THE SOCIAL ORGANIZATION OF
BEST PRACTICE FOR ACUTE STROKE:
AN INSTITUTIONAL ETHNOGRAPHY

by

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Since 1995, a thrombolytic therapy, rt-PA, has been approved for use with acute stroke that significantly reduces, and sometimes reverses, neurological damage. Treatment has to be given within a few hours of the start of symptoms and can only commence once a CT-scan has confirmed a particular type of stroke. In the evidence-based medicine and knowledge translation literature, variations in practice are constituted as a problem to be solved. It is assumed that a physician decides whether or not to use this therapy based on his/her evaluation of the scientific evidence.

In this thesis, I demonstrate that what are less evident in many of these claims are issues related to the social production of knowledge. Little attention is paid to who conducts research, who promotes its findings, and who is expected to implement them. 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.

Institutional Ethnography is an approach in sociology developed by Dorothy Smith. Based on Smith’s understanding of the social organization of knowledge, it allows for an examination of
the complex social relations organizing people’s experiences of their everyday working lives. Beginning in the experiences of physicians who provide acute stroke services, this dissertation explores an example of how best practice medicine is developed, translated, and taken up in practice across various sites in the province of Ontario. For Smith, texts mediate and organize people’s experiences. In my study, the discourses of both evidence-based medicine and knowledge translation, designed to improve patient care, come into view as managerial tools designed to control the delivery of care. I render visible how in fact things work as they do in real life settings in a way that links back actual people to the texts, or discourse, organizing their experiences. In so doing, I am able to uncover some of the assumptions and hidden priorities underlying the current emphasis on translating scientific knowledge in medicine into practice.
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Chapter One:
Introduction

Health care in Canada is in a period of emphasis on change and improvement (Health Canada, 2003; Health Council of Canada, 2008). The concurrent sense of urgency around implementing best evidence care is increasing and can be read in both medical and media accounts calling for greater investment by governments in health care research (Rosenberg, 2003). There is a growing accumulation of scientific and medical evidence, information technologies to help both spread and monitor new evidence, and a focus on developing strategies to urge physicians to implement research findings in their practice. Some critical scholars have argued that inherent in this movement is the implicit idea that science can perfect the delivery of medicine through ever more sophisticated drugs and treatments (Traynor, 2002; Walker, 2003).

This focus on change and improvement arises at least in part from the rise of evidence-based medicine. For the past two decades, the field of medicine has been dominated by what has been commonly referred to as the Evidence-based Medicine (EBM) movement. The basic premise of EBM is that by using methods of scientific and epidemiological inquiry, clinicians can deliver best practice medicine. Best practice refers to interventions that are based on results from research that range in hierarchy from meta-analyses of double-blinded randomized control trials (RCTs), considered to produce gold standard evidence, to anecdotal or clinical experience. However, as one author has noted, “The term hierarchy of evidence is a misnomer; the hierarchy is actually a hierarchy of methodologies. That is, it focuses not on the actual results of a particular study or group of studies – in other words, on the evidence they provide for the efficacy of a treatment – but on how that evidence was obtained (Bluhm, 2005, p. 536). The promise of evidence-based medicine is that it will improve health outcomes for patients. As
defined in the literature, the problem arises when individual physicians do not implement best practices in their delivery of care (Cabana et al., 1999; Davis et al., 2003; Graham et al., 2006).

Physicians who do not keep up with best evidence have been characterized as suffering from information overload (Boissel, Amsallem, Cucherat, Nony, & Haugh, 2004) or being illogical (Roos, 1993), among other things. Further, patients and their families are said to have a right to this best evidence treatment (Rosenberg, 2003). To withhold best practice care is considered unethical and uncaring (Davis, 2006; Graham et al., 2006; Grimshaw, Santesso, Cumpston, Mayhew, & McGowan, 2006). Strategies have developed with a clear aim to change physician behaviour (Armstrong, 2002). Some of these studies focus on physician compliance (Cass, Smith, Unthank, Starling, & Collins, 2003) or adherence (Gifford et al., 1999) and discuss the dilemma of how to change physician behavior (Lucas et al., 2004). These efforts uncritically accept that physicians should change their practice.

Added to this, there is pressure for clinicians – physicians, nurses, physiotherapists and other allied health professionals - to also become scientists, to become involved in the production and implementation of new and ever better knowledge. The notion that research plays a key role in improving the health of Canadians is increasingly accepted (CIHR Newsletter, 2009). Rarely are questions asked regarding how patient’s participation in clinical research affects their care. As Myhalovskiy and Weir note, “Evidence-based medicine creates a demand for clinical trials and thus the recruitment of patients into these trials. What are the effects of the evidence-based market in clinical trials on patients, on physicians and on health care?” (Mykhalovskiy & Weir, 2004, p. 1066).
In this thesis I will demonstrate that what are less evident in many of the claims of EBM are issues related to the social production of knowledge. Little attention is paid to who conducts research, who promotes its findings and who is expected to implement them. 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. For the most part these assumptions remain empirically unexamined, despite social science critiques of these processes (Campbell, forthcoming; Lambert, 2005; Mykhalovskiy & Weir, 2004; Pope, 2003; Traynor, 2002; Walker, 2003).

Institutional Ethnography is an approach in sociology developed by Dorothy Smith. Based on Smith’s understanding of the social organization of knowledge, it allows for an examination of the complex social relations organizing people’s experiences of their everyday working lives (Campbell & Gregor, 2002; Smith, 2002, 2003, 2005). Beginning in the experiences of physicians who provide acute stroke services, this dissertation explores an example of how best practice medicine is developed, translated and taken up in practice across various sites in the province of Ontario. However, while physician accounts provide an entry into the social relations of their setting, they are not the end point of my study (Smith, 2006).

For Smith, texts mediate and organize people’s experiences. In my study, the discourses of both evidence-based medicine and knowledge translation, designed to improve patient care, come into view as managerial tools designed to control the delivery of care. I aim to render visible how in fact things work as they do in real life settings in a way that links back actual people to the texts, or discourse, organizing their experiences. In so doing I am able to uncover some of the assumptions and hidden priorities underlying the current emphasis on translating scientific knowledge in medicine into practice.
Since 1995, a drug known as rt-PA has been defined as best practice for acute stroke treatment. Prior to this, little could be done on an emergency basis to assist the recovery of patients who had suffered an acute stroke. This changed when a drug study produced gold standard evidence that when thrombolytic therapy (rt-PA) was administered to ischemic\(^1\) stroke patients, a benefit could be seen.\(^2\) Experimental results showed that this therapy potentially had the power to halt and even reverse the life-altering neurological damage caused by ischemic stroke. Occasionally it produces an immediate benefit; more usually, this benefit takes place over time. Nevertheless, its potentially transformative effect continues to be likened to the Lazarus Effect by some stroke specialists. There are, however, risks involved in administering it: it carries a 6% fatality rate. In 1999, when rt-PA became established as best practice care for acute stroke in Canada, an infrastructure was created in Ontario to bring it into practice. Promotion of the utilization of rt-PA for acute stroke was accomplished through the development of the Ontario Stroke Strategy, a joint initiative between the Ontario Ministry of Health and Long Term Care and the Heart and Stroke Foundation of Ontario. Through a model that involved creating Regional and District Stroke Centres, best practice care was to be standardized across the province.

A distinctive feature of rt-PA is that eligibility for treatment is determined in terms of the time between possible treatment and the onset of stroke. In addition, only patients with ischemic (rather than hemorrhagic) stroke can be treated, since rt-PA can cause fatal bleeds. A Computerised (Axial) Tomography (CT) scan must be taken – and professionally read – in order

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\(^1\) Strokes are classified in two main types according to the cause of stroke: ischemic (blockage) and hemorrhagic (bleed or tear)

\(^2\) The NINDS Study Group reported that “Despite an increased risk of symptomatic intracerebral hemorrhage, treatment with intravenous t-PA within 3 hours of the onset of ischemic stroke improved clinical outcomes at 3 months”. (New England Journal of Medicine 1995; 333:1581-7).
to determine what type of stroke a patient is suffering from. This involves both technology (the scan itself must be available 24/7) and human resources (radiologist to read the scan). At the time of my study, stroke onset of less than 3 hours before rt-PA is administered was a core criterion for treatment (recently this time window has been increased to 4.5 hours on the basis of two studies known as ECASS III and the SITS-ISTR registry (Hacke et al., 2008; Wahlgren et al., 2008). Due to a number of factors, less than 10% of all acute stroke patients are ever eligible for this treatment because of the strict requirements around its use.

I originally set out to investigate empirically why there was regional variation in physician use of this new evidence-based treatment. In the EBM literature, variations in practice are constituted as a problem to be solved (Rankin & Campbell, 2006). Through my study I discovered a disjuncture between the best practice treatments developed through clinical trials and the actualities of their translation into practice. For Smith, disjunctures point to the social relations underpinning the coordination of people’s actual work in real life settings. Here on the one hand was the text-based discourse of EBM and on the other, physicians’ experiences of the practicalities of conforming to its requirements in the actual situations of their work, often through texts, which are largely invisible to them. This became the problematic (Campbell & Gregor, 2002) of my study, that is, the general formulation that gives direction to and focuses the research and responds to questions such as ‘what can we learn from this research? What can it tell us?’

In this study I treat the literature of both evidence-based medicine and knowledge translation as discourses. Understanding – and changing – physician uptake of what is commonly referred to as best practice medicine falls broadly within a field known as Knowledge Translation (KT). Over the past two decades efforts have been made, often by professional
organizations, to increase physician uptake of best practices. Professional societies develop guidelines and other protocols (Mykhalovskiy, 2003) describing recommended best practices. Knowledge Translation\(^3\) is aimed toward understanding how scientific evidence is then translated into clinical practice.

Although the field of KT is inextricably linked to EBM, it has become to some extent discursively disconnected from it. Within the KT field, the focus is always on problems and processes associated with transferring knowledge. In this way, the KT discourse obscures the basis for the knowledge being produced in the first place. The knowledge to be translated, or transferred, is usually developed from a positivist scientific model. The development of KT techniques, frameworks, and strategies presupposes that the knowledge should be implemented. The focus is turned away from knowledge production and toward strategies for translating that knowledge into practice. This is an important and unexamined area as creation of knowledge increasingly becomes a “significant element in the coordination and control of all aspects of work in health care settings” (Campbell, in press). I will situate KT as the managerial arm of EBM in order to bring back into view the assumed neutrality of the evidentiary base in knowledge based medicine.

By focusing on treatment for acute stroke, I explore empirically what actual people are doing in their concrete settings as they produce, promote, or try to implement best practices. For Smith (Smith, 1987, 2005, 2006) people’s everyday lives can be studied as sites of interface between individuals and a vast network of institutional relations, discourses, and work processes. Beginning from the everyday lived experience of those in the field I am able to trace how best

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\(^3\) KT is also referred to by a host of similar names that refer to both stages of the research process and/or to the research process as a whole. For a fuller discussion, see the Chapter Three.
practice for acute stroke is produced by actual people in real settings. I explore how that knowledge is then coordinated across various sites, even when the conditions for uptake are not present in all settings, through the development of the Ontario Stroke Strategy. Finally, I compare the experiences of those delivering care ‘on the ground’ against the ideal model of care delivery as it has been institutionalized through the models developed through the Ontario Stroke Strategy.

The involvement of specific people in developing best practice medicine is rarely obvious. Best practices are developed through a complex set of textual rules that erase the actual people who have been involved in their production. They are often disseminated through texts such as professional guidelines that take for granted and leave unexamined the complex of what is available technologically, the local work conditions, plus the availability and support of other professional staff in carrying out these practices. Within the KT discourse, this is subsumed under the heading of context. Context generally refers to any organizational barrier that impedes physician use of best practices.

When this local context is recognized, it becomes a problem to be solved (McCormack et al., 2002) insofar as it must be taken into account in designing strategies to change physician behaviour. There is very little acknowledgement that these practices might simply not fit the local context, no matter how the settings, or those within them, are manipulated and changed. I set out to ask how this happens. As I did, I discovered that medical specialists in clinical trials taking place in academic hospitals are usually involved in developing best-practice evidence. These trials are funded by the pharmaceutical industry and a portion of the funds received are directed to the university. Due to these aspects of their organization, best practices that are
developed are usually acute-care based. The coordination of these complex relationships is largely absent from the EBM discourse.

The systematic reviews producing EBM in specific areas rely heavily on statistical probabilities in arriving at their conclusions. But those expected to implement the best practices derived from such studies are acting in relation to particular individual patients and under particular local conditions. The clinician’s knowledge may thus come to be seen as being at odds with scientific knowledge (Denny, 1999). My study extends this disjuncture to include the texts that are partially produced by academic medical specialists who participate in clinical trials, and thus are part of producing evidence, and the non-academic physicians who are then expected to practice it. All of these factors change how medicine is practiced and introduce forms of management which may constrain, or attempt to constrain, professional practice.

Physician practice, however, cannot be directly controlled and physicians are considered autonomous. The EBM and KT literature tends to treat them as a homogenous group. Thus, the notion of the ‘physician problem’ arises in conversations related to ‘how do we get physicians to change their practice?’ In January of 2008, I attended a workshop with leading researchers and clinical-researchers to discuss wait times, a by-now recognizable marker of what is ‘wrong’ in Canadian health care. The speakers at this conference condemned doctors for their alleged inertia. The problem, it was stated by a leading elite physician, was that physicians had too much autonomy. He went on to declare, “If only General Motors were running this … If we went to GM and saved $1m/day it would be done tomorrow and it would be better for the patient, the doctor and the nurse”. The “it” to which he refers is best practice medicine. The assumption that EBM practices both save money and are better for both patient and clinician has come to play an important role in the discourse around health care reform. The reference to GM also suggests the
valuing of the corporate which is part of the new management of health care. The goals behind knowledge translation efforts are often intertwined with health care reform involving other considerations than the interests of individual patients such as competitiveness, cost efficiency and productivity (Rankin & Campbell, 2006). What, then, is the complex set of social relations underpinning these claims that better health care can be achieved through the development and application of new scientific knowledge? What do these initiatives look like when we explore the lived experience of those providing, and receiving, care? How do the values of competitiveness and cost efficiency factor into those of a positivist and neutral science whose discursive aim is to improve the health of Canadians?

The discourse of the physician problem is troubling, as it directs attention away from the interface between embodied individuals and institutional relations. I am not arguing that physicians don’t have power, collectively through their professional organizations, or in relation to other medical staff such as nurses, within certain medical settings. The assumption behind most strategies designed to address the problem of regional variation is that individual physicians are choosing on an individual basis not to incorporate new and ‘better’ findings in their practice. For example, Mykhalovskiy and Weir (2004) have noted that EBM has “criticized clinical decision-making based on individual experience as hopelessly out of date” (p. 1059).

This study draws on⁴ the notion of situated practices to describe what happens in the everyday working world of delivering acute stroke treatments across various hospital sites. This term is utilized to draw attention to the everyday work of carrying out what is referred to as best practice in EBM discourse. Through this work I am able to hook different physician experiences to the discourse of evidence-based medicine by showing how the participation of specialists in

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⁴ Term “situated practices” has been used by other critical scholars, e.g., Pope and Timmermans and Berg.
clinical studies means they are contributing actively to that discourse. In other words, those who promote best practice are directly involved in developing it in the first place.

This study brings back into sharp view the forms of coordinated work involved in the delivery of acute stroke therapy and reveals the institutional conditions that are taken into account in making a decision whether or not to use rt-PA for the treatment of acute ischemic stroke. My ethnography raises serious questions about some of the concepts embedded within the KT discourse; specifically, the notion of a homogenous physician making decisions autonomously and individually. It will also challenge the theoretical basis for KT research, including psychological theories of physician behaviour and show how conforming to best practices according to the evidence for rt-PA’s effectiveness works within the overall organization of health care delivery. The ethnography will bring into view actual conditions of providing treatment for ischemic stroke and suggest how the notion of situated practices can be used to investigate the ideal of evidence-based practices.

The disjuncture arises when the best practices derived from evidence developed in the idealized EBM settings are applied to the local setting in which the majority of care is delivered. In order to explicate the social relations organizing the moment at which a decision to use the treatment has to be made, my ethnography begins with the development of the Ontario Stroke Strategy as an ideal model for standardizing acute stroke treatment across the province of Ontario. I then examine the various problems that arise in the implementation of this strategy across various hospital settings, linking these problems back to the discourse and ideology underpinning the physician problem as it arises in relation to the EBM and KT literature.
Chapter Two:
Developing The Study

**Institutional Ethnography**

This study used institutional ethnography to explore the original puzzle of why there was variation in best practice stroke care, although as noted, this was not the problematic I later came to identify. Institutional Ethnography (IE) was developed by feminist sociologist Dorothy Smith. Smith refers to this approach as a method of inquiry that uses people’s everyday experiences as the starting point for an exploration of the often invisible social relations underpinning or organizing their experiences. It is a highly sophisticated approach based on her understandings of the social organization of knowledge, although its application does not require an extensive reading of her academic work. The central premise of IE is that we live in a text-mediated world in which relations of ruling are accomplished through texts that coordinate our activities with those of others, although this is rarely visible to us from our particular standpoints. Understanding the social world requires taking up a specific position as a starting point from which to begin to explore how things are put together the way that they are. In this sense, IE is sampling an institutional process rather than a population and provides an alternative to the highly abstract and theoretical accounts of the world often provided through mainstream sociology (Smith, 2005).

The standpoint I take up here is that of physicians working in cities and smaller communities and who are involved in delivering rt-PA for acute stroke. However, while I begin from their perspective, physicians are not the objects of my investigation. The physicians with whom I spoke are held responsible for making clinical decisions in the use of rt-PA for acute stroke. Unlike most qualitative methods, these experiences constitute an entry rather than an end
point into my exploration of stroke care. In this way an IE study cannot be subsumed under the
category of qualitative research although it makes use of its methods.

Locating an institutional standpoint within the experiences of physicians as a framework
of relevance allows me to direct my gaze to how things are organized to standardize a textually
established best practice that must be enacted across multiple locations. These Ontario locations
differ widely in the social organizational conditions under which best practice can be delivered
and hence in the empirical practicalities of treating stroke cases using rt-PA.

**Autobiographical Research Narrative**

Like many other institutional ethnographic studies, my own begins with what has been
called an “autobiographical research narrative” (Mykhalovskiy, 1999). In much research, the
researcher’s presence is treated as a bias that must be overcome (Campbell & Gregor, 2002). As
Smith (2006) notes,

An IE does not rely on notions of objectivity in order to produce “validity”.
However, it does strive to “produce accurate and faithful representations of how
things actually work; it must be truthful. Political commitment here enforces the
researcher’s responsibility to get it right”. It must remain faithful to the accounts
provided by people of their lived experience while going beyond that experience
to explicate how that experience happened as it did. (p. 42)

In February 2002 I was hired by a large urban hospital into the role of Community
Planning Coordinator for a Regional Stroke Centre. I came to this work as a non-clinician whose
background included health services research, project management, as well as administrative and
teaching roles in universities. I was unaccustomed to hospitals, hospital organization, and more
specifically, to stroke. For me, the learning curve was significant. I struggled to learn medical
terms, such as ischemic, endartectomy and care pathways, among many others, as I attempted to
make sense of this new world I had entered. As a sociologist this allowed me a perspective on
what I was observing that was different from those around me. This would change, however, as I slowly become part of the environment in which I worked. Being immersed in the environment which I was studying had implications for the way I conducted and analyzed my research (see section on “institutional capture”).

In my role, I was charged with the task of establishing District Stroke Centres, funded by the provincial Ministry of Health, in seven communities in Ontario. One of the primary designation criterions for becoming a District Stroke Centre was the ability to deliver acute stroke treatments (see Appendix A). This involved the capacity to administer rt-PA for acute stroke. Each centre, was also to provide best practice stroke care across the continuum to a larger region comprising community hospitals, long-term care centres and rehabilitation centres, to name but a few.

The care continuum refers to the various sectors involved in providing care, for example primary care, acute care, rehabilitation and community services. I did not originally consider that the continuum of care did not exist beyond textual accounts developed to discursively organize the goals of the strategy, nor did I suspect that there were any competing resources between the various settings where care took place. It seemed reasonable to me that the entire strategy could be organized around the delivery of acute care without in any way affecting how that care was equitably delivered. The work of establishing District Stroke Centres (DSCs) primarily involved setting up local committees with representation from across the continuum of care. Through the local District Health Councils, I identified key players in each community across the continuum – leadership from health promotion through to acute care on through patient community re-integration – and then invited them to meetings to explain the OSS and seek their participation.

5 The DHCs have been since dismantled and reconstituted as the Local Health Integration Networks (LHINs)
on the committee. These meetings were generally held at the DHCs or in a hospital boardroom. In each community I presented community profiles which related to the capacity for stroke care and asked stakeholders to identify any information or resource gaps. These profiles were largely based on a survey conducted by the Institute of Clinical Evaluative Sciences (ICES) to determine what type of technology and human resources existed in each community related to stroke care (Tu & Porter, 1999). Rarely did the data I present fit the experience of those I sought to represent. At each meeting people expressed that they were not used to working with others from different sectors; for example, physiotherapists has little experience working with neurologists and family physicians rarely attended meetings. The evaluation forms collected at each meeting consistently revealed that few people felt that the numerically generated data – which identified a community’s strengths and weaknesses in relation to stroke care - represented their concerns or experiences. This disjuncture was puzzling to me.

The Regional Stroke Centre into which I was hired originally consisted of a Regional Stroke Coordinator, to whom I reported, and whose job it was to promote best practice and provide care across a large geographic region. A Medical Director lent his medical expertise and credibility to the Region, although he was not involved in the planning work of the region. We were all housed within the Academic Health Sciences Centre within our city although in separate offices on different floors.  

In order to be able to in some way serve the needs of its large and complex geographic region, a Regional Steering Committee was established with representation from across the

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6 There are several levels of hospitals in Ontario. For this thesis I have used the simplified designations of “Academic Health Sciences Centre” and “community hospitals” This distinction refers to hospitals that deliver specialized services and smaller hospitals with fewer resources. For more information, please refer to: http://www.health.gov.on.ca/english/public/contact/hosp/hosp_mn.html.}
continuum of care and across several counties. This involved over nine counties and eventually also included five District Stroke Centres which were designated in the Southwest region. Thus, the geographic area to be covered by one Regional Centre consisting of two full-time staff and one part-time Medical Director comprised 105 long-term care facilities, nine Community Care Access Centres and Public Health Units, three Base Hospitals, over 40 hospitals, and three District Health Councils. The model, then, presupposed capacity on the part of the Regional Stroke Centre – located in just one hospital, despite its implied regional responsibilities – to establish and maintain concrete relationships between the Region and all the organizations it served.

Within the hospital where I worked, I was also part of a large and highly qualified acute stroke team, which included several international fellows, all of whom were neurologists, and a Nurse Practitioner (a fellow refers to a clinician who has obtained funding to complete additional training, either in clinical care or research. They are often recruited internationally and tend to be in the early stages of their career). Two other nurses worked full-time on stroke-related clinical studies; I refer to them as “study nurses” through this thesis. The acute stroke team was distinct from the Regional Stroke Centre staff. Part of the everyday work of the hospital was to attend rounds which were often held over the lunch hour with food supplied by a pharmaceutical company. At these weekly stroke rounds, various expert physicians presented an interesting case, research, or both.

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7 The geographic area covered by each Regional Stroke Centre varied depending on its location. For example, there are three Regional Stroke Centres in the greater Toronto area, serving a smaller but more populous area. In Northern Ontario, there are two enhanced District Stroke Centres. They are not housed at academic sites, but offer higher levels of care, such as trauma, so that they can handle the stroke acuity.
At our hospital, when a patient arrived at the Emergency Department and was identified as having a stroke, a patient stroke protocol was implemented. One of the several stroke specialists, who were fellows, would be paged. A study nurse, whose sole responsibility was to assist in conducting research studies, would be notified to support the physician and also to speak to the family, to assess the time the patient was ‘last seen well’ and to obtain consent for both rt-PA and inclusion in a study. At the patient bedside, using a scale that measured the stroke level of severity, the patient would be assessed to determine the severity of his or her stroke. The patient would be quickly transported to the CT scanner by staff and while s/he was receiving a scan by a technician, the radiologist would be called, as well as one of the neurologists who were considered more senior. After quickly interpreting the scan, and identifying the patient as ischemic or hemorrhagic, a patient identified as having an ischemic stroke would have an IV tube inserted into her or his arm and the rt-PA would be administered. The patient would then be transported to an organized stroke unit where s/he would receive care from several highly trained and experienced nurses and physicians. Not all hospitals have acute stroke units.

