualitative research, used by anthropologists over 100 years ago (Hodgson, 2000). Anthropology grew out of “European discovery, colonialism and natural science” (Monaghan & Just, 2000, p. 1). Over the years, several shifts occurred. The focus in anthropology changed from an exclusive interest in the exotic or non-Western societies to include research on elements within the researcher’s own society, such as urban settings and groups. Despite this shift, however, ethnography remained firmly rooted in anthropology. Ethnography began to be used in other disciplines, such as sociology and nursing. This shift into other disciplines did not remove the interest in rich description that arises from participant observation (Monaghan & Just, 2000). Ethnography has been used to explore the reality of hospital and nursing work (Chambliss, 1996), and by nurses specifically to understand record keeping (Allen, 1998). Institutional ethnography has also been used by nurses to understand the impact of hospital reform for nurses (Rankin & Campbell, 2006) and the return to work process for injured nurses (Clune, 2011). Ethnography means ‘portrait of a people’ (Harris & Johnson, 2000) and institutional ethnography provides a portrait of how things work for people. Diamond (1986, 1992) used Smith’s early writings as his theoretical and methodological source for his investigation into the social relations in long term care facilities.

The theoretical framework of institutional ethnography is that settings are organized and ruled in definite ways. Two levels of data are needed for analysis in institutional ethnography (Campbell & Gregor, 2002). The first level of data (the entry-level) is about the local setting, the individuals that interact there, and the accounts of their experiences. The local setting was a secondary stroke prevention clinic, and the account from that setting is presented using data collection methods of observation, textual analysis and interviews. Level-two data are the organizational details of how the setting works, the data that explicates the entry-level data. Data
collection methods included observation, interviews and textual analysis. The informants and extra-local settings are outlined in Figure 2 below. Entry-level data reveal the setting; level-two data reveal the ‘ruling relations’ or, “forms of consciousness that are objectified” (Quinlan, 2009). The two levels of data are connected and linked through textual practices.

The Clinic

The setting for this study was a Secondary Stroke Prevention Clinic (SSPC) which is situated within a large academic hospital in downtown Toronto. This particular site was selected because it is well-known as a centre of neuroscience expertise in Toronto, as well as a centre known to serve a diverse population. The clinic space consists of six examination rooms on two sides of a hallway, a waiting room and a reception area with a registration desk, a large washroom, and a storage room which has also been turned into a study space. Four neurologists, one Fellow and the Advance Practice Nurse used the clinic examination space to see their patients. While waiting to consent potential informants, I would either sit in the neighbouring Memory Clinic waiting rooms chairs, or sit in the study space. The study space is where the Research Nurse and I would discuss patients that were eligible for my investigation. Another woman was also employed by the neurology department to recruit patients for studies including a blood pressure study; a cultural needs study, and an MRI study.

Administration of the Project:

Ethics

Research Ethics Board (REB) approval was received from the hospital site (protocol reference # 10-0812-BE) on March 10, 2011. Continued approval was received on March 5, 2012. The University of Toronto administrative approval (protocol reference # 26289) was received March 25, 2011. This approval did not require annual renewals. A Certificate of
completion for the Tri-Council Policy Statement: Ethical Conduct for Research involving Humans was received on April 2, 2009.

Consent

Informed consent (Appendix E, F, and G) was obtained prior to all interviews with local informants, such as patients and local health care professionals, and extra-local informants.

Data Management and Confidentiality

As per the protocol approved by the REB, all data, including interview observational field notes, interview transcripts and texts was kept in a secure, locked cabinet in a locked office. Identifiers for all informants, and all organizations such as the hospital or external agencies were removed from transcripts. The doctoral supervisor, Dr. Sioban Nelson, played an integral role in verifying the findings through her review of the data and analytical procedures. All data brought to her was de-identified; pseudonyms were used during discussion.

Design

In this exploration, level one and level two data, as well as the connecting texts were collected. As mentioned previously, the first level of data are about the local setting, the individuals that interact there and the accounts of their experiences. The accounts included making visible the work of patients, understanding the work of the health professionals in the clinic, attending to and capturing links to the extra-local and noticing and acquiring texts that enter or exit the local setting.

These data were collected through observation and interviews. Behind closed doors, clinic appointments and intake assessments were directly observed. I sat in the room on a blue medical stool. I did not participate during the interviews but made field notes. I consistently
watched and listened for ways the local setting was organized externally, including the texts, names of external clinics, and companies or organizations. I also carefully attended to the dialogue between the health professional and the patient, the activities of both the patient and the health professional (for example: getting up on the clinic exam table, opening the computer), and the non-verbal behaviors of all parties (such as raising one’s arm for the blood pressure cuff, washing hands). Interviews were conducted with participants who came to see the neurologist (known in the clinic as patients) and their family members, spouses, or significant others. The setting and timing of these interviews worked within the rhythm of the clinic. Sometimes the interview began in the clinic room while we waited for the nurse or doctor; sometimes interviews occurred after the appointment. These interviews were audiotaped with consent and transcribed. Interviews were also conducted with the nurse and the doctors involved directly in the clinic appointments. Sometimes these were formal interviews; sometimes these were quick clarifying questions between patients or after clinic hours. Formal interviews were audiotaped and transcribed. Local health professionals that were recruited and consented to participate include the Advanced Practice Nurse (informant R.N.), a neurologist (informant N.D.) and a second neurologist, a neurology fellow in the clinic (informant N.D.2).

Texts that entered, were part of, or exited the clinic area were gathered. The nurse served as the point person for the texts. Specific details about the texts were gathered using a template. This data was acquired for each text that entered the study. A sample is provided below in Figure 1. The text in question is the clinic referral form.

<table>
<thead>
<tr>
<th>Date</th>
<th>June 11, 2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of Text</td>
<td>SSPC Referral form</td>
</tr>
<tr>
<td><strong>Sequence # or letter given</strong></td>
<td>1</td>
</tr>
<tr>
<td><strong>How did I acquire text?</strong></td>
<td>Nurse – in connection with patient observed with him, and his work</td>
</tr>
<tr>
<td><strong>Who wrote the text?</strong></td>
<td>Nurse</td>
</tr>
<tr>
<td><strong>How is the text produced and replicated?</strong></td>
<td>Word document, printed. Also available on intranet and through TORWEST stroke network.</td>
</tr>
<tr>
<td><strong>What is the purpose of the text?</strong></td>
<td>Refers patient to the clinic</td>
</tr>
<tr>
<td><strong>Who is the intended audience?</strong></td>
<td>Used by X, Y, Z ERs, GP’s Regional Centre, faxed to clinic, process by Secretary – chart created, goes to Nurse who reviews and begins triage</td>
</tr>
<tr>
<td><strong>What regulatory text (eg. legislation) directs this text?</strong></td>
<td>Scientific literature informs the ABDC2, risk factors, investigations</td>
</tr>
<tr>
<td><strong>What textual sequence is this text part of?</strong></td>
<td>Clinic processes</td>
</tr>
<tr>
<td><strong>What process is activated by this text?</strong></td>
<td>Assessment of a new patient, activities of said patient</td>
</tr>
<tr>
<td><strong>What is highlighted in this text?</strong></td>
<td>Targets specific stroke information for ease of decision making of team (nurse)</td>
</tr>
<tr>
<td><strong>What is the message of this text?</strong></td>
<td>How urgent is this situation?</td>
</tr>
<tr>
<td><strong>What is absent from this text?</strong></td>
<td>Social aspects of person referred, referees sense of urgency</td>
</tr>
<tr>
<td><strong>What comes next after this text has been used?</strong></td>
<td>Nurse enters this information into his decision making regarding how soon the patient should be seen</td>
</tr>
<tr>
<td><strong>Which languages is this text available in?</strong></td>
<td>English</td>
</tr>
<tr>
<td><strong>How is disability presented? (if it is)</strong></td>
<td>Physical neurological symptoms/deficits</td>
</tr>
<tr>
<td><strong>Comments:</strong></td>
<td>Nurse wishes to revise the form, as the clinic is being flooded with dizzy &amp; memory clients. Feels the GPs/ER have found a loop to have their patient see a neurologist quickly. These referees, in nurse’s view, jot down “query stroke” to manipulate entry into the clinic. The ability to match referring problem with actual problem is</td>
</tr>
</tbody>
</table>
Figure 1: Template used for textual analysis

Texts that specifically linked to the extra-local environment and were followed up accordingly are listed below in Figure 2. One informant declined participation.

<table>
<thead>
<tr>
<th>Text</th>
<th>Extra-local informant Interviewed</th>
<th>Date</th>
<th>Referenced as informant:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral form</td>
<td>Family doctor</td>
<td>August 2011</td>
<td>FD</td>
</tr>
<tr>
<td>ICES data form</td>
<td>Stroke Registry link</td>
<td>August 2011</td>
<td>ND</td>
</tr>
<tr>
<td>Fridge magnet</td>
<td>HSFO link</td>
<td>October 2011</td>
<td>HSFO</td>
</tr>
<tr>
<td>OSS Steering committee report</td>
<td>Ministry of Health link</td>
<td>November 2011</td>
<td>MOH</td>
</tr>
<tr>
<td></td>
<td>Ministry of Health # 2</td>
<td></td>
<td>COS</td>
</tr>
<tr>
<td></td>
<td>Ministry of Health Promotion</td>
<td></td>
<td>Declined participation</td>
</tr>
</tbody>
</table>

Figure 2: Empirical links to extra-local informants

Extra-local interviews were conducted as linkages emerged in the study. Informants were asked about their interest in participating, recruited, and provided with the Informed Consent process. These interviews used an interview template, and were audiotaped and transcribed. Goals of these interviews included knowledge regarding the work and role of the
informant, the connection to the local SSPC, the use of the particular text in the extra-local environment and the guidelines, texts, and/or principles the informant drew from.

Extra-local informants included an informant from the Heart and Stroke Foundation of Ontario (Informant HSFO, October 2011), an informant from the Ministry of Health who had been linked to the Ontario Stroke Strategy (Informant MOH, November 2011), and a family physician (Informant FD, August 2011) that referred a patient to the Stroke Prevention Clinic. A second informant from the Ministry of Health also agreed to confirm and subsequently did confirm details from the first analytic chapter. Figure 2 above details the vehicle by which the extra-local connection was linked into the study, the role or title of the person interviewed, the month and year of the interview, and how the informant is referenced in the analysis.

Screening and Recruitment Rationale
In order to understand the implications for patients at risk of stroke, my intention was to recruit solely patients who were experiencing Transient Ischemic Attack (TIA). This changed when I attended a research meeting at the hospital that I was seeking to recruit patients from. I joined them at their regular research meeting in order to describe the study, understand the setting, and seek team approval. I informed them of my plan to recruit TIA patients. One neurologist suggested adding minor stroke to the recruitment criteria. He advised that only enrolling TIA informants would drastically decrease the number of possible recruits. He argued that minor stroke would increase the recruitment base, that the anxiety and fear of the patients would be the same, and that the process was unchanged for these patients in the clinic. Minor stroke in the clinic was considered a patient with a Rankin score of two or less, that is, someone with a slight disability who could still carry out all of their normal activities. This change was made to the recruitment criteria.
In order to understand the work and experience of people in Toronto known to experience less health advantage, eligibility criteria were derived from Raphael’s (2009) work on social determinants of health in Canada. Raphael cites sources that consistently show that behavioral risk factors are weak predictors of health status in comparison to socio-economic and demographic measures, of which income is a major component (Raphael, 2009). Females, people with disabilities, and people of colour typically earn less, which impacts their health (Raphael, 2009). Education and income are linked to literacy, which is connected to health literacy and health status (Ronson & Rootman, 2009). Racialized communities, recent immigrants, and refugees experience social exclusion which contributes to health concerns such as hypertension (Galabuzi, 2009). At an individual level, obesity rates are linked to low income, low education, minority status, and a high incidence of poverty (Drewnowski, 2009).

A stakeholder consultation with the Living with Stroke recovery group in Toronto during the planning stage of this study suggested the inclusion of the patient’s significant other, as well as a six month phone call after initial clinic interviews. These suggestions were incorporated into the study design.

The inclusion criteria for the study included:

- Able to communicate using English.
- Minor Stroke or Transient Ischemic Attack (TIA).
- High school education or less (Mikkonen & Raphael, 2010).
- Unemployed (Mikkonen & Raphael, 2010).
- Visible minority (Mikkonen & Raphael, 2010), identified visually by the nurse as one who is non-Caucasian in race or non-white in colour (Statistics Canada, Employment Equity Act).
• Single or divorced woman working part time (Mikkonen & Raphael, 2010).
• Obesity (Drewnowski, 2009) identified by waist circumference (Seidell, 2010);
  Men: 102 cm or 40 inches or more, Women: 88 cm or 35 inches or more.
• Recent immigrant – 4 to 5 years in Canada (Mikkonen & Raphael, 2010; Asanin & Wilson, 2008).

Exclusion criteria for patients
• Non-English speaking.
• People who are not able to communicate to participate in interviews.
• People not able to participate in both the clinic interviews and telephone interview.

Inclusion criteria for significant other or informal caregiver
• Able to communicate using English
• Involved and aware of day-to-day experiences of person with TIA or minor stroke

Screening and Recruitment Procedure
The clinic employed a Registered Nurse whose role as a Research Nurse included surveying incoming patient charts to ascertain eligibility for clinical investigations and studies that were being conducted in the clinic. The clinic provided this nurse to me as a resource. Her role was to review patient charts and determine eligibility using the Screening Tool (Appendix D). The process of recruitment that was approved by the REB was for the Research Nurse to approach eligible informants, and speak to them using the following script (see Appendix C):

“There is a nursing doctoral candidate here who is studying the experience of patients who come to the clinic, how they got here, what happens in the clinic, and how patients
manage recommendations. She would like to observe our appointment, and interview you (both) afterward. Would you be interested in meeting her, and she will tell you more about the study?"

If the patient was eligible and agreed to learn more, the nurse would inform me of the possible recruit. I would then approach them and speak to them using the following script:

“Hello Dr, Ms, Mr., ___________. My name is Sarah Flogen. I am a doctoral candidate at the Lawrence Bloomberg Faculty of Nursing, University of Toronto. As part of this program, I am conducting a study exploring the experience of patients who have a stroke/TIA, and the social organization of stroke prevention.

The following script was used with extra-local informants:

Your name came up as someone who may be able to shed some light on a particular aspect of stroke prevention (insert topic). I would like to meet with you, describe the study in further details, and interview you, with your consent. Would you be willing to meet with me, and I can explain in further detail?"

I would then meet the patient and any significant others, describe the study, answer questions, provide informed consent if the patient was interested in participating, ensure the informed consent was copied, provide a copy to the patient, and provide the coffee card and transit/parking token that was intended as compensation for the extra appointment time they would spend at the hospital due to the study. Patient informants are referenced in this document by pseudonym and informant number, for example, Helen (informant 1). When a substantial passage is related to the informant, only the pseudonym is used for ease of reading, for example,
Helen. See Table One at the back of the dissertation for an overview of the informants who were recruited and consented to participate.

Informants in this study included men and women. In terms of age, one person was age 54; the other informants were between the ages of 72 and 85 years. Four informants were married, three were widowed, and one had never married. Two had less than high-school education, three were members of visible minority groups, and seven had prior disability, including for example hearing loss, arthritis, obesity, and musculoskeletal pain. All had prior health issues such as high blood pressure, diabetes, migraines, and blood or absorption deficiencies, previous bypass surgery, and sleep apnea. Most informants had children, some had grandchildren. No patient informants were currently working. The one informant younger than retirement age was on disability from work. All but one informant had immigrated to Canada at some point in their life, none recently. All spoke English sufficiently to consent to the study and converse with me. Two informants came to the clinic because of a transient ischemic attack (TIA), one of those also had a stroke four years prior; 6 informants came to the stroke prevention clinic after having a completed stroke; at the time of their appointment the stroke was considered minor by health professionals, as the informants were able to ambulate. All informants had a family doctor. Two patients who were approached about the study declined participation. Reasons given for declining include the need to get to the airport after the appointment, and being hard of hearing.

Data Analysis

The aim in IE as a method of inquiry is to understand the social organization of the area under study. The means to accomplish this examination is not to use analytic strategies such as coding and themes, rather, rigor in institutional ethnography comes from the integrity of the
developing map of social relations (DeVault & McCoy, 2006). Smith (1999) states, “Unlike the maps of seas, lands or coasts, the maps that institutional ethnography provides are maps of relations in motion” (p. 129). The focus of the analysis is always the ‘institutional,’ how individuals take up texts and coordinate their actions so that they produce the particular institutions, standard sequences, policies, decisions and outcomes.

During the data analysis and writing, I attended an institutional ethnography workshop with Dr. Susan Turner and Dr. Dorothy Smith. Communication from both Dr. Turner and Dr. Smith to workshop participants included teaching about a recent shift away from a critical analysis. Smith prefers the language of “building a knowledge of how things work” and “descriptive ethnographic account” rather than critical analysis (Smith, D. personal communication June 2012). Although this has not been formally published, this information clarified for me that there are different streams of thought within IE. Workshop participants recognized an emerging stream of analysis that provided a neutral descriptive account, as well as the more traditional documented critical approach. Critical ethnography, as opposed to institutional ethnography was considered in light of this new information. However, as the extra-local data was vital to the purpose of the study and the textual mediation of knowledge and power lay at the crux of the analysis, a determination was made that this was indeed research being conducted using the tools of institutional ethnography. The analysis provided in this study reflects the traditional critical analysis as Smith published originally, and other researchers have utilized. Examples include the use of IE to critique text mediated relations such as Rankin’s (2003) critical analysis of a patient satisfaction survey, Rankin’s (2001) analysis of the fiscal work that nurses were conducting as part of health care reform, the textual realities after the death of a ten year old child with Rett syndrome who died from ‘severe malnutrition’ in British
Columbia, Canada (Bell & Campbell, 2003); text-mediated relations of health-care restructuring in a community hospital in Toronto (Mykhalovskiy, 2001) and Diamond’s (1986) analysis of social policy and life in nursing homes. In each study above, the emphasis has been on ‘what’s going on’ to reveal power tensions and ruling relations – a critical analysis.

**Analytic process**

All interviews and field notes were transcribed and organized according to patient number. Readings of all patient data revealed organizational ‘categories’ of patient work: the work of getting to the clinic, patient work in the clinic, and patient work between the initial and the follow-up appointment. The initial descriptive write-up included the texts that moved through the clinic. For example, though the patient did not encounter it, the referral form brought the patient to the clinic. Descriptive writing facilitated my understanding of what was happening in the clinic and how the clinic processes worked and intersected with patients.

Smith’s (1990) *Conceptual Practices of Power* played a large role in my approach to the data. My data was fresh, close at hand, and very familiar through transcriptions and readings. As I re-read Smith’s work, her analysis of how things worked would resonate with the data. An example of the integration of Smith’s concepts and the data analysis can be illustrated using Smith’s concept of bifurcated consciousness which explains aspects of the patient work with social marketing products (a fulsome description is in Chapter 5). Smith’s arguments about the textual mediation of power and the suppression of people also shed light on the textual aspects of work in the clinic. I worked over the data and clarifications from Smith’s work as with a large jigsaw puzzle that gradually began to take shape. What was happening in the clinic became increasingly apparent.
Discussions with other researchers and committee members always served to clarify knowledge that had been taken for granted. An analytic journal (thinking notes) was kept through the data collection and analysis phases. At times this was ‘stream of consciousness’ writing, other times bullet notes were kept of a process, other notes included a phrase to capture when a ‘penny dropped’. Notes were kept about what I expected but did not find (for example lifestyle education), what I had previously taken for granted and was not initially visible to me as content, as process, or as an organizing relation (for example medications). Transcripts of interviews, field notes and texts were shared with my supervisor and new learning was discussed.

In order to deepen my understanding of the ideas of health promotion and disease prevention, I searched the Archives of Ontario. I found, retrieved, and viewed health promotion documents collected within the Ontario Ministry of Health materials. This facilitated my comprehension of the historical role of Government, and helped ascertain the methods, means, and content of health materials used by the Department and subsequently Ministry of Health in Ontario over the years.

*Personal location as a researcher*

In 1976, Michael Marmot opened a paper entitled, “Facts, opinions and affaires du Coeur” this way:

Someone has suggested that any scientist should begin a scientific paper with the phrase: "Ladies and gentlemen, these are the opinions on which I base my facts . . ." That scientists should have affairs of the heart with scientific theories marks them as being human, and to seek to defend one's lover against the attacks of others and to document her or his virtues is surely a worthy enterprise. This might be taken as implying that science is intuitive and irrational” (p. 519).
Our values affect our positions (Marmot & Friel, 2008). Accepting this ‘irrationality of science’ and the impact of our values, Marmot writes that there are also rational methodological guidelines used in science which inform the conduct of research (Marmot, 1976). As a woman with social roles including mother, step-mother, nurse, therapist/counsellor, wife, ex-wife, daughter, sister, I too bring a life story to my research. I have personal early life embodied-knowledge of exploitive power. I also have a lengthy personal embodied knowledge and experience of reshaping and rebuilding my life. This experience and process has shaped my values as well as my skill set; both inform this research. My values have been shaped to include ‘knowing’, consciousness, opening space and discussion, collaboration, and boundary maintenance. The skills that I have acquired include discipline, determination, reflection, breaking silence, finding my voice, and gently presenting data yet maintaining relationships. My past has impacted the selection of my research topic, the stance of the standpoint and the research methodology. I have sought to understand ‘what’s going on’ for those less visible in the health care system. I wanted to hear their stories and understand their work. My awareness of my values and my (at times ‘soap-box’) determination has informed the selection of the research methodology in two ways. First, I am curious about, and want to make visible, the power structures within the organization of health care delivery/services. Second, I have selected a methodological approach that provides structure and boundaries; and a “disciplined approach” (Marmot & Friel, 2008).

Undertaking this study as someone trained as a nurse and a mental health therapist has had its advantages and challenges. As a nurse, I am highly skilled in observation, which facilitated ethnographic observation. Building rapport with patients quickly and engaging in an interview with them was facilitated by my training in psychotherapy. These were advantages.
Challenges arose from what Smith calls ‘institutional capture’ (Smith, 2006). Institutional capture, “subsuming the actual under the institutional,” (Smith, 2006, p. 156) can occur if the researcher is familiar with the institutional process or environment. As a nurse, I am very familiar with clinical processes such as intake assessments, physical assessments, and use of computers, treatments, and investigations. In order to counter institutional capture, I listened for professional discourse, and asked particular clarifying questions whether or not the content was familiar. I also re-read transcripts to ascertain where and when this might have occurred. One area that was uncovered during a re-reading, that I had taken for granted was the ubiquitous presence of medications. For me, as a nurse, ubiquitous presence of medication was ‘normal’. It took time, careful attention to the data and reflection to ‘see’ the medications travel through the clinic.

**Conclusion**

The tools of institutional ethnography: observation, interviews with informants locally and extra-locally, and textual analysis provide a methodology to explicate the social organization of stroke prevention. Institutional ethnography makes use of concepts such as standpoint, work, bifurcated consciousness, and ruling relations. The voice and experience of the patients are retained through a materialist perspective. This exploration takes up Smith’s invitation to future writers to make use of these concepts, “The techniques of analysis and the concepts are there for your use. Feel free.” (Smith, 1990, p. 206).
chapter 4: The extra-local Ontario Stroke System

This chapter details the extra-local emergence of the Ontario Stroke System (OSS) and one of its components, the Secondary Stroke Prevention Clinic (SSPC). The chapter begins with a pitch delivered by a Toronto neurologist that generated financial support from the Ontario Government for the OSS and the provincial reorganization of stroke care (Black, Lewis, Monaghan & Trypuc, 2003). The model of care in the Secondary Stroke Prevention clinic will then be described, as well as the integration of the clinic into the wider health care system. Last, a glimpse at the underlying biomedical approach that shapes the work of health professionals and the patients will be made visible.

Clarke, Mamo, Fishman, Shin and Fosket (2003) argue that health care has become increasingly complex, and increasingly tied to industry. “Institutionally, biomedicine is being reorganized not only from the top down or the bottom up but from the inside out (author’s italics). This [reorganization] is occurring largely through the remaking of the technical, informational, organizational, and hence the institutional infrastructures of biomedicine and the life sciences through the incorporation of computer and information technologies” (p. 162). I argue that the Ontario Stroke System and the Secondary Stroke Prevention Clinic is created through a new interventionist paradigm governed by biomedical ideology, and supported, as Clarke et al. (2003) describe, through links to industry through pharmaceutical innovation, computer and informational technologies, without which this complex Stroke Strategy could not exist. Furthermore, I contend that the dominance of the biomedical view excludes other possibilities, such as social models of disability, socially-defined determinants of health, and the notion that processes, knowledge, and consciousness are socially organized.
My argument is supported through an analysis of the following texts encountered over the course of the study. I begin with the speech given at a Toronto luncheon to generate funds for the Ontario Stroke Strategy. The speech shows the extra-local adoption and privileging of biomedical knowledge. Second, an article published by senior Heart and Stroke officials sets out the organizing conceptual model for the Ontario Stroke Strategy. These first two texts provide the extra-local context for the stroke prevention clinic.

