WHY THE HOME CARE REFERRAL PROCESS DOES NOT WORK

by

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A thesis submitted in conformity with the requirements for the degree of Master of Arts
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ABSTRACT

Why the Home Care Referral Process Does Not Work

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Medical patients discharged from hospital are often referred to home care nursing for a 'medication management service' (MMS) with the aim of preventing potential medication-related problems (MRPs) that could lead to re-hospitalization.

This study collected accounts from 35 nurses providing home care to patients for MMSs upon hospital discharge. Using concepts from Dorothy Smith's (1987) work, including "relations of ruling" and the importance of textually-mediated professional control, I show how the home care referral process "orders" nurses' work. I also show how Rafael's (1998) ideas of 'ordered' and "assimilated" caring, and Broadbent and Laughlin's (1997) theory about "accounting practices" and "absorbing groups" reflect how the current home care referral process does not work. Nurses' accounts provide the stories of their struggles for decision-making autonomy in providing care to their patients. I conclude with nurses' recommendations for change.
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1. **INTRODUCTION**

Home care services are provided to enable persons who are unable to care for themselves to live at home. The aim of home care services is to prevent, delay, or substitute for long term care or acute care alternatives (Canada Health and Welfare Canada, 1990; Advisory Council on Aging, 1991). There has been an increasing demand for home care services, partially due to reduced funding to hospitals across Canada. This has meant fewer hospital beds and pressures to reduce patient length of stay and discharge patients to community programs such as home care, even in situations in which they may still require acute care hospitalization. Individuals who are elderly (i.e., 65 years of age and older) are the most frequent users of home care services (Lecsemann and Martin, 1993; Government of Canada, National Advisory Council on Aging, 1991). Because of these trends, the National Forum on Health has targeted home care as a major area of health care development (Canadian Home Care Association, February 1998).

Patients discharged from hospital medical programs to home care are frequently on a number of medications with complex medication regimens. While medication therapy may be beneficial for treating disease, the problems for the patient, family, and health provider associated with maintaining an adequate medication program are complex and varied. A medication related problem (MRP) is defined in the clinical literature as "an actual or potential sign or symptom which is related to medication therapy and is undesirable to the patient" (Horn Barbara et al. 1990; Hargest AH and Loh E. 1997; Strand et al.1991). A patient may experience one or more of eight categories of MRPs, which include: an untreated indication, improper drug selection, subtherapeutic dosage,
failure to receive a drug, overdosage, adverse drug reaction, drug interaction, and drug use without an indication (Strand et al., 1991); these could be severe enough to result in rehospitalization. Documented events that occur in the patient's transition process between hospital and home may contribute to MRPs. Such events include last-minute changes to the patient's medications and medication regimen, medication teaching conducted just prior to discharge (at a time when the patient is unable to concentrate or absorb the information received) and insufficient transfer of patient information and medication-use needs between the hospital and the home care providers in the community (Anderson and Helms 1994; Bero et al. 1991, Burns et al. 1992; Bul 1994; Col et al. 1991; Hepler and Grainger-Rousseau 1995; Hunter et al 1991; Jackson 1990; Kravitz RL et al. 1994; Naylor et al. 1999; Robertson et al. 1982; Vogenberg 1996; Wernick et al. 1996; Zuckerman et al 1986). Elderly patients (65 years of age and older) tend to have multiple chronic medical conditions (e.g., diabetes mellitus, coronary artery disease, chronic obstructive pulmonary disease, and congestive heart failure). Thus, they are frequently treated with a large number (e.g., five or more) of different types of medications with complex medication regimens. Coupled with the documented issues in the hospital transition process, such patients may be particularly vulnerable for experiencing MRPs such as adverse drug reactions or recurring problems with their medical condition due to difficulty complying with their medication regimens (Anderson and Helms 1994; Bero et al. 1989; Burns et al. 1992; Grymompre et al. 1988). Adverse drug reactions have been documented as the cause of hospital admission in 3-10% of admissions for the elderly (Williamson and Chopin, 1980). The risks of hospitalization due to MRPs are so significant that it is possible that the hospital medical team is
prescribing home care with nursing services for medications' for patients with these characteristics upon hospital discharge with the goal of managing the home care patient's medication regimens thereby preventing rehospitalization due to potential MRPs (Harrison Helen, Personal Communication, 1997; Bryson Brian, Personal Communication, 1997; Zeliotti Judy, Personal Communication, 1998).

There is a need for conducting research to evaluate what happens to patients receiving home care services. The need to evaluate outcomes of home care services was identified by both the Health Services Restructuring Commission of Ontario and the Ontario Hospital Association (Health Services Restructuring Commission, 1997, Ontario Hospital Association, 1997). However, prior to determining whether home care nursing for "medication management services" (MMSs) is actually achieving desired program goals (i.e., preventing rehospitalization) for which such services are prescribed (such as decreased number of medication-related hospitalizations and improvements in patient self-management with medications), it is necessary to first examine whether the transition process is actually working (Scheirer, 1994). That is, if we are to understand, resolve, and subsequently prevent the issues that may negatively affect the provision of nursing with home care for "medication management services", then we must first understand the current process by which home care services are referred, authorized and delivered to patients discharged from hospital to home care.
Thus, the purpose of this research is to examine the current process of the referral, authorization, and provision of MMSs for home care patients discharged from hospital, as well as issues and areas that need improvement from the home care nurses' perspective.

In Ontario, Canada, home care services are coordinated by community based not-for-profit corporations referred to as Community Care Access Centers (CCACs), which were created by the Ontario Ministry of Health in 1996 in order to provide a primary mechanism by which consumers could access home care and long-term care facility services. The CCACs assess clients to determine their eligibility for services and provide case management and monitoring of in-home services, which they purchase for eligible recipients. These services include professional services (nursing, nutrition counseling, occupational therapy, social work, physiotherapy, and speech-language pathology) and home making for personal support (Toronto CCAC annual report 1998-9).

In the year 1998-99, of the 15,262 admissions to the Toronto CCAC, Hospitals provided the majority of referrals to home care, representing 65 percent of the total number or 9,935 admissions; about 70 percent of these were from three Toronto teaching hospitals (University Health Network, St. Michael's Hospital/Wellesley Central, and Sunnybrook/Women's Health Sciences Centre). The elderly (those 65 years and over) comprised about 50 percent or 8,004 admissions, of persons receiving home care services. Nursing services were the most frequently authorized professional service, representing approximately 89 percent of all client visits (Toronto CCAC Annual Report 1998-1999, pages 16-17). This is consistent with national statistics, in which studies have shown that
patients over 65 years of age use approximately three times more hospital days per year and more community services, such as home care with professional support services, once they are discharged than any other age group.