Both the process, and the outcomes, seemed miraculous to me. I was very impressed by the efficiency of the system and also by the science behind the drug rt-PA. Why, I thought, wouldn’t every physician want to deliver this potentially miraculous cure to his or her patients? As I became more familiar with an acute care setting, and with the impact of stroke on people’s lives, as well as their families and caretakers, I was increasingly puzzled as to why some physicians chose not to provide the miracle therapy of rt-PA to their eligible patients. I attended national and international scientific conferences and learned how drug companies were attempting to find new drugs that would extend the amount of time rt-PA could be administered.
Other researchers called for new and better imaging (Silver et al., 2001). The reliance on pharmaceutical and technological advances for treatment struck me as innovative and exciting.

At the same time, I also continued my work across the southwestern Ontario region, meeting with nurses and physiotherapists and physicians working in community hospitals. As I drove for hours across country roads to visit community hospitals I became quickly aware of the limited resources and the lack of acute care specialists in the smaller hospitals. On my way to one meeting, I stopped for a sign that read “Horse and Carriage Crossing” and was struck by the physical, visceral differences between smaller community hospitals and where I worked in a large, urban teaching centre. Some of the assumptions hidden within the highly specialized environment in which I worked began to emerge in my consciousness. Smith has introduced the notion of “bifurcated consciousness” (Smith, 1987) in describing her disparate roles as mother and academic. In a similar manner, I began to experience my physical self out in the rural and semi-rural communities as being in contradiction to my administrative role to help the community hospitals expand their use of rt-PA for acute stroke. In my own unease in subordinating what I was discovering experientially to the institutional discourse of implementing the Ontario Stroke Strategy as standardized best practices, I was beginning to touch on those forms of ruling that are mediated by texts (Smith, 2005).

I began to sense, although not yet fully understand, that some relation existed between the ideal world of the evidence-based medicine movement which produced the best practice of rt-PA for stroke and the settings in which the textually specified best practices were taken up in situated practice. And so I began my ethnography, in my insider/outsider role as a non-clinical research associate working with a stroke team for 3 years in Ontario, by speaking with physicians in different settings about how they went about deciding to give, or not give, rt-PA for
acute stroke. In so doing, I began to move away from the theories and debates about physician uptake of best practice medicine to explore what they and others were actually doing in their work. My task as an institutional ethnographer, was to find the social - meaning the forms of organization coordinating people’s work - in the accounts being provided to me.

The Study

I spoke with physicians in various hospital settings about their decisions regarding whether or not to use rt-PA for acute stroke. This was important in order to begin to understand the activities of physicians doing this work. Best practice is a discourse that translates EBM into a guide for how physicians should proceed. The texts it produces include professional guidelines, protocols, and care pathways. But a physician has to make a decision in an actual work situation and be responsive to its realities as he or she enacts them. Most research-based descriptions of physician decision-making are abstract accounts that are not connected to the actual work that they engage in (Graham et al., 2006) or refer to individual psychological explanations for physician behaviour (Bonetti et al., 2003; Eccles et al., 2007; Green & Seifert, 2004). The physicians and other health care providers I spoke with described for me their knowledge of their own work and its part in the process of care. People can describe to you what Smith (2005) refers to as “work knowledge”. It is important to differentiate this from “perspectives”. Work knowledge is what people are able to tell you about their everyday practices and how they are oriented to the work of others active in the same process.

Institutional ethnography emphasizes people’s work and how it is coordinated with that of others. The concept of work refers to what people actually do in particular places, under definite conditions, and with definite resources (Smith, 2003, p. 65). This approach eliminates
the distinction between paid and unpaid work and includes activities that we do not normally consider part of work. For example, in Tim Diamond’s (1992) ethnography of seniors’ residences in Chicago, he describes two elderly women sitting looking at the elevator waiting for breakfast to arrive. Waiting, Diamond tells us, is work. This concept of work and of work knowledges is what the ethnographer draws on in talking to informants. Among other relevances, it opens the possibility of exploring informal aspects of care that are rarely accounted for in professional practice guidelines and of analyzing the role of texts and writing in the work physicians perform.

In Institutional Ethnography the interviews are not endpoints in themselves but instead are starting points which allow me to begin to analyze the context in which rt-PA for acute stroke actually takes place and to understand the features of institutional work that inform the organization required to deliver this care. “When interviews are used in this approach, they are used not to reveal subjective states, but to locate and trace the points of connection among individuals working in different parts of institutional complexes of activity” (DeVault & McCoy, 2006, p. 18). While the physicians, other health care providers, patients and their families I spoke with represented different standpoints, they did not represent different perspectives, which is a concept that individualizes each experience. The IE method is instead designed to capture, through the standpoint of the participants, the invisible institutional coordination of their work that can be heard through participant’s accounts.

The physicians I spoke with worked in settings with different institutional characteristics. Some were from urban, academic teaching centres, host to a Regional Stroke Centre; some were family physicians working in Emergency Departments in semi-rural areas; and at both District and Regional Stroke Centres. They were also from different professional backgrounds; some
were neurologists or stroke fellows; others were internal medicine specialists, and some were family physicians, rehabilitation specialists, or physiatrists. For the purposes of anonymity and clarity, I have referred to them as specialists or District/community physicians throughout this thesis in order to distinguish both the location of where they work and their degree of specialization within medicine. The term specialist refers to (or may occasionally be described as) physicians with specialization, usually in neurology, or clinician-scientists who work in Academic Health Sciences Centres (AHSCs) where Ontario’s Regional Stroke Centres are housed. The term community physician refers to physicians, generally without specialization, who work in either District Stroke Centres or community hospitals.

Institutional Ethnography looks for something outside of the experiences of key informants which is largely invisible to them and yet that enters into and coordinates their work with those of others of whom they may not be aware. Exploring relations beyond the physicians’ experience meant learning from others who were in various ways at work in the same settings. Hence, while I started with physicians’ descriptions, I also conducted approximately 40 interviews over 2 years with other health care providers, patients, and their family members across various sites in Ontario.

The Problematic

The notion of the problematic in institutional ethnography (Rankin, 2004; Smith, 1987, 1999, 2005) does not refer to what those within the setting would necessarily describe as the problem they are facing. It is a technical term that Smith and others use to describe that which is troubling beyond the range of what those working within a particular system can see. It provides the link between what is experienced at the local level and the extralocal forms of coordination
informing it. Those I interviewed identified the problem as the variation in the provincial rates of providing rt-PA, as I also did initially. However, I realized there were other troubling issues. While EBM may generate best practices, these practices have not been readily translated into local practices. Knowledge Translation emerged as a field, and a discourse, that focuses on the translation of EBM into practice. Its emphasis on the process of transferring knowledge directs attention from how that knowledge was produced.

There is also a strong focus on physicians as constituting the problem when knowledge isn’t transferred successfully. In much the way that patient compliance has been both advocated and critiqued, there has been increasing discussion of physician compliance in relation to best practice medicine. Physicians in the community setting are often the intended audience of strategies designed to control their practice. The notion of a change agent has been introduced to describe a person whose role it is to advocate for system change; this has been a notable aspect of the Ontario Stroke Strategy (Black, Lewis, Monaghan, & Trypuc, 2003; Hakim, 2007; Lemieux-Charles, McGuire, & Blidner, 2002). This is largely accomplished through texts such as care pathways and stroke protocols that still target individuals.

The most widely used strategies to change practice have included: educational approaches (Billings-Gagliardi et al., 2001; O’Brien et al., 2001, 2007); strategies that utilize opinion leaders and educational outreach (Doumit, Gattellari, Grimshaw, & O’Brien, 2007); the use of guidelines and clinical pathways (Grimshaw et al., 2006); reminder systems and clinical support systems (Wolff, Taylor, & McCabe, 2004); and financial incentives, such as pay-for-performance measures (Mehrotra, Damberg, Sorbero, & Teleki, 2009). A systematic review of these various approaches concluded only that some things seem to work some of the time (Grimshaw et al., 2004).
Physicians who do not deliver what can be identified as best practice are considered a problem and various educational, psychological or behavioural strategies are developed to encourage them into compliance. Although not a parallel case, Rankin and Campbell (2006) identified how the problems nurses were having with initiating a new work practice were constituted as interpersonal. They were then subjected to such solutions as workshops focused on building interpersonal skills. This diverted attention away from the organizational issues the nurses were experiencing in relation to patient care. In relation to acute stroke, physician work knowledges are trivialized as irrational fear (Katzan, Sila, & Furlan, 2001). I wondered what was being obscured by this particular focus.

IE evolved as a feminist approach to studying the social world and has been most frequently begun from within the experiences of those with relatively little social power. For many IE researchers, the method provides an opportunity to understand and respond to social oppression at all levels (Campbell & Gregor, 2002) and furthers the goals and values of democracy. For instance, Griffith and Smith studied the experiences of single mothers (Smith, 1987); Pence began her study in the experiences of battered women (Pence, 1997); McCoy and Mykhalovskiy (2002) shed light on the health care work undertaken by patients undergoing therapy for HIV/AIDS.

Physicians are often considered the elite within medicine, especially in relation to other health care workers and certainly in relation to patients. It might then seem an unusual perspective from which to take up an institutional ethnography. This does not mean, however, that there are not issues for physicians in relation to the new forms of ruling that invade earlier, well defined professional autonomy. These new forms of ruling would include how health care management (in Canada) or health insurance criteria for treatment in the United States control
physicians’ decision-making in various ways. They also include those forms of ruling or
governance that have been developed from evidence-based-medicine, translated into best
practices which increasingly, through such emerging discourses as Knowledge Translation, put
physicians under pressure to conform.

My study brings back into view all the various others who are involved in the delivery of
acute stroke therapy and reveals the invisible institutional factors that influence the use of rt-PA
for the treatment of acute ischemic stroke. Stroke is a serious chronic and often disabling disease
that has far-reaching consequences for patients, their families, and the health care system. As a
non-clinician, I feel humbled by the dedication of those I had the honour to work with for 3 years
with an acute stroke team. I also feel privileged to have been part of the Ontario Stroke Strategy,
whose members, from the regional and district managers, through to the nurse-educators and
policymakers, have worked tirelessly to improve the quality of stroke care for those afflicted by
this horrible disease. I hope that in some small way my work will be of use to those working
within this system of providing care and that the forms of coordination I have been able to render
visible will be taken up not as an attack but as an illumination. In the end, what I have tried to do
is produce accurate and faithful representations of how things actually work. I have strove to be
truthful and hope that in so doing I have lived up to my responsibility to get it right.

Data Collection Techniques

IE shares with other ethnographic approaches similar data collection techniques
(Campbell & Gregor, 2003, p. 8). Ethical approval for my study was received from both the local
university affiliated with the hospital where I worked as well as through the University of
Toronto where I was a student. All interviews were taped and transcribed. Taping interviews is a
standard process common to most qualitative studies and is not unique for the IE researcher. As two IE researchers describe, “Most IE interviewers tape conversations with informants, both as an aid in making notes and to preserve details whose relevance may not be immediately obvious. Taping also usefully preserves intonation and the emphasis that can be heard in people’s voices” (DeVault & McCoy, 2006, p. 24). The interviews were transcribed and entered into a software program (MaxQDA).

The Data

IE makes use of several types of data, including interviews, observations, and texts. This has been described as first-level data (Campbell & Gregor, 2002) and involves careful descriptions and observations of everyday life. Second-level data involves finding the organizational details that are missing from these experiential accounts. The physicians who I spoke with worked in different towns and cities in the province of Ontario. I also conducted approximately 40 interviews over 2 years with other health care providers, patients and their family members. These interviews were conducted with nurses, physiotherapists, social workers, nurse-managers, program managers, Ministry officials, HSFO officials, and patients and their families across various sites in Ontario.

My observations within the field also became data that I used in my study. Because of my particular location within the healthcare system, I was able to observe and interview everyone involved not only in the delivery of medical care but also in the development of the policies related to the delivery of that care. For example, I was a member of the Committee evaluating the Ontario Stroke Strategy at the provincial level (SEAC); had regular contact with officials overseeing the strategy at the Ministry of Health and Long Term Care; and helped to edit a
Memorandum of Agreement between ambulance services and hospital administrations that was developed to allow patients from outside the region to be diverted from the closest hospital to the nearest hospital providing acute stroke services so that they could receive rt-PA. Having contact with others outside of the direct delivery of rt-PA, but involved in its coordination, allowed me to broaden my understanding of the overall context in which the rt-PA debate occurred.

The literature of both evidence-based medicine and knowledge translation and within medical journals is second level data that is also part of my analysis (Campbell & Gregor, 2002). The idea that social life is discursively organized is a central component of the Institutional Ethnographic approach (Campbell & Gregor, 2002). In much contemporary scholarship it is recognized that simply ‘going and looking’ as a way to conduct ethnography is no longer sufficient. IE allows for the researcher to be attentive to hearing the social organization in people’s accounts of their lives. Analyzing the discourse of EBM allows me to then link people’s accounts back to that discourse and how it becomes enacted in the social settings of people’s everyday lives.

**Institutional Capture**

In addition to my interviews, I engaged in participant observation over a three-year period during which time I was part of an acute stroke team. This was, for me, an amazing and fascinating experience. I was truly immersed in my setting and became part of a close-knit group of international stroke fellows and nurses. It also brought its own difficulties in terms of conducting my research. Smith has identified the difficulties inherent in engaging informants in discussion that goes beyond their institutional rationale in which “the particulars of the informants’ local work are displaced by the “organizational account” (Smith, 2005, p. 156).
Smith has developed the concept of “institutional capture” (DeVault & McCoy, 2006; Smith 2003) to describe those situations in which both the informant and the researcher are familiar with and speak the same institutional discourse. She notes that the researcher may not be aware of the extent of their immersion in the discourse until she is reading a transcript. In my own situation, even while reading a transcript, I remained unaware of an institutional detail embedded in my informant’s account until a second reader drew attention to its remarkable detail. For example, in one interview with a specialist in an academic setting, he refers to how a patient arrived by helicopter. This reference did not strike me as unusual as I worked within an academic teaching hospital where this was the normal experience of everyday work. In crossing from the parking lot every day to the hospital entrance, I had to walk directly past the air ambulance landing zone. When a helicopter was landing, we had to stop and wait until it was safe to cross. Very soon this became a normal feature of my everyday experience and so during this interview conducted early in my study I did not initially notice this feature of the process of care as being notable.

While I sometimes lapsed into institutional language, I also believe that my social location as ‘one of the team’ facilitated the conversations I had with the physicians as they did not see me as an outsider and were perhaps less guarded in masking their accounts with professional discourse. The physicians and other clinicians in my study were willing and able to move beyond the professional discourse to describe to me what was actually happening, although this did not often occur until some time into the interviews.

Another and important aspect of institutional capture is not just how one is embedded within the discourse but also, because of the very nature of the approach, how the researcher is positioned in relation to those being studied. In many ways I have felt conflicted writing my
critique of the Ontario Stroke Strategy given my deep respect for those I have worked with and for their integrity and accomplishment. I believe that many aspects of stroke care have been improved through implementation of the Strategy. The conditions around how and when this happens are not necessarily the same as how they are described in the EBM discourse. In addition, those physicians I have worked with, and continue to work with, are deeply committed to evidence-based medicine as an approach that they believe will deliver the best care that they believe their patients deserve. And in some instances this is certainly the case.

The same is true for my position with the KT field. Knowledge translation as a field has become increasingly popular since I first began my study. I have also gone on to become more and differently implicated in its development. Between 2006 and 2008, I was employed by the Canadian Institutes for Health Research (CIHR) as the Assistant Director Knowledge Translation for two of the 13 Institutes that comprise CIHR. In this unique and interesting role, I was exposed to yet another aspect of the development of knowledge for health care as I worked collaboratively with others to advance researchers’ understanding and use of knowledge translation. Smith has noted that “insofar as ethnographers are at work in universities or other research bases and are teaching and publishing the results of research, or otherwise making it available to people, institutional ethnographers cannot avoid being part, directly or indirectly, of what we are investigating (Smith, 2005, p. 206).

Because of this, I have experienced some sense of betraying those with whom I have worked closely in accomplishing specific professional goals. I have been able to draw upon my personal feelings to better understand how EBM and KT are in fact organized discursively as morally grounded as causes for the social good. I am not alone in this experience. The rise of EBM has been likened by some researchers to a religious movement (Denny, 1999; Traynor,
2002). Pope (2003) applies a social movement perspective to analyze the emergence of EBM. Using Blumer’s theoretical framework (Blumer, 1951/1995), she describes how the evolution of EBM meets the criteria he outlines for defining a social movement. Social movements highlight areas of contested power and she views EBM as the site of a struggle between those within the medical profession, such as between specialists and family physicians, and also between those within the medical profession and those outside, such as Ministry staff or hospital administrators (Pope, 2003). There is tension between basic scientists and clinical scientists, between competing professional organizations (as I will explore empirically later on), between types of physicians, and between forms of management based on information systems and experientially and skill-based knowledge. The field of knowledge translation, then, as an extension of the EBM movement, can also be seen clearly as a struggle between those who produce evidence and those who are meant to apply it.

Those caught in these struggles rarely have any sense that they are struggling over sites of contested power. The moral undertones of EBM discourse, as I will elaborate later on, enter into individual conversations in a genuine manner, insofar as people believe in what they are saying. They believe that through the tools of EBM they will advance patient care. They have no sense that their activities support the interests of, for example, the government, or the pharmaceutical industry. The specific nature of IE’s focus on what is beyond the visible range of those working within a particular setting allows for an exploration of social relations that does not necessarily challenge the personal integrity of those who support ruling relations through their work.
Understanding this has allowed me to investigate and write up the social in a way that does not divorce it from the embodied lives of those with whom I worked and studied. It also does not limit my attention to them.

DeVault and McCoy (2006) note that:

There is no “one way” to conduct an IE investigation; rather, there is an analytic project that can be realized in diverse ways. IE investigations are rarely planned out fully in advance, identifying research sites, informants, texts to analyze, or even questions to pursue with informants. Instead, the process of inquiry is rather like grabbing a ball of string, finding a thread, and then pulling it out. (p. 20)

My own IE was not well planned out but rather emerged from the work that I was doing, located within an urban teaching hospital setting, and charged with the task of establishing District Stroke Centres in community hospitals. The “thread” that I was pulling related to my own observations of the primacy of t-PA in the development of the Ontario Stroke Strategy, as I helped establish District Stroke Centres. I heard, and then increasingly questioned, why this treatment was at the centre of the strategy, and why it remained controversial. How, I wondered, did the use of rt-PA for acute stroke come to be accepted as best practice based on medical evidence? What exactly did that mean? What did it presuppose? And why, if it was such a useful therapy, wasn’t it more widely used?

This study goes beyond representations of evidence-based medicine to examine the institutional settings, which are presupposed in its findings, and to describe how the relevant settings are actually organized in the realities of Ontario health care. The method adopted does more than disclose disjunctures, where they exist; it also draws attention to the realities of treatment as specific forms of work organization among the various professional specializations.
involved that has to be done under definite conditions in a definite time period and with variously available technologies.

The knowledge exists that there are systemic reasons for the failure of rt-PA to be taken up widely. In essence, the entire OSS is designed to restructure the delivery of health care services in order to facilitate uptake of this treatment without adding additional resources to the system. Smith’s understanding of the social is unique in that for the institutional ethnographer, the social does not refer to external and reified systems or policies that exist ‘out there’ but can instead be traced through the work that individuals do that coordinates their activities across various sites.

IE Studies in Health Care

Building on the work of a small but growing group of IE researchers doing work in the area of health care, I set out to study the concrete forms of coordination that informed physician use of acute stroke therapies. Throughout this dissertation I will draw upon their various contributions to the puzzle of how ruling relations are achieved in health care and how this is both created by, and influences, the actions of real people working with particular settings. My goal is to use and build upon some of the IE studies in health care in my analysis rather than isolating them artificially from my study through a formal literature review. For example, I draw upon Rankin and Campbell’s study of nursing work in achieving health care reform and in particular take up their notion of how virtual realities are created by the new information technologies, such as administrative databases (Rankin & Campbell, 2006). The notion of virtual realities is relevant to my study in which physician and hospital performance related to acute stroke is measured and evaluated through information collected through the Canadian Stroke
Registry. These textual realities are then used to further legitimize and privilege the use of a particular biomedical intervention. Eric Mykhalovskiy locates health services research as part of reform of health care in Ontario in his study of *informed*, a two-page publication developed by the Institute for Clinical Evaluative Studies (ICES) aimed toward primary care physicians. He notes that physician reading practices become an object of rehabilitation under the new demands of evidence-based medicine. Under this evaluative gaze, physicians are conceptualized as “indifferent readers” of EBM (Mykhalovskiy, 2003, p. 338). He concludes that critiques of EBM have tended to be abstract. I will in some sense extend Mykhalovskiy’s argument to show how different groups of physicians (academic specialists) are involved in the evaluative gaze of other physicians (community physicians). This produces a discourse of the physician problem that constitutes the non-academic physician as the barrier to the provision of best practice care. This notion then directs attention away from how best practices are developed and constructed. It also masks the process by which patients enter into evidence-based medicine, not just as fortunate recipients of best practice care delivered by academic specialists but also as subjects in clinical trials. I am interested in how the patient’s participation in research affects the clinical care that they receive.

This study takes up at the place where the physician not just reads but also develops and then implements EBM into practice. I did not treat the physician as an individual problem to be resolved but rather took up a physician standpoint to begin to explore and understand the forms of coordination informing their work. My study does not enter into the evidence debate as to whether or not the evidence for rt-PA for acute stroke is sound. Nor do I attempt to make claims about individual physician’s beliefs, attitudes, or psychological characteristics. I do not assume that physicians should or should not implement the best evidence in their practice. Instead I
sought to ask how it happens the way that it does and to render visible the forms of coordination organizing the work of different people at different places in time and space. I do not make, refute or argue theory of knowledge translation; instead I empirically investigate the concrete realities of what people do as they go about their work of delivering acute stroke care. Said another way, the relational aspect of physician application of evidence-based knowledge is the focus of this study. Through my work, I expose the complex set of working relationships, inter-textual relationships, and organization of health care that informs physician practice and argue that the increasing focus of KT efforts on changing physician practice obscures the production of knowledge that precedes it.

In the next chapter I present a brief history of evidence-based medicine and knowledge translation, explicating the processes by which evidence is produced and implemented. I examine both evidence-based medicine and knowledge translation as discourse and begin to identify some of the main assumptions of the literature that I will explore empirically.
Chapter Three:  
The Evidence Base:  
Discourse And Ideology

Background

The institutional ethnographic use of the concept of discourse draws on the work of Michael Foucault (1980). Foucault’s concept of discourse has been defined by Alec McHoul and Wendy Grace (1993) as follows:

In any given historical period we can write, speak or think about a given social object or practice (madness, for example) only in specific ways and not in others. “A discourse” would then be whatever constrains -- but also enables -- writing, speaking and thinking within specific historical limits. (p. 31)

Institutional ethnography has extended Foucault’s concept that is restricted to what is written, spoken or thought to actual “translocal relations coordinating the practices of definite individuals talking, writing, reading, watching, and so forth, in particular local places at particular times” (Smith, 2005, p. 224). People both participate in discourse and reproduce it.

This chapter explores the discourses of evidence-based medicine (EBM) and its complement, knowledge translation (KT) that aims to translate EBM into practice. The emphasis will be on understanding how these discourses act as regulators of how those working within the field of health care come to think, write, and talk about do as they go about the tasks of their everyday working lives (Smith, 1987). The concept of discourse focuses on the texts of evidence-based medicine and knowledge translation as objects of study.

EBM refers broadly to a relatively new yet widely used approach to medical practice that promotes the use of what is known as evidence, produced through particular technologies of both science and epidemiology, in medical decision making. Knowledge Translation is a discourse
that develops strategies and approaches designed to encourage clinicians to make use of this
evidence in their practice. Both EBM and KT rely on certain texts, such as care pathways and
protocols that are used in health care settings. Rankin and Campbell have argued that these texts
of EBM are part of the new public management which increasingly relies on “the expertise of
information professionals, auditors, and managers who generate and use a different kind of
expertise from that of health professionals” (Rankin & Campbell, 2006, p. 10).

The field of knowledge translation (KT) introduces a discourse that extends that of
evidence-based medicine at the same time as it obscures its relationship to the latter. Social
science critiques of evidence-based medicine (EBM) are not being applied to knowledge
translation but rather social science has been taken up in the promotion of knowledge translation.
In the KT literature, the emphasis and focus is increasingly on how to transfer knowledge. The
emphasis on getting knowledge into “action” (Graham et al., 2006) tends to reduce and limit the
opportunities for debates about what type of knowledge (i.e., experiential, scientific, and clinical)
has been excluded from the accepted evidentiary knowledge base. It also creates the misleading
impression that evidence, as it is defined in the EBM literature, exists for all procedures.