The next text is a diagram of the model of care for the Secondary Stroke Prevention clinics available on the Heart and Stroke Foundation of Ontario website as a resource to support health professionals to implement the Canadian Best Practice Recommendations for Stroke Care (Lindsay et al., 2008) for stroke prevention (Secondary Stroke Prevention, n.d.). I use this diagram to illustrate the activities and priorities of the local stroke prevention clinic in which the study was conducted.

Finally, a province-wide data collection form makes visible the movement of stroke data collected by health professionals in secondary stroke prevention clinics. This text reveals the link between the local secondary stroke prevention clinic and the extra-local Ontario Provincial government. The content of the form highlights the priorities of the clinic, and indirectly the work that the patients are recruited into.

The launch of the Ontario Stroke System

Dr. Frank Silver was invited to speak at an Empire Club luncheon at the Royal York Hotel in Toronto in the spring of 2000 (informant ND, August 2011). The Empire Club is a speaker’s forum established in 1903. Membership includes influential leaders from various professions, businesses, labour, education, government, and cultural organizations. Dr. Silver was invited to speak on a proposal, years in the making, to reorganize provincial stroke care. The list of people gathered around the lunch tables at an elite hotel in the largest city in Canada
provides important insight into the mechanics of health care decision-making. This group represents the stakeholders who have been drawn together to support a speech about the proposed Ontario Stroke Strategy, including representatives from the medical profession, the business community, government, and a stroke advocacy group. Guests at the head table during this luncheon included two influential men who had had a stroke, one was the cousin of the Government Relations Director for the Heart and Stroke Foundation of Ontario (HSFO), Attorney General Ian Scott. The other was Phil Lind, Vice-Chairman of Rogers Communications Inc. Yvon Bastien, President and General Manager of Sanofi-Synthelabo Canada Inc., a pharmaceutical company that co-markets Plavix with Bristol Myers Squibb was also in attendance. The Heart and Stroke Foundation of Ontario, an advocacy agency that works to eliminate heart disease and stroke (Heart and Stroke, 2012) was represented by Diane Black, Vice-President, External Relations, Rick Gallop, President HSFO, Robert L. Brooks, Chair of the Board, Robert Dechert, President of the Empire Club, a lawyer, and a Conservative party Member of Parliament, Catherine Steele, VP and partner of GGA communications, George Cooke, President and CEO of the Dominion of Canada General Insurance Company, and an Honorary Director of the Ontario Neuro-trauma Foundation and a former director of the Toronto Rehabilitation Institute (Empire Club of Canada Addresses, 2000; informant N.D.). This group at the head table represents a powerful group of stakeholders in Ontario business and politics, men and women who are leaders in their respective disciplines. The new paradigm of stroke could not have occurred without this “confluence of powerful forces” (Coburn, 2009, p. 51) and the new way to know stroke was generated through these informational, pharmaceutical, and biomedical technologies.
Dr. Silver’s speech points us towards the innovations and technologies that are the impetus for the Ontario Stroke Strategy. The speech was prepared by the Heart and Stroke Foundation speech writers (informant ND, August 2011) and is available online (Empire Club Addresses, 2000). Below are excerpts from the speech provided by the Heart and Stroke Foundation and delivered by Dr. Silver. This first section constitutes the first two paragraphs of the speech (Empire Club Addresses, 2000).

In 1945 the three most powerful leaders in the world met at Yalta to determine the boundaries of the New World order that would prevail after the Second World War: Franklin Delano Roosevelt, Winston Churchill and Josef Stalin. Their doctors were worried with good reason. Each of the world leaders was suffering from high blood pressure. Roosevelt, Stalin and Churchill would all die from a stroke. No medical treatment then available could have saved them. The most powerful leaders in the world were no match for stroke (Empire Club Addresses, 2000).

Smith (2005) argues that power, ruling relations, and social organization are made apparent through language. Through the naming of powerful world leaders at a significant point in history, the opening scene in Silver’s speech calls to the powerful leaders in the room, an invitation to relate to these heroic men. This section of the speech reminds the leaders in the room that all these great leaders died of stroke, and experienced high blood pressure, likely a condition some of those in the room also experience. The implication for the audience is clear: “you are at risk of a stroke too.”

Dr. Silver then moves on to the new era of stroke, invoking a fighting slogan coined by cancer campaigns.
Times have changed. There has been a profound shift in our approach to stroke. We have come from an extended period of helplessness, where medicine surrendered to the casualties left in the wake of stroke. We have now entered an era in which there is a new realisation that we can "beat" stroke. Our understanding of stroke has been reshaped and redefined. Today, we know that stroke is both treatable and preventable. People can and do recover from stroke (Empire Club Addresses, 2000).

In the next two paragraphs, Dr. Silver describes the studies involving a new drug called tissue-plasminogen activator (t-PA), a drug which “has the ability to stop a stroke in its tracks.” He goes on to provide a visual, miraculous image, one that summons societies’ fear of stroke and its capacity to create disability, tragedy and loss of independence.

The statistics are impressive but it is nothing compared to seeing patients brought into the emergency department lying on a stretcher unable to speak, one side of their body paralysed, start to move their paralysed limbs shortly after you inject this drug; then to see patients, normally destined to spend the rest of their life in a nursing home, able to walk out of hospital unaided (Empire Club Addresses, 2000).

Dr. Silver then brings risk factors into the speech, making it apparent that stroke prevention is tied to other conditions. Those in the room are being taught a new way of knowing prevention. Dr. Silver was not talking about preventing smoking, diabetes, or high cholesterol. He was speaking about preventing stroke and linking those conditions to it, organizing knowledge of risk factors.
Let's add in the other risk factors—smoking, diabetes, high cholesterol, the presence of heart disease and family history of stroke—and one thing becomes blindingly apparent. It is that we must do a better job in stroke prevention (Empire Club Addresses, 2000).

His next rhetorical move drives the urgency of general stroke risk factors to personal risk for those in the room. Dr. Silver states:

So, in your own self-interest, you should all be aware of the risk factors and the symptoms of stroke. On the table in front of you, you will see a card from the Heart and Stroke Foundation of Ontario listing signs and symptoms of stroke. Please take some time to read it and talk about it with your family, friends and colleagues (Empires Club Addresses, 2000).

Dr. Silver went on to describe the challenge, the urgency of heeding timelines required for t-PA administration, the need for stroke units, and stroke prevention. He shared the cost of stroke as published by Chan & Hayes (1998) using the language of burden.

In Ontario, the direct costs of stroke are approximately $529 million a year. Add another $328 million in indirect costs and the total burden to the Ontario economy is at least $860 million a year. Left out of this estimate is the sheer human cost to the stroke patient and the stroke patient's family (Empires Club Addresses, 2000).

In Siddhartha Mukherjee’s Pulitzer Prize winning book, *The Emperor of All Maladies: A Biography of Cancer*, Mukherjee argued that “for an illness to rise to political prominence, it needed to be marketed” (Mukherjee, 2010, p. 99). Dr. Silver marketed the need, and asked the members of the Empire Club to implement “what the Heart and Stroke Foundation and medical community knew, and would implement if they had the money.” After four to five years of pilot
projects, economic analysis, building a business case, joint committee meetings with the Ministry of Health and the Heart and Stroke Foundation to build policies, the creation of the document “Towards an integrated stroke strategy for the province of Ontario” (informant ND, August 2011), the request for funds was successful. In June 2000, the Progressive Conservative Ontario Government adopted the Report of the Joint Stroke Strategy Working Group (Ontario Ministry of Health, 2000; informant MOH, August 2011), a 117 page document that included 15 recommendations for stroke care in Ontario. The Ontario Provincial budget included a financial commitment of $70 million over four years and $30 million annually after start up (Black, Lewis, Monaghan, & Trypuc, 2003). The OSS package included a ‘continuum of care’ ranging from health promotion efforts, emergency and acute care at centers that were to be designated as Regional and District Stroke Centers for safe implementation of thrombolytic therapy (t-PA), secondary stroke prevention and rehabilitation. The funded package included infrastructure requirements such as telestroke systems for remote diagnosis, a stroke data registry, and human resources.

This concerted action between the HSFO, Ontario Government, Toronto neurologists and the pharmaceutical industry reorganized stroke care by shifting the paradigm away from stroke as a hopeless disability (Eakin, 1974) to stroke as an active site of medical and industry intervention. Smith terms this type of coordinated action the “mobilization of knowledge and power” (Smith, 1990, p. 80). This mobilization led to a substantial funding of the Ontario Stroke System in the subsequent provincial budget, affirming “the established order” (Smith, 1990, p. 136), bringing in the “technical, informational, organizational infrastructures of biomedicine” (Clarke, et al., 2003, p. 162). The extra-local links to industry, including pharmaceutical innovation and informational data houses are discussed below.
**Links to industry: Pharmaceutical innovation**

The leverage to promote the Ontario Stroke Strategy was a pharmaceutical innovation, a medication called tissue plasminogen activator (t-PA), known as a ‘clot-buster’ (Heart and Stroke Foundation, 2011). The use of t-PA as impetus for the creation of the Ontario Stroke Strategy is documented in *Hospital Quarterly* as a case example of health care system change leadership.

In 1996, the United States Federal Drug Administration approved the use of t-PA for emergency ischemic stroke. This ‘clot busting’ drug had a narrow window of opportunity: it had to be administered within three hours of onset of a non-bleeding stroke, and it had to be supported with specialized technologies, such as a CT scanner. The pressure to approve and promote t-PA in Canada was felt by the Heart and Stroke Foundation, a well-recognized organization with a mission of reducing the risk of premature death and disability from heart disease and stroke by raising funds for research and health promotion. Healthcare providers, especially neurologists and the healthcare marketplace, specifically the pharmaceutical industry, encouraged the Foundation to increase awareness of stroke symptoms and the importance of responding quickly with effective treatments (Black, Lewis, Monaghan, and Trupac, 2003, p. 44).

An informant from the Ontario Government described the early days of implementing the vision of the *Report of the Joint Stroke Strategy Working Group*,

We were at six regional stroke centers and in the process of determining who the district stroke centres were, ought there to be more regional stroke centers, and the issues around wanting concentration of skill and expertise and the constant
battle for local and close to home. There were still some institutions that were not convinced that the model that the stroke strategy was built on was correct - the use of t-PA - to certain physicians that was controversial and may still be (informant MOS, August 2011).

Initially, the use of t-PA was contested by emergency room physicians. The Canadian Association of Emergency Physicians (CAEP) actively resisted use of t-PA when it was being actively promoted in Canada. CAEP’s position was that the use of t-PA “should be restricted to use in the context of formal research protocols, or in closely monitored programs, until there is further evidence that the benefits of this therapy clearly outweigh the risks” (CAEP, 2013). Numbers of deaths within seven days, mostly due to intracranial hemorrhage were increased, but the overall rate of death was not statistically significant by the final follow up (Wardlaw, Murray, Berge, del Zoppo, & Sandercock, et al., 2012). T-PA as the driver and impetus for the reorganization of stroke care signaled the change from an observational, passive field of neurology to an active interventionist field, one that has newly-accepted high risk treatments within the discipline.

Launch of the Secondary Stroke Prevention Clinic

The Secondary Stroke Prevention Clinics (SSPC) that arose from this Stroke Strategy initiative was a brand new entity in healthcare in Ontario. Regarding their origin, one informant stated,

one aspect was stroke units, the next was stroke prevention - most physicians don’t have the expertise and the knowledge to manage stroke prevention so (it was felt) we should fund clinics for people to get the optimal stroke workup and care (informant N.D., August 2011).
The goal of secondary prevention is to prevent neurovascular disease from progressing to a completed stroke or to prevent another stroke. People targeted for secondary prevention include those “who are at very high risk of stroke, and those who have experienced transient ischemic attack or non-disabling stroke” (Ontario Ministry of Health, 2000, p. 45). Transient Ischemic Attack (TIA) is believed to be a warning sign of significant cerebral-vascular disease. Symptoms are related to the anatomical location of the ischemia or damage to the brain. The nature and severity of the symptoms can therefore vary widely. Weakness, a drooping mouth, body sensory changes, inability to speak or understand language, visual changes, altered coordination of movements, and cognitive changes are documented in biomedical fields as symptoms of TIA. The challenge of a TIA is that the experience is transient, ephemeral, gone by the time the patient can be medically assessed. This fact makes the work of the patient and the health care professional that much more complex and ambiguous, and the internal search for a source of this mysterious experience that is known in biomedical fields as increasing the risk of stroke that much more intense.

Urgency plays a role in stroke prevention. The language of statistical risk underlies the premise of the clinic, in that urgency surrounding TIA is due to the concern that 1 in 20 patients with a TIA will have a stroke in the next 48 hours. Those that do experience a stroke have a 15% chance that it will be fatal and a 60% chance it will result in a long-term disability (Shah, Kleckner, & Edlow, 2008). The transient ischemic attack is therefore described in the biomedical literature as ‘a golden opportunity for stroke prevention’ (Johnston & Hill, 2004).

*Situating the clinic within the health care system*

Secondary stroke prevention is a subspecialty within the field of stroke, which is itself a subspecialty of neurology. Access for patients was developed through medical referral. Therefore the role of the clinic needed to be communicated to the medical community in order to
This embedded referral process marks a radical shift from the traditional approach described in the early 1990’s. Muzzin (1991a, 1991b, 1991c, 1992) conducted a longitudinal study of 50 referrals to specialists in Ontario and Manitoba. Muzzin described referrals as part of a process that involves a triad. The patient seeks a consultation with the family doctor, who then may seek a consultation with a specialist (Muzzin, 1991b). At this time, patients drive the referral process. Patients may propose various illnesses, directly request a specific referral, (Muzzin, 1991a) or set expectations of the family doctor (Tabenkin, Oren, Steinmetz, Tamir, & Kitai, 1998; Mwabu, 1989). By building referrals to the Secondary Stroke Prevention Clinic through the continuum of care described by the Ontario Stroke Strategy, patient recognition of the need or the existence of the clinic itself was bypassed. It was pivotal to the success of the clinic, in terms of volumes (numbers of patients seen/year) that the right people know of the clinic and refer. The system depends upon emergency room doctors, inpatient attending physicians, and family doctors.
Twenty-four clinics were opened across the province. Each clinic had the autonomy to shape their role in their respective area or community and related activities based on the medical leader (informant N.D). Therefore, one clinic could embrace aspects or activities that other Ministry funded clinics did not. The layers of activities are depicted in the diagram below (Figure 3). According to the Heart and Stroke website, core activities of secondary stroke prevention management include identification of potential cases, triaging the urgency of referrals, diagnosis (including investigations), suggesting treatments, and follow up when needed. Moving outward in complexity and breadth, the next layer is management of risk factors. Health promotion and screening included aspects of health such as diet and exercise, weight control, smoking cessation, and limiting alcohol consumption, which are inextricably linked to the promotion of vascular health and screening for depression and cognitive impairment, as stroke patients were also at risk for these conditions. The clinic in this study did assess cognition on occasion, but general health promotion was not the focus. In summary, the SSP clinic setting in which this study took place engaged mainly in core activities, including triaging the urgency of referrals, identification of risk factors, diagnosis (including sending for investigations), treatment suggestions, and follow up when needed. Risk factors were identified but not managed directly. Communication went to the family doctor via a letter. At times education was provided to the patient by way of informative comments. An education class was offered by the clinic, but according to staff (informant RN, July 2011), was regularly cancelled due to low enrollment.
Figure 3: Secondary Stroke Prevention Model
(Secondary Stroke Prevention Model, n.d.)

*Information technology: the house of data*

Data circulates throughout the local and extra-local settings of the Ontario Stroke System. The movement of local data will be discussed in Chapter Six, the movement of extra-local data will be discussed here. The provincial government funding for the Ontario Stroke Strategy included infrastructure to support a stroke data registry. A Registry of the Canadian Stroke Network (RCSN) was established in 2001 with a research grant from the Canadian Stroke Network (CSN) to allow for the measurement and monitoring of stroke care delivery and outcomes in Canadian patients. In 2004, the RCSN became a prescribed registry under Ontario’s Personal Health Information Protection Act (PIHIPA). This status permitted the RCSN to collect data related to stroke care delivery in Ontario without patient consent (Tu et al., 2004). As of
November 1, 2011, the RCSN’s ownership was transferred from the CSN to the Institute for Clinical and Evaluative Studies (ICES) in partnership with the Ontario Stroke Network and the name was changed to the Ontario Stroke Registry.

In this clinic, the process is as follows, and as depicted in Figure 4 below. The data collection form (Figure 5 below) is put on the chart by the secretary. According to an informant (informant RN, January 2013) the health care professional that sees the patient (this could be the nurse and/or the neurologist and/or the Fellow) is responsible for filling it in as part of the patient’s appointment. The form, completed as thoroughly as possible, goes back into the patient’s chart. The chart goes back to the secretary and the secretary puts it in a particular slot from which a person assigned to do data entry collects the form and chart, and enters the data electronically into the secure database. The data from all of the respective Stroke Prevention clinics in Ontario is collected through the Stroke Registry which is housed at ICES. Data are analyzed by researchers at ICES, and reports generated. Mykhalovskiy (1999) in his comprehensive investigation into health care restructuring in Canada, notes the role of the ICES as “enjoined to produce research that is relevant to the contemporary health care policy concerns of the provincial government” (p. 50).
Figure 4: Process for ICES stroke prevention data collection form

The data collection sheet (Figure 5 below) provides insight into the data points of interest for evaluation of the stroke system. These data points are extracted from patients in an effort to produce evidence for medical practice. As of November 2013, eighty-six publications have been produced using the stroke registry data. Publications investigated gender differences in care received (Kapral, Degani, Hall, Fang, & Saposnik, 2011), presentation to the hospital on the weekend (Fang, Saposnik, Silver, & Kapral, 2010), and other finer details that ICES researchers have gleaned from the Stroke Registry data. Since 2001, an annual report on the Ontario Stroke System has been published.
**STROKE CLINIC FORM - INITIAL VISIT**

Date of referral: ____________ (mm/dd/yy)
Date of index stroke/TIA event (mm/dd/yy) (if applicable) ____________

Patient seen by the clinic prior to the SPC referral? □ Yes □ No
Patient discharged from an inpatient stay for an index event? □ Yes □ No
Patient enrolled in rehab prior to SPC visit? □ Yes □ No

1. Referral From:
   - □ Within region
   - □ Outside region

Referral By:
   - □ Emergency physician
   - □ Neurologist
   - □ Family Physician
   - □ Other primary care worker
   - □ Surgeon
   - □ Inpatient care
   - □ Other medical specialist

Reason for referral:
   - □ New stroke/TIA (<30 d)
   - □ Recent stroke/TIA (31-180 d)
   - □ Past stroke/TIA (>180 d)
   - □ Abnormal CT/MRI scan
   - □ Other:

2. Triage questionnaire: (check that applies - indicating the response is YES)
   - □ Recent stroke/TIA symptoms within past 3 months?
   - □ Patient seen for a rapid TIA assessment for the presenting issue
   - □ Patient seen to be at high risk of stroke/TIA (历史 recurrent events, ABCD score > 3, evidence of acute stroke)
   - □ Patient’s symptoms appear within the previous 24 hours?

3. RISK FACTORS:
   - □ Prior stroke or TIA - year diagnosed: ____________
   - □ Hyperension
   - □ Diabetes Type I □ Type II □ Gestational
   - □ Dyslipidemia
   - □ Smoker - Specify: □ Current □ Lifetime non-smoker □ Former smoked (quit > 1 Mo to 3 years)
   - □ Cardiac disease □ Angina □ Prior MI □ Prior CABG □ Prior PTCA □ Valvular heart disease
   - □ Carotid stenosis (extra cranial, >50%) Specify: □ Right side disease □ Left side disease □ Both sides
   - □ Peripheral vascular disease
   - □ Cardiac source for emboli - Specify: □ Atrial fibrillation □ Post-MI poor L.V function or aneurysm
   - □ Atrial myxoma or ventricular septal defect □ Phlebitis □ Patent foramen ovale or other shunt
   - □ Obesity
   - □ Prolonged clotting time - Specify: □ Factor V Leiden □ FPAAS □ Hyperhomocysteemia □ Prot S or Prot C Deficiency
   - □ Metastatic cancer
   - □ Cardiac thrombus
   - □ Alcohol consumption - Specify: □ Never □ Rare/Social □ < 2 drinks/day □ > 2 drinks/day
   - □ Known pregnancy or post-partum - Specify: □ < 6 months □ > 6 months □ Post-Partum

**SUMMARY OF DIAGNOSTIC TESTS ALREADY COMPLETED AND MAIN FINDINGS**

**Brain Imaging:**
   - □ CT
   - □ MRI

**Vascular Imaging:**
   - □ CT Angiogram
   - □ MR Angiogram
   - □ Cerebral angiogram
   - □ Carotid ultrasound
   - □ Doppler ultrasound

**Cardiac Tests:**
   - □ EKG
   - □ Holter monitor
   - □ 2D echo
   - □ TEE

**Other Tests:** Blood work ordered prior to the visit □ YES OR NO

5. Modified Rankin Scale (0-6, normal = 0)

   - □ 0 - no symptoms
   - □ 1 - no significant disability despite symptoms; able to carry out all usual duties and activities
   - □ 2 - slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance
   - □ 3 - moderate disability; requiring some help, but able to walk without assistance
   - □ 4 - moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance
   - □ 5 - severe disability; bedridden, incontinent and requiring constant nursing care and attention

MoCA (0-30, normal = 26-30)

Quick Cognitive Screening: □ Yes □ No

Blood Pressure: □ Systolic □ Diastolic (mmHg)

BMI: □ Waist-Hip circumference:

**MOST RESPONSIBLE DIAGNOSIS AFTER INITIAL VISIT**

1. New stroke/TIA (<30 days)
2. Recent stroke/TIA (31-180 days)
3. Past stroke/TIA (>180 days)
4. Query stroke/TIA (diagnosis unclear)
5. Abnormal CT/MRI scan
6. Other:

If new or recent stroke/TIA, which type:
   - □ TIA - Specify: □ Definite TIA □ Probable TIA
   - □ Uncertain but pragmatically treated as a TIA
   - □ Ischemic stroke
   - □ Intracerebral hemorrhage
   - □ Subarachnoid hemorrhage
   - □ Primary Intraventricular hemorrhage
   - □ Sinovenous thrombosis

Neurological Deficits? □ Yes □ No

If no, skip to follow up appointment section

If yes, please indicate:
   - □ Motor weakness
   - □ Sensory
   - □ Speech (dysarthria / aphasia)
   - □ Coordination
   - □ Gait
   - □ Cognitive (excluding aphasia)
   - □ Visual

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Figure 5: ICES data collection form
ICES data collection form: revealing priorities and goals

Smith (1990, p. 155) states that the material possibilities created by texts bring into view the ruling relations and activate those who encounter the text. This pre-designed ICES data collection text guides the health care professional to the expected outcomes of the clinic as they reveal the privileged data sets. The major data collection foci include patient risk factors (section 3), imaging that has been completed or ordered after the clinic visit (sections 4, 9), measurement of physical and cognitive disability through the modified Rankin scale and Montreal Cognitive Assessment (MoCA, section 5) and medications (unnumbered section). These data sections are explored below. Each individual patient that has gone to each Secondary Stroke Prevention clinic across the province has had their data entered according to the form. This form is submitted to ICES, where the data is collated, statistically analyzed, and a report with subsequent recommendations generated. Taken for granted in this report is the accepted discourse of risk, risk factors, and modifiable risk factors. Invisible to the report are the patients as individual people.