At the time of this research, nursing services were predominantly contracted from two agencies: Saint Elizabeth Health Care and the Victorian Order of Nursing Association, each receiving approximately 30 percent of referrals (Zeliotti, J., Personal Communication, November 1997; Stevens, P., Personal Communication, November 1997). The remaining 40 percent of referrals were divided among other provider organizations (Zeliotti, J., Personal Communication, November 1997). This trend is expected to change due to the competitive bidding process for awarding contracts for professional and / or personal support services for clients, which was implemented by CCACs in January 1998. The anticipated growth in the demand for home care services as well as the implementation of a competitive bidding process have given rise to an increase in the number of new home care provider agencies now aiming to compete for contracts to provide home care professional and personal support services. It is now quite possible that one agency would receive the contract for providing nutrition services while another agency provides nursing services; yet a third agency may be contracted to provide social work services. These changes reinforce the need to understand the issues that may exist in the current process in the referral and delivery of home care services.
1.1 Theoretical Orientation of this Research

As defined by Guba and Lincoln,

"a paradigm may be viewed as a set of basic beliefs...that deals with ultimates or first principles. It represents a worldview that defines, for its holder, the nature of the world, the individual's place in it, and the range of possible relationships to that world and its parts."


Thus, it is essential for the researcher to identify his or her paradigm at the outset in order to identify the methods by which he /or she will collect and interpret the research findings.

My original orientation to studying home care can be labelled 'post-positivistic'. In this research, using a post-positivistic paradigm might have quantitatively described the problems with home care as expressed by the nurses interviewed in the study. Such descriptions might be devoid of meaning in terms of the purpose of nurses' actions in relation to their patients when providing MMSs. This is because quantitative descriptions "strip" context from results. The ontological orientation of post-positivistic paradigms is that reality exists as "imperfectly and probabilistically apprehendable because of flawed human intellectual mechanisms" (Guba, E., and Lincoln Y 1994, page 100.) The inquirer remains objectively guarded, aiming to determine if the findings fit with existing knowledge through utilizing quantitative and qualitative techniques. As my research was originally envisaged, the meanings and purposes that nurses ascribes to their actions was to assist me in understanding how "the" process of home care worked. While analyzing notes taken from nurses interviewed for this project, my theoretical orientation changed
from post-positivism to critical theory. The ontology of critical theory is that reality is "crystallized (reified)" after being shaped by social, political, cultural, economic, ethnic, and gender values" (Guba and Lincoln, 1994, pages 109-110). These crystallized series of structures that are "now (inappropriately) taken as 'real' and immutable", i.e., as historical reality. Methodologically, with critical theory, there is an interaction between the inquirer and the participant in order to challenge the perception that historically mediated structures are infallible. The goal of the critical theorist is more informed consciousness of subjugated knowledges and the struggles of subjugated peoples.

How did this change in my theoretical orientation affect the course of the analysis of findings and the construction of the thesis? Since I had started my study within a post-positivistic paradigm, I had planned on doing a "process assessment" to understand "barriers" in the delivery of "MMSs. The research initially consisted of a feasibility study to understand the current process by which the hospital medical team refers, the CCAC intake coordinate authorizes, and the home care nurse provides MMSs for patients discharged from hospital to home care. During the feasibility study, I created the data collection forms and procedures for the study, followed by a pilot study testing the appropriateness of these forms and procedures. My viewpoint was that of a hospital pharmacy manager in a Toronto teaching hospital. From that standpoint, I believed that pharmacists are key members of the interdisciplinary team, and I was concerned that pharmacy services were notably missing from the list of services provided by the CCACs. Thus, at the beginning of the study, I had set out to identify areas of "inefficiencies" in the home care medication management process with the idea that pharmacists might fill the
gaps. My argument was that pharmacists held the knowledge about medications and as such should have a rightful place in providing that information to the patient. It was with from that standpoint that I conducted my feasibility assessment. However, during the feasibility assessment, and subsequently the study itself, my standpoint changed. I began to see the issues from a different perspective as I observed nurses providing home care to patients, and heard their stories. I found myself changing my idea that there must be problems with the way in which MMSs are provided because they are not provided by pharmacists in the home. Instead, I began to appreciate the way in which work is done through the home care nurses' accounts.

I realized that the process assessment framework that I had started out to use at the beginning of the study was deficient in interpreting nurses' experiences. I sought a theoretical framework that would guide the work of investigating and describing home care nurses' work from the nurses' standpoint as well as address the process issues described by their narratives. I found such a framework in the concepts provided by Dorothy Smith's methodology of examining the social organization of everyday activities from the standpoint of persons doing the work (1987). This study is not an institutional ethnography since the data had already been collected by the time that I read her work. Rather, it looks at the home care referral, authorization, and delivery process for hospital discharged patients from a critical perspective that examines the power relations within which home care takes place.
1.2 Purpose of this Research

Findings from the feasibility assessment of this research were critical in supporting the need for the research. The feasibility assessment methods and findings are presented in detail in Chapter Three. However, here I present the questions that the feasibility assessment raised.

Since the hospital medical team and the CCAC hospital-based community care coordinator prescribe and authorize home care with nursing for the purpose of providing some type of 'medication-management service', in the pilot study, I attempted to identify whether nurses have guidelines on these services. This involved contacting the College of Nurses of Ontario, who informed me that nurses have guidelines on medication administration; however, any other activities, such as providing medication counseling or medication education, would be based on expectations set through the nurses' education curriculum as well as the policies of her place of employment. I then reviewed the Standards of Medication Administration document that the College of Nurses provided. I found that while these Standards provided extensive guidelines on the "behaviours and tasks of medication administration by nurses," other medication-related aspects of the process the hospital team and CCAC community-based intake coordinator were not mentioned. I wondered how the hospital team determined whether to refer a patient to home care with nursing for MMSs, and what they communicated to the home care nurse about a patient's medications when making such referrals. I also wondered about how the CCAC intake coordinator determined whether to authorize such services and what she in turn communicated to the home care nurse.
Most importantly, I wondered how the nurse, in the midst of the nursing responsibilities that she is required to provide for the patient, conducted the MMSs. I knew that there were many ways in which new MMSs were enacted might deviate from what was originally envisaged. For example, while it is appropriate that professional judgment be used when professionals such as nurses, physicians, and pharmacists make decisions about care, (Schon, 1987), there are likely to be differences due to the nurse’s education and background experience. As well, variations may occur depending on whether the home care provider agency has policies that provide nurses with guidelines on how to conduct a medication review, or the type of information that the nurse should provide to a patient when providing medication education / or so called "compliance" monitoring. In particular, I wondered whether the time that may be available during a 30 minute home visit by a nurse to perform nursing care and an MMS for a patient would allow much time for anything else, such as identifying potential medication related problems and obtaining support to resolve those before resultant patient harm. I wondered whether nurses felt inadequate in providing MMSs if they lacked the education and background experience to do so, or lacked the resources or access to drug information centres that could provide prompt responses to their questions in the home setting.

Thus, I became interested in understanding in more detail how each of the steps in the referral, authorization, and provision of home care MMSs actually occurred from the perspective of the recipient of the information and provider of the services, i.e., the home care nurse. After learning more about what nurses did, ultimately, I wished to understand what changes they felt were required in order to enable them to conduct their work of
caring. It was thus no longer within the scope of this research to determine patient outcomes with medications as the clinical literature urges us to do; rather, my goal became understanding the process and any irregularities that might issues that may negatively impact the provision of services (hence, patient medication safety).