In this chapter I will closely examine what constitutes EBM and KT, beginning first with
a description of what these terms refer to and how they have developed historically. It is
important to understand EBM and KT within a historical perspective. I will present a brief
history of evidence-based medicine and knowledge translation and discuss social science
critiques of these discourses. I will also show how EBM has been taken up in IE research in
ways that make visible both its institutional character and its role in health care reform.
In this analysis, knowledge translation strategies and tools constitute the managerial arm of evidence-based medicine. Analysis will show how the notion of the autonomous physician, who is a member of a group treated discursively as homogenous and who is assumed to autonomously make decisions on an individual basis (Armstrong, 2002). This gives rise to what I refer to as the physician problem in which individual doctors are identified as barriers to implementing best practice care. On this basis, strategies are developed that are designed to influence physician behaviour (Eccles, Grimshaw, Walker, Johnston, & Pitts, 2005). By focusing attention on non-compliant physicians, who are ascribed certain shared personality characteristics or attitudes, their different locations and the varying conditions of their work within the health care system are erased.

Proponents of KT are sometimes quite explicit in their adoption of language from business models that have informed broader health care reform and in their uncritical belief in research evidence, coupled with a clear intent to change physician behaviour (Armstrong, 2002). For example, some of these studies focus on physician “compliance” (Cass et al., 2003) or “adherence” (Gifford et al., 1999) and “how to change physician behavior” (Lucas et al., 2004) and even proposed strategies that are active; multiple; and aimed at overcoming barriers to change (Davis, 2006). These efforts uncritically accept that physicians should change their practice. Some of these attempts have included the development of care pathways, protocols and other standardized texts for treatment. These text-based forms of control have given rise to tension between the clinical autonomy of physicians and non-physician experts.

These approaches re-direct attention away from the interface between embodied individuals and institutional relations. Health services research, in which much knowledge translation research is developed, is an evaluation-based knowledge (Mykhalovskiy, 1999).
Through the evaluative gaze of health services research, current health care practices not supported by evidence-based medicine are often viewed as “irrationality and potential waste” (Mykhalovskiy, 1999, p. 2). Under this gaze the physician problem arises through the KT discourse.

The following section describes what evidence-based medicine is, how and when it developed, and its relevance to my dissertation.

**Description and History of Evidence-Based Medicine**

The basic premise of evidence-based medicine is that clinicians can deliver best practice medicine if they adopt evidence that has been developed in the laboratory and then tested in clinical trials which are then systematically reviewed through meta-analysis. Science is developed in laboratory settings and clinical trials take place in hospitals. EBM originally brought into play the discourses of medicine, epidemiology, and science. Three people working within separate professions developed it. According to Timmerman and Berg (2003), Archie Cochrane was a physician captured by the Germans in World War II who become responsible for the welfare and health of 20,000 men. He administered medical aid within the constraints of limited resources and performed only the most basic interventions. He worried that this would result in many deaths and yet, to his surprise, it did not. Conversely, when he was later stationed at a better-resourced camp, he noticed that more patients died when conventional medical interventions were applied. In 1972, on the basis of these observations, Cochrane argued that much medical practice was ineffective or even harmful and advocated the use of randomized controlled trials (RCTs) to test the efficacy of particular interventions.
At approximately the same time, Wennberg, an epidemiologist in the United States, produced an atlas that mapped the frequency of a variety of medical interventions by geographic area. He found significant practice variations in rates of certain surgeries that were related to specific geographic areas. For example, in some areas, radical mastectomies were performed up to 33 times higher than breast-saving lumpectomies in other areas. Wennberg found that higher surgical rates corresponded almost perfectly with the availability of surgeons and diagnostic tests. Clearly these variations could not be explained by chance.

In the meantime, David Sackett in Canada was developing research methods for evaluating the scientific validity and clinical merit of medical innovations and for educating physicians in evidence-based medicine. He is credited with coining the term evidence-based medicine.

Through these combined approaches, levels of evidence are produced that are based on results from research that range from meta-analyses (or systematic reviews) of double-blinded randomized control trials (RCT), considered to produce gold standard evidence (Timmermans & Berg, 2003), through to what is considered less reliable evidence such as clinical experience and expert opinion. This process of developing and transferring scientific knowledge to clinical practice is commonly referred to as transferring knowledge “from bench to bedside” (Lowy, 1996).

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8 Level 1 Evidence: At least one prospective, randomized controlled study has shown that the intervention is beneficial; Level 2 Evidence: At least one non-randomized cohort comparison or multicentre case study or chronological series shows that the intervention is beneficial. Evidence may also be part of extraordinary results for randomized clinical trials; Level 3 Evidence: Professional guidelines in Canada, practice in other jurisdictions, descriptive studies, reports of an expert committee and/or Consensus Panel member’s experience and/or expert opinion
An RCT is considered the gold standard of all medical evidence. RCTs divide patients into two groups, intervention, and control, with results measuring a particular outcome being compared between the two. “Double blind” refers to a research procedure aimed at eliminating bias. Neither the research subjects nor the researchers are aware of whether individual patients are members of the control group or the group receiving treatment. Hence researchers’ judgments are assumed not be influenced by their preferences or interests.

EBM has evolved over time and a large part of its growth has been fueled by the availability of technology. Technology is necessary to run massive and multi-site RCTs, which require computerized databases and statistical software. Arguably, outcomes of RCTs have proliferated to such an extent that eventually physicians and nurses could not keep up with the results being produced. While EBM originally began with simple literature searches and review techniques, it now requires systematic reviews, clinical practice guidelines and care pathways.

There are six steps in the application of EBM as it was originally conceived by Sackett and others at McMaster University (Sackett, Richardson, Rosenberg, & Haynes, 1997). The patient is examined and a clinical question is constructed. Appropriate resources, such as MedLine⁹ are selected, and a literature search is conducted. The selected literature is appraised for its scientific validity. The best evidence, which has been identified from the literature and integrated with clinical expertise and patient preferences, is applied to practice. It is important to note that determining patient preferences and taking them into account is often not well explicated in the literature. Performance is then self-evaluated by the practicing physician. This process introduces new skills to the clinician, including efficient literature searching, and the application of formal rules of evidence in evaluating the literature (Sackett et al., 1997). This

⁹ Medline is a leading biomedical database produced by the National Library of Medicine.
description of EBM immediately reveals the enormous time, resources and skill that would be required to translate this into practice with each individual patient.

In order to help facilitate clinicians in more readily finding the current best evidence, Archie Cochrane and others established what is known today as the Cochrane Collaboration. The Cochrane Collaboration defines itself as “a worldwide endeavour” (Claridge & Fabian, 2005) that identifies, evaluates and synthesizes RCTs in all areas of medicine. It then produces systematic reviews of health care interventions (Claridge & Fabian, 2005) that are the basis of guidelines available for consultation by physicians in clinical practice.

The field of EBM has evolved and grown over time. It has been estimated that there is a 7% annual increase in scientific findings every year (Choi, 2005) or 17,000 new biomedical books along with 30,000 biomedical journals produced annually. One study has estimated that two million articles on medical issues are published annually (Mulrow, 1994). In response to this, professional organizations have developed clinical guidelines that summarize best practice evidence for physicians. Professional guidelines are then taken up in hospital settings as care pathways or protocols that introduce forms that must be filled out that direct the clinician’s attention to what is proper practice and thus standardize treatment.

Despite this proliferation of scientific findings, there are relatively few procedures that are considered best practice according to the standards of EBM. In fact, the majority of treatments fall within what is termed the grey zone; that is, no clear evidence is available for their use (Naylor, 1995; Haynes, 2002).
**Competing Knowledge Claims**

In the medical and health services literature, what constitutes evidence is produced through a biomedical science model that does not acknowledge other methods as producing legitimate forms of knowledge (Green & Britten, 1998). The positivist scientific model rests on assumptions regarding the objectivity of the scientific evidence that ‘should’ inform health care practice.

Haynes (2002), a colleague of Sackett and one of the original developers of the concepts of EBM, has acknowledged that “there is no way to win the argument without a universal standard of truth” (p. 5). EBM, he argues, established a dichotomy between “traditional knowledge versus the “new knowledge” that is based on results from clinical trials. The dichotomous tension produced by these debates, as being for or against scientific evidence, detract attention from investigations aimed at understanding the specific contexts of delivering clinical care. Using a Foucauldian framework, Kim Walker (2003) argues that that EBM is “profoundly imbricated in positivist philosophy and practice”. Foucault wrote “Each society has its regime of truth, its ‘general politics’ of truth: that is, the types of discourse which it accepts and makes function as true” (Foucault, 1980, p. 131). Walker (2003) views EBM as being harmful to nursing practice as it contradicts and undermines nurses’ “ways of knowing”. While she is making this argument in relation to nursing practice, I think it still has important considerations for physicians as well. Walker (2003) argues that:

There are tensions between evidence-based practice understood as a relatively neutral and disinterested system for the dissemination of scientific knowledge to the healthcare professional community and its (often unacknowledged) deeply ideological function as a set of ideas and practices designed to persuade and seduce specific audiences in pursuit of particular vested interests. (p. 145)
As Walker (2003) notes, “the positivist approach of numerical meta-analysis is blind to everything but outcome and fails to observe the generative mechanisms that give rise to such outcomes” (p. 152). She goes on to suggest that instead of asking, “Does this work?” we should be asking, “Why or how does this work in these circumstances?” (p. 152).

The presumption of a universal standard of truth underlying much of the literature is perhaps most strongly expressed in the writings of Lomas who states explicitly that research produces “facts” that must be used in “practices, policies and products” (Lomas, 2007). On the other end of the debate, others have argued that the evidence-based discourse is an example of “microfascism” within the contemporary scientific arena (Holmes, Murray, Perron, & Rail, 2006). Holmes and his team draw attention to how the evidence-based health sciences represent a Foucaultian “regime of truth” wherein only one form of truth, that produced through the RCT, is allowed as fact, thus dismissing 98% of all research. As noted, systematic reviews begin with a broad search of the research literature, which identifies hundreds or thousands of articles on a topic. Then all of those articles not based on rigorously designed RCTs are excluded. The authors then typically review and consider the results from the remaining studies which is typically a small proportion (e.g., 10-50%) of the research articles identified in the search. Yet all the excluded articles were published in peer review journals and were deemed to be valid research information by another group of academic researchers. Holmes et al. also point out how the current literature ignores the relational aspects of knowledge and dismisses the role of values in health care. For them, “the clinician can often be considered such an institutional subject who is presumed both to know the truth of disease and to have the moral and intellectual authority to prescribe treatment” (Holmes et al., 2006, p. 183).
Description and History of Knowledge Translation

Having briefly examined the discourse of EBM, I now turn my attention to the field of Knowledge Translation. Originally it was assumed that once best practice information had been transferred to clinicians through publications in leading journals or clinical practice guidelines, they would be taken up in practice. This was soon proved to be an erroneous assumption. The field of knowledge translation, then, is a discourse that addresses how evidence, once produced, is taken up by clinicians in the field. It introduces various approaches to changing clinician behaviour or improving clinician compliance. Early KT efforts focused on translating research into clinical practice by developing and promoting the use of practice guidelines and other forms of dissemination. When guidelines seemed to fail to change practice behaviour, research turned to finding ways to change physician behaviour, covering the ‘knowledge-to-action’ cycle of research. More recently, some Knowledge Translation researchers have begun to assert the necessity of developing frameworks that establish the theoretical basis of psychological interventions designed to change clinician behaviour (Eccles et al., 2005; Estabrooks, Thompson, Lovely, & Hofmeyer, 2006). For these researchers, lack of theory in Knowledge Translation studies is an important gap that is necessary to fill in order to develop strategies that will more successfully change physician behaviour (Estabrooks et al., 2006).

Graham et al. (2006) have provided a widely used model and related diagram to describe the Knowledge Translation process—the “Knowledge-to-Action” cycle. Graham based this model on a focused literature search related to theories of change. This model, then, represents an ideal model in which knowledge is created, implemented, evaluated, tailored to the local context, and then used again in the development of new knowledge. This model provides a useful text through which to compare this ideal account with what I will refer to as situated...
practice that takes place in real world settings. It also allows for an examination of the various stages and people involved in producing and then translating knowledge that, as it turns out, is not really such a simple or seamless process.

The idea that practice change is both possible and desirable is implicit in Graham’s description of the Knowledge-to-Action cycle. He notes, “there is growing recognition that implementation efforts could and should be guided by conceptual models or frameworks in order to understand the process of change” (Graham et al., 2006, p. 3). The model was developed through a literature search in which 13 planned action theories were subjected to further theory analysis. Graham then constructs a “knowledge to action model” from his analysis with a figure designed to demonstrate “how the steps/actions and factors interconnect in an iterative, organic fashion” (p. 22). This interconnection, however, happens in the abstract only.

In this abstract and textual model, the creation of knowledge is depicted as a funnel in which knowledge is developed through inquiry, refined through a process known as synthesis, and then disseminated through production of knowledge tools. There are no actors in this process and the knowledge produced is always neutral. But how does this model work in real life settings?

When the development of knowledge is taken into account, it is assumed that involving what are typically referred to as end users will resolve problems related to the local context of delivering care. Increasingly, the term end users refers to policy makers and other decision-makers whose priorities focus on funding and system-level issues as opposed to the issues arising at the point of care between physicians and their patients. For example, engaging these groups can lead to greater emphasis on cost-related priorities such as patient length of stay, thus limiting
the scope of physician decision-making to reduce unexplained, and what is assumed to be unjustified, variations in physician practices.

**The Moral Imperative of EBM and KT**

Knowledge translation experts warn that the delay in translating scientific research into clinical practice denies patients the best possible treatment (Davis, 2006; Graham et al., 2006; Grimshaw et al., 2006). Claims are made that the failure to base medical care on the scientific evidence leads to significant practice variation that deleteriously affects the patient’s quality of life and increases not only health care costs but also morbidity and mortality (Davis, 2006).

This moral imperative infuses much of the discourse around both evidence-based medicine and knowledge translation. In EBM, what constitutes evidence is produced through a positivist scientific model that rests on assumptions regarding the neutrality of the scientific evidence that should inform health care practice. It is difficult to argue ‘against’ science. As Mykhalovskiy and Weir (2004) note,

> The research agendas associated with EBM are heavily resourced and framed as win-win opportunities for social scientists. Who can argue with better evidence? Who would take issue with more effective and better quality health care? In EBM, the historic relationship of social science to biomedicine finds new grounds. The pressures and opportunities for social science to join in promoting evidence in health care can limit independent social inquiry of EBM. (p. 1067)

According to promoters of this regime of knowledge, as expressed in Rosenberg (2003), there would ideally be no gap between sound research evidence and its uptake by health care professionals in delivering health care. In accounts such as these, which are abundant in the KT literature, the notion arises that physicians who do not implement findings determined to be best practice are somehow providing inadequate care for their patients.
Originally, the types of variations in medical practice that were the focus of EBM efforts were considered fairly indisputable and quite simple. A commonly cited example is that of the use of Vitamin C to prevent scurvy (Timmermans & Berg, 2003). A more recent example would be the failure to wash hands between patients, for example, which remains an area of concern, and results in a high percentage of unnecessary infections every year in Canadian hospitals (Canadian Institute for Health Information, 2008). It would seem self-evident that getting physicians to use the best practice hand washing techniques is important. Critical scholars in other fields have noted how such self-evident explanations may act as a barrier to empirical study of how work is organized. For example, in discussing the ideological frame of multiculturalism, Ng observes that “commonsensical” explanations work to replace any need to study what is actually going on (Ng, 1995). In much the same way, it has become increasingly accepted that translating knowledge into clinical care and ensuring uptake will improve patient care and patient outcomes. This seems so “commonsensical” that there is no need to study what is actually going on.

Accepting that the evidence produced through meta-analyses of RCTs is best erases the work processes through which that knowledge was produced. It also links EBM to the caring aspect of medical work, in which clinicians seek to provide the best care to their patients. It allows for strong moral pronouncements by KT specialists against physicians who do not make use of best evidence in their work. The terms best practice or best evidence as used in clinical guidelines call up the ethical principle of doing no harm that forms the background of physician practice. It implies that the only alternative to best care would be less good care.

The discourse of evidence-base medicine is produced in part by those publishing in medical journals. For the most part, the specialists, or the clinician-scientists are writing into the
evidence base. The family physicians and emergency room physicians are usually not. So only the specialist is linked into the discourse of evidence-based medicine. Increasingly policymakers and other end users are also being invited to participate in research (Davis and Howden-Chapman, 1996; Kindig et al., 2003; Lomas, 2000; Newton et al., 2007). A stakeholder, end user or decision-maker refers to a person or group who will ‘make use’ of research findings often in policy or hospital administrative settings. They will thus be able to enter into the discourse. How will this change how health care is practiced? Some have argued that research is useful to managers and policymakers to cut costs (Angus, 2005; Denny, 1999; Dopson, Locock, Gabbay, Ferlie, & Fitzgerald, 2003; French, 2001; Rodwin, 2001; Traynor, 2002; Walker, 2003).

**Assumptions of Individual Physician Autonomy in the KT Literature**

Writing about nursing, Traynor (2002) describes the image of the local practitioner that is embedded in discourses that focus on translating medical research into practice. In particular, he cites the work of Jonathan Lomas from McMaster University who has written extensively on how to change practitioners’ decision-making. Traynor (1999) observes that,

Lomas’ picture of the “local” practitioner evokes a number of meanings. He or she is a symbol of individualism; the practitioner who does not practice in conformity to the evidence. At the same time, he or she stands for the multitude of practitioners as opposed to the few who reveal, as if they are priestly channels to another, contextual realm, the ‘external’ evidence. The “local” practitioner is also provincial as opposed to being located at centres of knowledge. (p. 189).

Social science critiques have analyzed this concept of physician autonomy and its decline (Rappolt, 1997; Rodwin, 2001). According to Timmermans and Berg (2003), for example, knowledge translation mechanisms such as clinical guidelines are the result of the movement toward standardization in medicine that had re-emerged in the late 1980s. The authors argue that standardization attempts shifted from a focus on skills, tools, and facilities for medical work to
the content of medical work itself. For them, evidence-based guidelines represent the farthest-reaching and most direct attempt to control the actions of health care professionals (Timmermans & Berg, 2003).

Clinical practice guidelines have increasingly been used in Canadian hospitals. Some social theorists view these guidelines as threatening physician autonomy while others believe they reinforce it. Rappolt (1997) views these guidelines as a clear threat to clinical autonomy, a concept she defines as “complex and ambiguous”. According to Rappolt, the rise of the use of clinical practice guidelines came about “under government pressure to regulate the growth of Ontario physicians’ fee-for-service public expenditure” (p. 977) and she attributes their rise to the new management of health care. The Ontario Medical Association promoted voluntary clinical guidelines in order to both constrain costs and preserve professional control over the content of medical care.

The relationship between various physician groups is obscured in accounts of medical knowledge production. Only some physicians develop evidence while them, plus many others, have to apply it. Despite the acknowledgement of various stages of research identified in the knowledge-to-action cycle that begins with knowledge creation very little critique of this first stage has been written. As I suggested earlier, those who produce evidence are usually acute care specialists working in large urban centres, but those who are to implement these findings are generally non-specialist or alternative specialty physicians working in entirely different contexts.

Knowledge Translation strategies often do not take local working conditions into consideration and when they do, they only become problems to be solved. For example, social influence theory has been used to study physician’s influence by “thought leaders” (Gifford et
al., 1999). An assumption in this discourse is that the practitioner is autonomous and works without the support of others, such as nurses.10

**EBM/KT and Patient Preferences**

David Sackett, considered one of the leading founders of this method, defined EBM as good clinical management supported by the best available evidence that also took into account patient preferences (Sackett et al., 1997). Despite this wider definition of what constitutes evidence, critical scholars have argued that a more narrow application has been applied that assigns primacy to the RCT in establishing best practice due to the hierarchy of evidence upon which its application depends (Klein, 1996; Mykhalovskiy & Weir, 2004). Genuis (2006) postulates that EBM’s emphasis on a hierarchy of evidence has led to what she terms a “reductionist approach” (p. 53). She argues that “this formal ordering of evidential reliability declares the greater credibility of conclusions drawn from RCT-generated evidence than from conclusions arising from other forms of evidence and that this focus on this hierarchy has promoted a sometimes exclusive emphasis on RCTs” (p. 53). One of the self-described founders of evidence-based medicine, however, reflecting on the assumption that this method would lead to better patient care, admits that “so far, no convincing direct evidence exists that shows that this assumption is correct”. (Haynes, 2002, p. 2).

In addition, the patients are not only the sites for the application of best practice care as developed through epidemiological methods; they are also the site for the production of evidence

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10 Certainly physicians are autonomous in relation to other professions such as nursing as they are not paid directly by the hospitals in which they work. They are not subject to the same types of managerial control that other clinical care providers are. For an excellent description within nursing of the role of EBM in health care reform, and how this deleteriously affects nursing practice, see Rankin and Campbell’s “Managing to Nurse: Inside Canada’s Health Care Reform” (2006). However, they are not as autonomous as KT strategies designed to change their behaviour assume. The work within specific local settings; their work is coordinated with and depends upon that of others, such as nurses or specialists; and the care they deliver is also to some extent determined by their patients and their families.
in research. Mykhalovskiy and Weir, in their review of the EBM literature, have noted “evidence-based medicine creates a demand for clinical trials and thus the recruitment of patients into these trials” (Mykhalovskiy & Weir, 2004, p. 1066). In Chapter Seven, I will reflect in more detail on how patients actively enter into research through their participation in these trials.

Summary

Over the past decade, evidence-based medicine has become increasingly important in the management of healthcare. It introduces forms of management which control professional practice and integrate professional decision-making into managerial-financial organization. Evidence-based medicine is based on experimental scientific studies that demonstrate the effectiveness of a given treatment. Both at the experimental stage and at the knowledge translation stage assumptions are made that render the conditions of findings, and of medical decisions, invisible. The conditions under which experiments are done are rigidly controlled and, as others have noted, do not match the real life conditions under which medicine is practiced. The technological and work organization conditions under which studies are conducted in order to produce best practice recommendations remain invisible.

Increasingly, knowledge translation efforts are aimed toward policymakers and other ‘stakeholders’ rather than clinicians. For example, the federal government funded both CIHR and the Canadian Health Services Research Foundation to establish mechanisms to fund research that is specifically administrative and relevant to decision-makers needs. Often researchers must demonstrate a relationship with ‘end users’ as a requirement to qualify for funding. The idea is that in so doing their research will answer particular problems of health care. What this
overlooks is that what is a problem for a hospital administrator or government official (the policy
makers) may well indeed differ from what is a problem as defined by a clinician or a patient.

When scientific evidence is translated into clinical practice guidelines that are then made
available to physicians, it is assumed that the individual physician will incorporate it into their
practice. There is little recognition that the physician who may indeed have individual or
personal responsibility for treatment recommendations does not work alone but rather works
with others (nurses, radiologists, emergency physicians, patients, patients’ families) who play a
distinctive part in how decisions are made and may disagree with the best practice knowledge,
especially on a case-by-case basis. In addition, the EBM notion of patient preferences, while
acknowledged discursively, is not often adequately studied in actual practice settings.

Many accounts of EBM do not examine the actual working conditions under which
physicians deliver care. Clinical decision-making is reduced to conducting a literature search and
finding the most appropriate treatment according to the scientific literature. Working conditions,
resources, texts, are assumed uncritically in these arguments. Dopson et al. (2003) notes,

The importance of local contextual factors, however, has consistently been
overlooked by proponents of evidence based medicine… the day-to-day rhetoric
of evidence based medicine accepts a high degree of predictability and
generalizability of well-founded research evidence. It relies on the assumption that
systematic review of randomized trials will provide reasonable certainty about
what works and what does not work, and that this will generally be true across all
relevant patients. (p. 324)

The participation of doctors and nurses in that research is also taken for granted.
Research has become part of the norm of the physician and nurse’s actual work that is performed
on a daily basis in hospitals and is often a part of the patient’s experience of care. The relation of
the physician to evidence, and how this may affect clinical decision-making, requires ongoing exploration.

In the next chapter, I begin my ethnographic exploration by setting the context for how care was organized in Ontario around the use of rt-PA for acute stroke. Thus my inquiry begins with an examination of the Ontario Stroke Strategy.
Chapter Four:
An Ethnographic Exploration of the
Ideal Model of the Ontario Stroke Strategy

Background

Understanding the context in which care is delivered is acknowledged as an important feature of improving the uptake of best practices (Graham et al., 2006). Yet few studies have clearly delineated what the term means or how it influences physician behaviour (McCormack et al., 2002). In combination with context, the term culture is often applied to account for differences between physician groups or between different health care organizations and to study variations in nursing practice (Manley, 2000).