This data collection and evaluative report methodology is not unique to the Ontario Stroke Strategy. There are many other such relationships throughout healthcare. For example, the Canadian Cardiovascular Congress held a workshop in Toronto in 2008 to discuss working together to develop common data standards for cardiovascular databases in Canada. The groups working together included Health Canada, the Canadian Cardiovascular Society and the Heart and Stroke Foundation of Canada (Davies, 2009). The ICES website provides information about the ‘cd-link’, the Ontario Cancer Data Linkage Project in which administrative datasets relevant to cancer health services research are linked, de-identified and provided to researchers. C’d-link is a collaborative agreement between ICES and Cancer Care Ontario. Datasets available include twelve different provincial or national datasets, such as cervical screening data, home care data,
Ontario Health Insurance Plan Claims (OHIP) claims, breast screening data, drug funding programs, and rehabilitation data. So much data is being generated that, in 2011, the Health Council of Canada hosted a Summit in Saskatoon which highlighted ‘Indicator Chaos’ (Health Quality Council of Saskatchewan, 2011).

**ICES data collection section 3: Risk factors**

The concept of risk factors can be traced to the Framingham study, an epidemiological longitudinal study conducted in Framingham, Massachusetts in the 1950’s (Greene, 2007). Epidemiology translated from the Greek implies “knowledge of that which surrounds the people” (Brown, 1985, p. 334). It has been defined as “the branch of medical sciences that deals with epidemics” (Lilienfeld, 1978, p. 87). Lilienfeld (1978) summarizes epidemiology as a method of reasoning, a chain of inference that is drawn from population statistics. Knowledge of the distribution or frequency of disease that is drawn from epidemiological science leads to determination of reasons for the distribution and the assignment of risk factors (Detels, 2009). The Framingham study was conducted in order to understand what was then considered an epidemic of heart disease among American men. Previous epidemiological studies sought single causes or agents responsible for the epidemic. The Framingham study was unique in that multiple factors were under consideration including increased age, male gender, high blood pressure, cholesterol, smoking, alcohol use, increased physical activity, increased thyroid function, a high blood hemoglobin, increased body weight, diabetes, and gout (Dawber, 1980). Through detailed physical examinations and investigations of the Framingham population over time, factors were identified which became known as ‘risk factors,’ precursors that could lead to the development of cardiac disease. In 1957, these factors were identified as high blood pressure, high cholesterol levels, and being overweight (Dawber, Moore, & Mann, 1957).
In the secondary stroke prevention clinic, work included ascertaining risk factors mined from individuals. Risk factor data was documented on the ICES data collection form, submitted to ICES to be collated and analyzed as aggregate data. New knowledge about risk factors circulated through ICES is reported back to the clinic and is subsequently applied to individuals. The original patient who contributed data has been made invisible. His or her data becomes a statistic that is applied to a different person. See Figure 6 for a diagram depicting this data movement. In applying this knowledge in a biomedical frame, knowledge is applied to individuals, creating what Wheatley (2005) terms a “truth trick, a shift from the logic of population based risk to the logic of the individual case” (p. 207).

Figure 6: Data Circulation in the Ontario Stroke System
ICES data collection sections 4 and 9: Imaging

The convergence of biomedicine with innovative sciences such as neurosciences, physical, chemical, and computer sciences (Burri & Dumit, 2007) has shifted both the ways of knowing and the knowledge production within biomedicine. Specifically, in the field of stroke, the development of imaging technology has provided new procedures for diagnosis and treatment. Developments in imaging allow a view inside the skull, a problem neurologists wrestled with for years prior to the development of the CT scanner. Imaging has provided a new frontier for the information quest that neurologists require for state-of-the-art treatments.

A computerized axial tomography (CT) scanner uses x-ray technology combined with computer calculations to determine absorption values of the tissue inside the skull, allowing slices of brain tissue displaying different densities to be displayed (Hounsfield, 1973). Today imaging of the brain as part of establishing a diagnosis after a TIA is expected. “Until you image the brain, you are practicing 19th century medicine” (Butcher, 2013) pointing out the reliance of computer technologies as part of the institutional infrastructures of biomedicine as noted by Clarke et al., (2003).

With the advent of ‘technoscience’, biomedical interventions and applications have provided a gaze into the interior of the body (Clarke, et al., 2003). Textually, the documents that constitute the care process within the SSPC all include and direct attention and action towards visual imagery. The letter of appointment to the patient asks the patient to bring any brain scans that have been completed. The referral to the clinic asks referees to check off investigations that have been completed. The data collection sheet for the Stroke Registry solicits information about the summary of diagnostic tests and their findings.
Joyce (2008) argues that MRI has become a cultural icon. Joyce demonstrates how MRI examinations represent an intertwining of economic interests, physical bodies, machines, and cultural and institutional practices. Rhetorical moves, both in popular culture and in professional settings, position MRI images as an authoritative truth. Joyce (2008) contends that the MRI image is positioned as interchangeable with the material body instead of a construction of it, that MRI represents neutral, objective knowledge that “tells the story” (p. 443).

Joyce (2005) illustrates how MRI examinations produce a ‘located, embodied and contingent’ truth that merges bodies, machines and work practices to constitute a particular body. Using an extensive analysis of medical professionals’ tacit knowledge, as well as economic variables, such as volumes and time, Joyce demonstrates how the production of images through decisions about the number and thickness of MRI slices and the use of numerical data to create a visual image produces the body rather than provides a window into it. Reading of the image to formulate an interpretation is influenced by professional vision (Goodwin, 1994). Professionals discipline and train their sight over time to code and highlight aspects of the image, and determine artifact from stable anatomy and disease (Joyce, 2005). The interpreted image is then translated into written form to be able to be entered into the person’s medical record, and read by other professionals.

One moment between the neurology fellow and Helen made visible the encounter between the human person and technology. The neurologist wanted to order an MRI for this woman, and asked about any metal in her body (an MRI is a large magnet, and metal in the body can be dragged within the body towards to magnet, causing serious internal damage). “No bullets, no metal in the eye, no shrapnel?” asked the neurologist (informant N.D.2). Helen, who had shared with me during her interview that she was German and moved here after the war,
said, “No, I was very lucky.” This brief encounter highlights the multiple meanings that can occur within a medical interview, and in that moment of shared meanings, which meanings are counted. For the physician, a piece of metal in the body is potential damage to the interior of the body if the MRI magnet should pull it through the tissues or eyes. To the patient, a German woman who survived the war, being asked about shrapnel brought up the historical, political, social and emotional aspects of her life. The direction taken highlights the privileged meaning. The physician excluded Helen’s comment and continued with the MRI preparation checklist.

ICES data collection section 5: Deficits

The modified Rankin (mR) scale in section five (5) of the ICES form represents an important lens that is adopted by biomedicine. This scale was developed in the 1950’s by Dr. Rankin, a physician who developed early theories of neural plasticity and the brain’s ability to recover after stroke (Quinn, Dawson & Walters, 2008). Rankin (1957) tracked the outcome of 252 stroke patients and developed a five point grading scale. Researchers in the United Kingdom later added scores of zero (no symptoms) and six (death) and slightly revised the wording of the gradings to allow for enhanced reliability. This became the modified Rankin Scale (mRS), see Figure 7 below (Quinn et al., 2008). As noted in the literature review, the use of the mRS informs the calculation of the stroke DALY (Disability Adjusted Life Years) through
the World Health and World Bank liaison.

Figure 7: The Modified Rankin Scale from the ICES data collection form

The Modified Rankin Scale is a “functional” assessment. It is the preferred measure of disability in cerebrovascular clinical trials (Quinn, Lees, Hardemark, Dawson, & Walters, 2007). Function in this sense is the action of purpose for which the (insert any body part) exists, a mechanistic, physiological idea. With a view that a body has parts and these parts fit into system which have functions (walking, moving blood through the body, thinking), in biomedical circles an impairment or dysfunction is when the body part changes or stops doing its role in the body. Assessments in stroke are derived with an aim to quantify the level of impairment with a broader aim of rehabilitation or reconstruction to allow one to engage in meaningful occupation and social roles. The mRankin is documented in the clinic, and submitted along with the other data on the ICES form to ICES where it is tabulated and presented in an annual evaluative report to the Ontario Government.

The Rankin scale is an empirical example of the biomedical view of disability. The Rankin scale’s location on the ICES data collection form, the documentation of this score, and its
submission to a provincial data set circulates and perpetuates one singular view of disability, that of loss and impairment. Robert MacKay (2003) and Kelley and Betselel (2004) both made this claim in their papers describing their experience of having a stroke. They noted the focus of biomedicine to ‘fix’ deficits and measure impairments in a particular way, based on the body’s ability.

The biomedical view was taught to patients in the clinic. Critical disability scholar, Titchkosky (2007) argues that medicine explains disability as a “departure from normalcy, a loss of a way of being in the world” (p. 134). This is the functional perspective that was noted in the clinic. A typical statement came from the neurologist to Helen (informant 1), “Our purpose is to make sure you aren’t left with a permanent problem related to a stroke.” The expert medical goal points to a possible permanent change as a problem. When he adds, “our goal is to review everything to make sure your chance of having a stroke is low,” he emphasizes that the concerns he will be reviewing during the appointment are the ones worth paying attention to.

Patients spoke about disability during interviews and they similarly located this disability in their bodies. They also expressed their fears and worries about being a burden. Helen (informant 1) said, “I have strong will-power. I try to avoid using a cane, after a cane the walker, then the wheelchair, and then it’s all over.” Bert (informant 7), “The last thing I want is to be paralyzed.” While we sat in the waiting room, Caroline, (informant 8) grimaced when a woman walked by using a ‘Rollator’. When asked, she stated, “The time will come that I need one of those; I don’t want to be dependent.” An 81 year old woman, Amy, (Informant 6) told me,

Two friends have died in stroke. One is paralyzed from the neck down. I am aware that could happen to anyone. I realize bodily health could be taken away.

One dear friend moved to Toronto and moved into a seniors’ residence, to my
horror - I find it unbelievable. I hope I don’t have to go into a home, I hope I live until I die in an independent situation.

One family was struggling with their father’s (Walter, informant 2) related behaviors, “He says that he doesn’t want to be a burden to people, and he tries to go out the door onto the street.” This expressed fear is also recounted by Stone (2003), who argues that fear of aging is a fear of disability, a fear that can be understood as a fear of dependence.

Stiker (1997) links our interest in avoiding disability to society’s value of the able-bodied worker, and its need for industrial productivity. Solutions for disability are treatments or training that are motivated by economics and focus on the individual body, not society. In pitching the Ontario Stroke Strategy at the Empire Club, Dr. Silver quoted financial estimates of direct and indirect costs for stroke care from a study done by two Waterhouse Management Consultants (Chan & Hayes, 1998). The direct costs ($530M) listed were calculated from Canadian Institute for Health Information (CIHI) data housed in the Discharge Abstract Database, pharmaceutical costs were captured through the Intercontinental Medical Statistics and itemized hospital expenditures through the Public Accounts of Ontario (Chan & Hayes, 1998). Indirect costs ($328M) were derived using a human capital approach (Chan & Hayes, 1998); disability from stroke was linked to the individual’s economic productivity.

From a global perspective, the World Health Organization (WHO) discusses the burden of stroke as DALY’s, disability-adjusted life years. As noted in the literature review, the DALY was created in 1992 through a partnership of the WHO, the World Bank and the Harvard School of Public Health as a measure intended to quantify the burden of disease and injury for the Global Burden of Disease Project. DALY lost is a mathematical determination, the “sum of years of life lost due to premature death and years of healthy life lost due to disability” (Hong, 2011, p. 110). Disability translates to a loss of productivity, which is not just economic loss, but
economic burden. Below, in Figure 8, is a copy of an extraction from the *World Health Organization’s Atlas of Heart Disease and Stroke*.

Figure 8: A quote from the WHO Atlas showing use of DALY (Mackay & Mensah, 2004, p. 15).

Figure 9: A snapshot from the WHO Global Burden of Stroke (Mackay & Mensah, 2004, p. 15).
Concepts and language used in the Ontario Stroke system are not isolated to the Province of Ontario, or to Canada. On a global level, stroke is understood as a burden due to lost productivity. Healthy life is a productive one that requires a body that functions, from a biomedical perspective.

The 1998 Economic Burden of Illness in Canada report (Health Canada, 2002) which provides the economic cost of 18 disease categories (stroke is included in the cardiovascular category) defines the indirect cost measure as “the value of economic output lost because of illness, injury-related work disability or premature death” (Health Canada, 2002, p. 1). In 2003 a report detailing the costs of heart disease and stroke was published by the Heart and Stroke Foundation, in collaboration with the Canadian Cardiovascular Society and Health Canada, with support from Solvay Pharma (Heart and Stroke Foundation, 2003). The report stated that cardiovascular disease and stroke are the most costly illness in Canada. The report identified that 80% of the population had at least one modifiable risk factor for these illnesses. The solution proposed to reduce cost was to treat these risk factors. Lalonde’s (1974) insights that health was more than health care similarly drew upon illness prevention through life style changes as a means to reduce health care expenditures through prevention in Canada. In Canada, the individual ‘body’ is both seen as the source of disability, and the site of solution.

The World Health Organization’s (WHO) *Atlas of Heart Disease and Stroke* (Mackay & Mensah, 2004) also identifies the global prevalence of stroke and related risk factors. The WHO list includes socioeconomic status as a risk factor for stroke. In this WHO document, socioeconomic status is located in isolation, there is no corresponding discussion regarding socioeconomic status as socially organized. The pathway to illness through this socioeconomic risk factor is noted as behaviors (p. 11). The prevention discussions in this document open with a Turkish proverb, “No matter how far you have gone on the wrong road, turn back.” Mackay and
Mensah (2004) advocate for personal choices and actions as a means for stroke prevention (p. 20). The suggestions for prevention on a population or systems level constitute blood pressure management, diet changes and medical equipment (p. 21). Those with a socioeconomic status risk factor for stroke are also the site of ‘solution’ through behaviour changes, in an effort to avoid an economic burden, disability. The dominance of the biomedical view, a view that locates disability as well as solutions through behavior change in the individual body, excludes other possibilities, such as social changes that reduce economic inequality.

**Conclusion**

Using imperial and colonial language embedded with risk, a speech delivered at an elite club pitched a new model of health care called the Ontario Stroke Strategy. Biomedicine, the Ontario Government, pharmaceutical companies and the Heart and Stroke Foundation linked arms, successfully mobilized knowledge and power, and launched a new system of stroke care aimed to reduce the cost of disability. The Strategy was formulated around the changing paradigm of stroke, an interventionist one. This “new” face of stroke revolved around the use of a medication administered to patients during the acute event of stroke, an example of Clarke et al.,’s (2003) reorganization of the biomedical model.

The circulation of data and the content of that data confirm the integration of computer and information technology described by Clarke et al. (2003). Biomedical dominance and exclusion of other social or political possibilities is illustrated on the ICES data collection form. The data that we will see act as a proxy for patient health makes visible the privileged knowledge and drivers of the OSS, that is, risk factors and disability as located in the body, visual images of the body, and medications.
In this study, the patients, doctors, government, and HSFO are in alignment. Patients want to prevent a stroke and work hard to participate in stroke prevention. Socially, the existence of this clinic and the urgent treatment of these symptoms as a threat of disability is one of the ways that people are educated that fear of stroke is a reasonable fear. Images from the WHO World Health Organization’s Global Burden of Disease Atlas which confirms the governance of the biomedical ideology in stroke care on an international level. The patients’ bodies were laden with variables known as risk variables in biomedicine. As will be discussed in the next chapter, the focus of the appointment was determining the risk of stroke, when in the case of these patients, “A region of the body that may have previously given forth little in the sense of sensory stimuli suddenly speaks up” (Leder, 1990, p. 71).
Chapter 5: The organization of patient symptoms

In this chapter, I argue that social marketing activities and prevention interventions exploit fear and use ‘certainty practices’ that identify warning signs for stroke as ‘truth,’ thereby engaging people who identify as ‘at-risk’ for stroke in a myth of prevention. I will show that social marketing products cast a large net into the public to draw them into a stroke system primed to perform interventions, and a clinical formula that is used as a proxy for certainty. Rather than the myth of prevention, I argue that the clinic offers ‘potential damage minimization’. Texts, including a refrigerator magnet, ethnographic field notes from clinic appointments and interviews with the local and extra-local professionals provide supporting data for this argument. The argument is illustrated through tracing patient symptoms.

The design of this chapter moves us from the extra-local to the local setting, and keeps patients’ symptoms at the forefront as guideposts. We will meet Helen and Amy at the beginning of their appointments, and Bert at the end of his appointment. Helen and Amy arrive in the local clinic setting after noticing something different in their body (a symptom) during their daily lives in the community. I will show how a social marketing product that they engaged with as part of their entry into the clinic. Again using the symptoms as the guidepost, the next part of the chapter focuses the interview with Bert after the hunt for the source of his symptom has concluded. This is the end of the specialist appointment. The analysis makes visible the knowledge that is privileged in the clinic, the logic that directs clinical decision making, and the tensions that are real for the patients.
“I’m no fool”

Helen (informant 1) is an 81-year-old widow who lives alone in a small house in Toronto. She has lived at that address for 57 years after immigrating to Toronto from Germany after the Second World War. She has a 28 year relationship with her family doctor. During the course of living in Toronto, Helen has had several encounters with different hospitals,

I have had the run around with Toronto’s hospitals. I keep forgetting what I had done at which one. When I had to go to X hospital, I had to take a taxi, it cost me 45 dollars, because I really did not know how to get there (Helen, informant 1).

Her story with regard to the Secondary Stroke Prevention Clinic begins when she was sitting in a waiting room for a physiotherapy appointment which she was attending in the hopes of resolving a problem with her shoulder.

I went to check my hearing aid, all of a sudden, what happened to my hand? It was stiff, numb. I thought ‘oh my goodness’, and they have a TV in the waiting room, and I looked at the TV and I thought, ‘it is not sharp’, and I thought ‘maybe it was the weather’, but it didn’t last long, and as quick as it came it went (Helen, informant 1).

Helen reported that since the head physiotherapist was not in, she told two different therapists and asked them if they knew what it was. She said that they said they didn’t know. Helen, after not receiving answers to her questions from the two physiotherapy staff, reviewed a Heart and Stroke magnet that she keeps on her fridge when she returned home. She noted that some of the symptoms were her symptoms, and sought further health care.
Smith (1990) describes a process of how lived actuality becomes produced as a factual account and how the reading of that account reads through the account to create a documented reality. Helen sought to understand her experience. “I thought in the back of my head what was that that happened?” Wondering what this experience may be, and having prior awareness of stroke symptoms through a magnet on her fridge, she read her experience as a stroke warning sign.

Amy (informant 6), an 82-year-old single woman, came to her appointment at the clinic. After greetings, she told the neurologist, “While shopping, I became so dizzy I thought I was going to fall down. Then, a few weeks later, this happened again while I was sitting reading.” Amy felt that something was amiss and that it might have something to do with stroke. “I’m no fool”, she said when asked why she raised her experience of dizziness with the doctor. “I realize that this could be a sign of stroke” she said as she pulled out list of stroke symptoms from her purse and showed it to me. She demonstrated her knowledge to me further by adding, “there are five symptoms of stroke, and he (the neurologist) asked me all of them.”

Both Amy and Helen translated their bodily experience and sorted it against a grid of stroke symptoms that included sudden weakness, headache, dizziness, trouble speaking, and vision problems, symptoms known to them through popular media and promotional materials from the Heart and Stroke Foundation of Ontario (HSFO). They read their experiences through the educational literature thus transforming these experiences into potential ‘symptoms’ for both self and others. Smith’s (1990) concept of ‘bifurcated consciousness’ is relevant here. Amy moved between two modes of knowing. One consciousness was the local consciousness of Amy’s lived actuality in the body, her dizziness. The other is the conceptual, governing mode of knowing which passed beyond her experience and categorized it. Amy knew her dizziness as a
possible warning sign of stroke and actively remembered all of the signs of stroke taught to her by promotional materials. Her statement, “I’m no fool” shows the degree of governance this conceptual mode of knowing has attained for her. When Amy shared this experience of dizziness, the neurologist asked her for more precise information.

Did you feel faint or did you feel like you were moving? Did you have a sensation of spinning, your heart racing, or any visual changes? A key thing, he informed her, if in your dizziness you felt like you were moving, that is stroke, the feeling faint means your heart paused a bit (Neurologist to Amy, informant 6).

Here, Amy was being taught what other bodily experiences to pay attention to. Her knowledge of the stroke symptoms was being fine-tuned. She was being drawn deeper into the work of self-detection required of risk management that organizes secondary stroke prevention. Amy is provided with supplemental information about the underlying potential cause of her dizziness that she could next attend to. The elements of time and analysis now enter into the body literacy work required in her management of stroke symptoms. Amy is being trained to note the experience as it is happening, recognize it as a possible stroke warning sign, and attend to the experience with reflective questions afterwards.

Social Marketing

Helen (informant 1) activated health care after using a refrigerator magnet (see Figure 10 below) to evaluate her symptoms against. Amy carried a list of symptoms with her. She had given a magnet with stroke symptoms to her good friend. A couple, Bert and his wife (informant 7) eloquently described their knowledge of symptoms, stating their source was “TV, you see it everywhere, it’s very public.”
Above is an image of the refrigerator magnet that was distributed by the Heart and Stroke Foundation. The logo, phone number, and website of the Heart and Stroke Foundation can be seen on the bottom right hand corner of the magnet. According to an HSFO employee, because of the HSFO’s experience and success working with media, the Ontario Government funds the Heart and Stroke Foundation to “execute mass media campaigns, such as the stroke warning signs campaign” (informant HSFO, October 2011). Since 2003, funds from the Ontario Stroke Strategy have been set aside yearly to run public education on the warning signs of stroke and getting to hospital. The informant referred to this activity as social marketing.

There is a whole media buying strategy, when you should be on air, how you should pulsate the commercials, two weeks on, and two weeks off. There is a whole science that goes behind it, that’s the whole media buying strategy for the TV commercial because the intention is to reach the broad number of people, it is
targeted to people 45+, where are you going to hit people with the most cost
effective manner. With the TV, what they found is if you layer that with
newspaper ads, online ads, and magnets, it supports what people are seeing on the
TV, it is actually a media buying strategy and promotional layering. It is part of
this realm that we call social marketing. The government is really adopting this
whole notion of social marketing (informant HSFO, October 2011).

The products described above are the products Amy, Helen and Bert engaged with.
These tools prompted the ‘knowing’ of symptoms and subsequent initiation of health care
consultation that ultimately led to their stroke prevention appointment.

Kotler and Levy (1969), American business professors, argued that marketing was a
pervasive but unrecognized social activity that was not solely a business enterprise. They
pointed out that though the terminology may not be used, organizations such as schools,
museums, public health departments were trying to influence a target group. “All of these
organizations are concerned about their “product” in the eyes of certain “consumers”, and are
seeking to find “tools” for furthering their acceptance” (p. 12; authors’ punctuation). Kotler and
Levy (1971) argued that marketing could sensitively serve and satisfy human needs and promote
social goals through the application of commercial ideas and methods, an activity they termed
social marketing.

Grier and Bryant (2005) define social marketing in the health field as a program planning
process that uses marketing techniques to promote voluntary behavior change. These authors
describe social marketing as an attempt to create an environment that “invites voluntary
exchange” (p. 321). Exchange theory, according to Grier and Bryant (2005), explains exchange
as consumers acquiring what they want or need in a way that they deem the greatest benefit for
the least cost. In the business market, a product is exchanged for money. In the social realm, social marketers offer benefits and consumers exchange with behavior. Social marketing uses the core concepts from commercial marketing: the four P’s: product, promotion, place and price (Grier & Bryant, 2005).

Figure 11: The 4 P’s of social marketing (Grier & Bryant, 2005)

Application of these concepts to the HSFO magnet allows a glimpse at how social marketing products organize health behavior. Grier and Bryant (2005) tell us that the first ‘P’, Product is the set of benefits associated with the desired behavior or service usage. The core product is what people will gain when they perform the behavior. The actual product is the desired behavior. Pamphlets and other promotional activities are designed to facilitate adoption of the behavior and are not the actual products. In the case of the HSFO magnet, the product being promoted through the marketing of stroke symptoms at first glance seems to be the health behavior of self-surveillance. The purpose of the action of self-surveillance more importantly is the reduction of stroke in the population through these individual behaviors. Individuals are directed to notice symptoms as the first act. The call for emergency help is the second step.
These actions together are intended to bring people to the emergency departments for possible t-PA administration, in an effort to avert expensive disability. Hodgson, Lindsay, and Rubini (2007) found that visits to the emergency departments for stroke and TIA increased during television campaign times. The goal of the magnet, designed as a promotional layer to support the television campaign, is increased visits to the emergency department for stroke.