The purpose of this exploratory research, then, was to describe the process by which medical patients discharged from hospital to home care are referred for and receive medication-management services, as intended by the CCAC.

1.3 Specific Objectives (Original and Revised)

The research involved two groups of patients, those with home care with nursing for a referred MMS, and those with home care with nursing but no specified MMS. My original study objectives were to:

(1) document patient demographic, medical, and medication characteristics of patients with a medical team referral for home care with nursing for a MMS as compared to those patients with a referral for home care with nursing services for other reasons;

(2) compare the number and type of MMSs requested by the physician/hospital team and those authorized by the hospital-based Intake Coordinator (HITC);

(3) compare the number and type of MMSs authorized by the HITC and the MMSs provided by the home care nurse. I was also interested in nurse-described accounts of the process problems that might act as barriers, accounting for differences between MMSs requested vs. MMSs authorized vs. MMSs provided, as well as suggested areas of improvement. Given the research paradigm shift from that of post-positivism to one of critical theory, this last study objective became the central focus of the research.
1.4 Thesis Organization

The thesis is organized into six chapters. The first chapter has discussed the significance of the study, the study paradigm and purpose. Chapter 2 contains a literature review outlining relevant research, theory, and practice literature. Also discussed is an overview of the study's theoretical framework based on concepts of institutional ethnography.

Chapter three explains the study methods. As these were derived from the study's feasibility assessment, the Chapter begins with a description of the feasibility assessment methods. I also describe in detail the study's data collection procedures, nurse interview procedure, and analyses. The findings of the feasibility assessment are described in Chapter 4. These were used to guide the development of the data collection forms and procedures for conducting the research and subsequently, the pilot study when these forms and procedures were tested. Also in Chapter 4, I describe study participants' demographically and medically, the 'ideal' referral process and an analysis of 'types' of referral. Chapter 5 provides a critical analysis of the implications provided by nurses' accounts of their experiences with the referral and authorization process. In particular, I critique how CCAC documents influence nurses' work of caring and workload. In Chapter 6, I conclude with a summary of the study's main findings and their practical implications as well as present theoretical implications and ideas for future research.
2. LITERATURE REVIEW

2.1 The 'Drug Use Process'

Medication management constitutes a major treatment modality for most patients served by home care agencies. While medication therapy may be beneficial for treating disease, the problems for the patient, family, and health provider associated with maintaining an adequate medication program are complex and varied (Horn et al., 1990; Jackson 1990; Kravitz et al., 1998; Naylor et al. 1999; Zuckerman, 1992).

As I reviewed the clinical and health services literature for a model that described the series of activities associated with medication use I came across a 'systems' model in the health services literature that I show in Figure 1. In the clinical and health services literature, a 'system' implies "a group of interdependent people, items, processes, and products and services that have a common purpose or aim" (Leap et al., 1995). As shown in Figure 1, Hutchinson et al. (1990, pages 634-37) conceptualized drug use as a multi-stage 'system' in which health professionals and patients perform a series of steps associated with assessing the need for therapy, and prescribing, dispensing, and administering the appropriate drug(s) and regimen(s). This 'drug use process' is described as involving a series of "coordinated efforts by health professionals" ... and patients" for "achieving the optimal use of drugs" (Hatoum and Valuck, 1996, page 71). This concept considers that "all actions related to drug therapy represent a continuum" (Hatoum Hind T. and Valuck Robert J., 1996, page 71).
This 'systems perspective' assumes rather than problematizes interrelated and coordinated decisions. A rational or positivistic approach is taken to 'patient problems' and the means to achieve the desired therapeutic outcomes. However, Hutchinson et al. (1990) claim that the "drug use process" is disjointed and inefficient in manpower use and resource consumption. Physicians, pharmacists, and nurses spend significant time carrying out technical tasks in isolation. Thus, Hutchinson et al. (1990) claim that the model and paradigm do not seem to work, because in the 'real world', many professional activities are poorly coordinated and without, in their words, 'adding professional value' (1990, page 633) and many professional activities are poorly coordinated.

2.2 Potential Sources of Medication Related Problems for Home Care Patients

According to this structural or systems approach (Hatoum and Valuck, 1996) medication related problems may result due to breakdowns at any point in the "drug use process" (e.g., there may be problems with medication-administration). For the process to function optimally, each step must be completed without problems (Hutchinson et al, 1990; Hatoum and Valuck 1996). In the next three sections, the literature on MRPs is reviewed and then reconceptualized. I present a different version of the "drug use process" for home care patients in Figure 2, derived from this study's feasibility assessment. Typical deviations from the figure by Hutchinson et al (1990), from the home care nurse's perspective, are presented in Figure 3.

According to Figure 1 by Hutchinson et al (1990), the hospital system and its interdisciplinary teams exist ostensibly to manage the "drug use process". However, in the
home care system; practitioners work independently and there may be duplication of effort of their actions with those in the hospital setting. In addition, they are required to carry out 'orders' given by the hospital team and CCAC, which may be suboptimal decisions with implications on the 'quality' of the "drug use process".

2.3 Clinical Risk Factors for Experiencing Medication Related Problems

In the clinical literature, rather than conceptualizing problems as arising from breakdowns in the process as described by process researchers, many articles apply positivistic statistical techniques to identify patient "factors" that may be predictive of the "outcome" of MRPs. In other words, this approach seems to "place the blame" on the fact that patients are elderly rather than on the possibility that the process of care broke down.

Patient risk factors identified in the literature for MRPs include (a) demographic characteristics such as the patient being 65 years of age or older, and having lower levels of education; (b) social factors such as patient lack of access to informal caregivers (family, relatives, neighbor, etc.); (c) presence of chronic medical conditions in the patient, with the most commonly reported ones being congestive heart failure, diabetes mellitus, coronary heart disease, hypertension, and chronic obstructive pulmonary disease; (d) impaired functional status of the patient in cognition, vision, hearing, and/or memory; (e) presence of an acute infection in the patient, such as pneumonia or urinary tract infection, and (f) metabolic abnormalities in the patient (Bero et al. 1991, Burns et al. 1992; Col et al., 1991; Grymompre, 1989; Jackson, 1990; Naylor et al., 1999; Robertson et al., 1982; Zuckerman et al., 1986; Zuckerman, 1996).
The prevalence of MRPs in the elderly is well documented in this clinical literature. Elderly patients are more likely to experience an adverse drug reaction than patients aged 20 to 30 years (Monane et al, 1997; Ray et al, 1990; Nolan et al., 1989; Grymompre et al, 1988; Courtman and Stallings, 1995). There is some evidence that the incidence is reduced in patients aged over 70 years of age. If this observation were interpreted from a medication use process model, it might be seen to be the outcome of greater caution in the treatment of very old patients. The observation might also result from difficulties in distinguishing drug-induced problems from those associated with multiple pathology in older people, which would make it an interpretive problem for the researcher using these methods of research. The high prevalence of drugs prescribed for the community-dwelling elderly, 85 percent, may also be seen as process or 'risk' related in the high incidence of MRPs observed in this patient population (Williamson and Chopin, 1980).