What is actually happening in various settings tends to disappear from view when the abstract concepts of context or culture are applied. For example, Rankin and Campbell (2006) have shown how the idea of a nursing culture obscures real people. An IE analysis starts in the actualities of people’s lives as they experience them and from there understand the organization of their work that may be taken for granted (Smith, 2003). I did not want to ascribe differences to the local context but specifically “preserve people as active and as doing things in definite places and in the time it actually takes” (Smith, 2003, p. 65).

As I have previously outlined, utilization of rt-PA for acute stroke in Ontario was promoted through the development of the Ontario Stroke Strategy, a joint initiative between the Ontario Ministry of Health and Long Term Care (MoHLTC) and the Heart and Stroke Foundation of Ontario (HSFO). Through a model that proposed the development of Regional and District Stroke Centres, best practice care across the care continuum was to be introduced across Ontario. Thus the Strategy aimed to be a vehicle for knowledge translation across the province
However, several problems arose in the implementation of this strategy, especially in relation to the model of regional delivery of services. This chapter begins with a brief description of the Ontario Stroke Strategy model and then describes how different physicians working in Regional and District Stroke Centres and community hospitals describe both the work that they do in their respective locations and how their work is coordinated with the work of others across the care continuum.

**The Ideal of the Ontario Stroke Strategy**

In the fall of 1998, the Heart and Stroke Foundation of Ontario launched the Coordinated Stroke Strategy (OSS). According to one informant, the Heart and Stroke Foundation had been under some pressure from their supporters to ‘do something’ about stroke. After piloting three OSS sites, HSFO then evaluated their progress. In order to do this, they provided funding to the Institute of Clinical and Evaluative Sciences (ICES) to develop a registry known as the Ontario Stroke Registry. On the basis of the evaluation commissioned by HSFO, the Ontario Stroke Working Group was formed. A report known as the Blue Book was written, by a working group including representatives from MoHLTC, HSFO and ICES among others, outlining what the best practice standards should be across the stroke care continuum in Ontario (Joint Stroke Strategy Working Group, 2000). Following this a 3-year demonstration project was tested and evaluated to pilot a model of regional coordinated stroke care that spanned the continuum of care. The Working Group then made a recommendation to the MoHLTC to provide $30 million

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11 A key informant tells me that through this Registry the Heart & Stroke has provided $2.5 million to the Canadian Stroke Network. That’s Heart & Stroke all across the country, Ontario’s $1.5 million of that. Its remaining money comes from Industry Canada as part of a program called the Network of Centres of Excellence. In this way, ICES became part of the institutional relations behind the developing Ontario Stroke Strategy.

12 The formal name of this report is “Toward an Integrated Stroke Strategy for Ontario, June 2000”.
It is worth noting that although evidence-based best practices were integrated into the strategy, there were also pressures from the healthcare marketplace and the pharmaceutical industry to develop the OSS.

The pressure to approve and promote rt-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”. While the Foundation was confident they could increase public awareness, they were concerned about “the ethical dilemma of increasing the demand for timely and effective care that was not available. (Black et al., 2003, p. 44)

A senior official whom I interviewed told me that the neurologists had first approached them because “their clinical trials weren’t successful because not enough people arrive in time”. There was hope that a government-supported province wide strategy would advance their recruitment of patients for trials.

The goal of the strategy was to provide equitable access to best practice stroke care across the continuum, achieved through the establishment of Regional and District Stroke Centres. The basic structure of the OSS for delivery of services is depicted in Figure 1, which shows the proposed the relationship between the Regional Centres, the District Stroke Centres and the community hospitals. Figure 1 shows that the Regional Stroke Centre was designed to support the District Stroke Centres, which in turn was designed to support the smaller community hospitals.
Figure 1. The Ontario Stroke Model from Southwestern Ontario Regional Stroke Centre (obtained during employment from a PowerPoint presentation made available to staff in 2004).

The model of care depicted in this figure presupposes a relationship between those working across various sites and across the continuum. In the organizational account described in the Blue Book the model “gives community hospitals the support they need to establish organized, evidence-based, patient-centred stroke care” (Joint Stroke Strategy Working Group, 2000, p. 94). But what is meant by support and how is it enacted in everyday working situations?
District Stroke Centres

I am sitting in a physician’s office in a small semi-rural community. He is telling me about the recent designation of his hospital as a District Stroke Centre. He was an experienced physician who had been practicing medicine for decades. He discusses with me how health planners and hospital administration feel that they have met the criteria to be a District Stroke Centre without input from physicians. He comments,

I think administration is going one direction, but the department of medicine is saying hold on, let's solve the manpower issues here before informing the community, as has been done in the newspapers that you have a stroke centre. We don't have a stroke centre …the problem with rt-PA in our community is that the Department of Internal Medicine can no longer provide 24/7 call. We’ve been defaulting regularly. Quite a few nights every month no internist is on call, so to call this a District Stroke Centre when there is no expertise around to manage stroke, is a thing that is really troubling me right now.

In this account, the physician expresses that the community has been informed of the designation of a stroke centre that he thinks does not exist in practice. District Stroke Centres were designated through a complex process involving the District Health Councils and the Ontario Ministry of Health and Long Term Care. The decision to designate a hospital was based on data that indicated the availability of CT scanners for instance, or radiologists. According to one administrator I spoke with, nobody within the OSS, or at the hospitals, would know who would be designated until it was announced. As Rankin and Campbell observe “accountability in health care is a textual product distinct from what actually happens” (2006, p. 21). In this instance, what counts has led to the creation of a stroke centre that exists only in documents. As
the physician points out, “obviously this will be a TIA clinic on paper only, it won’t be seeing patients”.

As I outlined in Chapter Three, proponents of rt-PA call upon the EBM construction of what I have termed the physician problem to explain why some physicians do not make better use of rt-PA for acute stroke. The problem becomes one of non-compliant or unmotivated individual physicians (Eccles et al., 2005; Schwartz & Shulkin, 1995). As one leading stroke specialist declared, “We need to put knowledge into practice. New knowledge is important but the reality on the ground is that patients are not getting the care we know we could provide” (Canadian Stroke Network, 2004, p. 1). The problem, as constructed here, is straightforward: we have the knowledge and just need to put it into practice. There is no awareness of the kind of situation that this physician is describing in which resources are lacking.

According to this physician, the failure of a patient to receive organized stroke care in his hospital had nothing to do with his appraisal of the scientific evidence or individual decision-making. As he states it, “we simply do not have the resources”. He further comments, “So we're not sure that our outcomes are the same as the administrative outcomes and frankly I suspect administrative outcomes basically are driven by the dollar”.

Outcomes in health care usually refer to the results from research or patient outcomes from treatment interventions. The most frequently used outcomes are morbidity and mortality for determining the efficacy of a particular treatment. This physician is commenting that the hospital administration’s notion of “outcomes” refers to financial outcomes.

He then provides a powerful example of the difference between knowing the evidence and being able to provide the best care. In the following account he describes various drugs that
can be used to help prevent stroke. The best class of drug – Warfarin – requires follow-up to monitor levels in the patient’s blood every week. This physician is working in a rural area. Many of his patients do not have a family physician to do a follow-up and that level of care is not provided by the specialist.

For instance, if I see someone in atrial fibrillation, they should be on, or many of them should be on Warfarin to prevent stroke. If there's no one to follow up I'll compromise that situation and put them on Aspirin because I don't have the follow up. If you're looking for one of the reasons why we might have difficulties, well there's an example there of a compromise in patient care, and, no, Aspirin is not as good a drug as Warfarin for stroke; it has some effect, but it’s not as good. But because we cannot manage someone on Warfarin safely, then they won't get it.

He knows the evidence – “Aspirin is not as good a drug as Warfarin for stroke” - but his inability to ensure the patient’s proper management means that he prescribes a less effective drug. The physician, then, cannot make his or her decisions exclusively on the basis of what is considered best practice in EBM terms. Decisions are made within the context of both local working conditions and of the work of invisible others – in this case the family physician to provide follow-up care.

Other staff at the District Stroke Centre believe that problems in setting up a stroke clinic arise out of conflicts between physicians. Jennifer is a young nurse working in the ICU unit of the same hospital as the physician I interviewed. Her job has recently changed from providing patient care to “teaching the staff things related to stroke care, best practice care”. In this account her reliance on the professional discourse related to best practice care is striking. Jennifer tells me that “if you ask one of the nurses what the Stroke Strategy is, or what it does, they wouldn’t
have a clue”. Jennifer knows the person who has recently been hired as the District Stroke Coordinator and through this relationship knows about the OSS. She is not involved with administering rt-PA for acute stroke. However, she has been active in attempts to establish an Acute Stroke Unit and describes for me the problems with establishing it that arise from the different interests of “our internists and our family doctors”. Jennifer recounts her impressions from a recent meeting regarding setting up a clinic. She says,

The problem of initially starting the clinic was the internists didn’t want it to seem that they were taking another thing away from them (the family doctors). The family doctors have their backs up that the internists are taking this away from them or that away from them, and when we were planning the clinic, to me, the whole time I was like, it doesn’t really matter what’s good for the patients, you are just thinking of yourselves and I was really frustrated with the whole process. I thought, we are presenting what’s best practice, what has been proven, and you guys aren’t doing it, it says right here, best practices … I think they’re all very territorial and most of them are older.

But as we talk, Jennifer describes other issues between family doctors and internists. Through the hospital internists can obtain community care for patients through the Community Care Access Centre. A family doctor, Jennifer tells me, is angry because he has to wait months for his patients to see a dietician, an example of patient benefit taking a lower priority to institutional priorities. Jennifer ascribes his response to this as personal and individual, saying, “like he had his back totally up about the fact that we were able to accomplish things the he couldn’t do through his family practice”. She says, “I think these [older] physicians here in this hospital need to be told that they are employees of this hospital and that this is what is going to happen. I guess [it’s because] they’re mostly older physicians too”.

Because of recent changes in training for both physicians and nurses, it is commonly believed that generational differences account for their willingness (or lack thereof) to use evidence-based practices. This issue came up in several conversations I had, with people attributing problems to someone being either young or old. This tendency has been noticed in other studies in relation to other health care professions (Rankin & Campbell, 2006) and also has not held up to empirical investigation (Schwartz & Hupert, 2003). Jennifer’s comments draws attention to some of the divisions between specialists and family physicians.

According to those I interviewed, the OSS was acute based, meaning that most of its focus was on delivering rt-PA, a treatment given at the acute stage in hospital settings. This was driven in part by neurologists in Ontario who needed more patients to participate in the trials for rt-PA. As one administrator said, “the main focus in the fiscal year of 2002 –03 was to really understand the acute piece, because that was predominantly the major goal. Now we understand the acute care piece, which is well over 65% of the funding. And now we’re trying to figure out what to do with the other piece, which is the entire continuum”.

This acute care focus may not necessarily reflect the interests of the physicians working in community hospitals, who were not involved in these conversations. For many of their patients, the three-hour window is simply not feasible, given the large geographic distances and difficulties posed by seasonal weather. Yet when physicians, such as the one quoted above, do not use best evidence medicine it is sometimes attributed to such factors as their age, much the way that Jennifer describes her view of the family physicians who were upset that they could not arrange quick access for their patients to community services.
Stroke victims in large urban centres who are treated in teaching or tertiary hospitals are most likely to undergo CT scanning, to be managed according to a stroke protocol based on the latest scientific evidence and to be considered for rt-PA. According to the 2000 report of the Joint Stroke Strategy Working Group, stroke victims in rural or remote parts of the province are less likely to receive this type of care. Given these systemic factors affecting the delivery of care, it becomes clear that providing equitable access to care rests on more than individual decision-making by physicians. How can community physicians provide best practice care that involves technology and providers, such as radiologists, who simply don’t exist? And in what sense, then, is this best practice if it cannot be implemented?

The clinicians I spoke with felt that the OSS was an rt-PA driven strategy rather than reflecting improved care across the continuum. That is to say, most of its resources are focused on what happens at the acute care stage, i.e., rt-PA for acute stroke. One Nursing Manager told me, “If you look in here [the Blue Book], it’s the first printing of that model that you keep seeing. It especially needs to be updated because its, it’s a very hospital acute-based program initially, there’s no question and it was criticized for that but there’s no question that rt-PA lead to all of this for everything and so you know, what the heck”.

Many others echoed the sentiment that although the OSS was acute care driven, it had drawn attention and funding to stroke and improved services in other areas of the continuum. One community physician described the strategy as opportunist:

My initial impressions were it was driven by rt-PA and that had provided a window of opportunity because it was sexy and it finally gave a tool for acute . . . to actually treat stroke. And as time went by it became clearer to the people there that they would need to incorporate other elements as well, prevention, rehab,
integration, but my impression of it was, initially, was that it was a rt-PA driven process and that the rest of it was there to kind of fill in, and I think it was somewhat opportunistic and we didn't see it as a bad thing.

Others felt that it had done very little to improve care of stroke beyond the acute phase as in the following account by a rehabilitation physician:

There are management problems, you’ve got some that are disabled, that need rehab, there’s no rehab beds up in the nursing home, they can’t speak, you know, there’s nothing sexy about it. And it’s not anything that anyone can fix.

Another community physician echoes the idea that the OSS continues to be driven by acute therapy and that this focus does not add benefit to other areas of care but instead detracts from them: “And its really rt-PA driven, very acute care driven, and there is very little in the way of rehabilitation, I mean, it’s kind of a shame”.

**Problems in the Continuum of Care**

In addition to the physician I interviewed at the District Stroke Centre that he felt existed “only on paper”, many I interviewed felt that the concept of setting up centres to deliver stroke care was not based on local realities. A nurse-educator working in a community centre that had been hired to work within a District Stroke Centre, described finding out that the floor did not even know what the OSS was.

Well starting was very difficult in that I think we had the understanding that everything was kind of in place and that the hospital had bought into the idea of the stroke strategy to find out that the floor wasn’t even really aware that they would start to see stroke patients, nor were the staff prepared for that, and then that there was no infrastructure in terms of having additional allied health that were trained in stroke, so basically you know, we were plunked in the middle of
this brand new program, very excited, and then to find out that really everything was starting from get-go and there was no infrastructure in place for us.

As far as her work was concerned, delivering stroke care was problematic as some of the best practices for stroke also applied to other conditions. She finds it difficult to dedicate herself exclusively to patients who have suffered a stroke when other patients could also benefit from her knowledge and expertise. As she puts it,

Our stroke program falls under Critical Care so there’s already an educator assigned to the Critical Care program. So I also work with her, but I’m only supposed to be doing stroke, and it’s really hard if you’re in a room within a neurosciences program, and you’re trying to do something for your stroke patient and Mr. Smith across the way also has paralysis and yet you’re not supposed to really be in there doing stuff that’s not stroke specific. But at the same time you’re trying to help the nurses. The information I give about stroke is also very applicable to your head patients who have paralysis. You would use a sling for all your strokes, and I’m doing education or in-services on stroke-specific information, but that can be carried over to Mr. Smith who had a head injury. So it’s really trying to stay very focused on stroke, but at the same time making the information applicable to all the patients on the floor, without necessarily being in all the rooms, seeing all the patients.

In this account, the nurse’s work is related to the work of others in the hospital, in this case with the critical care program educator. The models proposed by the Ontario Stroke Strategy did not take this reality into account when nursing educators were hired to deliver stroke education in hospitals. The notion of disease silos refers to the recognition that most diseases are treated separately, by different professionals, even though most risk factors are common across most major diseases. In the past decades, in the field of prevention, there has been a movement to
speak about chronic care models. Chronic care models are meant to challenge the professional and disease silos that permeate much of medicine.

Several strong organizational factors impede this happening. For example, health charities choose to increase their donation base by focusing on a disease brand. For example, the Diabetes Association raises money through focusing on diabetes; the Cancer Society raises money through focusing on cancer. Similarly, various professional organizations organize on the basis of a particular profession. For example, there is a Canadian Cardiovascular Society; there is a Congress of Neurological Sciences and a Canadian Association of Emergency Physicians. Thus, the various types of physician specialties are not actually formally connected to one another. They read different journals and participate in different conferences.

The physicians who worked outside of the acute care sector felt strongly that the relationship between physicians working with different sectors of the continuum was non-existent. In this sense, the continuity and relationship suggested by the term continuum was misleading. As a primary care physician working at a Long-Term Care hospital said:

Long-term care is not a popular area of medicine to be involved in. It is not where the fun is, okay. But they have to be cared for and so some of us who do long term care actually enjoy what we do, but its not the ivory tower, it isn’t that. You still get to prevent things, do a lot of good medicine. The gap between long term care and acute hospitals is the Grand Canyon. There’s never been good camaraderie between the groups, even among the physicians. And they don’t train the students to phone the physician at the nursing home. It’s as if it was a long distance call to Timbuktu.

A community physician specializing in rehabilitation echoed a similar sentiment, saying, “all the [money] went to rt-PA, and rt-PA you know is just where the big money is at, in stroke
care. It's the sexy thing, but you can only treat a certain percentage of people, and even then the impact is not that great. Whereas rehab has a huge impact, and it is starving”.

Relationships across the continuum do not only refer to those between physicians in the delivery of acute stroke therapies. Problems also arise between various professionals, for example, between physicians and nurses or physiotherapists. This becomes evident in the following account.

Judy was a physiotherapist working in a small community hospital. In fact, the hospital itself was so small that I drove past it twice before recognizing it as such. Judy provided an account of a situation with acute stroke where she felt the physician was not properly following the guidelines in terms of providing rehabilitation for a patient following a stroke. The patient was discharged home, which Judy felt was inappropriate. I asked her how she communicated with the physician and she told me, “After I assessed [the patient] the first day I documented all that on the chart. I wrote on my notes and I wrote a note on the doctor’s board. And I did talk to the patient and his wife and unfortunately there wasn’t a bed available then”. Judy comments on why this patient was sent home: “I think some of it is political … one physician said to me, well, it’s just so much paperwork”. In other words, Judy feels that the physician did not want to transfer the patient to rehabilitation because “it’s just so much paperwork”. Yet she does not seem to have a relationship with the physician in which she can verbally communicate her concerns. Instead, she must communicate by writing on the doctor’s board. This is an example of the lack of relationship not only between physicians but also between physicians and other care providers.
I often found it difficult to identify formal or informal relationships between physicians through my interviews. Most of the physicians I spoke with provided speculations about other physicians. As discussed earlier, this can take the form of physician’s general attribution of fear to emergency room physicians’ as a group who are reluctant to provide rt-PA for acute stroke. For example, a physician working in a District Stroke Centre told me, “You don’t have enough neurologists to deal with primary prevention. The GPs and internists out there don’t do it [because] basically they don’t have the time”. One specialist made a similar generalization when he observed “Poor GPs, they have to know the guidelines on so many things, it’s a wonder they keep one or two straight”. A family physician who worked in the emergency department of a community hospital said, “We're in the front line and we see all this stuff, you know. And I know Dr. Big shot and what he does, yea, I've been to a lot of his lectures. And you know, [these] guy’s got, I wouldn’t say tunnel vision, but they're very focused on what they do. But I'm out here seeing the real people, the first line you know, and that's what I see”.

The OSS did recognize that there were problems in the model it proposed of Regional and District Stroke Centres that could provide care to smaller community hospitals. They introduced tele-stroke to provide a link between community physicians and physicians working in the districts or urban centres. One physician working in the District comments on the extra work this creates. He says, “A major issue [now] is how a hospital is trying to become a partner with local hospitals, inside and outside the county. And for the first time in 25 years we suddenly get calls from the docs at these hospitals, ‘Well you're the internist, I've got this case that someone has shortness of breath or chest pain or maybe a stroke and I want to send them to you’. I don't need that”. For this physician, this new relationship is imposed; it does not arise naturally
out of his everyday working experiences of referral. The lack of relationships between various physicians indicates a flaw in how they are conceptualized as a homogenous group.

**Betty’s Story**

The lack of relationships between physicians across the continuum has important consequences for patient care. The following account tells the story of Betty, a 60-year-old patient who had a stroke while waiting for a diagnostic test (angiogram). Her experience is an example of the failure of the referral system and the coordination of care across the continuum. She was the first stroke patient I met in an interview setting and I found our conversation very moving. We met in her apartment a few months after she had returned home after an extended hospital stay for acute stroke. The lingering effects of her stroke were still visible. Although she lived alone, Betty now had help to assist her with the daily tasks of life—that most 60-year-old women can do without assistance.

Betty was already identified as a high stroke risk patient when she suffered a stroke. As mentioned, her stroke occurred while she was waiting for an angiogram, a diagnostic procedure that would potentially have averted her stroke. She had been through several previous transient ischemic attacks, known as TIAs, which often precede a full stroke. Along the way she had encountered several different types of physicians.

Betty’s first contact was with an optometrist. Betty, like many other patients, had problems with her eyesight but “didn’t connect [her problem] with a stroke”. So she makes an appointment with her optometrist who tells her, ‘there is nothing wrong with your eyesight but I think that you are probably having a TIA’. Betty then decided to visit her family doctor, who put
her on an aspirin a day, telling her it would take months to see a neurologist. And he doesn’t refer her. Betty describes this:

So, he just left me on the aspirin a day. Oh, and then I had another problem with the eye. So then I called the cardiologist and his secretary called me back and she said he said for you to get in to see a neurologist as soon as possible. She said there is a TIA clinic. And I said, “oh I didn’t know”. So she gave me a phone number and I did call them and they were saying how long it might take a long time to get in. But, anyway, I called the TIA clinic and then I had somebody from [the specialist’s office] call me and give me an appointment – that must have been his secretary. And I saw [the specialist] and the Stroke Team and they said definitely I needed an angiogram. I had really bad signs of having a stroke if I didn’t get it done.

However, it was another 2 weeks before Betty is able to come in for her angiogram. As she tells me, “I actually had the stroke a few days before my angiogram was booked”. Once again, however, Betty did not recognize the symptoms of stroke. A passerby sees Betty in distress and calls the ambulance. By the time they arrived she was feeling much better. They checked her blood pressure, and suggested she should go in for a check-up at the hospital. She refused, explaining to me, “I didn’t connect it yet. At that point I wasn’t thinking stroke”.

Betty went home and her friend came over. She begins to feel weaker. Her friend contacted the hospital, who instructed Betty to come in to Emergency. Betty phoned her son and his wife. Betty recalled that her son and his wife came over. She tells me that “they were all worried because I didn’t look right and I didn’t sound right on the phone. My speech had started to slur a little bit”. Betty, however, was unaware of these symptoms. Yet at the hospital, she was not diagnosed with stroke. In her words,
But, at the hospital, it ended up that I came home. They didn’t think that I had….
They had no beds, for starts, and they didn’t think that I was having a stroke at
that particular point.

Betty’s sense was that the fact they didn’t have a bed was connected to her misdiagnosis.
This may or may not be true but it is an interesting observation. She does, however, wish she had
been able to stay overnight. She continues:

I know they had no beds but they usually keep somebody until they do have a
bed. But anyways, the next day, I still had more signs of….I was just generally so
tired and couldn’t seem to wake up. So my son took me back to the hospital and
they put me in a bed, that day, on the Sunday. I was admitted.

In Betty’s account we can see how the lack of clear or formal relationship between
various types of physicians seriously impeded her ability to get the timely care she needed. What
also emerges from her account is how much work she has taken on in the coordination of her
own care. McCoy (2005) and Mykhalovskiy (2008) have referred to this as “health work” in
their study of patients with HIV undertaking anti-viral therapy. Although beyond the scope of
this current study, future empirical research could be conducted to explicate the patient’s role in
accomplishing the goals of the Ontario Stroke Strategy.

Summary

This chapter explored empirically how the model for stroke care developed through the
Ontario Stoke Strategy was taken up in practice. It shows how, through the Ontario Stroke
Strategy, “a diversity of experience, perspective, and interest [has been] coordinated into a
unified frame at the institutional level” (Smith, 1999, p. 195). In discussing the chilly climate for
women in academia, Smith describes how “knowing-what-we-are-talking-about does not
translate readily into terms that can be recognized and attend to at the institutional level of organization” (p. 197). Through texts that order women’s experiences, what they know disappears from view, and is invisible to the majority of their male colleagues. In a similar manner, the Ontario Stroke Strategy – grounded in the discourse of best practice care across the continuum - erases the experiences of physicians who do not implement best practice evidence. They are viewed as “resisting” evidence, even when they support evidence but simply cannot apply it in their situation. What they know disappears from the view of their colleagues who may be working in academic health sciences centres and who describe them as being unnecessarily fearful.