The ‘P’ of Promotion includes advertising, public relations, printed materials, promotional items, signage, special events and displays, face-to-face selling, and entertainment media (Grier & Bryant, 2005). In relation to the commercial and magnet, this ‘P’ refers to the media buying strategy and promotional layering described by the HSFO informant. Grier and Bryant (2005) tell us that the ‘P’ of Place entails ensuring the newly motivated person knows where to go or what to do in order to respond. In social marketing, place may be thought of as “where and when the target market will perform the desired behavior, acquire any related tangible objects, and receive any associated services” (p. 323). Place includes the actual physical location of these outlets, operating hours, general attractiveness and comfort, and accessibility, such as the availability of parking or public transportation. The HSFO magnets and commercials direct the public that “if you have any of these symptoms, call 911” (see Figure 10 above).

The fourth element, Price includes the money costs, opportunity costs, energy costs and psychic costs associated with the product. Grier and Bryant (2005) describe price as the cost or sacrifice exchanged for the promised benefits including intangible costs, such as diminished pleasure, embarrassment, loss of time, and the psychological hassle that often accompanies change. Price, in the case of the magnet is two-fold. The first is the individual ‘health work’ (Mykhalovskiy, 2002, 2008) performed by those who identify with the product. This health work includes the first act of keeping the magnet or noticing and possibly memorizing the
symptoms on the television commercial, as well as then internalizing the symptom detection and stroke warning sign recognition, activation of health care, and managing the related anxiety and worry, should a ‘symptom’ occur. The second ‘price’ is both individual and social. The list of symptoms on the magnet constitutes a ‘certainty practice’. Though only five symptoms are listed, the magnet and commercials cast a wide net into a pool of body experiences that may or may not be stroke warning signs. For example, migraine with aura, hyper or hypoglycemia, tumors, and seizures are considered possible differential diagnosis as they present similar symptoms to a stroke (Johnston & Hill, 2004). The neurologist describes the work of diagnosing stroke and TIA,

You are always trying to…there are always some benign things, like migraine, that can produce symptoms that can mimic a stroke. You are trying to tease out whether the patient has actually had an ischemic event, a clot up to their brain, and especially when they have recovered. I use the analogy of the TV, when the picture is scrambled, by the time the repair man comes you can’t figure out what was going on because it’s not happening anymore. It’s like that with the TIA patients. They had their event, and they are back to normal, it is crucial to try to understand was this nothing, or something. I don’t like the term TIA, doesn’t mean much, I like (the term) ‘threatened stroke’. A threatened stroke, it is important to understand why it happened (informant N.D., July 2011).

In other words, the magnet represents symptoms that can be due to another health concern that is mimicking stroke. Moreover, the symptom may be gone completely by the time the patient is seen. The magnet and commercial enters public space with certainty, “if you
experience this symptom, call 911” yet the symptoms are ambiguous. The magnet and commercials cast a wide net into a population fearful of disability and stroke.

Ivy (informant 5) knew the promoted symptoms to pay attention to, but was confused by the timing or duration of the symptom. She asked, “How do I know when to go to the hospital?” She was advised that if she had to ask herself, or debate with herself, you don’t have to go. “If a symptom lasts a while, at least 10 minutes, and it is OBVIOUS, you should get to a hospital right away” (neurologist to informant 5). Informant 7 and his wife were very knowledgeable of symptoms, stating that they had seen commercials on television. The couple was frustrated. This man was having the symptoms that were mentioned on TV, but the couple found when they arrived at the hospital they did not find the health care team addressing them with the urgency they understood to be vital from the commercials. They found some hospitals more engaged than others, and in fact changed the location of where they went for care accordingly.

The neurologist’s statement above, “was this nothing, or something” highlights the crux of his diagnostic work. It also sheds light on the explanations and directions that are given to patients in the clinic, such as provided to Amy regarding her dizziness. Patient work in undergoing numerous investigative tests is also driven by this quest to determine the “nothing or something” of a symptom.

In an environment filled with media, Bert, Amy and Helen (in this study, and many others in the community) kept the magnets, attended to the commercials, memorized stroke warning signs. They noticed and responded to this marketing. Social theorists, medical anthropologists and social marketers each contribute to an understanding of this identification with this particular health issue and/or social marketing product. Kotler and Zaltman (1971) tell us that social marketing works with the market’s core beliefs and values to present a formula by
which messages can be transmitted to target audiences. Briggs (2003), a medical anthropologist, raised questions about the concept of “public” in “public health.” He noted that information disseminated as a means of preventing diseases (in his case, cholera in Venezuela) entailed members of populations deemed to be ‘at risk’ interpreting the discourse as being about them. Briggs (2003) borrowed from Warner (2002), a literary critic and social theorist who developed an understanding of the contradictory nature of the concept of public and public discourse. Warner (2002) notes that “we encounter people in such disparate contexts that the idea of a body to which they all belong, and in which they could be addressed in speech, seems to have something wishful about it. To address a public, we don’t go around saying the same thing to all these people, we say it in a venue of indefinite address and hope that people will find themselves in it” (p. 59; italics mine).

Grier and Bryant (2005) tell us that social marketers are likely to divide populations into distinct segments on the basis of behavior and to devote attention and resources to segmentation research. This research provides information on whether or not people did ‘find themselves in the message’. The media strategy of the HSFO was to target members of the public over the age of forty-five (informant HSFO, November 2011). The knowledge gained from research findings circles back into the social marketing methodology.

If you have it on air a long time, for a sustained period of time, it’s called impression but it really is about the number of times people will see the ad. People’s education level increases, and when their awareness increases they go to the hospital. Numbers going to hospital decrease, then you have to spend the time to build awareness again. If you are off-air for six months, if you end your campaign at 80% awareness and you are off air 6 months, it may drop to 70% you
have to rebuild and then incrementally increase as well (informant HSFO, 
October 2011).

In Toronto, Silver, Rubini, Black and Hodgson (2003) evaluated stroke symptom 
commercials and found increased knowledge in the target segment. In Australia, Bray, Johnson, 
Trobbiani, Mosley, and Lalor et al., (2013) evaluated the impact of symptom commercials used 
as part of the Australian stroke strategy and noted that along with increased symptom recall in 
the public, there was a parallel increase in calls to the ambulance and increased use of t-PA in the 
hospitals.

Kotler and Zaltman’s (1971) point about the use of core values in social marketing can be 
seen in the patients’ motivation and interest in knowing and being attentive to the stroke 
symptoms. Douglas and Wildavsky (1982) arrive at this same point but come from the 
perspective of risk. “The choice of the risks we pay attention to, and the choice of how we live 
together, go together” (p. 8). The request by the government for the HSFO to execute mass 
media, the creation of the magnet, the uptake of the magnet onto fridges and lists into purses, the 
work of self-detection, and the arrival at the Secondary Stroke prevention clinic all show that as 
a society we have agreed to pay attention to stroke in this way, that is, as an individual risk.

Amy’s (informant 6) comment, “I’m no fool” and Bert’s (informant 7) comment, “The 
last thing I want is to be paralyzed” point to the interest and investment in the symptom 
identification work. Amy and Bert have identified themselves as people who should pay 
attention to the stroke warning signs. Recall Amy describing her experience, “Two friends have 
died in stroke. One is paralyzed from the neck down. I am aware that could happen to anyone.” 
Bert has had a stroke in the past. His fear of stroke was apparent “The last time I was in the 
hospital I was asked about DNR (“Do Not Resuscitate”), this is not a game anymore” (italics
mine). The commercials and magnet capture the attention of people who feel threatened by the possibility of disability or death due to stroke. Their motivation to participate in stroke prevention is high.

*Tracing a symptom to the prevention priorities*

Bert’s (informant 7) visit to the clinic highlights the organization of a symptom and its connection to prevention paradigms. Bert is a 54-year-old postal worker. When he came into the clinic exam room, he selected a round, armless medical stool as his seat (“big man, had to sit on round medical seat – obesity” – field notes, July 22, 2011); the other chair available had arms and he would not have fit. During our interview he shared that he had a brainstem stroke ten years ago, that he had migraines, and that his mother died at age 39 of brain cancer. She also had migraines. Bert shared his struggle with his weight. “I’m so big my belly interferes with driving, I can’t sit in a plane or in office chairs, and I can’t find clothes in Toronto.” The past spring he had felt dizzy and had a numb left side as well as a migraine. He went to the hospital and was admitted to the stroke service for possible stroke. During the Secondary Stroke Prevention clinic as part of his stroke admission follow-up, the neurologist interviewed Bert. His wife was present in the room. The medication list was confirmed: Fiorinal, Lipitor, Altace, and Percocet. Bert’s blood pressure was measured at 155/80 mm Hg. Bert presented his symptom and concern through a question to the neurologist:

Bert, “Why am I getting dizzy?”

Neurologist, “Dizziness is a different issue. Occasional dizziness or numbness isn’t a problem. Call 911 if pronounced. All the things you are doing are good.”

Bert, “It’s the dizziness that bothers me.”
Neurologist, “There are three kinds of dizziness: spinning, pass out, non-specific. Your dizziness isn’t a worrisome kind of dizziness.” (informant 7 and his wife, July 2011).

While seemingly dismissive of Bert’s dizziness, from the paradigm of the neurologist, the dizziness isn’t worrisome. The paradigm, and what matters, becomes apparent as the interview continues. A few moments later, Bert, his wife and the neurologist were all gazing at a computer image of the vasculature of Bert’s brain. The neurologist showed the couple where the carotid artery was narrow, “This pipe is supposed to split into two branches, you’ve got narrowing, plaque that’s grown in the wall, hardening of the arteries.” The neurologist then referred to a cartoon-painting on wall which depicted the brain, heart, and arteries, as a way to seemingly orient the couple to human vasculature. Bert and his wife were provided with an expert anatomy lesson, using images of Bert’s own internal body structures. He was told that a pipe in his neck was narrow and hard due to plaque in the wall. All of these terms are very precise anatomical concepts. Unless one is medically trained, one would not put together branches, walls and plaque as something inside one’s neck. The neurologist then provides information that informs why the dizziness is not worrisome. “The good news is that this narrowing is on the left side. It has nothing to do with your current symptoms.”

This was the answer to Bert’s question about his dizziness. The dizziness wasn’t worrisome, as it wasn’t being caused by the disease in the artery. The neurologist was on the hunt to determine a link between the reported symptoms and the visual image. The image, the privileged knowledge, provided clarity, the knowledge and the truth of his symptoms. The image showed disease, however the location of the disease in the body did not align to how the symptoms would manifest itself in the body. Though there was visible disease, and something to “worry about” (Stiker, 1997, p. 362), there was good news - the disease was not causing
problems from a stroke perspective. Bert learns that the symptom itself was not the risk, but how it connected to any apparent internal problem was. The image reinforced what mattered.

We noted with Amy the bifurcated consciousness, the ‘knowing’ of the experience, and the ‘knowing’ as governed by the warning sign magnet. For Bert, a third mode of knowing is made available, a mode that dives into the interior, mediated by a personal scan of the interior of Bert’s body, an interior text. The perspective of the neurologists in the clinic was that “people register a hole on the brain scan, they really had a stroke. People understand blocked pipes, especially when you can see it” (informant ND, August 2011). This is an example of the interventionist paradigm facilitated by computer and information technologies described by Clarke et al., (2003) without which the secondary stroke prevention clinic could not direct treatments. The patient is not the expert in this arena, and becomes reliant on the expertise of the specialist.

The appointment continues with the neurologist teaching Bert personalized symptom surveillance. He is asked to self-detect which eye he may be experiencing sudden blindness in at a potential moment of a visual change.

If you ever have the sensation of a blind coming down over the eye, try to sort out which eye it is happening on. If you have weakness on the right side, or slurred speech or a blind coming down over the left eye – get attention (informant N.D., July 2011).

The request for this quite extraordinary level of self-awareness and body literacy requiring precision symptom detection during what would be an alarming experience seems ordinary and taken for granted by both the neurologist and the patient. Bert did not ask any questions, nor did his wife. Bert, like Amy, is being drawn further into the work of self-detection, the recognition and subsequent reflection and analysis. Ambiguous symptoms, such
as ‘sudden visual problem, even if temporary’ requires the, “is it nothing, is it something”
analysis, in order to minimize possible stroke damage.

Next, Bert learned the treatment plan should he develop subsequent symptoms. His
worry about disability becomes authorized, as the neurologist informed him,
The current narrowing is not creating symptoms. If it does, we will send you to a
surgeon. As long as you are not getting into a stroke, the episodes of numbness
down the body, we don’t care, but everyone is worried that it’s going to cause a
stroke (Neurologist to Bert, informant 7).

The neurologist wrapped up the interview with a question that lacked the same intensity
as the prior discussion. “You quit smoking right? Smoking, BP, cholesterol, all promote this
plaque. The neurologist pointed towards the biomedical risk factors in the origin of the disease
in Bert’s neck. He continued, “You are doing a good job of managing that stuff. Keep on with
your weight loss, Lipitor and BP (medication).” Bert’s blood pressure measurement was 155/80
mm Hg, higher than the recommended level. His obesity was obvious. He had not been
weighed, nor his belly circumference measured, as recommendations suggest.

The recommendations that required behavior change were not given the same value as
the interventional secondary strategies. They were essentially dismissed in several incongruent
statements. Bert’s disease was apparently past these prevention methods. Using the lens of risk,
the neurologist was troubled by the carotid artery disease and focused on screening for an
intervention, the endarterectomy procedure. Though termed “prevention,” secondary stroke
prevention aims to minimize damage from stroke at the last minute in very high-risk patients.

Patient and professional prevention paradigms

After this visit with Bert in the clinic, a follow up interview was conducted with the
neurologist to clarify the goals of prevention. When asked what worked for prevention, the
neurologist (informant N.D., August 2011) categorized his answer, “Secondary stroke prevention?” His answer included medical evidenced based interventions and the related statistics that he evidently knew from memory,

Endarterectomy for those that need them, anticoagulation for A-fib – 70% reduction, antiplatelet therapy – 25% reduction. What works is tied to Number Needed to Treat. Four for endarterectomy. The rest – lowering BP, diabetes management, cholesterol – “lifestyle” – you have to do it all (informant N.D., August 2011).

In this study, patients did not classify or categorize prevention in terms of primary or secondary or risk ratios. Informant three’s wife, an articulate woman, commented, “Secondary stroke prevention? I didn’t realize the word secondary was there” when I drew the name of the clinic to her attention (wife of Tom, informant 3, November 2011). Patients did describe prevention in terms of actions. Bert’s wife (informant 7) said, “You have to change your lifestyle, you see it everywhere.” Other informants named food and activities as related to prevention. “Diet, exercise” (daughter of informant 2, November 2011). “Eat better, not get stressed out, not to drink” (wife of informant 3, November 2011), “I was always health conscious before, now a little more intense, I don’t skip exercise, alcohol definitely out. For New Years, I had apple cider instead of champagne” (informant 3, November 2011).

Bert, who had referred to himself as a ‘ticking time bomb’ was very invested in prevention. He described prevention and his role in his current state of health. Prevention, for Bert, is

not [to] agitate things, do the things that will help the process. Look after yourself. I let things go too far. Not intentionally, it just happens. I smoked for
42 years. It’s going to catch up to you. I made the excuse that I worked the midnight shift. Now I am holding myself responsible, trying to correct this, if I don’t do this, I am not going to last 5 years. It is a chore in itself to balance my conditions: pills, GERD, weight, teas, and side effects. I never thought I’d be in this boat (Bert, informant 7, January 2012).

Here Bert highlights his health work in balancing co-morbid conditions, he illustrates the actualities of living. Bert, as all of us, went about his daily life. We can see from what he tells us that he went to work, that he did not identify with health messages, that he smoked since his teens, and that his life had “caught up” to him. Now, blaming himself, Bert is paying attention, “being responsible,” and doing his health chores.

Davison, Davey-Smith, and Frankel (1991) explored lay and scientific theorizing about illness in the context of heart disease. The authors reported that in parallel to the scientific discourse about risk, people have a ‘lay epidemiology’ about high risk coronary candidacy that is based on their own experience and observations. In my study, different paradigms of prevention existed between the lay patients and the health professionals. The paradigm at work for the patients was in alignment with the primary prevention lifestyle messages that are ubiquitous in our society while the health professionals were engaged in identifying risk variables in these high risk patients, to determine eligibility for specific interventions that were deemed ‘secondary’ prevention.

The differing paradigms between the patients and professionals can be connected to categories of prevention from a health care delivery perspective. Primary health care is a public health endeavor and clinical medicine focused on the individual. Background information about the categories of prevention came up during an interview with a Ministry of Health informant.
This informant revealed the unique feature of prevention embedded into the stroke strategy, and pointed to programmatic delineation between primary and secondary prevention:

In the Ministry of Health, stroke care is housed in the Priority Programs unit, which is acute care focused (dialysis, cardiac, transplant programs for example). It was unique to have prevention as a component of the stroke strategy. From the outset the delineation between primary or secondary prevention, and who is best to deliver each component was something unique” (informant MOS, November 2011).

The authors of the executive summary of the Joint Report note that minimal attention was being paid to stroke prevention (Ontario Ministry of Health, 2000), and that prevention should be included as part of the continuum of stroke care. The authors recommend that “Stroke Prevention Clinics should be developed to improve secondary stroke prevention and to provide support to ongoing prevention efforts in the primary care, acute care and rehabilitation sectors and that Stroke prevention by primary care providers should be supported” (p. 3). The neurologist provided further details about the decision to create stroke prevention clinics, “Most physicians don’t have the expertise and the knowledge to manage stroke prevention so we should fund clinics for people to get the optimal stroke workup and care” (informant N.D., November 2011).

The current best practice recommendation for stroke prevention is that “all patients presenting within one week of a suspected TIA or non-disabling ischemic stroke should have an immediate clinical evaluation and investigations. All individuals with a diagnosis of mild stroke or TIA who are not admitted to hospital should be followed up in a secondary prevention clinic, as the time of highest risk for major stroke is within 48 hours after the index event” (Hall, Khan,
O’Callaghan, Kapral, & Hodwitz, 2013, p. 7). The delineation of secondary stroke prevention as a specialized clinic and primary prevention as a health service offered by the family doctor is well established in the Ontario Stroke System currently, but not known formally this way by patients.

The difference in the prevention paradigms between the patients and the professionals is a powerful illustration of why research from the standpoint of the patient is vital. While on a superficial level we could address this gap through providing an informative brochure, the differences between the two groups illustrates the workings of power and knowledge.

Smith (1990) reminds us that “our knowledge of contemporary society is to a large extent mediated by texts of various kinds” (p. 61). It is notable that the patients knew the commercial and magnet “texts”, and could name symptoms and primary health promotion lifestyle prevention methods, but they did not know about the role of the clinic, or the term “secondary.” They had been the target audience for the social marketing and health promotion materials, but evidently not for the purpose of their visit to the Secondary Stroke Prevention clinic. Possibly this relates to the realities of this recruited group, selected due to their alignment with those who are less health advantaged. More likely this represents a common occurrence when patients attend appointments with health care professionals. They are at a knowledge disadvantage on many levels. They can be agents in some aspects of their health, and are passive recipients in others, relying on and trusting professionals.

*Health, uncertainty and the patient*

Zinn (2008) presents a dichotomy between rational and irrational strategies for managing risk. She names rational strategies as weighing the pros and cons, and calculation. Irrational strategies she names as faith, hope, and belief. She argues that this dichotomy ignores a range of

In the secondary stroke prevention clinic, health professionals used rational strategies of calculation, such as the number needed to treat. The number needed to treat (NNT) is a number derived from a formula that is the “number of patients one needs to treat to prevent one patient having the target event” (Sinclair, Cook, Guyatt, Pauker, & Cook, 2001a). The University of Oxford Centre for Evidenced Based Medicine reports that, to calculate the NNT, you need to know the Absolute Risk Reduction (ARR). The NNT is the inverse of the ARR: 

\[ \text{NNT} = \frac{1}{\text{ARR}} \]

where \( \text{ARR} = \text{CER} - \text{EER} \) (Control Event Rate) - (Experimental Event Rate). The neurologist was using the application of this process when he informed me what works for secondary stroke prevention, “What works is tied to Number Needed to Treat. Four for endarterectomy” (informant N.D., August 2011). Rothwell, Eliasziw, Gutnikov, Warlow and Barnett (2004), analyzed pooled data from two large carotid endarterectomy trials in order to understand the risks for patients in undergoing this procedure. The report they provide provides an extensive breakdown of variables. For example, a table displaying risk is provided in three separate columns, one for all patients one column for patients with 50-69% carotid stenosis and one for patients with greater than 70% stenosis. The risk analysis was broken down further into other categories: gender (men, women), age (less than 65, 65-74 and over 75 years), time since last event (less than 2 weeks, 2-4 weeks, 4-12 weeks and more than 12 weeks), duration of time of the symptomatic event, the type of symptomatic event, the type of internal plaque surface, the
presence or not of diabetes, smoking, myocardial infarction, angina, hypertension, prior TIA or stroke (Rothwell et al., 2004). Each of these variables was identified with its own Absolute Risk Reduction percentage. For example, the absolute risk reduction for men who have a greater than 70% stenosis is reported as 15 percent. This works out to a number needed to treat of seven. If \( \text{NNT} = \frac{1}{\text{ARR}} \), then \( \text{NNT} = \frac{1}{0.15} = 6.6 \) or 7 (seven). Seven men with a greater than 70 percent stenosis are needed to have the carotid endarterectomy procedure in order for one man to benefit.

Highly specialized knowledge generated through epidemiological studies has determined the absolute risk reduction, and, discussed as its inverse, the number needed to treat for each stroke risk factor. Clinical decision-making is challenging with complex high-risk patients so these formulas establish a means for professionals to work with uncertainty. Specifically, NNT acts as a proxy for certainty, creating a ‘certainty practice’ which patients are unaware of. These statistics were provided to patients on occasion, but were not discussed in a reciprocal way.

Zinn’s (2008) ‘in-between’ strategy of trust seemed to be present in the clinic. One 80 year old Filipina woman was asked prior to her appointment why she was there. She did not know. “Maybe I’m dying” she said (informant 8). She reported that she had not heard of this clinic before, but came because the word stroke was at the top of the letter she received. At the end of her appointment, I asked her what prevention meant to her. I had been present during her appointment, which ended after the neurologist told her, “You are on all the right medications to prevent stroke.” Without hesitation, this woman repeated what she had just heard from the doctor, new knowledge shaped by his expertise, its fragility evident in her shadow of doubt, “Taking the meds is the best way for prevention. Sometimes they give you things you don’t need (meds), but I am confident about them” (Caroline, informant 8).
Conclusion

Patients or their families in this study identified a symptom that brought them to a health care provider. Patients reported the work of self-detection of symptoms that was promoted through social marketing strategies including a Heart and Stroke refrigerator magnet and television commercials. As a marketing tool, these products cast a big net into a public who identify with ‘risk of stroke’. Their use of these products facilitates knowledge, self-detection, and management of symptoms. The products intend to channel these patients to the Emergency department for possible t-PA administration. The symptoms so clearly depicted on these products are in fact ambiguous, constituting a ‘certainty practice’.

The illustration of Bert, a man with substantial chronic illness and manifestations of those illnesses that drive his healthcare seeking behaviors, reveals tensions between his embodied knowledge and fears and medical expertise of what counts for secondary stroke prevention. Bert’s material body is “pried open” (Lock & Nguyen, 2010, p. 57) through the use of blood-work and brain imaging. Carotid plaque is viewed. The dizziness and numbness are deemed not relevant to the current health problems Bert is experiencing. The symptoms are not caused by the disease that has been found. Bert is taught what type of symptom to pay attention to. Bert is trying many lifestyle maneuvers, however, it appears there are no ready solutions for treatment until such a time that he may require a carotid endarterectomy. Bert waits in a liminal ‘ticking time bomb’ state.

The concept of ‘secondary’ prevention became visible as a separate classification than usual lifestyle media messages of prevention, known as primary prevention. Secondary stroke prevention as a category within health care sits at the far end of the health promotion, disease prevention spectrum. The role of this secondary stroke prevention clinic is to provide precise
targeted investigations and interventions to very high risk patients after they have presented to a health care referral source with symptoms of stroke or a completed prior stroke, in the hopes of minimizing damage should a stroke occur. The patients who attended appointments at this clinic were not all aware of why they were there, or what “secondary” meant. The clinical decision making formula, NNT, acts as a proxy for certainty. This means of making decisions was not transparent in the clinic.