The positive association between a patient’s age and the likelihood of hospitalization is often interpreted within a biomedical framework rather than within the process of care (Zuckerman et al., 1986; Burns et al., 1992). For example, age-related changes in sensitivity to drug effects, the prevalence of predisposing conditions, such as impaired functional status, and the presence of chronic medical conditions that require management with multiple drug therapy, as described as increasing the frequency and severity of adverse drug reactions. Thus, age-related changes in the elderly are seen as making them more vulnerable to experiencing medication-related problems (Burns et al 1992).
Studies of the prevalence of adverse drug reactions in the clinical literature have focused on those occurring in hospitalized patients. The problem of adverse drug reactions is identified as particularly pertinent to elderly patients in the "risk factor" literature because they consume a larger number of medications (Smucker, Kontak, 1990; Courtman, Stallings, 1995; Warren et al., 1998; Lowe et al., 1998;). Specifically, it is pointed out that while those over 65 years of age comprise only 12 percent of the population in the United States, 31 percent of all drugs are prescribed for this age group. In the same study, nurse interventions provided to home care patients reported that approximately 41 percent of these patients were taking five or more prescription medication concurrently; this did not include as-needed or over-the-counter medications (Zuckerman et al., 1986). In another study, also in patients receiving home care, patients were taking 4.9 medications on average. The implication here is not specified as biomedical or process-related.

Similarly, "polypharmacy" has been documented as a risk factor for adverse drug events (Monane et al., 1997) and has been reported to contribute to hospital admissions for elderly patients (Ray, et al., 1990). While clinical researchers tend not to speculate about the process leading to hospitalization, adverse drug reactions due to biomedical causes have been estimated as contributing to the need for hospitalization in 10 percent of geriatric inpatients, and noncompliance with medications may account for another 10 percent of hospitalizations (Meyer and Schuna, 1989; Williamson and Chopin, 1980).

The biomedical literature defines an 'adverse drug reaction' as an injury caused by medical management (rather than the underlying disease). This injury prolongs hospitalization or results in a disability at the time of discharge (Localio et al., 1991).
'Compliance' is defined in the biomedical literature as "the extent to which a person’s use of medications coincides with medical or health advice" (Monane et al., 1997). The biomedical literature speculates that the reason for these adverse reactions is "age-related increases in the frequency of drug use, sensitivity to drug effects, and prevalence of predisposing conditions that can increase the frequency and severity of adverse drug reactions" (Ray et al., 1990). There is no reference to the possibility that the process of care itself may break down. That is, "rational care" is always assumed.

Because the elderly patient is seen, in the clinical literature, as more sensitive to side effects of medications, such as sedation, anorexia, confusion, or orthostatic hypotension and dizziness, these states, rather than a lack of monitoring or care, are assumed to "cause" falls, which lead to hospitalization. In addition, drugs with anticholinergic side effects are associated with an increase in heart rate, confusion, blurred vision, decrease in gastrointestinal motility rate and bladder contractility, and drying of mucous membranes. The same classes of drugs which are more likely to cause these side effects are also the ones most commonly used by the elderly; these include cardiovascular drugs, antimicrobials, analgesics, hypoglycemic agents, psychotropic drugs, and anti-arrhythmic (Williamson and Chopin, 1980). The use of multiple drugs (polypharmacy) thus has been identified as having several consequences, such as adverse drug events, drug interactions, and duplication of therapy, decreased 'quality of life', and unnecessary financial costs (Monane et al., 1997).
Because the clinical literature tends to use biomedical explanations for MRPs, the frequency and consequences of undermedication or omission have not been extensively studied. The actions of the professionals involved are always assumed to be rational and above reproach with a blame-the-victim tendency. The authors of these clinical articles may, however, postulate that a number of elderly who might benefit from drug therapy are not taking the appropriate medications or taking no prescription medications. These researchers also note that the consumption of alcohol and medications may lead to interactions that can result in adverse drug events, such as increase the potential for experiencing a gastrointestinal bleed or potential drowsiness and falls as a result.

2.4 System Related vs. Clinical Risk Factors

In contrast to the literature on "patient risk" factors for MRPs, other researchers point out that system-factors may contribute to causing MRPs. "System" failures in the hospital discharge process are not attributed to a culpable professional in the same way that the patient is blamed for his or her falls. In this literature, the problems are instead attributed to the system. Problems instead are identified as due to (1) last minute changes to the patient's medications and medication regimen; (2) medication teaching conducted just prior to discharge, at a time when the patient is mentally unable to concentrate or absorb the information received; and (3) insufficient transfer of patient information and medication-use needs between the hospital and the home care providers in the community. The articles in this area are predominately observational studies or review articles (Jackson, 1990; Hallas et al., 1992; Bero et al., 1991; Bul, 1994; Naylor et al., 1999; Burns et al., 1992; Leape et al., 1995; Rich et al., 1995; Stewart et al., 1995).
A Nursing Approach to Home Care

Since neither the structural nor clinical literature gives any glimpse into the process of home care, it is necessary to consult the nursing literature for conceptions of how it works. The home health nurse has as her/his focus providing care to individuals and their families in community settings that include homes, group residences, school classrooms, shelters and the street. (The Community Health Nurses’ Initiatives Group of the Registered Nurses Association of Ontario, 2000). Home health nursing is also referred to as Visiting or Community Health nursing. Because the focus of the home health nurse is caring for the patient in his or her home environment, the key to performing her work is first to obtain an understanding of the patient's environment. This enables the patient and his/her family to adapt to changes in the patient's life as a result of medical needs and the multitude of required relationships with caregivers in the community.

In Ontario, about 13 percent of employed nurses, or approximately 6700 nurses in total, listed home care as their 'practice setting' in a 1999 College of Nurses Annual Payment Form. (The Community Health Nurses' Initiatives Group of the RNAO, 2000). The majority of those nurses were home health nurses who were employed by home care service agencies as well as other Community Health organizations or agencies or who were in independent practice. It is estimated that by 2010, about 70 percent of employed nurses will be practicing in the community (College of Nurses of Ontario, 1999).

Where the work of the home health nurse has traditionally been viewed as that of a generalist, requiring that the nurse be competent and flexible in caring for patients with
diverse medical needs, ages, and socio-economic abilities, home health nurses are increasingly required to provide care for patients with complex medical conditions. These include patients with high levels of care because they were discharged from hospital too quickly or not stabilized on therapy prior to discharge; patients with complex dialysis regimes; or chemotherapy regimens; mental health patients; patients requiring palliative care; patients requiring medication delivery with intravenous pumps; and ventilator-dependent patients. Hence, the home health nurse has the challenges and needs to remain competent with general clinical skills as well as obtaining specialists skills due to the complexity of home health practice.

The requirement for specialized knowledge and skills in certain clinical practice areas has meant that the home health nurse has to demonstrate not only what the nursing literature terms critical thinking, comprehensive assessment, and clinical decision-making skills, but also has to master new areas of specialization, such as mental health, home chemotherapy, palliative care, and others.