In the next chapter I present the accounts of physicians working in the ideal context in which evidence for acute stroke was first developed, at the Regional Stroke Centres located within Academic Health Sciences Centres.
Chapter Five:
Variations in the Implementation of Evidence:
The Ideal Model

The Ideal Model

The ideal model of the Regional Stroke Centres represents a very different standpoint from the conditions experienced in the community setting. The first physician I interviewed from a Regional Stroke Centre is a neurologist. He is part of a large, tertiary care urban teaching hospital and practices in the ideal setting presupposed in the original NINDS Trial for rt-PA. We are sitting in a small musty library in the hospital with shelves lined in medical journals and stacks of books piled on the floor. It’s quiet and far away from the floor where care is delivered. Just outside the window is the helicopter pad where some patients arrive by air ambulance. The specialist will be paged several times during our conversation and I will soon come to recognize this as part and parcel of every interview with a physician that I will do, underscoring for me how busy and unpredictable clinical life is and not lending itself readily to standardization. Various codes will be called at fairly frequent intervals, denoting different levels of response that are required. Nevertheless the specialist is polite and patiently willing to answer my questions.

As we begin, I ask him to take me through an account of delivering rt-PA for acute stroke. He chooses a case and then, leaving out any patient detail, describes the process of care. Within health care, every patient is turned into a case by a set of textual practices that erases his or her experiences and subordinates them to the categories artificially produced. The specialist is describing how he makes the decision about whether or not to treat this case with rt-PA. In this first passage, he references a particular patient he recently treated:
It’s kind of interesting. There were multiple different sorts of novel techniques, things we did, and we probably wouldn’t have done elsewhere. But, essentially they called me. I was on call. [I asked] several questions to make sure, to rule out things. I would not give rt-PA [without ruling out] things like hemorrhage and severe injury or seizures. He had none of those.

In this account, the physician talks about making decisions autonomously. He discusses the conditions under which he would give or not give rt-PA. He also makes reference to the fact that he was on call when he was contacted about the patient. This is a critical component of being able to deliver this service. With few specialists working in the community, there are also fewer physicians with whom to share call. One specialist may have to be on call several days a week, with enormous impact on their personal lives and their levels of fatigue.

The account continues. The specialist notes casually that he arranged to have the patient airlifted by helicopter. He then examines the patient again. As he recounts it, “I examined him; he had effectively a moderately severe stroke. And then I gave him [the drug] in the Emergency Room”. It is notable that the physician refers to the fact that he “gave him” the actual drug in the Emergency Room. As I will show later, the nurse and not the physician normally does this, a small example of how people are invisible in professional accounts of work. The specialist continues to tell me how he had felt confident with his decision. He explained, “I had called all the appropriate people, [such as] the radiologist, to actively get them to come in and set up the angiographic suite for the direct rt-PA”.

This specialist emphasizes to me that he always uses a CT scan. In response to my question as to whether or not he undertook a CT scan in this case, the specialist responds emphatically,
Always, always, always. CT, always, there’s no doubt. I will do three CTs, a CT is like basic. It’s probably even more important than my neurological examination. It’s key, and it provides so much information, so definitely.

In the ideal setting of the Academic Health Sciences Centre, a CT scan is readily available. The specialist can do “three CTs” if necessary. In the community setting, even when a hospital has a CT scanner, there may be heavy demands on it or “no radiologist around” to interpret the results.

Once the patient has been deemed eligible for treatment, rt-PA must then be given. The following is a description by a specialist working in a large urban teaching hospital about the actual process of administering rt-PA. This response is in answer to my question, “Is giving rt-PA time consuming?”

Yes, it is, because first you have to have a fairly well organized team that responds appropriately and effectively and quickly. So you have to be available and be able to sort of leave the ER for 15 to 20 minutes and then once they arrive and if you’re going to give rt-PA, then they’re admitted for the next 3 to 4 hours. You’re doing things, luckily, and you go down and get the patient set up for admission, make sure all the blood work is done (and that) the IV is in the appropriate space. You’re keeping an eye constantly on the patient, clinically making sure there hasn’t been any change, different things.

In this account a “fairly well organized team” is in place that allows the specialist to respond appropriately and effectively. For this specialist, the presence and availability of this team is a taken-for-granted reality. How this gets acted out in the various situated practices is quite different, such as when a stroke specialist is not available to coordinate all these different activities.
The professional discourse of this account hides the presence of many others involved in the delivery of this care. As previously noted, Smith identifies two aspects of what she refers to as “work knowledges” (Smith, 2006, p. 151). The first of these is a person’s experience of what they do, think and feel. The second is the “implicit or explicit coordination of his or her work with the work of others” (Smith, 2006). Citing the example of an interview she did with a steelworker, Smith notes that in his account “there were other unexplicated presences”. She says, “We might think of this aspect of people’s experiential accounts of their work as doors through which the ethnographer may go to open up further resources of knowledge from those at work on the other side of a particular story. Of special importance are the texts that enter into the organization of people’s work and how the text coordinates different work processes. Here are often to be found the key linkages between one person’s work and that of others”. Through my observation, a door was opened through which I began to see “those at work on the other side of a particular story”.

**Observations**

In March 2005, I was speaking with a specialist in the hospital cafeteria when he received a page from a nurse in Emergency that a stroke patient arrived who might be eligible for rt-PA. He and I walk quickly down to the Emergency Department, through a route I’ve never taken before, at the back of the hospital that leads us straight into one of the examining rooms in the Emergency Department. On the way down, the specialist is explaining to me what he knows about this patient from the page. Someone, presumably a nurse already in the emergency department, has already gathered some information. The patient, who I will refer to as Lucy, is 80 years old and has come from another town. Lucy was not sent to her home hospital, as it could not administer rt-PA; this is referred to as a bypass. Her stroke onset was 9:00 a.m. The
specialist says he will need to decide if she is an eligible patient or one at risk for hemorrhage, which he refers to as a bleed. He also mentions that these strokes are generally severe in order for others to recognize them.

We walk into the examining room where a woman is lying quietly in a bed. She looks peaceful and younger than my image of an 80-year-old woman. She also looks well to me; there is nothing about her that strikes me as unusual.

The specialist begins speaking to the two nurses who are already in the room and seem to have already begun some of the steps involved in providing care. An emergency department nurse is drawing blood. The other nurse, who seems more senior, tells the physician that the patient is aphasic [can’t speak], was weak, couldn’t support herself, and that the husband was a witness. The specialist responds “so, it’s good” (meaning she may be eligible for rt-PA). They also discuss whether or not the woman may have come from a non-English speaking country and if this is affecting her lack of response to questions. The specialist points out that the woman’s weakness is already resolving. He says, “See how she puts her legs crossed; she can’t do this if she’s paraplegic”.

A study nurse then arrives and tries to talk to the patient. This nurse is a trained Registered Nurse whose role in the hospital is to manage clinical trials. She rearranges the woman’s air tube and talks to the Emergency Department nurse. It looks to me as if Lucy smiled at her but later I’ll notice that this is her response to everything. The study nurse asks the nurse if the patient is on aspirin – yes.

The physician then receives a page from a stroke fellow from within the hospital. He picks up the phone in the treatment room. Stroke fellows are neurologists who are completing a
two-year research or clinical fellowship. The fellow is paging with a research question about a research database he is setting up. The specialist indicates that he is in Emergency and will have to call him back.

The specialist then approaches Lucy. He asks her to smile, stick out her tongue and asks, “How old are you?” He suggests some ages … 60? 70? 80? She does not respond. This is when I begin to notice that indeed something is wrong. The study nurse and the specialist begin ranking the severity of the woman’s deficits using the NIH Stroke Scale.\(^{13}\) They are sharing the same plastic card and go through the questions together and come up with a number; 10. But there are still other tests to be performed.

The study nurse is then paged out of the room. The Emergency Department nurse picks up the telephone and asks to book a CT scan. She has taken the woman’s blood pressure and reports that it is high. The study nurse comes back in the room and lightly pricks both sides of the patient’s face with what appears to be a simple, silver pin. The specialist says “do her leg, it might be 11. Her one leg is weak, so then, OK for our study, score her a 12”. These actions being performed by the study nurse, then, are to determine the patient’s eligibility for a drug study.

The more senior nurse leaves the room and another arrives. I do not know who the new nurse is. The new nurse says that the woman is 86 years old. The specialist fills out a form called a Consultant’s Report. As he does this, the new nurse telephones the patient’s husband. She tells the specialist that the person with Lucy in the morning had been her friend, not her husband. The specialist then takes the phone and speaks to the husband. He says “do you know what a stroke

\(^{13}\) The NIH Stroke Scale measures 9 indicators, 7 for language and 2 for neglect. Because of this, some scientists have argued that the scale favours the detection of left hemisphere strokes, which are those affecting language. In addition, Canada developed its down stroke scale, which is a modified version that is more suitable for administration by nurses.
is? A stroke is caused by a blockage in the artery. When part of the brain dies, it causes symptoms. It seems like your wife is having a stroke”. The study nurse then takes the phone and speaks to the husband, asking him for his consent to include Lucy in the study she is conducting for the physician.

A social worker then arrives and announces that the patient’s daughter is on the telephone line for the specialist to speak with. In the meantime, the study nurse has telephoned the patient’s son, on another line, to ask for consent for her study. The specialist confirms with the daughter that the patient was ok when she woke up this morning. The specialist asks “Did she speak to you? Do you live together?” It is critical to determine the time when the patient was “last seen well” given the three-hour time window in which rt-PA can be administered.

The paramedics then come in to the room briefly. They don’t speak, except to say hello to the staff, look around, and then leave. I am told that they will now wait to see if the patient needs to be transported back to her home hospital. At 9:50 a.m. an unidentified person comes to take the patient for a CT scan. This entire process in the Emergency room has been quick and hectic.

Both the specialist and the study nurse end their respective telephone calls. The two Emergency Department nurses begin getting the room ready for the administration of rt-PA, setting up I.V. drips and checking for the actual drug. The study nurse reports that the son is on his way into the hospital. She will give him more information about Lucy when he arrives. Her son has described his mother as “independent” and “stubborn”. Interestingly, I am told that this information will be used by the team to assess what the patient’s preference might have been in terms of receiving treatment. The specialist says that he found out that the patient was with a
friend by chance. “He’s an old friend as well” and confirms that Lucy was well upon waking. The specialist then begins filling out notes in his Consultant’s Report.

The study nurse, the Emergency Department nurse, the specialist, and I walk to the back elevator. The specialist is still writing notes. He says “so the son will be in his 70’s” and the study nurse replies “68”. The specialist explains that he doesn’t need official consent but will explain rt-PA to the family. The study nurse does need consent for the study she is coordinating for the physician. The study nurse provides information for this to the Emergency Department nurse who is filling out the consent form.

We arrive at the CT scan department where another patient’s scan is in progress and sit waiting in a small room beside the scanner with two large screens upon which to view the CT scans. The specialist continues to write up notes for his Consultant’s Report. Lucy is taken in for her scan by a technician. The technician goes into the scan room and says, “Hold still”. Another nurse arrives so we are five in a small room. The nurses are discussing the weather; the specialist asks what the date is; a nurse calls to make an appointment for a haircut.

Within a very short time, the specialist is reading the scans that are now up on the screen. He wonders out loud if he’s looking at an old stroke. He also comments that the scan is not clear because Lucy kept moving. She had her head tilted and because she couldn’t respond to directions, they couldn’t communicate with her to remain still. The specialist says “this is the brain of an 80 year old woman”. But he finds it “hard to say” about her current stroke and so pages a senior consultant. We’re also told by one of the nurses arriving to the room that the son has now arrived. The specialist says out loud “son is here by 11:30, 2 hours after onset, so we still have time”.
Someone tells the specialist that Lucy’s blood pressure is a bit high. The study nurse indicates that she is being treated for high blood pressure. The nurse is waiting for a list of medications from Lucy’s pharmacy to be faxed over from another town. At 10:58 a.m. Lucy is wheeled back to the treatment room in Emergency by a staff person. We remain in the scanner room. The telephone rings; it is the consultant answering the specialist’s page. The specialist recounts to him the following information, quickly and without pausing:

Bypass protocol, ½ hour ago
Woke up this a.m. fine
9:30 or 9:15
Having breakfast
(Study Nurse says: “we should look at the ambulance record; I’ll get it when we go downstairs”)
Global aphasic, alert
NIH scale 11 or 12
Study Nurse is here
Son on his way (within 20 minutes)
Have CT scan that is in front of me
High blood pressure and prior stroke – recovered except for problem with writing
Waiting for list of meds
Blood pressure of 185/114 – 10 minutes ago
Independent – does her own cooking
She (the patient) has gone back down to Emergency

The specialist hangs up and the consultant is then on his way to the CT scanner. He arrives within minutes. Everyone who is in the room is staring at the scans of Lucy’s brain. I try to see if I can visibly discern anything but I cannot. The consultant says:

No bleed
Signs of more then one infarct (stroke)
Look for acute ischemic changes
Hard to say because she’s turning her head
Older brain with fragile vessels
10-15% chance of bleeding
Could worsen – won’t recover

A nurse informs both the consultant and the specialist that the neuro-radiologist has the scan now. I assume this has been sent to him electronically as he is not in the room with us. The study nurse, the specialist, the consultant, and I all walk out of the scanner room and back to the emergency room. At the elevators, the consultant says “I’m not comfortable with you seeing a patient” and asks me to leave. The specialist comes back down later to tell me that they have decided not to give Lucy rt-PA after the neuro-radiologist had seen the scan.

**Summary**

Both these accounts describe the administration of rt-PA by stroke specialists in Regional Stroke Centres. They represent what can be offered in an ideal setting. This is not to suggest that problems do not arise in these settings; however, the treatment of rt-PA was designed within and tested in these settings in which a high degree of technology and human resources are available. The number of other people involved in this process is quite striking. Within one hour during my observation, the procedure has involved three trained nurses, two paramedics, a neurologist, a stroke consultant, unidentified staff who have transported the patient to and from the emergency room, a technician who operates the CT scanner, and a neuro-radiologist. An advanced practice nurse has assisted the physician in determining the severity of the patient’s stroke; several nurses have been involved in obtaining relevant clinical information from family members and friends.
But what happens in other centres? What assumptions underlie this account that do not occur in the situated practice of the community setting? I draw upon the accounts provided by the physicians, other clinicians, family, and patients in order to proceed through the process step-by-step of delivering acute stroke care. In doing so, I begin to uncover the disjuncture between the assumptions of evidence based medicine and the local actualities of its translation into practice.
Chapter Six:
Variations in the Implementation of Evidence:
The Community Setting

Background

The impact of stroke on individual patients cannot be adequately described. In the following account a nurse describes a terrible experience she had with a patient afflicted by stroke:

We did have a gentleman who had a stroke, who pulled out his feeding tube and, said “no, no, no”. And the nurses felt it was very purposeful that the wanted to die, he wanted the tube out. The family wanted it back in so he was restrained and an urgent psychiatry consult and we’ve now tied down the feeding tube. I mean he’s 60. He just wanted obviously to die, and that’s not uncommon. And it’s hard for the nurses to see that. The doctors will say, “Well this person is just depressed from the stroke, if we treat the depression they may feel differently”. I don’t know how many times I’ve heard people say that. He’s only 62, and his future is going to be a nursing home. Physicians usually will obviously not want to override the family. You’re not going to get them doing that very much in this day and age of suing and legalities, so this gentleman is tied down and fed again, so. He’s pulled it out now twice so he’s pretty clear on what he wants.

My point in including this nurse’s standpoint is not to argue whether or not stroke patients should be assessed for depression. However, I think it illustrates the enormous impact of stroke on patients, their families, and the medical staff who provide care. It also highlights the implicit promise of EBM, for clinicians as well as patients, and makes very clear why the notion of an intervention that can completely reverse stroke damage is so appealing. However, in the example of rt-PA, the reality may not be quite as clear or dramatic as the ideal suggests it might be.
This chapter presents the accounts of physicians in both community and District Stroke Centres as they go about ‘deciding’ whether or not to treat acute stroke patients with rt-PA. I then discuss the invisible social relations underpinning and making possible the work that is being described. Writing about mainstream sociology, Smith makes the observation that in theory and the attempt to be “objective”, people, and activities “disappear from view” (Smith, 2005). In the physician accounts provided in the next section, the presence of many others that were absent in the discourse of stroke best practice, suddenly appear into view.

Identification of Stroke

The first step in receiving acute stroke care begins with the patient, or an observer. Someone has to be able to recognize a stroke. Even when the patient can recognize a stroke, someone else must be present to confirm the time when the patient was last seen well. However, it is not easy to identify stroke, for even the most attentive observer. For example, with right-sided stroke, patients may be unaware of their own symptoms as damage to the right side of the brain affects the person’s perceptions of self and others, as well as muting emotional responses (DiLegge, Fang, Saposnik, & Hachinski, 2005). A right-sided stroke may not always be apparent to others as well for the same reasons. A deficit in emotional awareness may not present as dramatically as, for instance, a drooping arm or facial feature.

This is what happened for Betty, who I described in Chapter Four. Betty suffered a stroke when she was 60 years old and was unable to recognize her symptoms. She describes for me what happened during her first stroke. She says,

Actually, I was in my car. Well, I hadn’t been having symptoms when I went out in my car. But I had gone to a store, parked my car, and I couldn’t get the door open with my left hand, it went quite weak. And I thought “what’s wrong with
me”. I couldn’t connect anything. I just thought, “this is stupid”. So, I put my other hand over and I opened the car door. I had stopped the car but I just couldn’t get out of the car because I couldn’t open it. I opened it with the right hand and I fell out of the car. But it wasn’t as if I couldn’t stop myself, I just didn’t realize that I was falling out. And I banged my head on the pavement.

In order to increase public awareness of the signs and symptoms of stroke, and to reinforce the idea that stroke constituted an emergency, the HSFO launched an education campaign in 1999. Print, radio and television advertising was shown and evaluated across several regions in Ontario in order to determine what method worked best to raise awareness levels of the signs and symptoms of stroke. Earlier survey research had found that a third of respondents aged 45 and older could not name any of the five warning signs. Advertising was created that focused on the five warning signs of stroke. These are the sudden onset of: weakness, trouble speaking, vision problems, headache, and dizziness. Following the television advertising (which was chosen as the most successful method of communication), the ability to name one or more warning signs increased 27% among those under the age of 65. Interestingly, awareness levels did not change for those 65 and older, although this is the age group most likely to suffer stroke. The Ontario Heart and Stroke advertisements for stroke have been continued until the present time.

Despite these “gains in public awareness”, stroke remains difficult for both the public and for professionals to accurately diagnose, as real life situations are more complex than those implied in the advertising. This produces a rather striking disjuncture between both the marketing literature and the debates regarding physician uptake of rt-PA in medical journals in which difficulties with patient and clinician identification of stroke are often glossed over. The following account, by Ron, a patient’s son, describes the difficulty for onlookers in correctly
identifying stroke. His 80-year-old mother suffered a stroke while she was at the cottage. Bystanders did not recognize it as such. She was taken to a small community hospital and sent home, still undiagnosed. She was transferred to a Regional Stroke Centre (at the son’s urging) where she was diagnosed as having had a stroke. The son, John, was interviewed while his mother was still in a rehabilitation hospital. He tells me,

She was up at the cottage and that’s where it happened. Earlier in the day she had gone into town and I guess that’s when it happened. She banged into a couple of cars in the parking lot. Fortunately one of the guys that she hit was kind enough to take her to an ophthalmologist because she was complaining about her vision. They probably saw her as an old lady who’s just confused. Yea, she’s an old lady driving around in her car, hits a couple people, in the parking lot, gets out, really is sort of confused, doesn’t know what’s going on, so they probably just assume that she’s an old lady. I assume most stroke don’t happen around family members. So yea, that would be kind of hard to catch. I don’t know.

In this account, John is reflecting on the Heart and Stroke campaign to help the public identify the signs and symptoms of stroke. He points out that the symptoms of stroke may not be as easy to identify as the advertisements suggest. This is the case not only for the public but also for clinicians and other caregivers. Once a stroke has been identified by the patient or onlooker and an ambulance has been called, paramedics must then be able to correctly identify stroke and bypass the patient to the nearest hospital offering acute stroke services. The same difficulties in diagnosing stroke that exist for patients and bystanders also apply to paramedics. In addition, ambulance services are a scarce resource. Ambulances attending one situation are not available to attend another. This is especially an issue in rural and semi-rural areas in which an acute stroke patient must be bypassed from the local hospital to the specialized urban regional center. Hospital bypass protocols require explicit coordination between hospitals and between the
provincial government and the local town or city. Bypassing one hospital for another also involves complex issues of repatriation; when and how the patient, after receiving specialized acute care services, is transported back to the home hospital. In order to improve the paramedic’s ability to recognize stroke, a paramedic prompt card was developed through the OSS.

Once the patient arrives at the hospital, clinicians must then be able to diagnose a stroke. Recall John, the son of the woman who was not accurately identified by onlookers in the parking lot as having had a stroke. John describes in detail how once they arrive at the community hospital where his mother was first taken, the attending physician did not immediately recognize his mother had suffered a stroke. He commented: “They did an assessment of her and didn’t think there was anything wrong with her … But it just seems that it was such a basic assessment to me, you know, like if they make a poster about it so that every lay man knows what the five signs of stroke are you would think that the doctor [would know]”. Despite John’s earlier recognition that the signs and symptoms of stroke may not be as obvious as he had assumed from the advertisements, he still attributes the misdiagnosis of his mother to the failure of the individual physician. He states that it just seems like such a “basic assessment” to him. However, as I will discuss in the next section, this is not the case.

In summary, these types of differences in local settings are not addressed in the campaigns, which urge the public to treat stroke as an emergency. The general public assumes, of course, that clinicians will be able to accurately diagnosis a stroke once they reach hospital. The current emphasis on getting new knowledge into practice – such as the advertising campaigns for acute stroke treatments - may have important considerations for patient expectations of the health care that is available to them. This would be an important area for future study.
Problems in Clinical Diagnosis

Many conditions mimic stroke and often physicians, even specialists, cannot accurately identify a stroke through its clinical signs (Hand, Kwan, Lindley, Dennis, & Wardlaw, 2006). One study quoted in the American Stroke Association (2003) Guidelines for the Early Management of Patients with Ischemic Stroke found that in one series of 821 consecutive patients initially diagnosed with stroke, 13% were later determined to have other conditions. One of the key clinical tasks in these cases is to take an adequate medical history in order to establish that the stroke onset is less than 3 hours. This raises the need for stroke specialists to be on hand to deliver care, which contradicts the model of the OSS. As one specialist described it:

Somebody has to know how to ask the really tough, hard questions. When was this patient normal? You know that this patient was normal, how do you know this stroke happened in the last hour? What was this patient like yesterday? That's the biggest problem; emergency doctors don't ask enough questions. They just take whatever the first answer out of the family's mouth or nurse's mouth or paramedic's mouth. That's my big issue with emergency doctors.

As this account makes clear, specialists do not believe that the provision of stroke paramedic cards or other training provided to community nurses or physicians necessarily provides them with adequate skill to diagnosis stroke. This may or may not be the case. However, it again refers back to the disjuncture regarding the type of knowledge that is developed, by whom and for whom. In the above account, a specialist identifies a problem with emergency physicians, that they don’t ask enough questions. He is not specific as to how he knows this or from who, besides the family, nurse or paramedic, the physician would ask these hard questions.
A family physician delivering care within a community hospital corroborates this view that community physician should not deliver rt-PA for acute stroke. He discusses the lack of access to specialized colleagues in his work setting. As he points out,

Not everything that presents with neurological symptoms is stroke. This is another issue and it’s quite difficult for us because we don't sometimes have adequate coverage in the emergency room and people who are skilled in making that determination.

So for this physician, not having enough staff in general, and qualified staff in particular, affects his ability to provide rt-PA. Emergency physicians, usually a family physician, who work in the emergency room of a community hospital, often do not have specialized back-up at their disposal. They do not have highly specialized colleagues with whom to confer.

**On-Call Issues**

In order for a hospital or centre to provide rt-PA for acute stroke, a physician must be on-call 24 hours a day. This is particularly an issue in community hospitals or semi-rural District Stroke Centres, where there are few specialists to share the load of being on call. Physician shortages are common in rural and remote areas. Less than 4% of specialists in Canada practice in rural communities of less than 100,000 population areas (Wootton, 2002). This has led to competing priorities of professionals for whom stroke care may not always be a priority. As one specialist who had worked in the community commented:

There's no compensation for [being on-call to provide stroke care]. You are supposed to know that this is going to be a lifelong learning and you're going to try to do it the best you can, but you know, you get involved in so many things and you end up disregarding something else, sometimes your family, sometimes your personal life, sometimes studying.
While funding issues are of concern regionally and provincially, they have a specific flavour in rural communities. Rural physicians face a different scope of practice than their urban colleagues and may be inadequately compensated for this (Wootton, 2007). In the following account, a community physician describes how being on call to provide acute stroke services affects his personal life.

Yea, I have to be there at the bed side, I have to push the plunger on the syringe. I guess the big issue for me is it's a lifestyle thing. You've got get it to [patients] within 3 hours. And that's part of the stroke thing, you have to be there as soon as the patient comes, so that you can't go out to a nice restaurant, or shopping if you like, you just have to sit there and be available. And I think, a lot of us are pretty resentful about that sort of obligation because it’s not funded. If I come in, in the middle of the night, I think I get paid $50. To do that, if I call for an X-ray, or if the X-ray tech comes in and she gets 3 hours of pay whether she's there for 10 minutes or half an hour.