In the clinic, subjective patient symptoms motivated the neurology team to search for an objective cause of stroke which could be treated based on a number needed to treat formula. The search is supported by biotechnology, specifically neuro-imaging. The symptom itself, while an experiential problem for the patient, was therefore not important in itself in the clinic. Symptoms in themselves are not risks. The next chapter will trace patients through the clinic appointment, where their work as directed by the team, activated by their symptom, will be analyzed.
Chapter 6: The body meets stroke prevention

In the clinic, the patient’s body is known through gathered textual and numerical representations. The neurological team, activated by the patient symptoms and directed by texts, expertly “prises open” (Lock & Nguyen, 2010, p. 57) the patient’s material body and mines for images, numerical data and information about risk factors and functional abilities. The term ‘mines’ or ‘mining’ used in this chapter is derived from the work of Upshur and Tracy’s (2005) concepts of ‘gleaned and inspected’ (p. 480). These textual and numerical representations include: visual images of the brain, numerical values of the blood pressure and the blood work (laboratory) results, scores and verbal responses from standardized assessments and scales that patients are assessed with. The list of medications that patients are asked to bring to the appointment, while not ‘extracted’ from the patient, acts as a proxy for patient co-morbidities. Medication usage is an expedient way of ‘knowing’ the health of a patient.

Entering the clinic: the Referral Form

Ideological practices enter into the production and interpretation of factual accounts (Smith, 1990) before the person arrives at the SSPC clinic. The concept of risk is embedded in clinic practices, and is apparent as a frame on the pre-made referral form that external doctors use to send a patient to the clinic. In the Ontario medical field, a referral form is a document that one doctor uses to link a patient with another doctor. The referral form is intended to provide the second doctor with the reason why his or her opinion is requested with regards to the patient. It is not uncommon for specialty clinics to devise a specifically structured referral form, in order to gather information considered vital to the work in the clinic. Figure 12 below provides a copy of the referral form.
Figure 12: Referral Form to the Secondary Stroke Prevention Clinic
The Secondary Stroke Prevention Clinic referral form is crafted so that the patient name and contact information is written or pressed using an addressograph into the right top corner of the form. The date and source of referral fields are left open for the writer to jot down. There are prepared choices in the Reason for Referral section that point to the work of the clinic and the ways of knowing stroke. Stroke-specific neurological symptoms or deficits are noted in predetermined categories called Motor, Visual, Speech, and Dizziness. The form then prompts the writer to choose risk factors, which include hypertension, DM, dyslipidemia, smoking CAD, A fib, or other. In medical circles these short forms are accepted ways of naming illnesses. The writer is then provided with space to document the medications, the allergies, and investigations already completed, including CT, CTA, MR, MRA, Angiogram, Doppler, Echo, Holter, Other. The biomedical focus is apparent. This is not a form to fully inquire into the broad domains of the patient’s life. Rather, the form is precisely targeted at the body. It directs the writer to attempt to capture what the clinic’s secondary stroke professionals really want to know. The experience of the patient has already been translated into medical language.

At the top of the form, underneath the addressograph is a table called the ABCD2 score. Rothwell, Giles, Lovelock, Redgrave, and Warlow (2005) tell us that the ABCD2 score was developed to allow primary-care doctors to identify which of the patients in whom they suspect a diagnosis of transient ischemic attack (TIA) should be referred-on for assessment as an emergency. The score tool was built using the concept of risk factors, which were already part of the established discussion about TIA. Through a process of following patients identified with TIA, tracking their clinical manifestations and who among them went on to have a stroke, Rothwell et al., (2005) prioritized which risk factors were most prevalent.
The ABCD2 score is presented on the form as a table. In one column are the letters, underneath each other in rows A, B, C, D and the second D. The next column states Indicator, and labels what the prior capital letters stand for. A stands for Age, B, Blood Pressure, C, Clinical Features, the first D stands for Duration of symptoms and D2, Diabetes. The next column is Criteria. Each criterion has points. Age (A) = one point for age over 60; blood pressure (B) = one point for a blood pressure greater than 140/90 mmHg; clinical features (C) = 2 points for focal weakness or 1 point for speech disturbance; duration of symptoms (D) = one point for 10-59 minutes duration, or 2 points for duration of symptoms greater than 60 minutes; diabetes (D) = one point. The referring physician is intended to add up the score (for a possible total out of seven points) which has meaning for the team who ‘triages’ the patient.

This referral form is received by an Advanced Practice nurse in the Secondary Stroke Prevention clinic. The nurse uses the form as a decision-assisting tool for a process known in medical circles as ‘triage,’ or the sorting and classifying of patients for priority appointments using a grid of severity of symptoms and length of time. The disembodied ABCD score helps inform the assessment of urgency for the appointment for the patient. Since the time of this data collection, Perry, Sharma, Sivilotti, Sutherland, Symington et al., (2011) conducted a prospective validation of this tool within emergency departments which has added some controversy to the use of the ABCD2 score. Perry et al., (2011) found that the high risk ABCD2 score is not sensitive enough to be the sole guide for assessing risk. The referral form in the clinic has been changed since data collection, as the ABCD2 score was not “sensitive or specific enough as a risk score” (L. Casaubon, personal communication, April 29, 2014). As of this same date, a second secondary stroke prevention clinic uses this score on its online referral page (Rapid Referral, n.d.). Since Perry et al.,’s (2011) publication, Magin, Lasserson, Parson, Spratt, Evans
et al., (2013) have argued that risk can be stratified according to the ABCD2 prediction score. Current guidelines suggest specialist assessment and treatment within 24 hours for a high-risk event (ABCD2 score 4-7) and seven days for an ABCD2 score ≤3, considered low-risk (Magin, Lasserson, Parson, Spratt, Evans et al., 2013).

The nurse in the clinic described how he used this score, revealing the way in which he operationalized urgency. The nurse did not only use the numerical score itself, but also supplemental information from the referral form and/or from a telephone call he made to the patient. He informed me that if the ABCD score is high and none of the diagnostic investigations are completed, the patient will be ranked as more urgent that a person with a high score whose investigations are completed, or someone with a low score. The more that has been done, in terms of the diagnostic work-up, the less urgent the need for an expedited appointment (informant RN). The nurse documented the urgency on a second triage form (Figure 13 below).

Figure 13: Section of Triage Form used by RN
Textual relationship between primary and secondary medical care

A family doctor who had referred a patient to the clinic was interviewed in order to understand the role of a referee and the stroke prevention clinic. The complexity of treating patients from a medical perspective is highlighted in this interview, and the guiding discourse of risk is apparent. When asked the rationale for referring patients to the secondary stroke prevention clinic, the family physician stated that she would make referrals to the specialized stroke prevention clinic for atypical things, things that don’t fit within the guidelines neatly, for example, a stroke with someone at the age of 30. Other things would be if you have exhausted the options available to you. For example you are trying to get somebody’s cholesterol to the target, you have them on a high dose agent, you may have added a second agent, and they are starting to get side effects (informant F.D, August 2011).

This physician stated that family physicians use the same information as the neurologists, the same targets, the same guidelines.

The challenge for family doctors is that there are guidelines for every disease. A family doctor interviewed in this study provides a glimpse at that challenge, and illuminates the physician’s work tasks.

In addition to being on top of the stroke guidelines, we are also doing it for every system and across the lifespan. You also have the added challenge of contextualizing it to the patient in front of you. You know that the stroke guidelines say that the LDL (cholesterol measure) should be less than 2, but you
have a guy in front of you when he is put on a statin, he has difficulty getting out of the chair, because of leg pains, and he’ll get depressed. You have to manage the guidelines very well, and then you have to tailor it to the patient and manage all of their other systems. You might put them on medication to treat one thing, and medication to treat them for another, both of which are recommended, but they are contraindicated to take them together. It goes back to the life-threatening piece. How much bang for your buck are you getting from one intervention over another. Decrease your risk of this by this percent, and that one by this percent (informant F.D, August 2011).

Upshur & Tracy (2008) discuss the challenge of complexity and chronicity in primary care, a challenge he links to aging. This family physician links the challenge of complexity to risk.

_Letter of Appointment_

After the nurse processes the referral form and makes a decision about clinical urgency, the form is given to the clinic receptionist. The receptionist creates an appointment for the patient within the electronic scheduling software. Then, a letter is mailed out to the patient by the receptionist (see Figure 14 below) to inform them of their appointment date. This letter seems factual and impersonal. The patients name is filled out on a line after the word ‘Dear’. The appointment date has the same style: Your appointment is on _________________. Written in bold font, the patient is asked to call to confirm the appointment and is provided with cancellation information and the consequences of ‘not showing up’. The patient is requested to bring a list of five potential items: an OHIP card, the hospital blue card, a list of their medications, any brain images they have had done (with stipulations depending on where the
images were created and a firm statement that the neurologist could not assess them without these images), and finally, to bring a caregiver if they needed any help or assistance.

The location of the appointment is provided. There is no map, nor directions, and no invitation to call if they had questions about the process or the content of the letter. The clinic phone number is provided in the letterhead. The tone and direction of the letter is, ‘this is what we need you to do in order to see you’. The instructions start with bolded, underlined directions about the appointment itself, stressing the importance of the appointment, the importance of confirming and the consequences of being categorized as ‘no-show’ (language used to describe patients who do not attend to a pre-made appointment). There is work, knowledge and substantial organization skills required by the patient at every step, including the invisible work of getting to and finding the clinic. Below is the section of the letter (anonymized) to the appointment that informs them of the expectations. The description of related work follows, linked numerically to the list. For example, number 1 on the list is the OHIP card, the description below starts with the number 1 and discusses the OHIP card.
Figure 14: Section of Letter of Appointment sent to patients

Following is a description of the patients’ work as directed by the text above.

1. The OHIP card: In Ontario, a Health Card allows patients to access health services and allows the physician to bill OHIP for the service provided. If patients do not have an OHIP card, they can apply if they have proof of citizenship or proof of residency. A social worker well-versed in assisting people to acquire OHIP coverage notes that people who are making a refugee claim are not eligible, and that people new to Canada often do not know how to apply to these programs.

2. Hospital blue card: Hospitals have their own internal method to identify patients. These cards include the name, address and a ‘medical record number’ to link back to hospital patient records, paper and electronic. If the person has never been a patient at a particular hospital, they need to ensure that they go to the Admitting department to be registered as a patient and get a card. A patient needs to factor this into their appointment time, their leaving time, their transportation time, and possibly parking time.
3. The list of medications: This instruction requires a patient to either think ahead while at the pharmacy to ask the pharmacy for a list of medications, to write down the names of their medications themselves, or to bring in the medications. The patient needs to remember to bring this list with them.

4. Brain scans: The patient needs to know or learn what brain scans are, and what CT, MR, Angiogram and CD mean. Once they have deciphered what this brain scan may be, the patient needs to acquire this scan. As a nurse, I know that there is a medical imaging department that will download scans on to a portable transport system (such as a CD), but patients do not usually know this information. Patients therefore need to inquire and navigate through this work, including going to the other hospital, finding the department, acquiring the CD, and remembering to bring it.

5. Bring help: This instruction implies that the patient needs to decide if he or she can come on their own or not, and if not, what sort of help they require.

Gathering and bringing their required documents, medications and scans is an example of Smith’s ‘generous concept of work’ which Campbell and Gregor (2002) describe as “everything that people know how to do and that their daily lives require them to do, whether or not people recognize these activities as work” (p. 72). Mykhalovskiy (2002, 2008) terms this type of work ‘health work’.

Helen’s story: the Golden Years of retirement

Helen experienced bodily changes on the first Friday in April. In the last chapter, her use of social marketing products was detailed after she experienced blurred vision and numbness while sitting in a waiting room for a physiotherapy appointment. She noted that some of the symptoms on the magnet were her symptoms, relayed this information to the Head Physiotherapist at her next appointment, and was directed to her family physician, who she
visited that same week. The family physician directed her to the Emergency department. Helen, an 81-year-old widow, went to the Emergency department, and had a CT scan on the same day. She took the bus, and went alone, despite having “terrible arthritis” (Helen, informant 1) in her knees. No one was present to ensure she had her lunch, no one was present to hold her spot should someone come for her while she went to the bathroom. She had her dinner when she got home at seven o’clock that evening.

A referral was filled out in the Emergency department for Helen to attend the Secondary Stroke Prevention Clinic. Behind the scenes for Helen, the nurse received that referral form, completed the Triage form, and decided her appointment was urgent. Rather than the usual process of sending the Letter of Appointment, Helen received a phone call to come to the clinic on the following Friday, a week later. Helen came by TTC, alone, for a nine-thirty appointment. Helen informed me that she “lives by the calendar” and makes changes to accommodate specialist appointments as “health comes first”.

Smith (1990) states that “knowledge can be investigated as the ongoing coordinated practices of actual people. This means addressing ideas, concepts, and beliefs as expressions of actual social practices – as things that are spoken, written, heard or read” (p. 63). Subjective experience is separated by the “fact” (p. 69) that creates an externalized object of knowledge. Smith (1990) uses an example of wolves hunting caribou. Each wolf is oriented to the caribou and through that to each other – they coordinate the hunt. “A fact is such an object, the fact coordinates the activities of anyone who is positioned to read and has mastered the interpretive procedures it intends and relies on” (p. 69). Knowing how to read, and reading a given factual text is to enter a coordinated set of relations which subordinate an individual’s actuality (Smith, 1990). In the clinic, the entry “fact” is the patient symptom. Initially the blurred vision and
numbness led to the patient health work of attending appointments and health professional work of assessments, investigations and clinical decision making. The symptom activates the secondary stroke prevention team to look for a source of potential stroke, and hunt for risk factors through the assessments and blood work investigations.

Helen came to the clinic with three little black moleskin note books full of information about her treatments for her arthritis and high blood pressure. At this appointment she diligently shared details of her reason for being at this clinic, as well as her medication list. She did not share that she had stopped taking a diuretic (a medication she referred to as a ‘water pill’ which is frequently prescribed as a first line therapy for high blood pressure) that had been prescribed to her, because it interfered with her ability to get out of the house in the morning. The impact of the water pill meant she needed to stay in the house to be able to have access to a washroom. Helen subordinated her medication ‘self-management’. Even when specifically asked if she was taking all of her medications, she did not disclose this piece of information. Her medication list, already an authorized text, became the authorized working information. When the neurologist took her blood pressure, and found it to be seriously high (180/100), Helen, who attends her family doctor regularly and has a blood pressure gauge at home, was shocked.

I don’t know what happened today, because I wasn’t frightened or afraid, I was so surprised, ‘you want to know how much it is?’ Yeah for better or worse, she said it was 180. Well that really surprises me, this time I couldn’t feel it. Because sometimes when it goes up I get really warm or hot and tired like, but on the other hand, with this arthritis, my doctor says I have it from head to toes (Helen, informant 1).
Helen equates high blood pressure with fear and anxiety. The medical professionals equate blood pressure with vascular disease and as a risk factor for stroke. Later, still during this same appointment, Helen’s CT scan was reviewed by the neurologist with Helen present in the room. One sign of stroke was made evident on the scan and this was shown to Helen on the computer. The neurologist later informed me that he showed this to Helen because, “People register a hole on the brain scan, they really had a stroke.” This finding led to further referrals for an MRI, an echocardiogram, and blood test requisitions which required her to fast. Helen, wearing a hearing aide, was given verbal instructions about the tests she needed to undergo. Helen’s symptom aligned with a sign on the CT scan, which led to further fact finding to ascertain risk factors and the source of the stroke. These new referrals would mean new ‘health work’ for Helen (Mykhalovskiy, 2002, 2008), a new appointment to attend, another bus to take, more information to share, in order to, in the words of the neurologist, “prevent stroke to avoid disability.” These facts would create further specific, precise details about the vascular disease and help quantify the stroke risk.

In a very literal fashion, Helen’s work became driven by time and texts. Helen left after noon with a list of investigations that needed to be completed. This list (see Figure 15 below) is a pre-written list which informs the patient that some tests may be needed to determine whether or not they may have had a stroke. The list has five items on it, including CT scan (which she had in Emergency), Carotid Doppler, echocardiogram, Holter monitor, and blood tests with electrocardiogram. Helen’s list included an MRI (she already had a CT scan), the echocardiogram, the Holter monitor and blood work.
Figure 15: Investigations List

Helen followed the recommendations and had an MRI, a blood-work appointment on May 20, an echocardiogram on May 25, and a follow-up appointment on May 27. In the space of six weeks she had six medical encounters which she navigated herself. Despite being verbally told that she was intended to have a Holter monitor that was requested, this test was not done as the list of investigations she received did not have Holter checked off with a date. The blood test for the fasting blood sugar also was not done. “I told you when you came for your MRI, you can do the fasting blood sugar” said the neurologist.

At her follow-up appointment at the stroke prevention clinic, the doctor asked Helen to get up on the table. Helen, who had been providing a narrative throughout in a very talkative way, hoisted herself up, fell silent, and lifted her elbow up to allow the blood pressure cuff to be wrapped around her upper arm. The blood pressure is discovered to be 200/90. “Oh my god,
“this is worse than the last time,” said Helen. The neurologist asked Helen if her family doctor was going to change her medications. Helen replied no, that the family doctor says ‘ok’ every time she is there. Helen was asked whether she was taking her medications and did not answer. The neurologist decided to refer Helen to a specialized Hypertension clinic and sought out the details for how to coordinate that appointment. A decision was made to double the blood pressure medication. The neurologist relied on Helen’s memory regarding the medication change, “I want you to double the Atacand, that would be 16, will you remember?” The neurologist verbally provided the complex plan, and asked Helen to repeat it. Helen left with a new verbalized list: Holter, blood work, change in medication, family doctor for blood pressure. During her initial visit she had looked at me and commented “I have to take so many pills.” On this day she looked at me and reflected, “These are the golden years of retirement.” Helen is not alone. One of the most common things told to Upshur (2005), a family physician practicing in Ontario, by his elderly patients, is that the “golden years are not so golden,” that “they are alive, but they suffer and endure” (p. 481).

The encounter between the patient and the specialist regarding the blood pressure and water pill highlights the specific lens and purposes of each participant. Helen knows her blood pressure as a sensation of heat and possibly fatigue, possibly linked to fear. She is surprised by the high reading in the clinic as she did not have the sensations she would expect. Helen also knew the procedure of the blood pressure measurement, as she became abruptly silent once she extended her arm for the cuff. Helen knows the water pill as interference in her daily activities and chooses to not disclose this information in the clinic. She seems to know in some way that reporting her noncompliance will not be favourable in the clinic. She does not seem to connect the pill to her blood pressure treatment. When the doctors states that another medication that she
was on for blood pressure was going to be doubled, she has no comment or question about the water pill. Helen, the only data source available to the specialist regarding the events and perceptions of the family doctors, informs the specialist that her blood pressure is ‘ok’ from all accounts from her family doctor. The neurologist interprets the data of the blood pressure as elevated and decides that this warrants further investigation at a specialty clinic, and medication changes. The complexity of the patient is further complicated by two medical professionals who are not in direct communication with each other, attempting to manage the risks of the patient.

During our interview Helen described managing her health as “the Toronto hospital run around,’ is now engaged in the “merry-go-round” (Rachlis, 2004, p. 57) of appointments. Her family doctor is managing her blood pressure, the neurologist at the secondary stroke prevention clinic has modified the blood pressure treatment, and she is being referred to a third expert at a Hypertension clinic.

The quest to manage stroke risk seems to direct the neurologist to notice and privilege some details about Helen and not others. The neurologist consistently provides long lists of verbal instruction, perhaps not noticing Helen’s hearing aids. When Helen does not answer about taking her medications, the neurologist doubles the dose and sends Helen to a specialty clinic.

Nancy: The search for what counts

The following exchange between the stroke prevention nurse and a patient highlights the translation and suppression of a patient’s experience into a ‘glean and extract’ textually mediated encounter. Nancy (informant 4) was referred to the clinic for memory and visual changes. The setting of this exchange is inside a medical clinic examination room. Smith’s (1990) “actuality-data-theory-circuit” (p. 148) will be used here to show how Nancy’s lived actualities are encoded
into a clinical account, subjugating her realities into governing medical work. You will see
Nancy become a patient.

Nurse, “I’m going to do intake with you, what is happening with you, you have a referral from your family doctor.”

Nancy, “My doctor wanted me to come, I didn’t know why, but I came.”

The nurse brings forward a large magnet that lists stroke symptoms. I see that the social marketing product from the Heart and Stroke foundation (as described in Chapter 5) has entered into this nurse’s clinical practice. The nurse continues, “did any of this happen lately that your doctor was concerned?”

We see here that Nancy (informant 4) has been moved in a textual way from one physician to another through the referral form. She does not know why she is there, but implies that she trusts her family doctor. The nurse in the clinic then starts to encode her lived actualities into an account, the boundaries of which are pre-set as concerns authorized by her doctor, and the risk factors authorized by the stroke system.

He starts with the symptom listed first. “Dizzy?”

Patient, “No”

Nurse, “Visual?”

Patient, “No.”

Nurse, “Your doctor says you are having memory loss.”

The nurse has now shared the reason for the visit with the patient, providing her with some understanding of why she is there.

The patient nods yes.
The nurse takes a memory assessment form out of his drawer and begins the test seen in Figure 16 below. The patient is not asked about her experience of memory loss, troubles she is noting, glitches that memory loss may make apparent, safety concerns such as forgetting to turn off the stove. When the patient, whose ability in English is functional but not expert enough for the test does not understand question, the nurse raises his voice. The patient subtracts 7 from 100, and continues subtracting 7 from each previous answer perfectly. She did not know the names of the animals on the test sheet. The test assumes the patient can hear adequately, has sufficient English to perform the test, knows a clock face as opposed to a digital clock, and has sufficient literacy to follow numbers and letters in the trails component of the test (the first section).
Figure 16: The Montreal Cognitive Assessment (MoCA)

The nurse continues to interview Nancy who is encountered as a patient (informant 4).

Nurse, “Are you independent in your activities at home?”

Patient, “I do it by myself.”
Nurse, “Any change in functioning, hobbies?”

Patient, “I feel angry, I don’t know why. My daughter wants me to swim, I don’t.”

Nurse, “What do you do for activities, exercise for instance?”

Patient, “I would like to but I don’t have time. I watch TV. I like movies, no exercise.”

Nurse, “What do you eat?”

Patient, “I do the accucheck every day, the doctor says control yourself with food, the doctor doesn’t want to give me medication.”

The nurse, reviewing laboratory results on his desk murmurs aloud, “Increased cholesterol…”

Patient, “I’m afraid to eat – so afraid what I can eat, what I can’t eat. My weight was 130 – now 120 – I lost weight.”

The nurse continues, “List of meds?”

Patient, “A lot, brought pills too, big sack. These are my 7 o’clock pills; these are my 9 o’clock pills.”

Nurse, “Warfarin, Accupril, Statin, Synthroid, Vitamin D, B, Calcium+, Co-enzyme Q. Do you want to see a dietician?”

Patient, “Yes, I would be happier if I knew what to eat.”

The doctor appears at the door, ready to proceed with the medical examination. The nurse, through the prepared intake and referral forms has created a factual account based on the prevention framework. He has read her experience according to his prescribed referral form, cognitive assessment forms, and laboratory results. The nurse provides the following verbal report to the neurologist:
The nurse begins, “This is not such an appropriate referral” while the neurologist logs on to his computer.

This is an illustration of Smith’s (1990) critique of a clinical encounter. The informant, Nancy, has been “encountered in the form of a case history already written” (p. 127). The nurse apparently used the referring information in the interview to “disclose only pieces of her life that fall into slots” (p. 127). The nurse is engaged in his routine clinical work day, guided by the texts we have seen he activates (the referral form, triage form, the magnet, the ICES data collection form). His interest is in risk factors, referring to available professional supports and informing the doctor about precise stroke prevention particulars.

In a vivid demonstration of the lived actualities of the patients have been documented and encoded as a biomedical factual account through his data collection, he continues his report to the neurologist, “SDH (subdural hematoma), 63, history of SDH (subdural hematoma), mitral valve at (X) hospital, A-fib (atrial fibrillation), diabetes, seen by another neurologist for right sensory loss, very briefly, she had an echo (echocardiogram).

The authority of the visual image and the biotechnoscientific transformation (Clarke et al., 2003) of biomedicine on which secondary stroke prevention relies become apparent. The neurologist reviews the MRI from the time of the SDH, “Little bit of blood, oh, here, lots of blood.”