Thus, increasingly, home health nursing is becoming a specialized nursing practice requiring a unique set of competencies related to the nature of the home health nurses' role. Nursing practice in the home setting requires the nurse to be able to work in an autonomous manner within an unstructured environment, while assuming a high level of responsibility (Meyer, 1997). In addition, the home health nurse plays a prominent role in coordinating care and in communication of client status and needs to health providers based in the community and hospital. In doing so, according to the nursing literature, the
nurse aims to communicate the needs of her patient and the patient's perspective as well as her own assessment of the patient's needs without imposing her own values or judgements (Benefield, 1998).

2.6 Understanding Referral Problems Through Nurses' Experiences

My study goes beyond all of the literature on home care by examining nurses' experiences with the process. This study sees the home care nurse as the key link in the process of providing care and coordinating services among multiple hospital and community providers for the home care patient. I take the view that the home care nurse, who is in the patient's environment and closest to the patient, is in the best position to anticipate and confront complex problems and to participate with other members of the health 'team' to provide much needed services for the home care patient. However, I seek to identify rather than assume the issues that the home care nurse must battle in this environment in order to go beyond what I came to call "ordered caring". This concept, which emerges from a critical perspective on the home care process, argues that it is structured through the medical model, funding issues, and performance measurement demands. In the next chapter, Methods, I describe in more detail how the study's theoretical framework was used to interpret home care nurses' experiences and to reconceptualize process issues with home care referral for hospital discharged patients.
3. METHODOLOGY

3.1 Theoretical Framework

In this section, I describe the original process assessment framework. The theoretical framework that I eventually used draws on three different sources: Rafael's (1998) concept of caring (reviewed in Chapter 5), Broadbent and Laughlin's (1997) description of "accounting logic", and Smith's (1987) theory of relations of ruling. The later two are discussed after a brief consideration of my original paradigm.

3.1.1 The Original Process Assessment Framework

As noted earlier, my research on the home care process for the referral, authorization, and provision of MMSs for patients discharged from hospital was initially constructed within a process assessment framework, which guided my choice of methods. "Process assessment" in the clinical literature must precede "outcome assessment" of a program in order to avoid making incorrect inferences about program effectiveness, or inferring that the program was ineffective when it was in fact effective (Scheirer in Wholey et al., 1994). Process assessment aims to understand the core process of patient care by answering three questions (1) what is the aim of the program/system; (2) what is actually delivered; and (3) why are there gaps between what is planned and what is delivered? (Scheirer in Wholey et al., 1994 page 40). These answers are obtained through the following steps:

(1) conducting a feasibility assessment to help to specify the desired interventions that will achieve program goals, as well as describe the potential recipients and their characteristics, and current operations and interactions;
(2) acquiring an understanding of theory and prior studies that will aid in developing a plan for recruiting intended participants as well as data collection methods;

(3) conducting data collection to measure the extent of service delivery and interventions received by participants; and,

(4) assessing the quality of the intervention in order to:
   (a) make program/service delivery more congruent with the intended program/service objectives,
   (b) identify 'who' and 'to what extent' a program is reaching its intended participants, and,
   (c) Increase knowledge about the program/service components that, if changed, would most likely contribute to desired outcomes.

In this study, I had initially intended to pursue steps 1 to 3 of the process assessment framework. However, process assessment as described here would not have allowed the reflections of nurses and my observations about their sense of frustration and oppression. Rather, the "view from nowhere" of the research would have been presented. After I summarized my analysis of nurses' accounts from my field notes, I saw how important were their experiences in understanding how the process of home care works. At about the same time, I took a course, which helped me to reconceptualize the theoretical framework from my study. Although I am still learning about critical feminist theory, in the next sections, I sketch out a critical methodology for exploring the process of referring, authorizing, and providing home care with nursing for MMSs.

3.1.2 'Accounting Logic' in the Work of Caring

In an article by Jane Broadbent and Richard Laughlin (1997) on 'Accounting logic and controlling professionals,' which was assigned for a feminist course in which I was a student, I found a way of reconceptualizing the home care process. In the article, the
authors seek to provide a link between accounting principles and professional work in education and medicine. The authors are 'outsiders' in that each has experience in accounting but neither are health professionals. Thus, they apply their 'inside' knowledge of accounting and economic principles as 'outsiders' to the professions of medicine and teaching. In their article, they present the argument that performance measures and workload statistics are, in essence, 'report cards'. According to their interpretation, these accounting principles are used by administrators to develop controls over professionals. However, these performance measures, statistics, and workload indicators to recognize the work of caring. Instead, a numeric value using accounting principles is assigned to measure outputs of performance. This process disempowers professionals in many ways - among these, by hiding the caring component of their work. This aspect of their work, I maintain, takes the longest time, requires the most of their knowledge, skills, and values as well as intervention on behalf of their patient. Yet in 'accounting logic,' it receives no attention. In essence, 'accounting logic' fails to credit their professionalism. The result is that professionals work overtime and 'absorb' the work in order to improve their statistical output as well as perform their professional responsibilities. As they begin to spend their own time and resources in caring for patients, in so doing they begin to feel disempowered and frustrated. Ultimately, such feelings may result in an outcry and even strike, such as occurred with the strike by the Victorian Order of Nurses in Hamilton. Alternatively, an increase in time off due to 'illness' may be observed.
3.1.3 Relations of Ruling and Home Care

Dorothy Smith's theoretical framework provides another and related way of conceptualizing nursing care. She provides a basis for the critical feminist researcher to examine what people do, their activities, and to connect these to specific power relations mediated by text.

Methodologically, this implies understanding social events and circumstances as coming to pass through a process of coordinated activity. Smith asserts that the everyday world is organized in social relations of power; these can be detected both by attending to subjective experience but also by examining the 'accounting logic' of predetermined ordering. Smith draws attention to 'organizing logic' of social relations by which decisions that affect everyday lives are made elsewhere by 'relations of power' or a 'ruling apparatus'. While the exact relations that are manifest in each situation varies, these include spheres of bureaucratic, managerial, and professional control. The structure, conceptual organization, and policies and procedures created by a ruling apparatus give an appearance of neutrality and impersonality that conceals class, gender, and racial subtexts.

Dorothy Smith's methodology guides us to examine and explicate the boundaries set by the relations of ruling (power relations, ruling apparatus) such as the network of governments, professional and other regulatory organizations, and their associated discourses, which, in effect, rule the concerted efforts of the work that people do. Her methodology, called institutional ethnography, is used to reveal invisible determinations
that aim to confine. Ruling practices originate outside the situation where they apply, such as in a government or regulatory agency, but extend into it to share local action. An example could be the "ruling practices" of the Ministry of Health via the Community Care Access Centres (CCACs) or hospitals.

3.1.4 How a 'Relations of Ruling' and 'Standpoint' Perspective Changed My Theoretical Framework

I could see how knowledge of the process and the way work is done could be constructed through both an objectified account from discussions with the hospital providers and CCAC providers and the nurse as well. The concept of standpoint from Dorothy Smith's work also appealed to me and I believed that the social organization of the home care process could be seen from the nurses' standpoint.