In this account, what the community physician is describing as a “lifestyle thing” actually refers to the physician’s work conditions. He is also referring to issue of physician compensation, which is a topic of debate within Canada and other countries, such as the United Kingdom.

A physician working in a community setting below refers to the on-call schedule as “enslavement”. Even in an urban teaching hospital, with many stroke fellows sharing call, I observed that their schedule was quite overwhelming. They would frequently be called into the hospital many times during the night, interrupting their sleep and their family lives. As one physician described his experiences of working in the community:

I don't see reluctance on the part of the neurologists except for the enslavement that it produces, so if you are one of two or a single neurologist in a community for a hospital and you agree to do rt-PA, then you have to be available. If you
establish that as your standard of treatment in your hospital, then you have to be available and it’s enslaving because you cannot go anywhere. You're there all the time.

Recruitment and retention of health care professionals has become an important issue within Ontario. Another physician in a community hospital was particularly vocal about discussing these issues. From his perspective, difficulties in recruiting more staff are directly related to issues of what he terms “onerous on-call schedules”:

The on-call is really becoming a huge issue because the younger people, they place lifestyle issues very, very high. They judge a community in terms of how much time they can devote to leisure time activities and if they're faced with an onerous on call schedule, they're not so tempted to come.

This physician attributes the concern with lifestyle, rather than working conditions, as being an attribute of the younger generation of physicians. As noted earlier, younger clinicians also attribute problems to older physicians. These individual-level explanations based on personality or attitude are representative of explanations within the knowledge translation field that attribute variations in physician practice to personality differences or attitudes rather than looking at what people are actually doing in the work that they perform and how that work is organized.

**Problems with Technology**

In 1999, a 35-page survey was sent to 190 hospitals in Ontario inquiring about the spectrum of stroke care (Tu & Porter, 1999). The survey was designed to capture information on many issues including imaging technology and the readiness of hospitals to administer thrombolytic therapy. This study found that family physicians were the attending physicians at
78% of acute hospitals. At the time, only 59 of 190 hospitals reported that they had a CT scanner. Since that time, more CT scanners have been purchased for hospitals.

However, in addition to having a CT scanner, someone must be available to read the results. A community physician described the lack of a radiologist to read a scan properly in the following account:

So a lot of time I'm looking at the CT scan myself and trying to read it myself, and I don't know what I'm looking at. I try, I've looked at lots, I've looked at it with the radiologist, I've taken courses, I've looked at video computer pictures. And time and again, the next day I come back and the radiologist looked at things I didn’t see. And I remember one case a guy came in with a pretty major stroke. I looked at his CT scan, I didn't see much, I gave him rt-PA. And then we reviewed with the neuroradiologist in the [city] a little later and he said oh gee, bad thing you gave him that rt-PA; look at all the damage on the CT scan.

I asked, “Why isn't there a radiologist on call?” and he responded, “There are no radiologists around.” In this example, a patient died as a result of being given rt-PA when the CT scan showed that he was not an eligible candidate. Only later, when a radiologist reviews the scan, is the cause of the patient’s death uncovered.

Robert, a retired high school principal, experienced a stroke in a community setting. His experience underscores that even when the technology necessary for identifying stroke is available, it is not always sufficient. Following a CT scan, he describes his experience of the physician’s uncertainty.

Well I waited there for half an hour until the doctor had the results. And he came in and talked to me briefly… I guess they were a little nebulous and he wasn’t
totally sure whether I had had a stroke or not. So he suggested that it would be a good idea if I went to the stroke clinic.

Robert’s experiences suggest that a CT scan is not always the only, or best, way to diagnose a stroke. Robert goes on to recount how a neurologist in the stroke clinic where he had been sent for further investigation finally diagnosed him through a clinical exam. He says,

[The specialist] said I had had a stroke. He made it very clear, yes, you had a stroke. He was able to determine that by performing tests [the same tests performed by the original physician]. He just did them for himself and determined that it had been a stroke by comparing muscle strength from the left side of the body to the right. That’s basically how he made the determination.

**Patient Preferences**

Within the EBM literature, patient preference should be an important part of physician decision-making\(^{14}\) (Sackett et al., 1997). Not surprisingly, however, stroke patients are often unable to make a decision for themselves about their treatment and so the decision falls to the family. This turns out not to be easy for patients or their families, especially given the time sensitive nature of the decision. One specialist says,

Not being able to make a decision is fairly common because you’re giving them all this information [and saying that] this person who you had previously seen perfectly well, if he only had high cholesterol and he was on nothing initially, is now quite ill. So this is a complete shock, this person, no medications, quit smoking a long time ago. This person was perfectly well and is now all of a sudden is having a severe stroke. If we do nothing he’s going to be completely disabled. And you know, it would take me weeks and months to digest that information alone. And we’re giving them minutes. And the second element is

\(^{14}\) These steps are outlined on p. 38 of this dissertation.
can we now do something potentially very dangerous, potentially something that might kill them.

Others have noted how meaningless it can be to ask patients to be invited to participate in medical decision-making when they do not understand the discourse of medicine (Rankin & Campbell, 2006). Using the example of a case manager who adopts a “patient-centred” approach when speaking with a client who is seeking home care, they note that, “without access to adequate information, he [the client] cannot make sensible choices” (p. 95). In the above comment, the specialist is aware that families are being asked to digest information in minutes that it would take him weeks to absorb. To the extent that such decision-making is difficult, the EBM method of taking into account patient preferences cannot be easily applied in the real world setting. One patient described for me her decision-making process in relation to rt-PA for acute stroke when she was 51 years old. In this example, her treatment was ultimately successful. She told me,

Then they discussed rt-PA and said, “the way you are right now is the way you’re going to be if you don’t have it”. And I was paralyzed completely on one side. I couldn’t process things. I’m going by what they told me too, [they said that] I would look at them with a vacant look like, “what are you talking about?”…. They told me that I would be like that, the way I am now, I’d be in a wheelchair, you know probably, or I could have the rt-PA and it may make a difference. It may not, it might kill me. I remember that, that you could die. I was scared. I thought, what do you mean I could die? I can’t die, you know. It was terrifying.

In this account, it becomes clear that the patient could not really have made the decision to have rt-PA. She is scared. She describes not being able to process information, and explains that bystanders later described her as having a vacant look.
In addition, the EBM method does not take into account the impact on the family of making the ‘wrong’ decision. Since rt-PA carries a 6% bleed rate, the patient can die of the intervention rather than from the stroke itself. A community physician described for me the impact of this outcome on the family. He said,

Usually there's a family member making the decision. It’s rare that the patient themselves make the decision for rt-PA because they are too sick or they don't understand, whatever. So the family member makes the decision. You're telling this family member look you're going to sign this paper because there's a risk that this patient could bleed, and if it happens you feel terrible. And you see their grief and you see they're torn. I made this decision. I mean, doctors, we're accustomed to making these decisions. But as relatives, you know, they do it once or twice in their life time and it is a very hard decision, it’s very hard to cope with to see that you have created such a state of grief and regret on the part of someone who gave consent.

A physician working in a small District Stroke Centre also describes how the decision to treat with rt-PA has a profound affect on family members. These family members are not referenced in the discourse promoting the use of this treatment. It is one thing to have a family member die of stroke, he tells me; it is another to have a family member die because of a decision that was made to treat that stroke.

The final step in the process involves actually administering rt-PA for acute stroke. Again, many aspects of this step are taken for granted in textual descriptions that simplify what is actually a complex process. In the following account, a physician working in a community setting describes what happens when the Emergency Department physicians have initiated a stroke protocol:
Well you establish a protocol. But human nature being what it is, the Emergency docs, as soon as they make the notification that the patient has a stroke and is a potential rt-PA candidate, then they wash their hands of the case. So you get there to find that the lab work wasn't sent back, that the CT scan is still awaiting, that you know, the blood pressure is sky high and nobody has given them a squirt of anything. So they don't manage the case when they get there. The relatives may not have been spoken to or sought. The patient comes in through the ambulance, so nobody made an effort to find the family so they can provide consent. So those are the types of frustrations that one sees in the real world in the small community hospital. It's a little diluted in a teaching hospital because there is house staff and they deal with all the issues.

This physician has described how the best practice text has been activated – in this instance a stroke protocol – but he stresses how in the situated practice setting of the community hospital this gets acted out very differently from the textual account. The protocol is meant to activate a specialized stroke team that doesn’t exist. The emergency doctors have assumed the existence of that team and “washed their hands of the case”. And when the lone specialist does arrive, the entire series of steps outlined in the ideal process have not occurred. The paramedic prompt card, in this instance, has been used to identify the stroke but this has not been sufficient. The process of ambulance transport has itself hindered the identification of relatives from whom consent can be obtained. The CT scan has not been done because no one was in charge to order it. As the physician concludes, “it’s a little better in a Regional Stroke Centre, but in the community it’s difficult”.

**Evaluation of the Ontario Stroke Strategy**

In October 2005, following the release of a report on the evaluation of the Ontario Stroke Strategy, the Minister of Health published a media release with the headline “Ontario Stroke
Strategy Saving Lives, Improving Access to Life-Saving Treatment”. The evaluation to which Smitherman refers was completed during the time period in which I collected my data. In this document, then Health Minister George Smitherman stated that “We are ensuring that all Ontarians have access to quality stroke care as soon as possible. We now have put all the pieces in place for a fully functioning regional stroke care system that will ensure that people affected by strokes get the care they need, when and where they need it”. However, some of the accounts provided in this chapter do not support the idea that a “fully functioning regional stroke care system” has in fact been put in place.

Smitherman goes on to note that initial evaluation of the Ontario Stroke Strategy by the Stroke Evaluation Advisory Committee indicates that Ontario's stroke care system is already having a positive impact through, among other things, reducing “the time it takes for patients needing life-saving clot-busting drugs to receive treatment… by … 35% since 2000”. This would seem an extraordinary success.

What this release doesn’t mention, however, is that these statistics only represent the rates at the participating Regional Stroke Centres, which as I have shown are all urban hospitals with access to the best technology and resources, including stroke teams and physician specialists. The rate for the use of t-PA at acute centres continues to be considerably lower. Some of the official literature acknowledges that “many community and rural hospitals are unable to provide this treatment because of their location or a lack of resources” (Lindsay et. al., 2005). Nevertheless, the Ministry of Health continue to document the uptake of rt-PA use as part of a core set of indicators for measuring “optimal” acute care.
Commenting on the evaluation data, a pronouncement was made in a 2004 newsletter of the Canadian Stroke Network. A high ranking official commented, “There’s no going back … The strategy will lead to huge improvements in outcomes … the CSN has a registry to gather data and monitor progress in hospitals” (Canadian Stroke Network, 2003). Interestingly, this description suggests that because we have a registry to gather data and “monitor progress in hospitals, we will necessarily see significant improvements in outcomes. There are several things to note here. First, the focus on gathering data in hospitals means that what we are measuring relates only to the acute episode. But how accurate is this claim? How did it come to be accepted that measuring and monitoring would lead to better outcomes? And by better outcomes, does she mean patient outcomes or economic outcomes?

The assumption that measuring and monitoring will improve stroke care is not backed up by empirical evidence. Anyone who works in health care has heard the statement, “We cannot manage what we cannot measure”. I have heard it spoken multiple times and have also been at workshops with the widely reported author of the quote, Michael Dector, the former Chair of the Board of the Canadian Institute of Health Information (CIHI). The quote originated in the business literature but was used by Dector in 2000 in relation to the need for more and better data in health in order to measure performance of health care workers and systems. A particular focus of this measurement was on cost. Since that time health care costs have risen dramatically and are now reported to be consuming more than 50% of many provincial budgets.

If the evaluations of the OSS do not necessarily match the reality ‘on the ground’ as I have described it in this thesis, what then could be its purpose? It is in sketching an answer to this question that I am able to sketch a possible and preliminary link from the Ontario Stroke Strategy to the project of health care reform. Rankin and Campbell’s work (2006) explicates the
accounting logic that is at the heart of the new public management of health care reforms. They draw on the work of Geoffrey Bowker and Susan Leigh Star to describe the nature of information systems that are currently utilized in the evaluation of health care and that we can see at work in the evaluation of the Stroke Strategy. They state:

We want Canadians to look at so-called successful health care reform. We point out the danger inherent in treating as ‘truth’ the virtual reality that has been generated within and for the purposes of contemporary management practice. This is the knowledge relied on for constructing (or in this case, restructuring) health care. Our analysis offers many instances where objectified textual accounts of people’s poor health and suffering and their care and treatment – the stuff of health care – may be adequately represented for the calculation of costs and benefits, but be deceptive about lives lived in the everyday world … As ruling practice, the textual representation supports the work of public policymakers, health planners, and accountants even when their interests are different from health care workers and patients.

The Ontario Stroke Strategy has been developed through the texts and also generated through provincial evaluations that collect indicators only at specialized Stroke Centres. These numerical and textual accounts produced through the evaluations of the Ontario Stroke Strategy may be deceptive about lives lived in the everyday world.

Nevertheless, providing rt-PA for acute stroke care continues to be an important indicator of a hospital’s overall rating. For example, Lindsay et al. (2005) state that “To achieve ‘best practice’ stroke care across the country, continuous surveillance of the quality of stroke care will become increasingly important” (p. 364). They continue,

Increasingly, hospitals are being judged on their ability to demonstrate that they are providing “best practice” stroke care. We hope that these indicators will be adopted by hospitals and embedded in routine clinical care as a means of ensuring
a minimum standard of practice and to make transparent to front-line clinicians the criteria by which their performance is being judged. Systematic documentation of these indicators on every stroke patient’s hospital chart, using standard forms or checklists, should be encouraged. (p. 364)

The discourse of such accounts erases the possibility of exploring if perhaps the evidence, as it was developed in the first place, was not intended to serve the needs of all stroke patients, in all settings, and is perhaps inadequate to do so. I am left reflecting on the words of one community physician who explains it thus:

The numbers of times I can use [rt-PA] in a small community like this [is small] and every time I use it it's with some trepidation. So as I say, it’s been an advance, but it’s not something revolutionary. It's moving stroke care along but I think we've got just as much out of the recognition that looking after these patients in a detailed and skilful manner is going to accomplish as much as practically any other physician intervention, you know, controlling their blood sugars, controlling their temperature, preventing aspiration, preventing breakdown, urinary tract infections, enrolling them in very early rehabilitation, these things and skilful nursing, all these things that this is to me the realization of getting this through the heads of people, looking after stroke has been just as exciting and probably has a greater impact than giving rt-PA to a selected number of patients … if you happen to qualify for rt-PA, along that continuum, so be it. But I don't see it a simple therapy that is going to answer the problems that we have about stroke.

Summary

This chapter demonstrates how the situated practice for delivering acute stroke care in the community, or at a District Stroke Centre, does not fit the ideal model of the Regional Stroke Centres developed by the Ontario Stroke Strategy. The steps that are easier to implement in an RCT or in an Academic Health Sciences Centre are more difficult to replicate in a community hospital setting.
Specifically, it is not easy for patients, their families or onlookers to identify stroke and in fact it turns out that it is difficult for physicians to identify as well. Even when paramedics are trained to identify acute stroke, bringing a patient to hospital by ambulance may actually impede the process of delivering care, by separating the patient from their family. In addition, since ambulances do not fall under provincial jurisdiction, emergency personnel may or may not agree to bypass a local hospital to a specialized stroke center, as it will use many valuable resources. Once at the hospital, a stroke protocol might be initiated even in the absence of a qualified stroke team to then carry out the tasks associated with that protocol. A CT scanner might not be available, or the appropriate staff with the right expertise might not be available to read the scans. Families or patients may not always be able to absorb information related to acute stroke and thus are unable to make an informed decision about its use.

The attempt to standardize this treatment across the province does not take these factors into consideration. The medical research of EBM is specifically designed to eliminate or washout the effects of situated practices. EBM has to be taken up and put into action by actual people in actual everyday settings of their work. In the ideal setting where rt-PA for acute stroke was developed, a stroke specialist is on-call who has the support of the Emergency Department physicians, access to adequate technology as well as radiology staff, and specialized nurses. In the situated practice of delivering care, there are often physician retention issues, few specialists, lack of technology and/or staff to interpret CT scans, and few dedicated nursing staff.
Chapter Seven:
Reflections on Developing the Evidence Base for
Acute Stroke in Situated Practice

Background

While beyond the scope of my thesis, several topics arise from this ethnography that merit discussion. The first of these relates to the production of evidence through RCTs. It became clear to me through the course of my ethnographic investigation that physicians and nurses are involved in RCTs as a feature of their everyday work. Anthropologist Helen Lambert (2005) outlines what she believes to be the main critiques of EBM into six categories:

1. Incommensurability of population evidence and individual patient needs
2. Bias towards individualized interventions
3. Exclusion of clinical skills
4. Production of formulaic guidelines
5. Failure to consider patient views
6. Difficulties in translating evidence into practice

It is this latter category of “difficulties in translating evidence into practice” which has been the focus of my own work. Lambert points out that this approach to EBM is “produced as often by proponents as by critics of EBM and does not seek to question the status or value of evidence production and collection itself. Most contributions focus on the problem of introducing, disseminating, and implementing evidence [that is, research findings] in clinical practice” (Lambert, 2005, p. 3). As noted, the focus on dissemination and implementation falls under the Knowledge Translation field and can be thought of as the managerial arm of EBM as it
leads to strategies and texts that are designed to increase physician compliance to standardized treatments across multiple sites.

In this chapter I describe what I observed or was told by nurses and physicians about their everyday practices of participating in clinical trials as they go about their work of providing care in academic teaching hospitals. Through these accounts the invisible social relations underpinning how research and care are coordinated emerge. It becomes increasingly clear that only one group of physicians is in fact part of the development of this knowledge and that this group tends to then promote that knowledge.

*The Clinical Trial in Situated Practice*

As noted previously, there is a paucity of empirical description within the KT literature regarding how evidence is concretely developed in local situations. As I was looking over my transcripts and field notes, I began to notice that evidence is, of course, produced through various types of research. But the participation of doctors and nurses in the clinical arm of that research is taken for granted and unexplored. Research has become part of the norm of the physician and nurse’s actual work that is performed on a daily basis in hospitals. The line between clinical care and the work of producing knowledge is often blurred.

The idea that medical evidence is partly developed through clinical trials was one with which I was very familiar and did not particularly examine. I wasn’t sure where clinical trials took place but assumed it was ‘somewhere out there’. The term held for me some great authority. Yet this changed when I observed the assessment of a patient in an Emergency Room for rt-PA. My observation recounted in Chapter Five records the first time I became aware of how integrated research was with the process of delivering care in an academic health care setting. I
observed the central role of the study nurse in not only recruiting patients for trials but also in providing highly expert care. At first I took it for granted, as did everyone around me, that the study nurse’s purpose in attending this patient is to support the work of the physician, helping to assess the patient’s status, finding out critical information from observers as to the timing of the patient’s stroke, etc. Although she performs these functions, her purpose in carrying out these activities is to determine whether or not the patient is eligible for participation in a RCT regarding neuro-protectants and to seek consent from the family or patient. In this way, the nurse’s work for the study trial means that the patient will benefit from her assistance in the treatment, as these two activities overlap. In a community setting, there are less likely to be study nurses to assist in the work of delivering rt-PA, although there will be other nurses available. But they will not be specifically trained in stroke care. If the patient does not fit the criteria of a particular study, then she or he will not benefit from the presence of this highly trained health care professional. The ethics of this are rarely discussed in the KT or EBM literature.

Conducting clinical research in a hospital setting also impacts the daily work of other health care providers. In one interview, a floor nurse who worked at a Regional Stroke Centre complained to me that one physician’s study was conflicting with the operation of the stroke unit where patients were receiving care. As noted, the re-organization of stroke care relies heavily on bypass agreements that allow patients to bypass their home or closest hospital to be taken to a stroke centre offering rt-PA services. This coordination of services is managed through memorandums of agreement (MoAs) between hospitals. The MoAs specify that patients, following assessment and possible treatment, will be repatriated to their home hospitals. Unless patients are repatriated, then beds in the host hospital are used that could be taken up by local patients.
The floor nurse explained to me how a patient’s enrolment in a drug trial interfered with this process of repatriation. One of her primary jobs, as she describes it, is to facilitate transfers back to their home hospitals. She describes how she originally believed that being sent to a regional centre would be “in the patients’ best interests”. The intent is to allow them to receive testing and other care not available through their community hospital, including rt-PA, before they are sent back to their home hospital. As she explains, the patient’s involvement in research studies delays this process. She said:

I thought the idea of [providing] 24 hours rt – was an excellent idea and it really was in the patient’s best interest. Even if there wasn’t a bed available. I thought it was, but [in] my experience, it’s not working anymore. Because there are now several studies that we’re involved with here that keep patients for 5 days post rt-PA, even if they’re by-pass patients, so I can’t remember the last person I sent back from by-pass.

For this nurse, caring for bypass patients who remain in beds for 5 days post-rt-PA solely because they are involved in research studies is not in the patient’s best interests. In a sense, part of the work being done at the hospital is the production of evidence. It becomes part of the day-to-day work performed by clinicians and affects their practice, as the nurse describes above. It is assumed that the production of this evidence will benefit patient care. A closer empirical examination reveals that this is not always the case. As the floor nurse explains to me, above, the bypassed patients are not being repatriated to their home hospitals because they are participating in “several studies”.

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15 Rankin and Campbell (2006) have described how the practice of setting and monitoring patient’s length of stay (LOS) as a key indicator of hospital performance has led to some staff viewing patients as bed blockers.
This also affects the work that physicians do. For example, one community physician explained to me that he didn’t mind being on call while he was in the community because “to be truthful, I was running a clinical trial so my way of capturing every patient was to tell the Emergency Room docs and nurses as soon as a stroke comes in, call me on the phone and then I'll decide if its appropriate or not”. In this instance, the physician’s decision to make her or himself available to be on-call for any potential stroke patients is partially related to his involvement in a clinical trial. He says that he doesn’t mind being on call because then he can screen patients for participation in his trial.

Participating in clinical trials is a way of maintaining or increasing a physician’s academic status. Increasingly, physicians working in academic health centers are called upon to train in Master’s programs, usually in epidemiology, so that they can become clinician-scientists. Few have studied how this affects their working conditions or their ability to provide care for their patients. The assumption remains that research will lead to increasingly better treatments and interventions. But it may also reduce the hours a physician is available to provide direct patient care.

In the EBM and KT literature, physician decision-making is sometimes theorized as being the result of their personal experiences of any given treatment (Gabbay & le May, 2006). So, for example, if they have a good experience they will continue to use a treatment; however, if they have a bad experience, they will not. The physicians I interviewed who were involved in research trials for rt-PA were more likely to advocate its use regardless of their experiences. In the following account, two physicians I spoke with described witnessing the miracle of rt-PA. In the following account, a specialist describes his experience:
I infused the patient within half an hour and the patient began moving his arms and within an hour he was talking to me. So you know, it was one of these Lazarus phenomenon and whether it was the rt-PA or not, who knows, the point is that it was such an impressive thing that I fell in love with it. I said, “wow, this is the way to go”. So if I had a bad experience I would have been more cautious, but my first case was a Lazarus type of thing. Get up and go, pretty well. He walked out of the hospital with no deficit.

The specialist also observes, “whether it was the rt-PA or not, who knows”. The mechanism by which rt-PA resolves ischemic stroke is not as well understood as one might expect. For a certain percentage of strokes, there is no way of knowing if the patient’s symptoms would have resolved on their own. Hence, though the physician was unwilling to attribute the resolution to the rt-PA, he “falls in love” with it. Later, this same specialist went on to have negative experiences. As he described it:

To the extent that years later I was wondering what I was doing and sure, I began double guessing myself, not wanting to do it because I had disasters. I had bilateral brain haemorrhages in people whom I felt were ideal candidates, and not just from the site of the stroke bilateral, disastrous, so you know, I’ve killed probably three to four people with rt-PA since I started giving it in 1996.

Despite “not wanting to do it because I had disasters”, this physician continues to administer rt-PA for acute stroke. He was involved in the trials for rt-PA and works at a specialized centre who deliver this treatment and so he continues, despite having “killed probably three to four people”. Another community physician I spoke with references the long-term benefit that rt-PA could provide and acknowledges that it is a benefit he may never witness but still believes in. He says,
I've seen the data from the studies and there's not a lot of magic in that, but to me it just raises the whole issue of disability, of later disability. With the drug you might make a 50% recovery. Without the drug you might make a 30% recovery; well that's a big difference to a person's life even though I might not see that. I can't appreciate it at the bedside whether it’s done good or not.