The nurse continues, “INR, warfarin, LDL, family doctor referred for memory loss and left field visual loss. Cognitive testing – maybe she couldn’t understand my instruction – she seems depressed, we have a (culture) psychiatrist, maybe refer to him, dietician also? She’s not overweight, no exercise, has family support.” Here the predetermined solutions (Smith, 1990) that are part of the labour of secondary stroke prevention inform us of the rationale for the nurse’s questions and assessments.
The neurologist interjects, providing a glimpse into the research focus, “Make sure cognitive isn’t the reason she doesn’t want to participate.” The nurse continues, “Craniotomy 2009, back on anticoagulants, followed by cardiologist, also seeing another neurologist, she’s seeing all the neurologists, this was for headaches.” Nancy has been busy, like Helen, with the merry-go-round of medical appointments.

The nurse’s way of knowing the patient is made visible in this exchange. The body is mined for an activating symptom and risk variables. The patient’s lived actuality of, for example, doing the Accucheck daily and wondering what to eat, became suppressed through the transformation into a documented reality of acronyms. Her eating fears and worries about her children have been categorized for “predetermined solutions” (Smith, 1990, p. 127), and in this setting, medicalized as referrals to a psychiatrist and dietician. These referrals activate and connect collaborating points within the ruling biomedical apparatus and extend biomedicalization (Clarke, Mamo, Fishman, Shim, & Fosket, 2003) into the realm of personal food choices and parenting concerns. Her body’s information has produced more biomedical work, and she herself will participate in that work. Predetermined language (‘intake, functioning, activities, meds’), a pre-determined symptom check list, and a predetermined English-based cognitive assessment have governed her experience. Nancy’s struggle with her diabetes, her role in her family, how she is managing her medication, and the bouncing between neurologists are not part of the conversations. Sinding’s (2010) ethnography in a similar clinic setting, albeit for cancer, found that the health assessment included social and material aspects of patient lives. These aspects were not included in the assessment at the secondary stroke prevention clinic.
Patient work: Blood Pressure

During Nancy’s interview, the nurse took her blood pressure with an automated machine. He asked her if she had a machine at home. Her response was, “Yes, but I don’t know how to use it.” The nurse reached into his desk drawer, and gave her a two-sided cardboard educational card, shown in Figure 17 below. I will make two points using this clinical card. The first point is that the health work that individuals perform to manage their blood pressure at home is their active participation in the risk ideology that governs the clinic. Then, using the precise details on the card, I will critique the “certainty” of blood pressure as a proxy for health.

In the Secondary Stroke Prevention Clinic, during every patient appointment that I observed, patients had their blood pressure taken. With some patients it was taken more than once, sometimes the blood pressure was taken with the patient both sitting and standing, and sometimes it was taken while the patient sat on the office chair, or after they climbed up onto the clinic exam table. In the clinic, an elevated blood pressure is known as hypertension, a risk factor for stroke that is listed on the referral form and on the ICES data collection form.

One difficulty of including high blood pressure as a risk factor is that taking blood pressure is laden with challenges. Blood pressure measurements are subject to variability or error (Brett, 1991). The recommendations from the Canadian Hypertension Education Program (2010) for the management of hypertension include the method for measuring blood pressure. The standardized steps include ensuring that the patient has

- no acute anxiety, stress or pain, has not been smoking or had coffee in the preceding 30 minutes, has not used any substance containing adrenergic stimulants such as phenylephrine or pseudoephedrine (as in cold medication), that the patients don’t need to use the washroom, that they have no tight clothing on
their arm or forearm, that the room is quiet with a comfortable temperature, that they rest for at least 5 minutes before measurement and that the patient should stay silent prior to and during the procedure (CHEP, 2010).

Taking a blood pressure according to the guidelines is not easy, nor is it done reliably in daily clinical practice. I did not witness this assessment or these steps being taken. However, each patient that I observed was well versed in this measurement taking, and required no instruction. They lifted their arm when the cuff was in sight, they stopped talking, and sat still. I observed one woman for whom the embodied “knowing” of this procedure was quite dramatic. She was chatting in a lively, excitable way about her medications, and the impact of the weather on how she felt, “I have arthritis from head to toe and the rain in the last few days!” When she was asked to climb onto the examination table, she ceased chatting, and raised her arm to accommodate the cuff. The silence and posture made her knowledge evident.

During the clinic appointments that I observed, I noted that most patients asked to know the measurement and some wrote it down. Most patients also had a blood pressure machine at home. They stated that they used it daily and that they kept a log of their blood pressure. Bert, a man with obesity, when asked by the neurologist if he had a big cuff at home, concurred that he did. During my interview with Helen, I asked her if she was surprised by the information about the high blood pressure reading during the appointment. “Kind of, I have a gauge myself, my doctor advised that,” said Helen (informant 1). In the case of Walter, an 85 year old man with Alzheimer’s disease (informant 2), the family monitored his blood pressure daily and managed his medication regime. Patients in this study were actively engaged in the health work regarding their blood pressure.
Blood pressure management at home is seen as a solution to ‘white-coat’ syndrome (Palatini & Frick, 2012). “White coat syndrome” is named after the laboratory coat wore by the doctor and the resultant anxiety of seeing the doctor which is believed to raise the blood pressure of the patient. This brings into question the accuracy of the ‘usual’ blood pressure. Palatini and Frick (2012) raise the limitations that health care professionals need to be aware of with the use of automatic home BP monitors. They state that there are possible limitations to the performance of these devices in diabetic patients, in elderly patients and that their use in patients with arrhythmias is controversial. These three types of patients are common in stroke clinics. As well, Palatine and Frick (2012) claim that blood pressure measurement in obese arms may be inaccurate. Furthermore the accuracy of home blood pressure monitoring itself is questionable.
Add to the challenge the requirements of the instruction card (Figure 17 above) given to Nancy (informant 4), and one can see the planning necessary to integrate a blood pressure measurement into a daily routine. With the requirement of no coffee, food or smoking in the preceding hour, no exercise in the preceding thirty minutes, a calm room, sitting for five minutes, one would need to actively schedule this into the day to ensure it is done correctly.

*Patient Work: Medications*

Like the threads of a blanket, medications are ubiquitous and woven, even embedded throughout the processes and purposes of the secondary stroke prevention clinic. In the textual process, the first document to participate in the flow of care for the patient, the referral form provides space for the writer to include the medications that the person is taking, providing a medical glimpse into the patient’s body and maladies before the patient arrives. This portrait is continued with the triage form, and the list is reviewed during the appointment. The ICES data collection form completed after the appointment explicitly and comprehensively creates spaces for the medication profile of the patient. Almost 25% of the data collection space is provided for medications, revealing their importance in the clinic and in the greater system.

All patients who attended the clinic were taking some form of medications, and all, once they were identified as at-risk for stroke, were taking an assortment of related medications. These included cholesterol medication, blood pressure pills, and blood thinners. Patients were usually also taking medications for other reasons, including conditions such as arthritis, diabetes, Alzheimer’s disease, pain, migraines, thyroid and bowel issues, and a wide assortment of vitamins, minerals and other supplements. The use of multiple medications was common and was not raised by the medical team as cause for concern. It seemed to be taken-for-granted. I did not hear or see professionals ask about side effects or interactions although conversations about
medications happened in each clinic visit. Medication dosages were fine-tuned and changes or suggestions were communicated back to family doctors through a follow-up letter to the doctor.

From a patient work perspective, the clinic’s Letter of Appointment requests that people attending the clinic bring their medications to the clinic. As requested, patients brought in their medications. Textually in the clinic, these medications became a list of names, dosages and times. For the patients this was “a big sack” for Nancy (informant 4) to bring, and connected with real time and real space. In order to manage their medication, some used pill organizers, and some knew their pills by the time they took them. “These are my 7 o’clock pills, and these are my 9 o’clock pills,” said Nancy (informant 4). Amy (informant 6) moved medication bottles to the back of the row after she took the correct medications, depending on day or night. Their regimes were not without problems. Helen (informant 1) stopped her water pill and did not tell this to her family doctor, as the “problem with the water pill is when you are trying to get out of the house.”

Although textually medications moved quietly through the clinic as a list on a form, during clinic appointments medications had a much more dominant and complex role. In some cases patients were asked very specific, complex questions. Tom, a 72-year-old very active man (informant 3), had a cardiac stent put into his heart nine years previously. He was subsequently taking the prescribed blood thinner. He was in the SSPC after experiencing a hemorrhagic stroke. In response to the neurologist’s questions, Tom responded that he previously took both aspirin and Plavix due to the stent, but due to the hemorrhagic stroke, the medications were stopped. He was now taking aspirin only. “Is the stent drug alluding or bare metal?” the neurologist asked, seemingly in an effort to make a decision about the medications. Neither Tom nor his wife could answer this highly technical question.
Amy (informant 6), an 82-year-old single woman was taking an anticoagulant medication called Coumadin, and having “countless blood tests.” The neurologist assessed her and said,

Your pulse is irregular right now – I felt it and heard it when I took your blood pressure. You are protected right now because of the warfarin. There is a six percent risk of stroke when you are not on Coumadin. You INR should be 2.5.
(Neurologist to informant 6).

The neurologist looked up her INR on the computer, and informed her of the result. Amy asked about eating green leafy vegetables, which she apparently knew interfere with clotting time. “The key is to be consistent”, said the neurologist. “They affect the Vitamin K in your blood, which also affects clotting, so the key is to be consistent. There is a new drug – Pradex- that does not interfere with food – it will be covered soon” (Neurologist to informant 6). Amy noted the challenge of paying for off-label drugs. She gave 15% of her income as part of her religious beliefs, and could not purchase this medication, despite her interest in being able to eat her preferred vegetables.

Ivy (informant 5) was taking Plavix to prevent clots which cause stroke. Prior to using this medication, she had been taking Coumadin. The cardiologist had taken her off of Coumadin when she had an ablation for atrial fibrillation. Her brother was taking Plavix when he had a stroke, so she was worried that the choice of Plavix may not be the right one for her. A discussion about the classification of aspirin and Plavix versus Coumadin occurred. Ivy had fallen several times due to an inner ear condition. The discussion moved to the risk of falls. The doctor described how there is a risk of falling, and bleeding into the brain, and a risk of stroke. The neurologist quoted a study, saying that the findings showed that it is a mistake to take people
off of Coumadin even when they are falling. He stated, “In medicine there is always a risk for everything, we have to decide what the greatest risk is” (Neurologist to informant 5).

Conclusion

People who come into the clinic are encountered as patients. The patient, as the embodiment of vast amounts of clinical data, is mined by health professionals for data. Patients’ lived actualities are subjugated into biomedical clinical accounts through this data collection. I bring into question the validity of the objective data mined from each patient as an accurate measurement or assessment, and also as a measure of risk. The list of medications and blood pressure are examples of this. The “breadth of uncertainty” (Upshur, 2008, p. 1656) is not acknowledged during the appointment or during the hunt for risk factors, during clinic assessments, or in treatment decisions. The visual images become a proxy for certainty. People who attended appointments were at times passive as illustrated by informant 4, “I don’t know why I’m here, my doctor wanted me to come.” Yet, overall the patients I observed had a high level of participation with the health work of secondary stroke prevention techniques and the ideology of risk.
Chapter 7: The ideology of risk

In this chapter, Smith’s (1990) perspective of ideology will be reviewed and then applied to an analysis of the ideological practices of risk both in the local clinic and in the extra-local environment. I will discuss how risk as an ideology helped to create the Ontario Stroke System, and will argue that the activities that coordinate and objectify risk create the illusion of certainty in the face of the unknown. Finally, I will discuss the communication that occurred (or lack thereof) with patients on the topic of risk.

Ideology from Smith’s perspective

In her work, Conceptual Practices of Power, Smith (1990) proposes a reflexive critique of the ideological practices which we all create, participate in and which “express objectified forms of knowledge that are constituents of power” (p. 11). Smith’s use of the terms ideology and ideological practices is derived from Marx and Engels (1998), specifically The German Ideology. According to Smith, Marx “was developing methods of reasoning and inquiry about historical and social process that express actual organization and relations.” In fact, for Marx, “ideology is a method” (Smith, 1990, p. 45).

For Smith (1990), “we render ideological by taking the way social reality is constituted for granted” (p. 53). Smith (1990) argues that “to treat assumptions about human nature as active forces in social and historical processes is an ideological practice” (p. 36). An example of an ideological code described by Smith in the 1990’s is the North American conceptualization of the family. Smith (1999) describes conceptualization as SNAF–Standard North American Family, a code which carries with it an expectation of a legally married male and female couple living in a household, the male the breadwinner, the female the child care provider.
The use and ease of ideology allows people to “grasp in abstraction the real relations of their lives” (Smith, 1990, pp. 36-7). Ideology provides a common way of speaking and acts as a reference point in everyday life, “yet these ideological practices render invisible the activities in which those relations arise and by which they are ordered” (pp. 36-7). The everyday person takes up the ideology, but unless these practices are explored, inquired about, or made visible, the ‘actualities’ of what is happening socially are hidden. Smith argues the need for a ‘reflexive critique’ due to the everyday nature of the ideological practices that we typically are not conscious of. Or, as Smith puts it, “what ought to be explained is treated as fact or as assumption” (p. 43; my italics). At the heart of Smith’s interest in explicating ideology, and the taken-for-granted practices and beliefs that seem beyond question, is the interest in making visible ‘how things work’.

The illustration of Dot provided in the introduction is an example of the taken-for-granted in stroke care and training. My nurse practitioner role included the responsibility of a stroke assessment. My training taught me that an assessment of Dot included inquiring and educating about the ‘four horsemen of the apocalypse,’ (a term popularized by D.J.Sahlas, personal communication, 2003), the stroke risk factors: high blood pressure, high cholesterol, diabetes and smoking. When Dot exclaimed to her grandchildren not to smoke, I had no language or accurate knowledge to bring up the role of socioeconomics. I ‘knew’ biomedical risk factors. Dot also did not question my presentation of behavioural risk factors, we concurred on the link of stroke to smoking.

Smith describes the workings of ideological practices as an ideological circle with two phases. The first phase is the ‘underlying schema’ originating in a textual discourse, the second is the use of the schemata as a procedure for selecting, assembling or ordering facts or
observations (Smith, 1990, p. 156), or more simply, “schemata plus particulars” (p. 165). These schemata may be identified through textual analysis if a reproducible text is present, but also through the conceptual frameworks learned through our training. Smith (p. 24, 25) describes a story of riding a train to illustrate schema. She saw a family of ‘Indians’ standing above a river watching the train as it went by. She realized she could portray what she saw to others in this way, but recognized that her description was built upon her own position and interpretations. She had called the group ‘Indians’ and termed them a family, and assumed they were watching the train. Our training as nurses and doctors provides us with our own schemata, which I argue in the case of secondary stroke prevention, is ‘risk’. The previous chapters articulated the particulars of the texts and observational and interview data. The following discussion will draw from the arguments in the previous chapter to pull the risk threads through so that the workings of this risk ideology are clear. The infrastructures which maintain the ideology of risk will also be identified.

*Risk ideology and the extra-local Ontario Stroke System*

On an extra-local level, the very existence of the Secondary Stroke Prevention Clinic is itself an example of Smith’s (1990) ‘particular’ that is assembled by the schemata. The new interventionist paradigm in stroke, made available through the integration of technological as well as pharmaceutical innovations (visual imaging, data circulation and t-PA) reveals the biomedical foundation that draws upon risk (the schema) and justifies the rationale for the clinic (the particular). In this acute care paradigm, the Ontario Stroke Strategy was built around the delivery of t-PA, a last-minute highly risky pharmaceutical intervention. The use of this ‘Lazarus-like’ medication can “stop stroke in its tracks” (Empire Club Addresses, 2000). Lock and Nguyen (2010) argue that politically and historically biomedicine has been “harnessed to bring about the goal of normal” (p. 47) and t-PA meets this goal. The use of the ideology of risk
and the attraction to the last minute acute interventionist rescue from the danger of stroke was successful in launching the Ontario Stroke Strategy. The speech presented at the Empire Club (a ‘particular’) used personal and public risk of stroke and economic consequences as leverage for the stroke continuum of care. The analysis of the Institute for Clinical Evaluative Studies (ICES) data collection form (another ‘particular’) shows the biomedical risk schema: disability and risk factors are located in the body. Biomedical values, beliefs and goals were the operating schema. The ‘particular’ is the stroke system overall, and, in this study, the secondary stroke prevention clinics specifically.

*Risk ideology in the local clinic*

One of the Secondary Stroke Prevention Clinics that opened as part of this Ontario Stroke Strategy was the setting in which my study was conducted. The goal of these clinics is to “prevent disease from progressing to a completed stroke or to prevent another stroke. People targeted for secondary prevention include those who are at very high risk of stroke and those who have experienced transient ischemic attack (TIA) or non-disabling stroke” (Ontario Ministry of Health, 2000, p. 45). Here we can notice that the ideological thread of risk, the ‘particular’ is attached to people. People, specifically their bodies, are at risk.

In the clinic, the body meets secondary stroke prevention when neurovascular disease makes its presence known through a symptom (a ‘particular’ I will revisit shortly) known as a minor stroke or a transient ischemic attack (TIA). Whatever else a Transient Ischemic Attack (TIA) might be, and however else patients might experience it, it is regarded as a warning sign of significant cerebral-vascular disease. It is a downstream sign, a late sign of cerebrovascular disease. When a TIA occurs however, rather than being conceptualized as a late sign of cerebrovascular disease, it is renamed as an early sign of possible stroke. This early sign is so
named as a ‘golden opportunity’ (Johnston & Hill, 2004) for stroke prevention. Here, I argue, the schema of risk is tied to the ‘particular’ of time.

Smith (1999) remarks that the “social must be understood as an ongoing process, in time (my italics) and in actual local sites of people’s bodily existence” (p.97). The statistical window between the sign of TIA and the 1 in 20 chance of stroke over the next two days (with a chance of death and disability) (Shah et al., 2008) authorizes the existence of the clinic and multiple investigations and interventions. This ‘golden opportunity’ between the sign of late disease/early stroke is the biomedical opportunity to assess and intervene to ‘prevent’ a stroke. Hence the health care professional’s urgent chase for variables that are deemed to create risk. The referral forms, triage forms, and intake phone calls of the nurse are the labour that coordinate the risk ‘particular’ of time. Helen’s (informant 1) “lived time” (p. 76), her six appointments in six weeks for urgent diagnostic tests illustrate the patient work in this schema.

The key to the golden opportunity to intervene, that is, the link between the patient arriving in the clinic and the actions of the stroke prevention team is the work of symptom identification performed by patients. Helen, Amy and Bert, through the social organization of stroke symptoms (as described in Chapter Five), “knew” the symptoms of stroke as advertised. Helen referred to a magnet she kept on her refrigerator, Bert and his wife spoke about Heart and Stroke television commercials and Amy showed me a list of stroke symptoms she kept in her purse. The symptoms on the products are presented as certainty, although clinically and in the stroke literature they are noted to be ambiguous, or mimic other conditions. Discussions that at the core centered on the certainty of these symptoms occurred in the clinic. For example, when Bert (informant 7) asked about his dizziness, he seemed to surmise that the dizziness he was experiencing was not a ‘certain’ sign of stroke and repeated his questions. When Ivy (informant 5) asked, “How do I know when to go to the hospital?” she was showing her confusion about
ambiguity of these symptoms. (For example, which headache or dizziness or vision problem is the one I should take to the hospital?)

The products that the patients spoke of are created by the Heart and Stroke Foundation, through funding from the Ministry of Health (informant HSFO). The ideology of risk is supported through the ‘particulars’ of this formal partnership and the infrastructure it provides to the larger system, the execution of social marketing, and the research associated with evaluation of the social marketing strategies, such as that conducted by Silver, et al., (2003). The related risk labour is the activation of the patient to acquire health care and the behind the scene work of a primary health practitioner who assesses and writes the referral to the secondary stroke prevention clinic. This work is initiated by the work of symptom identification by the patient, noticing the bodily change, and recognizing it as a possible warning sign of stroke.

When the patient arrives in the clinic, health care professionals look to the body for ‘particulars’ that fit the biomedical risk schema, known in the clinic as risk factors. These risk factors are internal body variables that were determined as risk factors through prior published epidemiological knowledge and mathematical formulas (Goldstein, Bushnell, Adams, Appel, Braun et al., 2011; Whisnant, 1997). The fact that collated public data is applied to the individual patient is not disclosed to the patient. The risk factors, when identified through tests, are presented as certain for the individual. These factors include hypertension, dyslipidemia, diabetes, previous stroke or transient ischemic attack, atrial fibrillation, carotid stenosis, and lifestyle variables such as diet, exercise, smoking and alcohol intake (Lindsay, Gubitz, Bayley & Phillips, 2012). Biomedical epidemiological knowledge is one thread of the risk ideology that is maintained through the data circulation from the individual patient to ICES via the data
collection form, through to the Ministry of Health and the stroke field through evaluative reports (see Figure 6 in Chapter Four).

Risk and its measurement are linked historically to statistical data collection and pattern development. Hacking (1990), in his book *The Taming of Chance* argued that our ways of thinking and reasoning changed over time. He identifies a transformation from a theoretically predictable cause and effect to a reasoning based on statistical patterns. He claims this transformation is a result of the “avalanche of numbers” (p. 35, 73) collated through statistical bureaus from as early as the era of Napoléon and throughout the 1800’s (p.35). Using examples such as data gathered regarding suicide, Hacking (1990) argues that statistics and statistical laws generated norms (and deviation from norm). Statistics underlie the risk management techniques employed in professional fields that map risk onto life as if life can be read as an objective hazard (Fox, 1999).

Greene (2007) tells us that a “pivotal moment in the articulation of risk in health and medicine” (p. 4) occurred through the Framingham study, an epidemiological longitudinal study conducted in the 1950’s in order to understand what was then considered an epidemic of heart disease among American men. Through detailed physical examinations and investigations of the Framingham population over time, factors were identified which became known as ‘risk’ factors for the development of cardiac and subsequently neurovascular and other disease. The ‘risk’ factor became identifiable when chronic disease categories were delineated through epidemiological analysis. Symptomless precursor states such as dyslipidemia, hypertension, and diabetes were categorized as a pre-disease of another possible vascular disease. Risk became a “distinct way of reasoning and interpreting society” (Smith, 1997, p. 36), a (medical) ideology.
At the same time the field of epidemiology, in particular its means of statistically presenting data, became the way to legitimize that ideology.

In the clinic, the ideological ‘particulars’ of risk work began with the nurse reviewing the documentation from the referring physician on the referral form. Rothwell, et al., (2005) developed a formalized stroke score, known as the ABCD2 score which mediated the lens through which the team approached the patient, beginning the patient’s relationship with stroke risk in the clinic. The ‘particulars’ of risk factor scoring and triage decision making through the ABCD2 score was an ‘internal use’ process that is an apt representation of the priorities of the clinic. Symptoms of TIA and/or stroke, as determined through the ABCD2 score and through review with the patient were the trigger for the appointment, the assessment and subsequent deeper inquiry into the source of the symptoms that put the patient at risk for stroke. This information (or lack of information) was confirmed through the work of the nurse and neurologist with the patient in the clinic. The neurologist would then conduct a physical examination and subsequently make decisions about inquiring further into the body using investigative tests. An example observed in the clinic was the case of Helen’s blood pressure. The measurement was found to be 200/90. Subsequent biomedical work was generated through a referral to a specialized Hypertension clinic and the use of diagnostic investigations, such as blood tests, carotid Doppler examinations, echocardiograms, and Holter monitoring.

Biotechnological investigations are required for secondary stroke prevention. The images facilitate the search for disease and risk factors that the symptom may represent. The risk ideology is reinforced through these investigations and the technological infrastructure that supports them.
Blood pressure was a risk factor that had a robust presence in the Secondary Stroke Prevention clinic. This risk factor entered into patients’ daily lives as they took their blood pressure using personal ‘at-home’ gauges, and documented their blood pressure to bring as a log for their doctor. Patients had significant knowledge of blood pressure numerical norms, and reacted accordingly when their blood pressure was in what they had learned was a high range. In this way, patients were confronted daily with the risk and work of their blood pressure, an invisible proxy for the state of their health. Blood pressure is linked to substantial patient work, has historical links to the insurance industry (Davis, 1981) and multiple pharmaceutical solutions. As such, blood pressure as a ‘particular’ is an illustration of the “choice of risk we pay attention to” (Douglas & Wildavsky, 1982, p. 8).