Institutional ethnography does not begin in theory but rather by identifying a problem or situation in the world. Often, individuals performing institutional ethnography have insider's knowledge as a resource. When I had identified a research problem that I wanted to investigate initially, through a post-positivist paradigm, I was entering an area of practice that I knew little about, which also had very little documented about it. The 'feasibility assessment' that I conducted at the outset of my research was done through a post-positivist framework. However, through my initial reading about home care as well as by talking with informants and observations during home visits, I developed ideas about the institutional relations of accountability and processes for referring as well as authorizing home care. That knowledge base allowed me to later change my standpoint
from a post-positivistic one to one that critically examined the nature of power that is textually mediated such that it controls and accounts for the way in which the home care nurse provides the work of caring for her home care patient. I subsequently developed a standpoint that allowed me to understand, through nurses' reported experiences, how textually mediated relations of power could negatively affect his or her management of her patient's medications with resultant potential harm to the patient. Such an event would negate the purpose for which home care with MMSs are referred and authorized. Yet, unless these text mediated relations of ruling were made visible, a patient's negative consequences with medications, resulting in MRPs or potential rehospitalization, would be blamed on the patient or on the nurse provider.

The concept of 'social relations of ruling' is an important one to understand in Smith's ontology; it refers to those relations of the ruling apparatus (e.g., the CCAC decisions and regulations) that are intended to control and coordinate the sequence of actions ('work') of individuals. As applied to this research, 'social relations of ruling' would refer to the CCAC's activities conducted from the point of initiating and authorizing all the way through to providing home care services. By unfolding the series of steps that occur in a process over space and time, Smith asserts that we can begin to understand how to form conditions for future activities (Smith, 1997). Smith emphasizes that this coordination occurs through text (e.g., a form). When we learn to read the language and visual representation in textual form as manifestations of ruling relations, this opens our eyes to ways in which textual practices coordinate activity.
As applied to this research, I realized that an understanding of the referral form as it is used to initiate and authorize as well as provide home care services might reveal how the CCAC controls and influences the series of activities that are performed by the hospital 'team', hospital-based intake coordinator, home care provider, and home care nurses who are involved in this process.

Thus, by understanding the things that people do and the concerted activities related to the textual practices of the powers that regulate (e.g., decide, authorize) what people do, we can begin to understand how things work. A place to begin is to focus on what the problems are, from the standpoint of those who live the experiences within the structures and processes that affect their work. Different accounts bring about a different understanding of the issues. From the standpoint of nurses' experiences, I saw that my feasibility study generated different accounts of the issues than that presented by the referral form or in managerial accounts. However, my original understanding was not very elaborate. By sifting through the details of 35 nurses' accounts, I gained a picture of the issues affecting the breakdown of the current process and how it is not working. These issues, I began to see, are critical to address not only because they pose potential risks to home care patients on medications, but also because nurses will reach a point at which they are unable to continue to absorb the extent of work imposed on them. The work of caring, as Broadbent and Laughlin (1997) have emphasized, cannot be measured by current performance measures or accounted for by current reimbursement methods for time per visit.
It is important to clarify that the notion of 'institution' as intended by Smith references the cluster of organizational and discursive relations that aim to standardize activity sequences that have been taken for granted. She describes institutions as being self-reproducing, and explains that they arise through patterns of normalized forms or hierarchy and aim to shape the work that people do. Her explanation challenges the idea of presupposing their existence as an element in the environment.

I found Smith's feminist perspective more relevant than the process approach described earlier, since Smith advocates the taking of a standpoint, e.g., from the home care worker, and aims to analytically describe the planning strategies involved in controlling everyday work so as to create intervention strategies that will lead to change or reform.

3.2 Research Framework and Design

The study was conceptualized as exploratory research, utilizing both quantitative and qualitative methods, conducted in two groups of medical patients discharged from an acute tertiary care Toronto teaching hospital. Patients with a referral for home care nursing for MMSs and for other types of nursing services were to be included.

The study's feasibility assessment was conducted over a one-moth period in the hospital's General Medicine and Cardiology Programs from October 1997 to November 1997. Changes to the study site in April 1998 because of a hospital merger made it necessary to conduct the main study at the merged hospital.
As I originally conceived it, a way to investigate and understand the study participant's experience and meaning of his or her experience was going to be possible through using qualitative methods. Thus, I collected and documented quantitatively information from the patient’s hospital health records. These findings are described in Chapter 4. I relied upon qualitative methods for describing nurse interviews. Nurse interview themes and accounts are also presented in Chapter 4. My critical re-analysis and contextualization is summarized in Chapters 5 and 6.

There are many forms and uses of quantitative research methods, but I was encouraged by my original thesis committee to pursue a deductive analysis producing a numerical summary allowing conclusions about the null hypothesis and use of statistical significance tests. I was allowed to experiment with qualitative research, which also has many forms and uses. The type I learned about relies primarily on inductive analyses leading to a narrative summary, which synthesizes participant information and creates a description of human experience. (LoBiondo-Wood, page 217) One text that I read indicated that the method was useful as a way to learn firsthand about people who function within a specific context or role (Silverman, 1993, p. 24; Smith, 1997). However, I eventually went beyond this into critical enquiry and analysis. My feeling was that critical methods were particularly relevant for understanding the home care process because they would allow me to emphasize the participant's experience and to explicate her interpretation of social reality.
As I have detailed above, in my re-analysis of my data, I was informed by Smith's ideas about relations of ruling. What made the re-analysis possible was that I had documented how the nurses did their work and the network of concerted efforts in producing this work. Specifically,

(1) I obtained documents on CCAC home care program goals, also conducting a feasibility assessment to help to specify the desired interventions that would achieve program goals according to a rational process approach. Much of this data is useful for doing institutional ethnography, including my descriptions of potential recipients and their characteristics, and current operations and interactions.

(2) I documented steps involved in the home care referral, authorization, and provision of home care with MMSs for patients discharged from hospital.

(3) I conducted data collection through medical chart review (a text), home visits, home care chart review and nurse interviews, and text analysis of the home care referral form.

(4) Lastly, I analyzed and then contextualized nurses' narratives to make visible exactly the ways in which the process does not work.

During the feasibility assessment and pilot study to pretest the data collection forms, I observed and conducted informal discussions with members of the medical team, the CCAC hospital-based intake coordinators, and home care nurses. This was necessary to map out the work that each of these persons performs in initiating the home care referral, authorization, and provision of MMSs. This sketch (Figure 2) that I produced was useful for summarizing the coordinated activities of the medical team in the hospital, the hospital intake coordinator, the CCAC, the home care agency, and the nurse intersected activities (i.e., the concerted activities of each of the persons and organizes involved in the process). This later allowed me, as presented in Chapters 5 and 6, to show how home
care services aligned to the CCAC requirements for the provision of home care services and where they are failing.