This physician was one of the few who referenced the fact that the main affect of rt-PA in the original NINDS Trial could only be observed at 3 months. No scientific evidence produced through RCTs supports the observation of the Lazarus effect. It is interesting that it continues to play such a large role in public promotion of rt-PA and also in physician conversations.

In the accounts provided above, the physician’s experience does not explain their treatment decisions. Yet most doctors predicted that, for other physicians, having an early bad experience could affect your decision to treat with rt-PA in the future. This echoes the professional discourse of KT in which individual-level explanations are used to explain variation in physician practice. For example, one specialist said,

I think you just have to have one bad bleed and it colours your whole use of things, you know. A young man of 56 that was a diabetic, he came in and he fit the bill very nicely and he had a moderately severe deficit. He was a good candidate for it and unfortunately he bled [after receiving rt-PA]. But he had a very high sugar at the time and it wasn't completely controlled so we recognized that as an adverse feature to his case. But it was a sad one because he was a young man. Once you have a big bad bleed the chances are you're going to go to the happy hunting ground, as we say.

Again, this “one bad bleed” did not prevent this physician from continuing to deliver this treatment. He is, however, postulating that a negative experience might effect someone else’s treatment decisions when he says “I think you just have to have one bad bleed and it colours your
whole use of things”. Another specialist claims that he bases his decisions on the scientific evidence. As he describes it, “I understand that the outcomes are worse without it so I’m willing to impose on the patient the small risk of hemorrhage for the large benefit of results. It’s just a trade-off issue”. This same specialist, however, also believes that other non-specialists will not understand and so will be more strongly influenced by their negative experiences.

In situated practice, the experience of delivering rt-PA for acute stroke may or may not fit the experiences reported from the original NINDS trial. The results can be positive but not necessarily attributable to rt-PA; they may be positive but not necessarily observed; and they may be negative but not prevent the physician from using it again. The contradictory outcomes from delivering rt-PA for acute stroke are well highlighted in the following account by a physician who worked in the community:

And I've had one other case that I can remember well of a patient that presented with a brain stem stroke that we thrombolysed and who had complete resolution of symptoms, remarkable resolution and 24 hours later … he died.

**Physician Support of rt-PA**

If personal experiences do not necessarily shape a physicians treatment decisions, what does? Most of the physicians I interviewed who actively supported the use of rt-PA were neurologists practicing in Academic Health Sciences Centres, which were also where the Regional Stroke Centres were located. They had often been involved in the original trials associated with rt-PA. Their excitement about rt-PA for stroke had less to do with the evidence as with the fact that there was now something that could be done at all. One specialist told me:

Oh great, for the first time we can use something. I mean, I wanted to jump on the bandwagon of treatment because I grew up in neurology when we didn't have
much to offer. So when somebody came along and said “look do you want to do something acutely that can improve outcomes”, I jumped on the bandwagon right away.

I want to draw attention to this statement. The image produced through the discourse is that of the unbiased clinician who appraises the scientific evidence and then decides whether or not to use it in any particular instance. What was driving this specialist, who deals exclusively with acute stroke, was the fact that “for the first time we can use something”. He “jumps on the bandwagon right away”. He has reasons, good ones, beyond the science base to implement this new treatment. This type of institutional factor related to medical decision-making is rarely described in the KT discourse.

Early in my analysis I created a map (see Figure 2) showing the relationships between the Regional and District Stroke Centres, the community physicians and the OSS. The map shows how in the model of the OSS, the specialist’s working knowledge has been central to the development of the OSS and the specialist occupies the position of initiator or innovator. The specialist is also the person who has the connection with the medical research discourse through participation in RCTs. Not surprisingly, in my study the specialists working at Regional (and sometimes District) Stroke Centres were most likely to be involved in producing the evidence for acute stroke. They were also most likely to promote its use. In addition to being developed in urban, specialized settings, and perhaps because of it, rt-PA is most useful within those settings. In the community setting access to such treatment varies with several central features of organization, as I have outlined previously.
Figure 2. Organizational structure informing physician decision making.

Despite the relative absence of debate amongst the physicians I spoke with regarding the scientific evidence for rt-PA, it is worth noting that its acceptance as best practice care did not come about readily. Following the NINDS Trial, in August 2000 The American Heart Association (AHA) upgraded its recommendation of rt-PA for acute stroke from an optional class to a Class 1 definitely recommended (Lenzer, 2002). Some felt that this recommendation came despite continued concerns about the safety and efficacy of the treatment. I will summarize these concerns here. First, the recommendation by the American Heart Association was based on one trial. Unlike the NINDS Trial results, most other RCTs have shown that thrombolysis increases mortality in acute ischemic stroke. In addition, many more patients in the treatment arm had mild stroke scores at baseline, while more in the placebo arm had worse scores.
Therefore, at least some percentage of those patients in the treatment arm had symptoms that would have resolved themselves without any intervention. In addition, the external validity of this particular trial has been questioned since the proportion of patients enrolled in the 0-90 minute group was artificially increased through study design criteria. Chance alone could explain the benefit shown in this single study.

Because many physicians did question the scientific validity of evidence produced through a single study, the European Agency for the Evaluation of Medical Products called for another RCT to establish its efficacy. In response to this challenge of the scientific evidence, various clinical and observational studies were undertaken to see if real life experiences of delivering rt-PA for acute stroke would mirror those of the NINDS trial. For instance, one study followed patients treated with rt-PA from December 1, 1998 to February 1, 2000 at a Regional Stroke Centre in Ontario (Silver et al., 2001). The NINDS criteria were followed, except for one major exception. Patients with less severe stroke were not included. Compared to the NINDS trial, more patients were treated after 90 minutes and also tended to be older, factors associated with poorer outcomes. Despite this, the results of the NINDS trial were matched and even excelled. The authors conclude that “imaging exclusion criteria may optimize the benefits of rt-PA”. Proponents of the use of rt-PA for acute stroke now marshaled this additional, although less robust evidence (according to EBM standards), to support their advocacy for its use.

However, this ‘real life study’ was still conducted at a Regional Stroke Centre, in turn housed at an Academic Health Sciences Centre. The improvement in results was related to better imaging, achieved through CT scans that were expertly read by specialized radiologists. And efficacy in expert hands is not the same as clinical effectiveness in usual clinical practice.
Through the OSS this intervention was standardized as best practice and implemented in settings different from that where it was originally designed.

**Debates About Who Should Provide rt-PA**

One of the key questions that arose in relation to this treatment was that of who should deliver the therapy. The emergency stroke patient arrives at the Emergency Department and will be assessed by an Emergency Physician, who in the community setting is typically also a family physician. Yet the Canadian Association of Emergency Room Physicians (CAEP) issued a position statement in January 2001 that questioned the scientific evidence for stroke. They stated that “until it is clear that the benefits of this therapy outweigh the risks, thrombolytic therapy for acute stroke should be restricted to use within formal research protocols or in monitored practice protocols that adhere to the NINDS eligibility criteria” (Canadian Association of Emergency Room Physicians, 2001, p. 11). They recommended limiting the role of the Emergency physician to identifying stroke and initiating CT-scans, but urged that “only physicians with demonstrated expertise in neuroradiology should interpret head CT scans used to determine whether to administer thrombolytic agents to stroke patients. Neurologists should be directly involved prior to the thrombolytic administration”. (p. 8). In these statements one can see emerging the different professional standpoints informing the experience of physicians.

The CAEP position statement led to many arguments taking place in medical journals and at conferences. In these textual exchanges, the discourse of EBM was drawn upon to debate the evidence for and against the use of rt-PA for acute stroke. For example, in the journal Stroke, the editor argued that awareness of the risks and benefits of rt-PA was insufficient “regardless of specialty”, and further argued that “an unjustified fear” of rt-PA side effects might limit a
patient’s access to this treatment (Katzan et al., 2001). In this discourse, then, the issue of patient access becomes the discursive moral centre of the argument for rt-PA and notions about individual physicians’ feelings or attitudes are to blame for their ‘insufficient’ practice.

Indeed, most urban specialists I interviewed attributed the variation in use of rt-PA for stroke in community settings to irrational fear on the part of the community physicians. They tended to make this judgment even when it contradicted their experience. As one specialist stated, “I don’t know of any [doctors] personally that don’t give it, but I know from the literature that people are afraid of it. “Knowing from the literature” is a phrase that provides an example of how the discourse produced through texts is taken up as reality. As Rankin and Campbell (2006) have noted in their study of the impact of Canada’s health care reform on nursing practice, knowledge produced through statistics represents a virtual reality that overrides the professional’s own experiences (p. 55). In this instance, the specialist describes how he “knows from the literature” that others are “afraid of rt-PA” for their patients.

This specialist then acknowledges that the fearful physicians he is describing “might not have neurosurgical backup in their local hospitals”. Therefore, it would seem, their fear is valid. Fear of hemorrhage is different from the knowledge that one does not have neurosurgical backup in their local hospitals. The one is a psychological fear of possibly negative outcomes, while the other is recognition of lack of structural resources.

Several physicians expressed their belief that the fear of delivering rt-PA reflects a difference in personality between emergency room physicians and stroke specialists. In the following account, a specialist is emphatic that the fear must be disregarded and also stresses that
evidence from the literature ("when case studies are fully published") will reduce that fear. The
solution to fear will be information. He says,

Yea, I think we've got to get over this fear. Emergency physicians have been pretty reluctant about this whole thing because they don't want to be landed with it. You know, and this is just the situation that has been done for cardiology, well why not for neurology, but I think they're scared. The difference is that the brain bleeds and the heart doesn't, basically, and so therefore they're nervous and obviously there are more parameters we have to evaluate in a stroke case as compared to a cardiac case. I think I can understand their reluctance, but you know, when the case studies are fully published and emphasized, our Canadian study, I think that will help also to improve that, as far as this perception goes with the emergency physicians.

In a survey published in 2005, 1,105 emergency physicians in the United States indicated that they were unlikely to give stroke patients rt-PA, even in an ideal setting, mostly because of their concerns of causing brain bleeding (Brown, Barsan, Lisabeth, Gallery, & Morgenstern, 2005). But the majority of doctors from this study also said that if they had appropriate back up from neurologists and the right personnel to help them diagnose and treat appropriate patients, they would give rt-PA. Obviously, having appropriate personnel and back up aren’t considered part of the ideal setting according to this survey. Another specialist told me:

I think reluctance on the part of the Emergency doctors is that they don't want to be made responsible for the interpretation of CT scans… so unless you make available to them real time interpretation of CT scans ... wouldn't it be nice if we had a test, a component for the brain that would let them know that this is in fact what's happening, so you know.
Efforts have been made for specialists in Regional Centres to provide real time interpretation of CT scans through telestroke. Telestroke is designed to allow specialists working in Regional Stroke Centres to read CT scans taken in other sites and thus increase the use of rt-PA in remote or semi-rural areas. But of course the introduction of this approach imposes a new set of difficulties. As Italian sociologist, Nicolini (2005) observes, the tendency of technology in medicine is to modify the existing coordination of health care services “in the direction of existing centres of power, both professional and economical” (p. 2756). In the case of stroke, an argument can be made that interventions such as rt-PA for acute stroke clearly modify the existing coordination in favour of specialized centres that have access to the technology and human resources to carry out best evidence therapies. It also privileges which types of patients can receive best standard care. As one study found (You, Venkatesh, & Laupacis, 2009), the recent investment in Ontario in magnetic resonance imaging (MRI) scanning doubled the utilization of these machines over 5 years. However, “utilization increased disproportionately for those living in the richest neighbourhoods” (You et al., 2009, p. 23). They also conclude that it is not clear if more access to MRI will result in better outcomes.

**The Patient’s Body as a Site for Conducting Research**

Some EBM research has focused on doctor-patient communication (Ford, Schofield & Hope, 2003; Haynes, Devereaux & Guyatt, 2002) although critical scholars have argued that the technologies of EBM do not adequately take into account patient preferences (Mykhalovskiy, 2003). Currently, the notion of shared decision-making is coming into use as a model for understanding and improving the role of the patient in clinical decision-making (Légaré et al., 2008). Yet the extent to which can patients engage meaningfully in conversations about their medical care is not well understood.
Instead, research into why patients do not participate in research is often explored from the perspective of learning how to better seek their participation in clinical trials (Whitstock, 2003). For example, one qualitative study interviewed patients who were recruited to an epilepsy treatment trial with the explicit goal of learning how to train future trial recruiters (Canvin & Jacoby, 2006). The researchers labeled patients who did not participate in research as having weak altruism. The moral imperative that faces physicians to become researchers also plays a role in how patients are constructed as altruistic in their willingness to contribute to the development of scientific knowledge. Their study found that some patients participate in research trials as a way to achieve clinical treatment. In other words, the patient participates in research in order to have access to medical care. This can be seen in the following account by a patient named William at a stroke clinic. He tells me:

I could have used some more information about foods, I could have got it had I thought to ask but at the time I didn’t. I was told the dos, but I wasn’t told the don’ts. Maybe that wasn’t necessary and I wasn’t told that and I have wondered about that. I was able to straighten that out this morning in the interview I had. Yes, that was the real purpose [to participate in research]. I wasn’t supposed to see (the doctor), I was to see his nurse who is coordinating this study, but I brought up a series of questions so I ended up seeing the doctor as well, although it wasn’t intended [for me to do that].

William understands that the “real purpose” of his visit was as a research subject. Through his participation he is able to access a physician to ask about more questions related to his concerns around food and symptoms. Patients at community hospitals, or who are patients with physicians who do not run studies, would not have this type of access. I ask William what his next steps will be in terms of his medical care. Again, we see how his role as a study
participant is intricately interwoven with his status as a patient receiving care. William describes what will happen next in his care:

Well, the first step is this heart scan that I’m going to have probably within the next couple of weeks. And then I’m involved in this study, just starting so I don’t really know exactly in detail what’s going to happen, but it does involve medication, 50% of which is a placebo and I’ll never know which one I’m on. And then I’ll be contacted every couple of weeks by telephone and also I’ll have the conferences, maybe three to four times a year about that. And I think as far as I’m aware right now, that’s about it.

**Summary**

The practice of evidence-based medicine is based on clinical trials that take place in ideal conditions. The medical research of EBM is specifically designed to eliminate or washout the effects of what I have referred to as situated practices. The process for developing and testing the evidence for rt-PA was not as simple or as obvious as it would appear on the surface. Evidence was achieved through one randomized control trial in which only ideal patients were selected for participation and at sites in which a high degree of technological expertise was available. Not everyone agreed that the evidence for rt-PA warranted its uptake by such organizations as the American Heart Association.

The development of research through clinical trials has important consequences for those patients who participate and for those who do not, as well as for nurses and other hospital staff. Little is known about the patient’s experiences of participating in clinical trials. It is an important and often invisible part of the coordination of the production of knowledge for the evidence-base as well as for delivery of care. Studies exploring the patient’s standpoint often explicitly conduct their analysis with a view to increase patient participation in research. Patients who do not
consent to participate are viewed as having weak altruism. According to my interviews, research also can deleteriously affect the work of nursing when the patient’s participation in research directly contradicts how nurses have been asked to care for their patients. Finally, when access to additional care is provided to patients through their participation in research, how can we meaningfully speak of providing equitable access to those patients who do not live close to teaching hospitals?

As I will discuss in the next chapter, its focus on RCT evidence, which favours acute care treatments, may also have an important effect on care across the continuum.
Chapter Eight: 
Reflections on RCTs and the Continuum of Care

Background

The basic goal of the OSS was to improve patient access to best practice care across the continuum. However, as noted, the strategy did arise from advancements for an acute care intervention. In this chapter I consider how the centrality of acute care in the development of the Ontario Stroke Strategy has affected the rest of the continuum, especially since RCTs cannot be as easily conducted in most sectors for reasons of funding or design.

In the course of my work establishing District Stroke Centres I began to hear, from nurses and physiotherapists, what they considered to be a significant and relative lack of resources provided for stroke rehabilitation and long term care. For example, the MoHLTC does not have a branch for Rehabilitation or Long-Term Care. At scientific conferences, rehabilitation and prevention are called allied health and are segregated with nursing into less well attended sessions. I also learned that with proper care, such as the reduction of blood pressure, approximately 80% of all strokes may be preventable (Beaglehole, 2001).

Other critical scholars have written about the nature of the evidence that is produced through meta-analyses of RCTs, which is widely considered by the medical and scientific communities to be the gold standard of research evidence. As previously mentioned, RCTs favour both technology and pharmaceutical interventions. It is difficult to get gold standard evidence about poverty and health, for example, or prevention (Petticrew, 2007). As one researcher noted, “In an era of competing priorities, decisions to fund clinical research are also decisions not to fund other things” (Gupta, 2003, p. 118). This is particularly important for stroke
care, which is both preventable, and for which the majority of patients will require some form of rehabilitation.

All the physicians I spoke with expressed how important primary and secondary prevention was in relation to stroke care. They saw this as the place to invest money and resources. This was true for both specialists and community physicians. In the following account a community physician compares prevention to rt-PA, saying, “Prevention, I guess, is the main issue more than anything because that’s the thing we can do something about. Most of the other things you know, like rt-PA, I don't want to belittle it too much, but there's a certain amount of band aid to it”. Many others echoed the sentiment that rt-PA was a useful but insufficient response to stroke. One specialist said, “Well you know rt-PA is all I got to offer people in the emergency room and I think it’s important to realize that it’s just a start and it’s not the end. Because God forbid if the best we've got to offer people is thrombolysis, that doesn't pump me up at all”. He went on to sum it up this way:

[Prevention is] where you're ultimately going to have your biggest effect, although it’s probably not really sexy or appealing to do it. It’s easy to intervene with somebody in the emergency room … but I think there's a bigger question and they've got to address the issue of primary prevention. That goes across diabetes management, endocrinology, internal medicine, cardiology, neurology, across the board.

In a period of health care reform in which strong emphasis is put on controlling costs, the lack of resources going into prevention stroke is puzzling. One study found that while it would difficult to calculate specific estimates, improving stroke prevention would yield substantial benefits, including the reduction of costs (Goldstein, 2008). A community physician said, “I
think it’s what the province should be doing, it should be saying, boy we can save millions of dollars by preventing strokes, we should be investigating it, finding out how to do it better”.

As noted, primary prevention does not lend itself to pharmaceutical or technological interventions that can be subjected to an RCT. This has been summed up by the statement, “it takes a lot of gold to meet the gold standard of the clinical trial” (Hess, 1998, p. 17). Or, As Timmermans and Berg (2003) note,

The reliance on what is currently considered the “best” evidence, findings validated with randomized clinical trials, often remains out of reach for emerging medical professionals and medical practices at the health care periphery. Randomized clinical trials are labor intensive and expensive to run, they are tailored to particular patient populations [often not those regularly encountered in primary care, such as children and elderly patients], and do not apply easily to all clinical situations. How, for example, does one design a clinical trial for “cultural competency”? (p. 93)

The institutional explanations for why more resources do not go into prevention are rarely explored. Instead, as I have suggested, the tendency to apply psychological or individual-level theories to explain physician behaviour permeates the EBM and KT literature (Alderson, 1998; Eccles et al., 2007). These explanations came up time and again in my discussions with physicians as well. For instance, one family physician I interviewed spoke in detail about how many new family physicians, in his opinion, did not want to deal with elderly patients as they were too time-consuming. He told me, “Many family doctors now might choose to do just sports medicine. There’s nothing wrong with this, but some will—and I think this is unethical—set up shop three floors up, no elevators, make no house calls. Guess what happens? They don’t get any
geriatrics”. When I ask if he thinks they are doing this on purpose, he responds, “Of course they are, of course they are. And that’s almost unethical; it’s just on the edge”.

When I query this physician why new family doctors don’t want to treat elderly patients, he explains,

Because they’re a lot of care. You have to sort of like older people, and admittedly some people aren’t too fussy about that. It’s just a personality thing. They are not as lucrative; we’re not paid as well for geriatrics. You can’t see four elderly people in 20 minutes. You can see four ears in 20 minutes. So there’s some cruelty to that. So since all strokes are 50+, and most of them are even older, they sort of fit into that.

The idea that it is a “personality thing” is a persistent theme in the KT discourse. As previously noted, individual-level explanations abound and there is a tendency for older physicians to speak about the attitudes of younger physicians, for example, or for specialists to theorize about family physicians. These types of explanations were also provided by the physicians I spoke with. Some physicians felt that more education was required in the community in order to deliver more effective prevention care. For example, one specialist at an urban teaching hospital said,

I think there's a tremendous amount of education required in the community to prevent stroke. I think this is really the issue, because the therapies for stroke are still fairly primitive and it's better than it was, we no longer put patients on the back wards and let them aspirate, you know, we have very good stroke protocols, we've made progress. Every patient who is admitted to our hospital now goes to the unit and is monitored and has an aspiration protocol so, but it’s just that we simply can't manage the numbers that we have in [our area].
In this explanation, an implicit assumption is made that education rather than resources are required to prevent stroke. In addition, despite their recognition of the need for prevention, physicians, especially stroke specialists, were less certain of who should deliver prevention services. This parallels the debate around who should deliver acute care interventions. Both specialist and community physicians thought that no one had the time or resources to practice prevention, either primary or secondary. As one specialist said, “A neurologist intervenes with people with TIA's or stroke so we're already talking about secondary prevention. You don't have enough neurologists to deal with primary intervention. The GPs and internists out there don't do it”.

It becomes clear in these accounts that not only are physicians not a homogenous group, but also that they seem to have very little knowledge of what their colleagues do or don’t do by way of providing care. There is a clear lack of consensus as to who should be delivering primary or secondary prevention. While everyone acknowledges its importance, no one seems to be linked to producing evidence for it. Little by way of text or discourse formally links physicians who practice prevention (i.e., family physicians) with specialists, and nothing that links either with prevention. Prevention strategies are simply rarely funded for, or eligible for, an RCT. This results in a situation where there is little best practice evidence to support prevention.

Most attribute gaps in health care delivery at the primary level to how busy the primary care physicians are (Tremblay et al., 2004). This has become such an assumed convention in popular thought that it is rarely empirically examined. One specialist told me, “My impression here is that the family physicians are very busy. I don't really think the GPs in the community can do it all”. Other physicians had similar experiences, citing lack of time and resources to do adequate follow-up with patients as the following account by a community physician highlights:
No, we don't do any [prevention work]. I don't see patients back to do this. They get the smoking and the cholesterol lecture as part of the consult, but I don't bring them back as I would if I had more time to sit them down and let's discuss for the next 30 minutes your risk factors and how we might intervene. That's all given, or the treadmill experience or the single consult experience, but I rarely invite patients back for a follow up to do this and I think this is where we're failing.

The importance that everyone places on prevention is a clear moment of disjuncture from the actual resources that go into prevention. I would suggest that since prevention is not part of the production machine of evidence-based medicine, it cannot enter into the EBM discourse. Thus it cannot enter into practice. Within the KT discourse, other reasons are provided for why prevention is not more widely practiced, and these tend to centre on how busy primary care physicians are.

**Debating the Evidence**

Eventually I began to wonder how much physicians in the community actually disagreed with the evidence for rt-PA? As noted earlier, the variation rate in the use of rt-PA across hospitals and regions has often been addressed in the literature as a debate about the evidence. For example, an emergency physician writing in the Western Journal of Medicine, noted that an intervention is only beneficial if it can be practiced without harm outside of the “idealized setting of an expert-based study” (Hoffman, 2000, p. 149). He claims that there is an “enormous propaganda machine pushing the exciting new fashion of thrombolytic therapy for acute ischemic stroke” but believes there is good and even “overwhelming” reasons to question its effectiveness” (p. 149). For Hoffman, the only “realistic effectiveness study” was a trial that took place within an actual community setting, Cleveland, rather than through the idealized world of the clinical trial. In the Cleveland study, many patients died unnecessarily, as the community
physicians were unable to safely deliver rt-PA. The study was quickly halted. However, resources were devoted to improving the education and training of physicians and the studies again resumed, eventually resulting in better patient outcomes. The impact of these types of studies on patients and their families is not recounted anywhere. The patient experience is completely erased as science is tested in real life hospital settings.

Writing at a different time in the same journal, another emergency medicine physician, cites a different study, STARS, in order to claim the benefit of rt-PA. He argues that “coordinated stroke protocols can reduce such hemorrhage rates while also reducing treatment times and protocol violations” (Robinson, 2000, p. 148). He does not question the ability within the community hospital setting to develop a highly specialized stroke team.

Through these debates the curious reductionist character of medical knowledge and scientific knowledge are revealed. The official accounts of the benefit of a particular treatment have smoothed over these debates as they are written into practice guidelines or become protocols used within hospitals.