Risk communicated

The element of risky treatments for risk factors also became visible in the clinic. One example of a risky treatment was the use of a medication called Coumadin to treat an irregular heart rhythm called atrial fibrillation. This treatment is so complex that a decision aid for patients is available through the Canadian Stroke Network. I did not observe this decision aid used in the clinic, but it is reviewed here to illustrate the complexity of this condition, and also the underlying knowledge about this treatment. The decision aid is available for patients in four different risk groups (low to very high) and provides information to patients in the respective groups about their risk of stroke and how it changes depending on the selection (or not) of different pharmaceutical treatment options. For example, a low risk patient, (identified as less than 65 years old, with no hypertension, no left ventricular dysfunction, no previous stroke or TIA) has a two-year risk of stroke of 2% with no therapy, a 1.5% risk of stroke if taking aspirin and a 1% risk if taking warfarin (Coumadin). A very high risk patient, (note: all of the patients recruited into the study fall into this very high risk group), identified as older than 75 years old,
with hypertension or left ventricular dysfunction, or someone at any age who has had a TIA or stroke has a 20% risk of a stroke in the next two years with no therapy, a 16% chance with aspirin and a 7% chance if taking warfarin (Coumadin). The document goes on to describe risks associated with taking the medication, such as bruising, bleeding into the stomach, as well as lifestyle changes that occur with the medications, such as the need to abstain from alcohol, and undertake regular blood tests.

Direct conversations about the risks of treatments were rarely observed in the clinic. This may have been because patients in this study engaged with the health care team in primarily a passive way, took direction from the team, in some cases they had low English literacy, and in some cases, no real awareness of why they were at the clinic. Patients who entered this study were recruited based on criteria devised from the work of Mikkonen and Raphael (2010) that typically indicates lower health advantage such as described in Chapter Three. In this study patients were told they were there “to make sure your chance of having a stroke is low” or that they “were on all the right medications to prevent a stroke.” Amy (informant 6), an 82 year-old English woman was taking Coumadin, and required “countless blood tests.” She was informed by the neurologist that that she was “protected right now because of the warfarin” and that there was a “six percent risk of stroke if she was not on Coumadin.” She was informed that her blood level for INR should be 2.5 seconds, and that it was currently 1.8 seconds. A fulsome discussion about risk did not occur, nor did a discussion about the number needed to treat and related meaning of these formulas.

Ivy (informant 5) was unique in that her level of socioeconomic status stood out from the other recruited patients. Her higher level status was apparent when she spoke about pursuing a surgeon in the United States and the $200,000 expenses for an ablation, a procedure which is
intended to treat atrial fibrillation. The discussion of risk took a different form with this patient. In an effort to decide whether to take aspirin, Plavix or Coumadin (blood thinners), the conversation encompassed her atrial fibrillation, her past stroke, her family history, another specialist’s concern about her falls, and her inner ear problem. The neurologist noted that there is a risk of bleeding into the brain in the event of a fall, but also a risk of stroke. The neurologist quoted a study, “It is a mistake to take people off of Coumadin even when they are falling. In medicine there is always a risk for everything, we have to decide what the greatest risk is.”

Patients seemed to ‘know’ they were at risk of disability from stroke, as they spoke about their fears of possible disability. This fear maintains the patients’ contribution to the risk ideology. As noted in Chapter Four, Caroline (informant 8), came to the clinic because she got a letter that said “Stroke Clinic” on top. She was concerned that she was dying. Amy (informant 6) said she did not want to be dependent, and that she did not want to have to go into ‘a home,’ but hoped to live until she died in an independent situation.

Conclusion

Findings from this study lead me to argue that secondary stroke prevention is a form of downstream potential damage minimization that is held in place by the ideology of risk. I came to this finding through the entry point provided by the actualities of the people who attended an appointment as a patient at a Secondary Stroke Prevention Clinic in Toronto. As I observed patient appointments and interviewed patients and health care professionals in the local clinic through a materialist lens, data analysis led to the growing awareness and subsequent argument that the ideology of risk governs secondary stroke prevention in the province of Ontario.

Hansson (2005) reminds us that “risks are always connected to lack of knowledge.” The ideology of risk authorizes the creation of certainty in ambiguous ‘unknown’ situations. The
health care goal in the clinic is to “make sure your chance of having a stroke is low” (neurologist to informant 1; my italics). Chance is not explained to the patients, who engage in substantial work and at times, risky treatments.

Stroke has long resided in the unknown. Giddens (1990) tells us that “risk largely replaces what was previously thought of as Fortuna (p. 30). Stroke care today is considered through risk formulations as a way to predict the unknown. Historically, being “struck down by the gods” (Poirier & Derouesné, 1993) was just as mysterious. Risk ideology provides the illusion of control and certainty.
Chapter 8: Conclusion

I entered this study curious about how health practices were determined within the health care system in Ontario. In my experience working as a nurse practitioner within the Ontario stroke system in Toronto, having assessed 300 patients a year, I met patients from many cultures and many walks of life. After being exposed to the idea of social determinants of health and the work of Dennis Raphael at a conference, I started to experience ‘troubles’ in my clinical work. The example of Dot, the single mother with low socioeconomic status presented in the Background Chapter is but one example of a patient I wondered about. In my clinical work (in IE this would be known as my actuality) with patients, I found I was asking questions that went beneath the surface of the biomedical care I was providing. I wondered whether the impact of racism contributed to high blood pressure for visible minority patients, which then contributed to their stroke. I wondered if the stress of a very demanding job led to unmanageable high blood pressure for another patient. I was wondering about the social determinants, but assessing the biomedical determinants.

The actualities (defined by Bisaillon (2012, p. 610) as people’s lived experiences as they describe knowing and living them) of my biomedical clinical work were confronted by knowledge of the social determinants of health. For me this created the disjuncture (dissonance, split or rupture in consciousness that commonly provides the analytic impetus and starting point for an institutional and political activist ethnography, Bisaillon, 2012, p. 611) which led to the research investigation. Fundamentally, I was troubled by the lack of visibility of social determinants of health in my clinical stroke care and wanted to understand this more comprehensively.

Specific questions around which the study was organized were:
- Is knowledge of social determinants of health included in the Ontario Stroke System?

- If so, how, and from where, does this knowledge surface?

- What is the experience of patients who are deemed most vulnerable from a SDH perspective?

When I reviewed the scholarly literature, I found that the patient perspective of stroke was consistently reported as loss, fear and burden by both patients and the health care team by researchers such as Doolittle (1994); Clarke & Black (2005); Burton (2000); Ellis-Hill et al., (2000a, 2000b); Hafsteindottir 1997); and McKeivitt et al., (2004). Eakin-Hoffman’s (1974) study was particularly striking. She reported health care professionals as describing the stroke patient’s situation as “hopeless” and stroke patients as ‘gorks’ and ‘vegetables’.

My own “biomedical versus social” disjuncture was reflected in the competing perspectives or tensions in the literature. I learned that biomedical knowledge was consistently located in the body, whether the field of study was disability, risk, prevention, or stroke. Mackay (2003), a University of Toronto sociologist who had a stroke provides a vivid description of the contrasting biomedical and social models of disability that offer clarification of these two models for health care professionals. I learned that Toronto scholars Raphael (2009), Jarvis (2006), Gardner (2008) and Lightman (2008) all argue that lower socioeconomic status was is linked to what are called risk factors in medicine and that socioeconomic status has been linked to higher incidence of stroke, higher rate of stroke risk factors and higher mortality from stroke (Sapposnik et al., 2008; Addo et al., 2012). I noted that critical sociologists argue that risk is a form of surveillance. From a health care organization perspective, I learned that Marc Lalonde, one of
our Canadian Health Ministers, suggested other options for health other than the hospital. He posed “lifestyle” as a means to achieve health. This provided an alternative and broader perspective for health, yet one that perpetuated the view that health and disease prevention is located within the individual body. He presented a new idea, but not a radical one.

The methodological and theoretical source of this research is from the early writings of Dr. Dorothy Smith, a feminist sociologist who developed a method of inquiry that examines relations of power and knowledge. I draw from the tools of the method of inquiry she developed over time, known as institutional ethnography. Institutional ethnography, as Diamond (1992) describes it, makes the everyday world problematic and begins not within discourse, but the daily social relations between individuals in the context of capitalism. Smith’s (1987) main underlying points are to ‘build a knowledge of how things work’, make visible the social organization, through entering in via a chosen standpoint and looking up into the organizing relations. Smith describes numerous concepts, in fact Bisaillon’s (2012) glossary lists 52 terms. In my study, three of Smith’s concepts, texts, work and ideology, were used in a significant way to inform data collection and analysis.

In my study, the local setting was a secondary stroke prevention clinic. Local data collection began with patients and health professionals in this clinic using methods of interviewing, observation and textual analysis. Field notes, interviews were transcribed. With the goal of gathering data to include the actualities of patients, from which to then look up into the organizing relations, I chose to enter the study from the standpoint of patients known to have known less health advantage based on Mikkonen and Raphael’s (2010) work. Eight informants agreed to participate in this study.

Summary of findings
One significant finding of the study was that the paradigm of stroke has changed since 2000. The “hopeless” narrative in the literature is no longer the dominant discourse of stroke. The condition of stroke has become a site of active intervention with the successful launch of the Ontario Stroke System. Dr. Silver confirmed this in his Empire Club address (2000), “We have come from an extended period of helplessness”. The Empire Club Address in March 2000 revealed that biomedical knowledge is the exclusive lens which informs the Ontario Stroke Strategy. Within this address, and also through the published list of head table attendees, I did not find the inclusion of social knowledge. This was also the case with the data sets included on the Institute for Clinical Evaluative Studies (ICES) data collection form which circulates to and informs the Ontario Ministry of Health. The significant of this finding is the way it demonstrates that certain knowledge is privileged over other knowledges in this setting; this informs the context for the patients’ appointments in the stroke prevention clinic.

Regarding patient experience, I learned that informants Helen, Amy, and Bert attended appointments which were initially activated by Heart and Stroke Foundation materials, specifically a refrigerator magnet and television commercials. These patients informed me that they wondered if the changes that they noticed could be a warning sign of stroke. They described their activity of checking the list of warning signs and comparing it to their experience. According to IE, this constitutes patient work, and is also understood as an example of knowing within a power-knowledge context. The patients knew themselves two ways, through their embodied experience within their body, and through the grid of possible stroke symptoms provided to them by our biomedical health system. Having been ‘activated’ by the texts, the patients sought health care, with eventual attendance at the secondary stroke prevention clinic. From the Ontario Stroke System perspective, the social marketing product “worked”, patients
with symptoms sought care. The refrigerator magnet names physical changes that are known biomedically as stroke symptoms, yet though they may or may not be stroke symptoms, they are depicted as certain. The perspective and patient work of self-detection, worry, wondering when and if their symptom is enough to go to the hospital is invisible however. As well, the presentation of uncertain or ambiguous information as certain maintains the expert status of health care professionals, and perpetuates the idea that this group must be consulted to demystify one’s experience.

I found that the concept of ‘prevention’ was understood by patients as making changes to their lifestyle. However, prevention was identified by the neurologist as ‘secondary prevention’; a term patients did not use or realize was in use (This term was on the clinic wall in the waiting room and on the clinic appointment letter). Both the patients’ and the neurologist’s knowledge of prevention, though different, locate prevention activities within the body. The activities and treatment plans though are substantially different. The importance of this difference impacts patient autonomy. Without acknowledging that proxies for health and health care decision making are in use in the clinic to support the decision-making of clinicians, patients cannot exercise autonomy in their choices.

The overarching ideology in the clinic was found to be ‘risk ideology’. This was evidenced through the use of risk factors as proxies for health, stroke warning signs presented as certain, and the use of risk formulas such as Number Needed to Treat (NNT) to facilitate clinical decision making. Clinicians use these risk practices as they are functionally useful. Uncertain health professionals balance competing and complex patient health risks. Risk ideology authorizes the creation of certainty in ambiguous unknown situations. Ideology, however, conceals (Smith, 1990). In the SSPC, risk ideology conceals the complexity of patients.
In Chapter One, I introduced Dot, a woman whose substantial stroke left her with paralysis of half of her body. Dot and I both located her risk for stroke in her smoking behavior. Though I had questions about the role of social factors as contributors to Dot’s stroke, I had no training in a type of assessment that would allow me to explore these risks with Dot. Social risks were not part of the stroke care plan and not included on texts as variables. Anthropologist Douglas and political scientist Wildavsky (1982), in their analysis of risk and culture determine that “the choice of the risks we pay attention to and the choice of how we live together, go together” (p. 8). The risks that the secondary stroke prevention clinic pays attention to, as a component of the larger Ontario Stroke System, are the biomedical risk factors for stroke that may cause disability.

In this sense, biomedical “knowing” begins and ends in the individual decontextualized body, with no information derived from or fed back into the social systems in which this body is located. This biomedical knowing is governed in secondary stroke prevention by a ‘risk ideology’. The ‘ideological practices are at “war with a knowledge, or perhaps better, a knowing, that begins from the site of people’s experience” (Smith, 1990, p. 43). The ideology of risk subjugates consciousness and obscures the complexity of patients individually, biologically, socially, economically and morally. This can best be shown by revisiting the accepted medical conditions underlying stroke: hypertension, diabetes, smoking and cholesterol.

Biomedically, these conditions are accepted as medical problems that need treatment as chronic conditions. In the secondary stroke prevention clinic, when these conditions start to present themselves as symptoms of stroke, there is sudden urgency, and the conditions are re-named risk factors. The stroke risk factors are also contributors to heart disease and vascular
dementia (and other vascular related organ diseases). The clinic, set up to serve the neuroscience subspecialty of stroke, targets vascular disease in one singular organ of the body – the brain. This is despite the fact that half of the patients in this study were also under the care of a cardiologist.

From the patient perspective, these ‘risk factors’ are ‘lived actualities,’ health conditions patients are living with. Not only did these people have diabetes and hypertension, they had other conditions, such as hearing loss, arthritis, obesity, musculoskeletal pain, migraines, sleep apnea and more. All of the patients who attended the clinic were taking four or five different medications, including medications for arthritis, diabetes, Alzheimer’s disease, pain, migraines and thyroid and bowel issues. They were also on medications to reduce cholesterol and blood pressure, to thin blood, and a wide assortment of vitamins, minerals and other supplements (see Table 1). In the face of urgent risk, the health work for patients (“countless blood tests, living around the calendar” to attend health appointments, and financial consequences of paying for medications) seemed to be taken for granted by the health care team and accommodated by fearful patients.

From a ‘social model’ perspective, what are known as risk factors in the field of stroke are the same chronic conditions considered consequences of lower socioeconomic status. While knowledge that socioeconomic status is linked to higher incidence of stroke was noted in two substantial stroke documents, WHO Atlas of Heart Disease and Stroke (MacKay and Mensah, 2004) and the Report of the Joint Stroke Strategy Working Group (Ontario Ministry of Health and Long Term Care, 2000), this social risk was listed as an isolated, unmodifiable risk factor. Labelling socioeconomic status as unmodifiable for the population of Ontario is a telling “choice of the risks we pay attention to” (Douglas and Wildavsky, 1982, p. 8). By choosing to pay
attention to these conditions when they start to generate symptoms through the stroke system, we are choosing the economic cost of acute and rehabilitation care, and measuring DALY’s. This choice is “at war with the lived actuality” (Smith, 1990, p. 43) of the people living in the economically impoverished environments that predispose them to the underlying chronic conditions. The economic complexity of our health care funding choices is obscured through the ideology of risk.

Moral complexity (Aronowitz, 2001) is obscured in the local clinic when “what ought to be explained is treated as fact or as assumption” (Smith, 1990, p. 43; my italics). In this study, transparent discussions that dealt with symptoms, how risk factors are derived at and the number needed to treat formula that directed clinical treatment decisions failed to occur. Upshur and Tracy (2008) advocate for deliberation with patients that acknowledges the “breadth of uncertainty” (p. 1656) related to the available knowledge guiding clinical decision making. The model they suggest is one based on equilibrium, “establishing the most acceptable functional status amenable to the patient, then considering the use of powerful modalities of diagnosis and treatment only when there is agreement that the equilibrium has been sufficiently disturbed” (p. 1656). In the field of stroke, the added dimension of the fear of disability elevates the clinical moral responsibility for discussion. Moral complexity is also obscured when a broader dialogue of health as socially determined is not part of the public domain. A moral lens allows us to ask about social values, to inquire more deeply into the question of health, and how to achieve and sustain it, together as Canadians.

Adam et al., (2004) ask, “How can risks be more justly distributed?” (p. 7). This is where socio-political reflexivity is required. Lash and Wynne (1992), in their introduction to Beck’s (1992) work, argue that “reflexivity is excluded from the social and political interactions
between experts and social groups over modern risks, because of the systematic assumption of realism in science” (p. 4). These authors argue for negotiation between different epistemologies. The complexity of the patients who attended the secondary stroke prevention demands of clinicians (locally) and health care decision makers (extra-locally) the capacity to utilize more than one perspective. Biomedicine has a proven its ability to incorporate new knowledge – such as its integration of technological knowledge. However, the contextual social, economic and political knowledge surrounding the individual has failed to be integrated. In fact, these complexities are obscured in secondary stroke prevention, and the Ontario Stroke system more broadly, by the ideology of risk.

Recommendations

It is not usual practice for a researcher using the tools of institutional ethnography to provide recommendations. Smith advocates to ‘make visible’ for people, then let the people make changes. The following comments are provided, therefore, only as considerations and reflections about what could be different if we were to make changes based upon these findings. My comments are directed towards nurse leaders, Ontario Stroke System leaders and leaders with the Ontario Provincial Government.

Nurse leaders, researchers and educators

1. Develop scholarly depth in the fields of socio-economic and political health care delivery practices, and include this knowledge in nursing education.

Despite substantial important work in the social sciences regarding health and chronic disease, when the proposal was made to create the Ontario Stroke System, there was no incentive or ability to consider knowledge other than that of the dominant biomedical model. Courageously reconsidering health in terms of what is healthy for people rather than what is
corporately beneficial or politically safe requires ongoing research into how our society works, making visible components which can be altered. This is a role for nurses. Our nursing legacy of advocacy for social reform harkens back to Florence Nightingale. Nurses value ‘accessibility’ to our health care system for patients. Nurses need to argue that accessibility to health includes public accessibility to knowledge about how we have designed our system, the ideologies of what governs decision making, critical evaluation of what needs to change and advocacy for those changes. Advocate for the upstream social changes that could prevent stroke. Participate in this collaboratively with primary care physicians, primary care nurse practitioners, public health nurses and physicians. As well, this study made visible the need to better understand the role of patient advocacy organizations such as the Heart and Stroke Foundation, especially in the area of social marketing. There is very little research in this area, and health care professionals as well as the public need to understand the benefits, consequences and ideologies of these organizations.

2. Include the concept of work in “patient experience” knowledge translation activities.

Many workshops and arts based activities have been created to facilitate a deeper understanding of the experiences of patients for health care professionals. An example is Ronna Bloom’s (n.d.) Have you seen the patient? a workshop that explores what it is to “see” a patient. Jennifer Lapum’s (2011) installation, “The 7,024th Patient” is a 1739 square foot installation captures the raw, emotional and embodied experiences of patients in open-heart surgery and recovery and advocates for human approaches to health care and health care policy. These types of workshops facilitate knowledge transfer from patients to health care professionals, and facilitate insight and empathize with the ‘other’, the patient. I would suggest adding the concept of patient work in order to facilitate awareness of what Rachlis (2004) terms, “the merry-go-round of appointments” and what Smith (1990) notes as the movement of power and knowledge.
Secondary Stroke Prevention Clinics

1. Become educated about risk practices and certainty practices, and the clinical implications for patients. Use this knowledge to engage in deliberate conversations with patients.

Proxies for health such as risk factors and the Number Needed to Treat are functionally useful for clinical care but in fact obscure the complexity of the variables involved in decision making. It is important that clinicians engage in deliberate dialogues with patients which acknowledge the breadth of uncertainty and allow patients to participate in their health decisions in a different way. For instance the decision aid for anti-coagulation treatment for atrial fibrillation (Man-Son-Hing et al., 1999) is a good first step towards opening up a conversation about risky treatments. It is also critical that decision aides state the underlying assumptions. The online aid from the National Health Service (National Prescribing Centre, n.d.) states these assumptions, “It is impossible to know for sure what will happen to each individual person” and “All 1000 people will have to take aspirin”. Adding further details about how categories of “low, moderate and high” risk were ascertained would allow patients to understand that health variables have been used to determine risk. These aids should also include other possible consequences of anticoagulant therapy, such as hemorrhage in other organs and risks in connection with falls. Last, these types of tools could be developed for other clinical decisions related to high blood pressure, hypercholesterolemia and diabetes.

Secondary Stroke Prevention Leaders and the Ontario Provincial Government

1. Collect data that represents the social determinants of health on the ICES data collection form for the purposes of ultimately addressing these variables socially and politically.

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The World Health Organization’s (WHO) *Atlas of Heart Disease and Stroke* (Mackay & Mensah, 2004) identifies socioeconomic status as a risk factor for stroke. However, socioeconomic status is located in isolation, with risk connected to individual behaviours. There is no corresponding discussion regarding socioeconomic status as socially organized and no discussion about social changes that reduce economic inequality. Simpson (2012) notes that “every study confirms, that despite all the pressures to spend even more money on the health care system per se, a dollar spent on reducing inequality would do more for the system’s sustainability over the long term than another machine, nurse, doctor or hospital bed” (p. 48). Stroke is an example of a condition linked to inequality. Stroke leaders have the opportunity to reduce stroke incidence through upstream measures.

*Heart and Stroke Foundation of Ontario*

1. Integrate “social determinant of health” advocacy into stroke prevention advocacy practices.

Individual behaviour needs to be considered within its economic, social, and cultural context, Fenton, 2004). The links between lower socioeconomic status and higher incidence of stroke have been well documented in the literature. Connections and collaborations can be encouraged between these academics (many of whom are local Torontonians), as well as with the Public Health Department. Researchers and representatives from these knowledge domains could be invited to speak at Heart and Stroke Clinical Day conferences. The Heart and Stroke Foundation’s creativity could be directed towards working with Government and those known to have less health advantage in generating other preventive methods. International example of innovative solutions include activities to directly address poverty as a risk in the transmission of
HIV in Africa (Stratford, Mizuno, Williams, Courtenay-Quirk, O’Leary, 2008; Prather, Marshall, Courtenay-Quirk, Williams, Eke, O’Leary, & Stratford, 2012).

*Provincial Leadership*

(This group includes the Ontario Provincial Government representatives, including but extending past the Ministry of Health, as health encompasses our decisions regarding the environment, education, and labour).

1. Reformulate the team generating health related decision making at a Provincial level into an inter-Ministry collaboration fashioned after the “Toronto Model” of interprofessional education and practice.