3.3 Feasibility Assessment

A feasibility assessment was first conducted to determine the study terms and methods. These were later pilot-tested, according to the requirements of post-positivistic methods. When I did the feasibility assessment to understand the referral process, I was a pharmacy practitioner within the system. Because I knew the nurses and physicians and worked with them, we had an environment of trust in which they could openly share their experiences with me. Findings from the feasibility assessment led me to develop an initial understanding of the process for referring, authorizing, and providing home care MMSs to patients discharged from hospital. This was the point at which I designed the study data collection forms and nurses interview survey. The data collection forms for retrieving data from the medical record, CCAC documents, home chart, and the nurse interview questionnaire were pre-tested for four consenting patients discharged from the hospital over a two-month period, following Research Ethics approval by the University of Toronto (Appendix A) and the study site (Appendix B) as well as from the Toronto CCAC, STE, and VON (Appendix C).

Findings of the feasibility assessment led me to develop an understanding of the general process for referring, authorizing and providing home care MMS to patients discharged from hospital (Figure 2) as well as the study data collection forms and nurse interview survey. Forms and processes for patient recruitment by the CCAC hospital based intake
coordinators (HLTCs), and nurse recruitment by the study investigator, were pilot-tested and subsequently modified. This completed objectives 1 and 2 of my research and prepared me for conducting the nurse interviews.

3.4 **Participant Recruitment Strategy**

As this was exploratory research, convenience sampling was chosen. The first 35 patients who were referred and authorized to receive home care services upon discharge from hospital, and consented to participate in the study, and their nurses, who met the study inclusion and exclusion criteria were asked to participate in the study (see Appendix D, Patient Information Letter and Consent Form, and Appendix E, Nurse Information Letter and Consent Form).

The HLTCs based at the hospital conducted patient recruitment (Appendix F). Upon receipt of a patient referral form by the ITC, together with the patient’s anticipated discharge date, I visited the patient to review the patient information letter, and obtain his or her consent to participate in the study. The following patients were included:

(1) medical patients (i.e., of the General Medicine and the Cardiology Programs) discharged from hospital with a referral to receive home care nursing, either for MMS or other services;

(2) medical patients instructed to take one or more prescribed medications;

(3) medical patients assigned to a nurse from either St. Elizabeth Health Care (STE) or the Victorian Order of Nurses (VON).

Each signed consent to participate in the study. I excluded patients with a terminal illness who required palliative care, patients with a diagnosis of HIV / AIDS; patients with severe
cognitive impairment which precluded giving informed consent as assessed by the HICT; patients assigned to a nurse who did not consent to participate in the study; and patients assigned to a nurse who had previously participated. In order to accurately represent the population of patients who were discharged from the General Medicine Program to home care with MMS referral, it was necessary to include patients with some degree (mild to moderate) of cognitive impairment (estimated to be approximately 25 to 40 percent of this population) (Harrison, Helen, Personal Communication November 1998). Patients with severe cognitive impairment who were unable to manage their care were typically not authorized to receive home care services but were referred instead to a long-term care facility. Upon obtaining informed patient consent, I contacted the home care provider agency (either STE or VON) to determine if the patient had been assigned by the CCAC to their care. For patients assigned to either Saint Elizabeth Health Care (STE) or the Victorian Order of Nurses (VON). I asked the agency’s designated contact person to forward (by fax or put in her mailbox) a copy of the nurse information letter and nurse’s consent form to the patient’s primary nurse. I requested the nurse’s phone mail extension, so that I could conduct future follow-up with the nurse to determine her receipt of the information and her willingness to participate, and to set a date for the home visit. Nurses were asked to fax, mail, or to give the signed consent form back to me at the time of the home visit. A follow-up phone call was placed to the nurse for cases in which a response had not been received. I contacted consenting nurses in order to schedule a date and time to accompany the nurse on the third or fourth home visit. The home visit time frame was selected based on observations during the feasibility assessment, which indicated that a nurse has had opportunity to conduct the initial patient assessment, plan and implement
her approach to patient care by the third home visit. A team of two to three nurses is assigned to a patient, with one nurse designated as the primary nurse and another nurse within the same team as her 'back-up' when she is off or assigned to another patient.

### 3.5 Data Collection Methods

The data collection forms and procedures were designed to retrieve information that would answer the study's objectives. The study variables and corresponding data collection sources consisted of:

1. determining the patient's 'risk factors' for MRPs, based on documentation in the patient's hospital record as well as my observations during the home visit;
2. determining the number and type of home care nursing services referred by the hospital medical team, based on documentation on the CCAC referral form. When this form was not available, then I referred to the medical team's documentation in the hospital medical record; when this was lacking, then I referred to documentation in the patient's home care chart;
3. determining the number and type of home care nursing services authorized by the CCAC hospital-based intake coordinator, based on her Communication Form;
4. determining home care nursing services planned or provided by the home care nurse based on services observed during the home visit, documented in the home chart as planned for a future home visit or provided in a prior home visit, or from the face-to-face nurse interview;
5. understanding reasons for discrepancies between home care services referred or authorized with those provided.

The home visit observations and nurse interviews were critical for seeing and understanding the everyday work nurses do when providing home care. In particular, nurses' interviews described their concerns and suggestions for improving the home care referral process for his or her particular patient. These, in turn, helped to explain
variations between MMSs referred by the medical team and authorized by the HITC compared with those provided by the home care nurse.

The study's data collection forms for retrieving information from the patient's medical record, home visit observations, home record, and nurse interview questionnaire, are provided in Appendix G.

3.5.1 Data Collection Procedures from the Hospital and Home Visit

In keeping with the clinical paradigm that discusses patient "risk factors" (see section 2.3) in the hospital, data was collected from the medical record to determine the patient "risk factors" that may have led the hospital medical team to request home care with nursing for a MMS upon hospital discharge. Data was also collected from the CCAC documents (referral and HITC communication form) that determined the types of home care nursing services that were referred by the hospital medical team and authorized by the CCAC HITC. In cases in which I did not see the hospital referral, then that information was obtained from notes in the patient's hospital medical record or nurses' notes of CCAC referred services documented in the patient's home record.

The home visit allowed me to observe the nurse and patient in the patient's home environment and type(s) of MMSs the nurse provided. The nurse interview indicated the nurse's perceptions of the types of MMSs referred and authorized by the CCAC as well as those provided or planned by the nurse. This was done in order to understand whether the MMSs as authorized by the CCAC hospital-based intake coordinator were provided by
the home care nurse, and if not, the potential reasons for the variation. I was still working in a post-positivistic paradigm when I designed and pilot test the data collection forms and procedures, so the format and terms of the forms reflect that paradigm, for example, I used the terms "factors" and "system barriers" on the nurse questionnaire, instead of the term "issues", which would have been reflective of the critical paradigm that I subsequently adopted.

3.5.2 Nurse Interview

I conducted the interview with a semi-structured questionnaire that aimed to collect information on differences between MMSs provided and planned vs. those authorized by the HITC. The nurse interview also provided demographic data on nurses' educational backgrounds and their number of years of experience in providing home care services.