By the time I was interviewing physicians, the Ontario Stroke Strategy was several years into its development. I began to wonder to what extent the arguments taking place textually in leading science journals were echoed by physicians in the field. None of the physicians I spoke with ever argued against the evidence for rt-PA. As noted, some of them had often been involved in the original trials associated with rt-PA and they were the same physicians who promoted its use. One specialist saw it this way:

We were clearly looking for something in stroke and pretty desperate. It's hard to keep writing consultation notes about stroke, we're looking for something new,
something you can tell the patients, the people that something has changed, maybe you should consider revising your ideas about treating them on back boards, here's some new stuff, here's something that we can do, Aspirin, drugs, here's something about Statin. Here's a trial, a Progress trial, and maybe that combination would help them preventative. So I think you provide them with some of the excitement that you feel yourself about practice.

Studies looking at physician use of evidence in decision-making have assumed that all physicians participate in evidence debates. I asked the physicians directly how they kept up with the evidence. Some of their answers were surprising. Clearly their decisions are based on more than just appraisal of evidence in journals based on RCTs as in the following account of how a community physician ‘keeps up’ with the evidence:

Poorly. I mean, it's a combination of things. You cannot do it one way. This is not, its probably heresy in, like I'm eccentric, but I get a lot of information from the drug reps … naturally in a teaching hospital you go to rounds and you hear people at the forefront of whatever they are doing, and you can ask them. You can always go next door and say "have you heard about this or do you know about this?" and they explain it to you, so teaching centres are great for that. But when you're in the community, you're depending on publications, on going to rounds if you have the time, like I always came to rounds here you know over the years to keep myself informed. You go to conferences, some of the CME’s [Continuing Medical Education] that the reps put together and again are biased, but informative, and if you have any degree of critical thinking, you can get from that what you need.

This physician tells me that much of the evidence he reads is “from drug reps”. That is one of the ways in which he keeps up with the evidence. Despite his assertion that this is “heresy”, this tendency has been noted by others and the issue of determining the relationship
between drug companies and clinical decision-making is controversial (Brennan et al., 2006; Dana & Loewenstein, 2003). What I would like to draw attention to in this account is the nature of evidence to which he refers. The evidence, for him, is clearly related to pharmaceutical trials, underscoring the taken-for-granted character of EBM best practices as pharmaceutical or technological interventions. He also reports that it is difficult to keep up with all the growing evidence.

Researchers have commented on the growing accumulation of evidence (Graham et al., 2006) and how the sheer volume of evidence being produced makes it difficult, if not impossible, for practitioners to keep up with studies as they are produced. As one community physician told me with as he raised his hand and sighed, “Take a look around; I mean I've got piles of stuff everywhere and yea, it's a huge problem”.

These expressions of frustration about keeping up contradict the idea of a debate between the emergency room physicians and the stroke specialists in terms of their appraisal of the evidence for acute stroke therapy. The discourse of evidence-based medicine that is so familiar to the stroke specialists is distant from the work of the community physician. They try to keep up but are not linked to the production of evidence and thus are not part of the conversations taking place. Reading, rather than producing, evidence is part of their everyday working lives.

**Summary**

To summarize then, as I have shown, the majority of treatments that are considered evidence-based best practice are based on clinical trials that take place in idealized conditions. They favour interventions that are pharmaceutical or technological. The OSS was built around the development of an acute stroke intervention and around the principles of EBM. Through this
organization, other parts of the continuum became in some sense add-ons and being less central, were less resourced.

Through this analysis it becomes clear that scientific or medical knowledge erases or dismisses as inferior any other type of knowledge, for instance, the knowledge of the community hospital clinicians. Using the knowledge-to-action cycle described earlier, Graham et al. (2006) describe the knowledge creation stage of KT as a funnel. They describe it thus:

The knowledge funnel represents knowledge creation and consists of the major types of knowledge or research that exist and can be used in health care. Some of the phases are similar to those proposed by Haynes. As knowledge moves through the funnel, it becomes more distilled and refined and presumably more useful to stakeholders. Another analogy would be to think of the research being sifted through filters at each phase so that, in the end, only the most valid and useful knowledge is left. (p. 18)

In this description, knowledge is reified and abstracted. It exists and can be “used”. It moves through a fictional funnel, becoming increasingly refined and therefore more useful to stakeholders. It is sifted until “only the most valid and useful knowledge is left”. But who does the sifting? Who determines its usefulness to stakeholders? Who in fact determines who the stakeholders are?

The notion of the physician problem is generated within a discourse that favours interventions developed in settings with academic specialists but often aimed toward those working in the community settings. In addition, the organization of the Ontario Stroke Strategy provides a link between the work of the HSFO, the MoHLTC, and academic physicians. Through the academic physicians, it may also link the work of the pharmaceutical industry with the work of the university, although this would require further study. I would like to suggest that promoting rt-PA did seem to allow physicians to recruit more patients for their studies.
Promoting rt-PA also becomes important to the aims of the HSFO, a charitable foundation which relies on donations. The acceptance and promotion of rt-PA for acute stroke by the HSFO and MoHLTC legitimizes and neutralizes the interests of pharmaceutical companies, albeit unintentionally. Innovation, it would seem, does not just improve the health of Canadians, as is frequently claimed. It would appear that the direction of benefit may also run along the same lines as the direction of innovation.
In October 2006, HSFO launched a new advertising campaign heralding their involvement in the use of rt-PA for acute stroke. This emphasizes, once again, the acute care episode and the notion of an almost magical cure. The idea of preventing stroke, or of coordinating and improving services across the continuum of care, including the provision of rehabilitation, becomes lost from view. In the television advertisement, a flower droops while a narrator speaks of the devastating effects of stroke. Then, rt-PA is described, and the flower is shown returning to its original glory, intact and blooming. This is the Lazarus effect and it is compelling.

However, fewer than 10% of patients are ever eligible for this treatment, and outside of urban centres, this number is far lower. And of those 10% who are eligible, far less will experience the Lazarus effect. In the original NINDS trial, the benefit from rt-PA was seen at 3 months. As one specialist commented to me, “I don’t expect Lazarus to rise from the dead and I caution people on the risks and benefits of it and tell them that in the study it was apparent at the 90-day mark [that] there was a difference between treatment with placebo. I have not been blessed with patents that jump off the emergency room table thanking me for giving them rt-PA”.

The physicians with whom I worked and who I interviewed did not work in isolation. Their access to resources, both human and technological, seemed to shape their decision-making more profoundly than their appraisal of the evidence for rt-PA for acute stroke. It was not, in other words, that the evidence for rt-PA for acute stroke was questioned as being scientifically
unsound. It was that rt-PA for acute stroke did not suit the local context in which they practiced medicine.

Throughout this dissertation, and using the example of rt-PA for acute stroke, I have argued against the concept of the physician problem as an explanatory model for why best practice medicine is not more widely practiced. I have argued that in the case of rt-PA for acute stroke, the OSS was organized around acute services. This limited attempts, no matter how well-meaning, to practice health promotion, primary or secondary prevention as these sectors are unlikely to garner the type of resources necessary to ensure success. These sectors of the care continuum were also not evaluated as indicators were only collected from the acute care settings of Regional Stroke Centres.

My study explored the actual setting in which physicians provided care and made decisions about whether or not to treat a patient with rt-PA. In undertaking this study I soon discovered that the Academic Health Sciences Centres were also the sites for producing evidence, as nurses and physicians I interviewed participated in clinical trials. In this study, those most likely to be involved in the production of knowledge were also those most likely to promote the new therapies produced through meta-analyses or RCTs.

What I discovered provides something beyond dichotomous arguments for and against the uses of evidence, and beyond abstract theories about how to disseminate evidence to physicians, or encouraging them to change, to examining what physicians actually do in the everyday worlds of delivering care and making decisions. I began to understand the forms of coordination across different sites that produced variation in physician behavior.
The knowledge exists that there are systemic reasons for the failure of rt-PA to be taken up widely. In essence, the entire OSS is designed to restructure the delivery of health care services in order to facilitate uptake of this treatment without adding additional resources. For the institutional ethnographer, the social does not refer to external and reified systems or policies that exist ‘out there’ but can instead be traced through the work that individuals do that coordinates their activities across various sites. What I discovered is that the OSS establishes and attempts to standardize an ideal model of care that does not account for the various settings in which the everyday work of clinical care is provided.

It also became evident that when local context is recognized, it becomes a problem to be solved, rather than being considered a reflection of broader issues related to the organization of health care services. Lambert (2005) has noted what she terms the “assimilationist nature” of EBM. She states that “My review of the literature suggests that criticism has characteristically been countered not by rejection, contestation, or entrenchment, but by incorporation. This assimilationist response is fairly characteristic of the way in which biomedicine, as an institutionally dominant system, has dealt in many country contexts with other (traditional, indigenous and alternative) medical traditions” (p. 4).

In a similar manner, since I undertook my study the OSS has responded to some of the problems in implementation I have described by attempts to incorporate them into their work. A key example is the establishment of telestroke. As noted previously, telestroke is designed to allow specialists working in Regional Stroke Centres to read CT scans taken in other sites and thus increase the use of rt-PA in remote or semi-rural areas. But it cannot be provided 24/7 and puts a significant burden on the specialists at the Regional Stroke Centres. It also continues to place effort and resources at the acute level of care. Future studies will discover how telestroke
and other strategies designed to address gaps that arise across the continuum are affecting the everyday work performed by care providers at Regional and District Stroke Centres, as well as at community hospitals.

I originally set out wanting to know what was ‘wrong’ with those physicians who were choosing not to deliver rt-PA for acute stroke. Through my study I discovered a disjuncture between the best practice treatments developed through clinical trials and the actualities of their translation into practice. Smith (2005) wrote that “Institutional Ethnography is essentially a work of inquiry and discovery; it must move beyond what the ethnographer already knows or thinks she or he knows, and the ethnographer must be prepared for and open to finding out that matters are not as he or she may have envisaged them” (p. 207). Through finding out what physicians actually do in their work, including their relationships with others in the health care system, I was able to discover forms of coordination – in particular those with the Ontario Stroke Strategy – that were largely invisible in accounts of scientific evidence and physician decision-making. The physicians I spoke with did not decide to deliver rt-PA according to their appraisal of the evidence. Few physicians in any location, urban teaching centre or hospital, questioned the validity of the original NINDS Trial for rt-PA. They also did they not report relying on their personal experiences of delivering this treatment.

What did emerge from the accounts consistently is that the extralocal coordination of stroke care often overlooked the everyday conditions under which the individual physician was working. And this coordination seemed to determine the delivery of this acute treatment rather than individual decision-making. This seems at first glance to be a relatively simple point and has been documented elsewhere. For example, one Canadian study examined community factors, hospital characteristics and inter-regional outcome variations following acute myocardial
infraction [heart attack] in Canada (Alter, Austin, & Tu, 2004). Their research also supported the idea that “supply factors affect physician decision-making processes” (p. 254). That is to say, physicians with access to technology and advanced treatments will be more likely to use them. Again, this would seem a self-evident point in some respects. What remains un-examined is how health care is coordinated so that, despite clinicians’ emphasis on the need for prevention, the majority of funds are directed toward acute care and post-event pharmaceutical therapies.

Within Canada, the push to develop standards of care based on best evidence health care continues through such organizations as the Canadian Institutes for Health Research (CIHR). CIHR will not fund research studies that do not have a knowledge translation component. The OSS continues to channel $30 million per year into the organization of stroke care services that are organized primarily around the delivery of acute services, despite the claim to improve equitable access across the continuum of care. A national network has now also been established, based on the Ontario model, with funding from the Canadian Stroke Network as well as the provinces. Yet the analysis of data collected from the Regional Stroke Centres by the RCSN concluded that “we do not yet have data on long-term stroke outcomes such as mortality and functional status, so we cannot evaluate the association between the processes of stroke care and stroke outcomes” (Kapral et al., 2004, p. 1760). That is to say, the data that has been collected cannot show whether or not standards for stroke care, such as rt-PA, have been implemented. There is also no known connection between meeting the standards of care and improving patient outcomes following stroke. Given the emphasis on best practice care that is so dominant within the EBM discourse, this is an extraordinary admission.

The best practice stroke care on which hospitals should be judged are not linked to patient outcomes. It may or may not improve or save a patient’s life. And yet the assertion is
made that systematic documentation of these indicators – using standardized forms or checklists – should be encouraged. The textual basis of the Ontario Stroke System comes full circle. The evidence that produced rt-PA for acute stroke as a best practice was developed through the specific technologies of EBM; that evidence then became the basis for the Ontario Stroke System, which produced the ideal model for care delivery that was arguably focused on acute care. Evaluation of the OSS then evaluated specifically those indicators that reflected both acute care and the realities of the specialized Regional Stroke Centres. On this basis, the model was deemed successful.

Yet KT strategies continue to be developed to target individual and autonomous physicians. Far from being a lone practitioner making decisions autonomously, I found that the physicians I spoke with were involved with an entire network of others in their everyday work, often invisible to them. The decisions that they made relied upon the presence of many others active in the care delivery situation, including technicians, radiologists, nurses, paramedics, and of course patients and their families. They were not out of date, old, or ignorant of best practice evidence nor did they resist using it.

Another tendency in the KT discourse has been toward involving end users in the production of research. This sounds harmless enough and in fact echoes the spirit of participant research in some ways. It would also seem to hold the answer for the problem of local context; that is, involving those who are likely to deliver care in the development of research. Despite theoretical acceptance of this principle, it wouldn’t appear to be happening in practice. Who are these end users, how are they identified, and what role do they play in shaping the direction of research? We need to pay attention to this question rather than accept uncritically that their involvement in research will necessarily lead to better patient care.
Finally, I want to clarify that through this analysis, I am not arguing against the validity of scientific knowledge, or biomedical research, or suggesting that the neurologists involved in RCTs were in some way uncaring or self-interested. To do so would be well beyond the scope of this thesis and also beyond my own skill set, and also against my standpoint as a researcher. I have attempted instead to render visible how care has been coordinated so that various standpoints, such as that of the stroke specialist, are taken up in the creation of ideal models that are then transferred to local settings.

Evidence-based medicine can be thought of as a discourse that informs how the relationship between scientific knowledge and medical practice is thought to be ideally coordinated. In this discourse, delays in bringing basic science advances into clinical practice are said to cause patients untold harm every year. Writing an editorial in a leading medical journal, Rosenberg (2003) pronounced that: “The American people need to know that the current system for bringing promising biomedical research to the bedside is operating at an obsolete level of efficiency, causing great delay, and consequently resulting in the loss of many lives” (p. 1306). The idea that promising biomedical research can indeed be quickly brought to the bedside in order to save lives is not backed up by scientific or empirical evidence. But this argument does reveal very clearly some of the competition for resources within health care that takes place in relation to evidence-based medicine. It is also representative of how science is generally constructed within this literature. It is objective, neutral, and can be readily used for the public good. Any delays in its use are unethical.

For those patients who are eligible, thrombolytic therapy can be life-saving and dramatically improve their quality of life post-stroke. The focus on acute therapies for stroke has also created an opportunity to improve how stroke patients are cared for post-stroke through the
development of an organized system, the Ontario Stroke System. However, the issue is not as simply defined as determining if one particular therapy is useful or not for some patients. There is increasing emphasis for physicians and patients to become involved in the production of new scientific and acute-based knowledge, regardless of how these new treatments may or may not be practical to implement across various settings. This emphasis on new knowledge also erases the need to increase resources and expand other forms of knowledge in relation to areas such as prevention and rehabilitation. This affects both their everyday working lives as well as the everyday working lives of nurses and other health care practitioners. And I have only just begun to show, it may also significantly affect patients whose bodies become the site of knowledge production.

The guiding aim of the OSS has been to provide equitable access to care across the continuum. My work has suggested that the continuum is largely ideological and may not exist in actual practice situations. The OSS has been based on the premise that good scientific evidence exists that “strokes can be prevented and acute care and rehabilitation appreciably enhanced” (Joint Stroke Strategy Working Group, 2000, p. 2). Yet the acute care point of care has been emphasized and resourced. This has affected the extent to which prevention and rehabilitation have been “enhanced”.

This study can be thought of as another piece of the puzzle of how health care is coordinated. The evidence base, I would suggest, does not need to be dismissed but perhaps as, anthropologist Helen Lambert (2005) points out, “negotiated and broadened” (p. 2). Until knowledge translation strategies are developed that take into account the institutional context within which medical care is delivered, and the relational aspects of decision-making are acknowledged, it is unlikely that efforts to eliminate variation in practice will be successful. The
assumption of the autonomous physician underpinning much of the KT literature needs to be addressed so that local practice may be better understood. Through this lens, variation in practice and local context become more than just problems to be solved, but may in fact reflect the recognition that the narrow band of strategies for which we have evidence does not reflect the full range of work that is being provided in hospitals on an everyday basis.
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Appendix A
Ministry of Health and Long-Term Care (MOHLTC)
Ontario Stroke Strategy (OSS)

Service Guidelines – District Stroke Centers (DSC)

SECTION A

DSC Role
- The DSC is accountable, in conjunction with their Regional Stroke Centre (RSC), to provide leadership, development, implementation and integration of stroke care throughout their district and across all points in the spectrum of stroke care (promotion, primary and secondary prevention, acute care, rehabilitation and home care).
- The DSC will assist community hospitals in their district to localize and implement stroke protocols and stroke teams.
- The DSC coordinates and assists the community-based agencies responsible for health promotion and stroke prevention in building inter-organizational relationships throughout their respective catchment areas and across the spectrum of stroke care.
- The DSC is committed to participating in ongoing education/training in stroke care within their region and providing an integrated stroke service based on best practices.

Accountability
- In partnership with the Regional Stroke Steering Committees (RSSC) and the RSCs the DSCs are accountable for the leadership, development, implementation and coordination of stroke care within their district and the provision of stroke care based on best practices and evidence.
- The DSC is accountable to adhere to the stroke line-by-line infrastructure allocated for stroke care for the provision of care and service. Stroke funding cannot be reallocated within the DSC’s operating budget.
- The DSC is accountable to maintain and submit separate quarterly and year-end financial reports on the stroke infrastructure.
- The DSC will sustain the stroke infrastructure roles, descriptions, responsibilities and requirements as per Section B of the Service Guidelines.
- The DSC will work in partnership with their health-care community including District Health Councils, the rehabilitation and long-term care community, community acute hospitals and Community Care Access Centres.
- The DSCs will also partner with other stakeholders such as local boards of health and the Heart and Stroke Foundation to fulfill their accountability in the leadership, development, implementation and coordination of stroke care for their region.
- The OSS aligns with the DSCs operational and strategic plans.

Responsibilities
1. Regional/District and Community Leadership
   - Develop a district plan for stroke care across the continuum, which builds upon the existing regional plan as per the RSSC.
   - Partner with other RSCs and DSCs where appropriate to ensure the province wide system based on best practices that builds on the expertise of the centres, provides for the sharing of tools and processes to decrease duplication and develops consistency of approaches.
   - Develop plans and reports on the status of the regional stroke plan to the MOHLTC on a scheduled basis.
Administers the district and regional strategy to maintain the regional network.
Ensure timely communication to all stakeholders (e.g. MOHLTC, local communities).
Ensure the implementation of the regional plan for stroke care based on best practices and continuous improvement.
Implement acute stroke protocols (e.g. ambulance dispatch communication policies, paramedic hospital bypass protocols, community hospital triage and transport process including bypass with clustered hospitals without 24 hour CT scanning or which are missing other critical acute stroke care components).
Facilitate outreach services to support enhanced consultation in rural and remote areas of the region.
Organize and continuously upgrade stroke treatment in the district by adopting best practices based on a model of continuous learning and continuous improvement.
Working in collaboration with their regional and provincial partners to ensure the collection and coordination of key data.
Provide leadership in measuring and monitoring by working with other stakeholders to define further data needs, collect data, assess performance, evaluate outcomes and develop standards.
Provide consultation and mentoring to other hospitals in the region to promote access to tPA and other interventions and organized stroke care.
Development of human resource capacity plan in anticipation of staffing issues/shortages.

2. Provision of Patient Care and Services

**The DSC is to be fully operational to provide 24/7 access to tPA care with established acute care rapid response protocols by July 1, 2005.**

On-staff Neurologists/stroke specialists organized to provide service with an established on-call schedule
Access to a neurologist/stroke specialist within 15 minutes of patient’s triage.
CT scanner on site, with available technical staff to access scanner 24/7.
Protocols and processes to support patients accessing CT scan within 1 hour of referral
Radiologist/Neuroradiologist accessible 24/7 (may include teleradiology).
Neurosurgery accessible through established processes within facility or with the RSC.
Rapid emergency care accessible through established triage procedure.
Clinical protocols established for all acute aspect of care from the ED to inpatient admission to discharge planning and case management.
Dedicated clinical team of specialists in stroke care (e.g. RN, Physiotherapy, Occupational Therapy, Dietician, Social Work, and SLP). If human resource issues in the region preclude the hiring of staff (e.g. SLP) strategies must be in process to still provide access to that care.
Provide coordinated services for all high-risk patients to allow for access to prevention programs, clinics, referrals and communication with primary care providers.
Develop end implement care guidelines that enforce best practice standards that include transition of care management.

3. Systems

Demonstrated clinical leadership, board and senior leadership commitment and track record of working collaboratively, establishing alliances and planning structures for the region.
Partnership agreements and repatriation guidelines/agreements with DSCs, community hospitals and local facilities (e.g. Community Care Access Centres, Rehab. facilities, long-term care) to ensure appropriate and timely return of patients to their communities (cross border issues to be addressed).
Develop transfer protocols (to include redirect) for community hospitals that do not have access to CT scanning.
SECTION B - DSC Infrastructure

1. **OSS District Stroke Coordinator**

**Requirements**

- Licensed member in good standing with a professional college and/or member of the RHPA.
- Minimum of 5 years experience in clinical care with the following skills an asset:
  - Strong consultative skills combined with clinical, institutional and community development knowledge;
  - Leadership, interpersonal, communication and conflict resolution skills, with the ability to work both collaboratively and independently.

**Responsibilities**

- The DSC Coordinator will participate in the development and implementation of the stroke infrastructure within the DSC facility to support the regional strategy, e.g. transition management of patients, inpatient team development.
- The DSC Coordinator will administer the DSC stroke budget in co-operation with DSC processes/procedures and in partnership with the Regional Stroke Steering Committee and regional strategic plans.
- The DSC Coordinator will sustain the role and responsibilities of the DSC in co-operation with the Regional Steering Committee and the ministry.
- The DSC Coordinator will be the contact person for the ministry regional office and/or corporate offices.
- The DSC Coordinator will act as representative for the DSC and the Regional Steering Committee and appropriate sub-committees and/or working groups.
- The DSC Coordinator will administer the strategy within their district, including developing and implementing support systems to maintain the network activities.
- The DSC Coordinator will facilitate the management of the stroke care system to be organized in the various institutions and agencies across the continuum of care (e.g. acute care, rehabilitation and community).
- The DSC Coordinator will identify district specific needs for provider education and facilitate the regional education activities in conjunction with the Regional Education Coordinator.
- The DSC Coordinator will develop a local network of care providers and consumers across the stroke care continuum to define, develop and implement the local Stroke Strategy in partnership with the RSC.
- The DSC Coordinator will collaborate with other and stakeholders to ensure that the province-wide system supports the sharing of tools and processes.

**On-Call Infrastructure**

- Neurologist and/or Stroke Specialist physicians On-Call Fees are provided to meet the designation criteria in your role as a DSC.
- The expectations for the on-call physician includes but are not limited to:
  - 24/7 on-call for provision of specialized stroke care to patients.
  - 15-30 minute arrival/contact to the patient from time of call for appropriate patients and protocols.
  - Provision of clinical leadership.
  - Consultation (e.g. telephone, telestroke) to other physicians and/or regional specialists.
Appendix B
Semi-Structured Interview Guide
The Social Organization of Best Practice for Acute Stroke:
An Institutional Ethnography

Please note that this guide only represents the main themes to be discussed with the participants and as such does not include the various probes that may also be used.

- **Background Information/warm-up**

Thank person for participating, go over consent and have them sign, explain process, how confidentiality and anonymity will be protected, etc.

- It would be nice if you could let me know a little bit about yourself. How long have you been practicing neurology?
- What is your area of specialization?
- How many strokes do you treat in an average month?

- **Practice - General**

- Let me begin by asking you to describe for me your understanding of the usefulness of rt-PA? Probes: *How does it work?*
- Where did you obtain your information? Your training? Is this typical?
- Is it something you use often? Why/why not? When would you use it? When would you not use it?
- When did it first come into use? Do you know what led to that?
- Who, if anyone, should use it? Why/why not?
- What is needed to use it?

- **Practice - Acute**

- Can you take me through a typical case in which you used or were asked to use rt_PA?
- Can you take me through a typical case in which you were asked to administer rt-pA but chose not to?

- **Cool-Down/Wrap-up Questions**

- Is there anything else I haven’t asked you about that you’d like to add?