The model for health care education and practice in Toronto is in the process of being significantly redesigned to ensure that health care professionals who work together are able to communicate with each other across professional boundaries, to share knowledge for the benefit of the patients (Nelson, Tassone, & Hodges, 2014). The Ontario Provincial Government has the opportunity to learn from this pioneering approach, and to start to address issues like health that crosses Ministry boundaries. Health is impacted by the environment, by transportation decisions, by employment, by education and housing. Including leaders from each of these Ministry areas to think through the complexity of health more thoroughly could revolutionize the understanding of health in Canada, and ultimately make ‘health’ more accessible to all Canadians.
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APPENDICES

Appendix A: Scripts for Interviews with TIA/Minor Stroke Patients and Caregivers

Text in *italics* indicates what the researcher will say during the interview

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>1.</td>
<td>Introduction and brief description of the study, as per information sheet.</td>
</tr>
<tr>
<td>2.</td>
<td>Allow for questions:</td>
</tr>
<tr>
<td></td>
<td><em>Do you have any questions for me about the study or your participation?</em></td>
</tr>
<tr>
<td>3.</td>
<td>Inform the informant of potential risk</td>
</tr>
<tr>
<td></td>
<td><em>You may feel uncomfortable with answering questions and talking about their experiences;</em></td>
</tr>
<tr>
<td></td>
<td><em>You are free to decline to answer any of the questions;</em></td>
</tr>
<tr>
<td></td>
<td><em>You may end any interview or withdraw from the study at any time;</em></td>
</tr>
<tr>
<td></td>
<td><em>You will have your name removed from all scripts and presentations about the study. Do you have a pseudo name that you would like to use?</em></td>
</tr>
<tr>
<td>4.</td>
<td>Inform the informant of health risk</td>
</tr>
<tr>
<td></td>
<td><em>Your health is important to me. Please let me know if at any time you feel too tired, unwell or no longer wish to continue the interview. I will immediately stop our conversations and reschedule at a time when you are feeling better and able to continue.</em></td>
</tr>
<tr>
<td></td>
<td><em>If our interview is not finished I would like to use the information up to the point that we finish. Are you comfortable with that?</em></td>
</tr>
<tr>
<td>5.</td>
<td>Allow for questions:</td>
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<tr>
<td></td>
<td><em>Do you have any questions for me before we begin?</em></td>
</tr>
<tr>
<td>6.</td>
<td>Obtain informed consent</td>
</tr>
<tr>
<td>7.</td>
<td>Before we begin I would like to ask you some demographic questions.</td>
</tr>
<tr>
<td></td>
<td>Refer to demographic form.</td>
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<tr>
<td>8.</td>
<td>Begin interview:</td>
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<tr>
<td></td>
<td>In this study I am interested in finding out about the experiences of patients who have a possible TIA or stroke, attend the stroke prevention clinic, and receive recommendations. I would like to know about your experience as a patient in following suggestions/recommendations, reading any materials, and so on.</td>
</tr>
<tr>
<td></td>
<td>I am interested in finding out about your life prior to this current episode. Do you work, have children, retired, volunteer, pets (makes visible day to day experiences which may lead to other questions)</td>
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<tr>
<td></td>
<td>Can you tell me about your TIA/stroke? (What brought you to the clinic)?</td>
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<tr>
<td></td>
<td>How did you know something was different/wrong?</td>
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<tr>
<td></td>
<td>Can you tell me what you did to get help, and the steps that brought you to the stroke prevention clinic?</td>
</tr>
<tr>
<td></td>
<td>What were the challenges you faced? (prompts: emotions such as fear, mobility, sleep, knowledge of health care system, access to MD, transportation)</td>
</tr>
<tr>
<td></td>
<td>What were you told (at the MD/ER)?</td>
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<tr>
<td></td>
<td>Is the information about (insert risk factor) new to you?</td>
</tr>
<tr>
<td>Question</td>
<td>Probes/Comments</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Who did you bring with you?</td>
<td></td>
</tr>
<tr>
<td>How are things different?</td>
<td></td>
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<tr>
<td>Have your daily events changed? If so, how? (prompts: food, activities, driving, relationships)</td>
<td></td>
</tr>
<tr>
<td>What are the next steps for you?</td>
<td>(probes: referrals, recommendations, materials)</td>
</tr>
<tr>
<td>9. Generic Probes I may use throughout:</td>
<td></td>
</tr>
<tr>
<td>Can you tell me more about that...</td>
<td></td>
</tr>
<tr>
<td>Let me see if I have understood…</td>
<td></td>
</tr>
<tr>
<td>These are tough things to talk about (*Reutter et al., 2005)</td>
<td></td>
</tr>
<tr>
<td>These are awfully hard issues to deal with (*Reutter et al., 2005)</td>
<td></td>
</tr>
<tr>
<td>That’s a very common thing I hear about (*Reutter et al., 2005)</td>
<td></td>
</tr>
<tr>
<td>10. Second Interview and Telephone Interview:</td>
<td></td>
</tr>
<tr>
<td>What were the challenges you faced since your first appointment here?</td>
<td></td>
</tr>
<tr>
<td>How are things different?</td>
<td></td>
</tr>
<tr>
<td>How has this changed your daily events? (prompts: food, activities, driving, relationships)</td>
<td></td>
</tr>
<tr>
<td>Did you find the brochures, educational materials given to you helpful, relevant? Was it enough, too much?</td>
<td></td>
</tr>
<tr>
<td>What stroke team members or agencies have you been linked to?</td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>Interview closing</td>
</tr>
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<td>-----</td>
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</tbody>
</table>

*Thank you for sharing your experiences.*

*It is likely that once this study is complete I will share the findings. Would you like to be informed when the results of the study are presented in oral or written format? If so, how would you like to be contacted?*


Appendix B: Question Plan for health professionals working in the clinic

*“Tell me about your work.”*

*“What guidelines or principles do you draw from?”* (paying attention to texts that lead to social organization)
Appendix C: Interview script and question plan for extra-local informants

Text in *italics* indicates what the researcher will say during the interview

<p>| | |</p>
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<thead>
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</thead>
<tbody>
<tr>
<td>1.</td>
<td>Introduction and brief description of the study as per information sheet</td>
</tr>
<tr>
<td>2.</td>
<td>Allow for questions:</td>
</tr>
<tr>
<td></td>
<td><em>Do you have any questions for me about the study or your participation?</em></td>
</tr>
<tr>
<td>3.</td>
<td>Inform the informant of risk</td>
</tr>
<tr>
<td></td>
<td><em>When people participate in study interviews they may feel uncomfortable with answering questions and talking about their experiences; You are free to decline to answer any of the questions; You may end any interview or withdraw from the study at any time; Your name and all identifying information removed from all scripts and academic presentations and papers about the study.</em></td>
</tr>
<tr>
<td></td>
<td><em>Do you have a pseudo name that you would like to use in this study?</em></td>
</tr>
<tr>
<td>4.</td>
<td>Allow for questions:</td>
</tr>
<tr>
<td></td>
<td><em>Do you have any questions for me before we begin?</em></td>
</tr>
<tr>
<td>5.</td>
<td>Obtain written consent.</td>
</tr>
<tr>
<td>6.</td>
<td>Begin interview:</td>
</tr>
<tr>
<td></td>
<td><em>In this study I am interested in finding out about the coordination of stroke prevention care to better understand the experiences of patients who experience a TIA or minor stroke.</em></td>
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</tbody>
</table>
| 7. | Specific questions for Ontario Stroke system professional:  
These will be designed based on the data that is gathered from the patients.  
Questions will be specific and focused on processes.  
Questions will be posed in an open-ended way. |
| 8. | Probes  
*Can you tell me more about that….*  
*Let me see if I understand what you have said….*  
*Can you tell me about a typical day when you work with TIA patients?*  
*Can you tell me about any experiences with TIA patients that stand out in your mind?* |
| 9. | *Thank you for sharing your experiences.*  
*It is my intention to publish the results of this study once my doctoral work is completed. Would you like to be informed of the citations for any oral, written or poster presentations that result from this study?*  
*How would you like to be contacted?* |
| 10. | *Are there other people or resources that you feel would be beneficial for me to speak to?* |

*a) Can you tell me about your role in the Health care/Ontario Stroke System?  
b) Can you tell me what you know about the process of TIA care/self-management/risk management/patient education regarding TIA?*
Appendix D: Screening Tool for Informants

Script:

“There is a nursing doctoral candidate here who is studying the experience of patients when they come to the clinic, for example, what happens in the clinic for patients, how patients manage recommendations. Can I ask you some questions to see if you are eligible?

Must be referred for possible TIA or minor stroke, be able to communicate using English, and have any one of the following characteristics:

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Question</th>
<th>√ and comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>High-school education or less</td>
<td>Could you please tell me what your highest level of education is?</td>
<td></td>
</tr>
<tr>
<td>Employment age but unemployed</td>
<td>What is your occupation? Are you currently working?</td>
<td></td>
</tr>
<tr>
<td>Visible minority</td>
<td>Visible to Nurse</td>
<td></td>
</tr>
<tr>
<td>Single or divorced woman working part time or less</td>
<td>What is your marital status? Employment information above.</td>
<td></td>
</tr>
<tr>
<td>Functional limitation related or not related to TIA/stroke</td>
<td>Do you have any physical limitations? Do you have a disability? What is it?</td>
<td></td>
</tr>
<tr>
<td>Obesity: Waist circumference (102 cm male, 88 cm female)</td>
<td>Measurement by Nurse</td>
<td></td>
</tr>
<tr>
<td>Recent immigrant</td>
<td>How long have you been in Canada?</td>
<td></td>
</tr>
</tbody>
</table>

Thank you for your time in answering these questions.

☐ No, I am sorry, you are not eligible for the study.
☐ Yes, you are eligible for the study. Would you be interested in meeting the nursing doctoral candidate, she will tell you more about the study?”
CONSENT TO PARTICIPATE IN A RESEARCH STUDY:

PATIENTS AND SIGNIFICANT OTHERS

Title
The social organization of stroke prevention.

Principle Investigator
Dr. Leanne Casaubon, MD, MSc, FRCPC
416-603-5768

Co-Investigators
Sarah Flogen, RN, PhD Candidate
Dean Sioban Nelson, PhD, Supervisor

Introduction

You are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. Please ask the researcher to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish. Participation in this study is voluntary.

Background and Purpose

This study is being conducted as part of a Nursing doctoral study program through the Lawrence Bloomberg Faculty of Nursing at the University of Toronto.

You have been asked to take part in this research study because research has shown that not all Canadians have the same experience of health. The purpose of this study is to describe the experience of people who are at a higher risk of health concerns as they try to take on the
recommendations of health care professionals. This study findings will be meaningful in ensuring relevancy of recommendations that health care professionals provide.

You are a good candidate for this study as you fall into one of the high risk groups for health concerns. About 12 patients and their significant other or informal caregiver from this hospital will be in the study.

Study Design

- You will be in this study for up to 6 months.
- The researcher will observe your stroke prevention appointments with the stroke prevention nurse and the stroke neurologist. The researcher will be taking notes about the process, and will ask questions to you and/or the health care professional in a follow-up interview. Follow up questions will include things like how you knew there was a health problem, how you got to your appointment, the challenges you faced in trying to do the things the doctor or nurse asked you to.
- There will be a total of 3 audio-taped interviews during the study, two in-person after your clinic appointments in the hospital, and one over the telephone from your home. The interviews will be from 30 – 60 minutes long.

Study Visits and Procedures

- Your appointments with the nurse and stroke neurologist will be observed.
- An interview will occur after these appointments.
- At 6 months, a telephone interview will occur.

Boxes marked with an X show what will happen at each visit:
<table>
<thead>
<tr>
<th>Visit</th>
<th>Observation of Appointment</th>
<th>Audio-taped Interview</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stroke Prevention Appointment # 1</td>
<td>X</td>
<td>X</td>
<td>60 min</td>
</tr>
<tr>
<td>Follow-up Appointment</td>
<td>X</td>
<td>X</td>
<td>60 min</td>
</tr>
<tr>
<td>Telephone interview at 6 months</td>
<td></td>
<td>X</td>
<td>30-60 min</td>
</tr>
</tbody>
</table>

**Risks Related to Being in the Study**

There are no medical risks if you take part in this study, but being in this study may make you feel upset as you talk about your health. You may refuse to answer questions or stop the interview at any time if there is any discomfort or emotional distress. You may share any information you feel comfortable sharing. Uncomfortable or negative feedback that you feel is important and relevant to share will not have an impact on your care at the University Health Network.

**Benefits to Being in the Study**

You may or may not receive any direct benefit from being in this study. Information learned from this study may help other people in the future.

**Voluntary Participation**

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without
affecting your care. You may refuse to answer any question you do not want to answer, or not answer an interview question by saying “pass”.

We will give you new information that is learned during the study that might affect your decision to stay in the study.

Alternatives to Being in the Study

You do not have to join this study to receive treatment for your condition.

Confidentiality

The information that is collected for the study will be kept in a locked and secure area by the researcher until the completion of the study. Your participation in this study also may be recorded in your medical record at this hospital.

All information collected during this study will be kept confidential and will not be shared with anyone outside the study unless required by law.

You will not be named in any reports, publications, or presentations that may come from this study. The audio tape and interview information will be done using a pseudonym that you select.

If you decide to leave the study, the information about you that was collected before you left the study will still be used unless you request to have it withdrawn. No new information will be collected without your permission. Once the data has become analyzed, it becomes part of a larger pool of data, and it is not possible to remove it. Study information (data) will be kept for a maximum of ten (10) years, after which they will be destroyed. Only Sarah Flogen the doctoral candidate will have access to the audio tapes. Ms. Flogen’s supervisor, Dean Sioban Nelson, and the Principal Investigator, Dr. Leanne Casaubon will have access to anonymized information. Your name will never be shared. The UHN Research Ethics Board will have access to study information for auditing purposes.
In Case You Are Harmed in the Study

If you become ill, injured or harmed as a result of taking part in this study, you will receive care. The reasonable costs of such care will be covered for any injury, illness or harm that is directly a result of being in this study. In no way does signing this consent form waive your legal rights nor does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities. You do not give up any of your legal rights by signing this consent form.

Expenses Associated with Participating in the Study

You will not have to pay for any of the procedures involved with this study. You will be reimbursed for transportation (parking or transit expenses) and one cup of coffee each.

Conflict of Interest

There are no sponsors in this study, and no financial conflicts of interest. However, the people involved in this study have an interest in completing this study. You should not feel pressured to join this study.

Questions About the Study

If you have any questions, concerns or would like to speak to the study team for any reason, please contact one of the following:

Dr. Leanne Casaubon
Phone: 416-603-5768

Sarah Flogen
Phone: 416-3403-042

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the (Organizational Name Removed) (REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.
Consent

This study has been explained to me and any questions I had have been answered.

I know that I may leave the study at any time. I agree to take part in this study.

Print Study Participant’s Name  Signature  Date

(You will be given a signed copy of this consent form)

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person Obtaining Consent  Signature  Date

Was the participant assisted during the consent process? ☐ YES ☐ NO

If YES, please check the relevant box and complete the signature space below:

☐ The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to, and has had any questions answered.

Print Name of Witness  Signature  Date

Relationship to Participant
Appendix F: Consent for Extra-local informants

(Organizational Logo Removed)

CONSENT TO PARTICIPATE IN A RESEARCH STUDY:

HEALTH CARE PROFESSIONALS: EXTRA-LOCAL SETTING

Title
The social organization of stroke prevention.

Principle Investigator
Dr. Leanne Casaubon, MD, MSc, FRCPC
416-603-5768

Co-Investigators
Sarah Flogen, RN, PhD Candidate
Dean Sioban Nelson, PhD, Supervisor

Introduction

You are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. Please ask the researcher to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish. Participation in this study is voluntary.

Background and Purpose

This study is being conducted as part of a Nursing doctoral study program through the Lawrence Bloomberg Faculty of Nursing at the University of Toronto.

You have been asked to take part in this research study because research has shown that not all Canadians have the same experience of health. The purpose of this study is to describe the experience of people who are at a higher risk of health concerns as they try to take on the
recommendations of health care professionals. The study findings will be meaningful in ensuring relevancy of recommendations that health care professionals provide.

Study Design

You are being asked to participate in an interview about your work and your insights into stroke prevention care. The interview may last from 10 to 60 minutes. Questions may include, “How does a patient get referred to your clinic?” “How are patients triaged/wait lists managed”. With your permission, you may be asked for clarification in a follow-up telephone call.

Risks Related to Being in the Study

There are no medical risks if you take part in this study. You may refuse to answer questions or stop the interview at any time if you are uncomfortable.

Benefits to Being in the Study

You may or may not receive any direct benefit from being in this study. Information learned from this study may help other people in the future.

Voluntary Participation

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. A decision not to take part in the study will not have an impact on your employment at this agency. You may refuse to answer any question you do not want to answer, or not answer an interview question by saying “pass”.

You will be given any new information that is learned during the study that might affect your decision to stay in the study.

Confidentiality

The information that is collected for the study will be kept in a locked and secure area by the researcher until the completion of the study.

All information collected during this study will be kept confidential and will not be shared with anyone outside the study unless required by law.
You will not be named in any reports, publications, or presentations that may come from this study. The audio tape and interview information will be done using a pseudonym that you select.

If you decide to leave the study, the information about you that was collected before you left the study will still be used unless you request to have it withdrawn. No new information will be collected without your permission. Once the data has become analyzed, it becomes part of a larger pool of data, and it is not possible to remove it. Study information (data) will be kept for a maximum of ten (10) years, after which they will be destroyed. Only Sarah Flogen the doctoral candidate will have access to the audio tapes. Ms. Flogen’s supervisor, Dean Sioban Nelson, and the Principal Investigator, Dr. Leanne Casaubon will have access to anonymized information. Your name will never be shared. The (Organization name removed) Research Ethics Board will have access to study information for auditing purposes.

Conflict of Interest

There are no sponsors in this study and no financial conflicts of interest. However, the people involved in this study have an interest in completing this study. You should not feel pressured to join this study.

Questions About the Study

If you have any questions, concerns or would like to speak to the study team for any reason, please call:

Principle Investigator
Dr. Leanne Casaubon
416-603-5768

Doctoral Candidate
Sarah Flogen
416-340-3042

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the (Organization name removed) Research Ethics Board (REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the
ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.

Consent

This study has been explained to me and any questions I had have been answered.

I know that I may leave the study at any time. I agree to take part in this study.

_________________________  __________________   _________
Print Study Participant’s Name   Signature             Date

(You will be given a signed copy of this consent form)

My signature means that I have explained the study to the participant named above. I have answered all questions.

_________________________  __________________   _________
Print Name of Person   Signature             Date

Obtaining Consent
Appendix G: Consent for Local Setting Informants

(Organizational Logo Removed)

CONSENT TO PARTICIPATE IN A RESEARCH STUDY:

HEALTH CARE PROFESSIONALS: LOCAL SETTING

Title   The social organization of stroke prevention.

Principle Investigator   Dr. Leanne Casaubon, MD, MSc, FRCPC

416-603-5768

Co-Investigators   Sarah Flogen, RN, PhD Candidate

Dean Sioban Nelson, PhD, Supervisor

Introduction

You are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. Please ask the researcher to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish. Participation in this study is voluntary.

Background and Purpose

This study is being conducted as part of a Nursing doctoral study program through the Lawrence Bloomberg Faculty of Nursing at the University of Toronto.

You have been asked to take part in this research study because research has shown that not all Canadians have the same experience of health. The purpose of this study is to describe the experience of people who are at a higher risk of health concerns as they try to take on the recommendations of health care professionals. The study findings will be meaningful in ensuring relevancy of recommendations that health care professionals provide.
Study Design

You are being asked to participate in an institutional ethnography in which your interactions, assessment, teaching with the patients and their significant other or caregiver will be observed. The doctoral candidate will be taking notes about the process and noting textual materials that are used in your work. You will also be interviewed about your work and your insights into stroke prevention care. Example questions include, “What shapes the decisions you make?”, “Which guidelines are relevant to your work”. The interview may last from 10 to 60 minutes. With your permission, you may be asked for clarification in a follow-up telephone call or private conversation in the clinic.

Risks Related to Being in the Study

There are no medical risks if you take part in this study. You may refuse to be observed, answer questions or stop the interview at any time if you are uncomfortable. Although the study is about the health care process, and not your particular health care practice, it is possible you may feel your practice is under surveillance. The nursing doctoral candidate will clarify the purpose of her observation and interview as often as you like, and will share the progress of the study and where her observations and interview findings led as requested. However, should unprofessional conduct be encountered while observing the health care professionals, or reported during the patient interview, direction will be taken as per the appropriate regulating College, as is the usual professional practice for any regulated practitioner.

Benefits to Being in the Study

You may or may not receive any direct benefit from being in this study. Information learned from this study may help other people in the future.

Voluntary Participation

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. A decision not to take part in the study will not have an impact on your employment at (Organizational name removed). You may refuse to answer any question you do not want to answer, or not answer an interview question by saying “pass”.
You will be given any new information that is learned during the study that might affect your
decision to stay in the study.

Confidentiality

The information that is collected for the study will be kept in a locked and secure area by the
researcher until the completion of the study.

All information collected during this study will be kept confidential and will not be shared with
anyone outside the study unless required by law.

You will not be named in any reports, publications, or presentations that may come from this
study. The audio tape and interview information will be done using a pseudonym that you
select.

If you decide to leave the study, the information about you that was collected before you left the
study will still be used unless you request to have it withdrawn. No new information will be
collected without your permission. Once the data has become analyzed, it becomes part of a
larger pool of data, and it is not possible to remove it. Study information (data) will be kept for a
maximum of ten (10) years, after which they will be destroyed. Only Sarah Flogen the doctoral
candidate will have access to the audio tapes. Ms. Flogen’s supervisor, Dean Sioban Nelson, and
the Principal Investigator, Dr. Leanne Casaubon will have access to anonymized information.
Your name will never be shared. The (Organizational Name) Research Ethics Board will have
access to study information for auditing purposes.

Conflict of Interest

There are no sponsors in this study and no financial conflicts of interest. However, the people
involved in this study have an interest in completing the study. You should not feel pressured to
join this study.
Questions About the Study

If you have any questions, concerns or would like to speak to the study team for any reason, please call:

Principle Investigator:

Dr. Leanne Casaubon

416-603-5768

Doctoral Candidate

Sarah Flogen

416-340-3042

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the (Organization name removed) Research Ethics Board (REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.
Consent

This study has been explained to me and any questions I had have been answered.

I know that I may leave the study at any time. I agree to take part in this study.

<table>
<thead>
<tr>
<th>Print Study Participant’s Name</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
</table>

(You will be given a signed copy of this consent form)

My signature means that I have explained the study to the participant named above. I have answered all questions.

<table>
<thead>
<tr>
<th>Print Name of Person</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
</table>

Obtaining Consent
<table>
<thead>
<tr>
<th>Informant Pseudonym and # d/m/year</th>
<th>Age</th>
<th>F/ M</th>
<th>Marital status</th>
<th>Co-recruited</th>
<th>Criteria</th>
<th>Health Co-morbidities</th>
<th>Medications</th>
<th>Cultural group</th>
<th>Seen in clinic by</th>
<th>Clinic Follow-up</th>
<th>6 mos Telephone</th>
<th>Referred by</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 – Helen 9/4/11</td>
<td>81</td>
<td>F</td>
<td>Widow</td>
<td>Alone</td>
<td>3, 6, 7</td>
<td>Hearing aids</td>
<td>Cod liver oil; ASA; atacand; Lasix; Tylenol; Vit B12</td>
<td>German</td>
<td>Fellow for TIA</td>
<td>Yes</td>
<td>No answer did not return vm</td>
<td>Family physician then Emerg</td>
</tr>
<tr>
<td>2 – Walter 13/5/11</td>
<td>85</td>
<td>M</td>
<td>Widower Daughter and son-in-law</td>
<td>3, 5, 6</td>
<td>Alzheimer’s</td>
<td>Alz med; ASA; statin; BP med</td>
<td>Guyanese</td>
<td>Fellow for post stroke</td>
<td>Did not attend appt</td>
<td>Yes</td>
<td>Inpatient Stroke Unit</td>
<td></td>
</tr>
<tr>
<td>3 – Tom 20/5/11</td>
<td>72</td>
<td>M</td>
<td>Married Wife</td>
<td>7</td>
<td>Bypass surgery Hearing aids</td>
<td>German</td>
<td>Fellow for post hem stroke</td>
<td>No</td>
<td>Yes</td>
<td>Inpatient Rehab</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 – Nancy 27/5/11</td>
<td>F</td>
<td>Married</td>
<td>Husband</td>
<td>5,7</td>
<td>Diabetes High blood pressure</td>
<td>Chinese</td>
<td>Nurse/MD for post hem stroke</td>
<td>No</td>
<td>No</td>
<td>Family Physician</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 1: Table of Informants
<table>
<thead>
<tr>
<th>No</th>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Marital Status</th>
<th>Informant</th>
<th>Date</th>
<th>Height</th>
<th>Weight</th>
<th>Other Health Conditions</th>
<th>Medications</th>
<th>Jewish</th>
<th>MD in Follow Up</th>
<th>New Patient</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Ivy</td>
<td>5</td>
<td>F</td>
<td>Married</td>
<td>Husband</td>
<td>11/7/11</td>
<td>5,7</td>
<td>Fabry’s arrhythmia</td>
<td>Amiodarone; Coumadin or Plavix</td>
<td>Jewish</td>
<td>No</td>
<td>No “new” patient from year ago</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Amy</td>
<td>82</td>
<td>F</td>
<td>Never married</td>
<td>Alone</td>
<td>11/7/11</td>
<td>6,7</td>
<td>Cane Atrial Fibrillation</td>
<td>Warfarin “big bag”</td>
<td>English</td>
<td>No</td>
<td>Yes Family Physician</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Bert</td>
<td>54</td>
<td>M</td>
<td>Married</td>
<td>Wife</td>
<td>22/7/11</td>
<td>5,7,8</td>
<td>Obese; high blood pressure; Migraines; Prior stroke; msk injury</td>
<td>Fiorinal; Lipitor; altace; Percocet;</td>
<td>Canadian</td>
<td>No</td>
<td>Yes Inpatient Stroke unit</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Caroline</td>
<td>80</td>
<td>F</td>
<td>Widow</td>
<td>Alone</td>
<td>11/11/11</td>
<td>5,6</td>
<td>Thyroid high blood pressure</td>
<td>Lipitor; stool softener; ASA; perindopril; l-thyroxine</td>
<td>Filipina</td>
<td>No</td>
<td>Inpatient Stroke Unit</td>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>

Table 2: Table of Informants (continued from previous page)