Specifically, the questionnaire was designed to determine:

(1) Nurses' access to information related to CCAC authorized services. Nurses' access to information about their patient's authorized MMSs was determined by asking whether the nurse had seen the CCAC referral (question 1), or, in cases in which a nurse was providing back-up coverage for the primary nurse on her team, whether she had seen the information transcribed in the patient's home record regarding the CCAC services authorized (question 2).

(2) His or her recollection of the types of MMSs authorized for her/his patient (question 3). This question was asked of all nurses; it served to verify responses to question numbers 1 or 2.

(3) The nurse's assessment of the patient's medication related problems and/or medication-related need(s) (question 4). This question was raised to determine whether nurses provided a MMS because they perceived that his/her patient had a need for one and also served to provide information on what nurses perceived to be "risk factors" for experiencing a MRP compared with those from the clinical literature.
(4) Whether the nurse had provided a MMS in a prior home visit, that I had not observed, or was planning to provide MMS for a future home visit, that I would not be observing (question 5). As I made only one home visit per patient, this question was important.

(5) Nurses’ perceptions of the 'factors' and system 'barriers' affecting his/her provision of MMSs for her patient (question number 6), potential areas of improvement for delivering home care with MMSs for her patient, i.e., 'facilitating factors' (question 7), and potential areas of improvement for providing home care with MMSs in general, for any home care patient (question 8).

Establishing rapport was important in encouraging nurses to share their experiences.

While I had the authorization from the home care provider agency to conduct home visits with the nurse, I wanted to establish a relationship with the nurse so that she could feel open presenting her concerns or recommendations to me. I was careful to highlight the fact that I was performing the project as a graduate student, and was careful not to indicate that I was a pharmacist as I did not want this to bias the nurse’s comments to me, however, I did indicate my role when asked.

The face-to-face interview was conducted with the nurse within the same day, immediately after the home visit, in an area away from the patient’s residence (e.g. the nurse’s car). In situations when the nurse was rushed for time, she was given the option of doing the interview by telephone, which was scheduled within the same day as the home visit. The questions were read in the order in which they appeared on the questionnaire. If the nurse requested the meaning of a question, I explained it by providing examples of the term(s) used. I wrote down the nurse’s responses in the nurse’s own words.
3.6 Data Analysis

3.6.1 Analysis of the Nurse Interview

I originally conducted what the qualitative methods literature terms a "content analysis". The procedures for conducting a content analysis, i.e., developing a coding scheme and identifying and presenting categories, were based on procedures described by Clifford, 1997, and Caudle, 1994.

My written field notes from all nurse interviews were first typed to facilitate analysis. All nurse responses to the open-ended questions concerning factors affecting the provision of home care with MMSs (i.e., barriers) and areas for improvement (i.e., facilitators), questions 6 to 8, were read in order to identify the common features of the responses. Then, I went back to each nurse’s set of responses and re-read each response several times in order to interpret the meaning of her response and the central point of each of her comments. As I reread each response, I had in my mind a context for the issues that the nurse was describing based on my understanding of the process for delivering home care for MMSs for hospital discharged patients. I inductively categorized frequently occurring (thus, 'emergent') themes in my nurse interview notes. This is referred to as 'preunderstanding' and represents the evaluator’s insights into the subject of assessment and significant processes. 'Face validity' of the content categories and elements was determined from the transcripts of six of the 35 nurses who participated in the study; they were asked to provide feedback as to the accuracy with which I interpreted and categorized their responses to open-ended questions 4 and 6 to 8. My insights into the process of the referral, authorization, and provision of nursing with MMSs for
hospital discharged home care patients, as summarized in Figure 2. Subsequently, when I moved to critical analysis, I applied my understanding of the issues to interpret the notes from the nurse interviews.

3.6.2 Data Analysis of MMSs Referred, Authorized, and Provided

Whether a MMS was required and the type(s) of MMS(s) referred were determined from the information documented by the hospital based CCAC intake coordinator on the study’s patient referral form, as well as information documented on the CCAC referral. Type(s) of MMS(s) authorized were also cross-checked from the CCAC referral as well as the HITC’s communication form. Types of MMSs provided by the home care nurse were coded based on home visit observations as well as information documented in the nurses’ care plan of the home care record. If a MMS was documented as planned but it was not observed during the single home visit, or if a MMS was neither documented in the home care record nor observed, then this information was obtained from the nurse’s response to question 5 of the nurse interview, asking the nurse whether she had provided MMSs in a prior home visit or plans to provide a MMS in a future home visit. In the event that there was a referral for MMSs but none were planned or provided, then this information was obtained from nurse responses to questions 1 or 2, asking whether the nurse had seen the home care referral for the nursing services requested by the CCAC.
4. PARTICIPANTS AND TYPES OF HOME CARE REFERRAL

This chapter describes findings from the feasibility assessment, conducted prior to the main study of 35 nurses and their patients. The chapter also introduces the participants in the main study of the research. To provide an overview of participants, quantitative summaries of patient demographic characteristics and their nurses' education and experience. Summaries of patients' medical conditions and medications that presumably contributed to the referral by the hospital medical team are presented. However, first, I describe the 'ideal' process of referral based on observations from the feasibility study and categorize "types" of referral observed in the main study. This background information is useful for setting the stage for the critical interpretation of findings contained in Chapters 5 and 6.

4.1 Feasibility Assessment

As shown in Figure 2, my feasibility investigations showed that when the interdisciplinary team or presiding physician wish to discharge a patient and assess the patient as requiring ongoing care with home care post-hospital discharge, then the presiding physician and/or nurse manager (or her delegate) of the program initiated a home care referral (also referred to as 'medical referral') form. On the referral form, the physician and/or nurse prescribe the type of home care service(s) that the patient will require (e.g., nursing, nutrition, rehabilitation therapy) and the reason for them (e.g., nursing services for teaching insulin administration). They also record the patient's clinical condition(s), course in hospital and a complete list of medications and medication regimen on hospital discharge (Harrison, H., Personal Communication, November 1997,
and Bryson, B., Personal Communication, November 1997). Upon being informed by the nursing unit that there is a home care referral, the HITC's goal is to determine if the patient is eligible for home care and the required type of home care services. The HITC:

1) Reviews the referral form;

2) The patient's medical record, which she is able to access;

3) Interviews the patient to determine his or her socioeconomic needs (e.g., ability to obtain own medications, availability of family / or other care-giver) and if the patient truly needs home care services or whether they would be able to, for example, manage their own medications;

4) Determines if the services prescribed by the physician/ interdisciplinary team are appropriate or if different services (additional/fewer) are required (e.g., community services; equipment, transportation assistance, laboratory monitoring, medication teaching, medication compliance monitoring, etc.);

5) Authorizes home care services ('entry' into the program). If she deems the referral is appropriate after her assessment of these documents and the patient, she will then complete a CCAC Communication Form, which describes the HITC's assessment of the patient's course in hospital based on her reading of the medical referral, medical record and patient interview; indicates the desired plan for home care services; and the goals to be achieved by home care services.

The home care referral and HITC's communication forms initiate the CCAC's home care chart. The HITC sends these documents to the CCAC by courier. The CCAC assigns a Home Care Provider and specifies (1) type of awarded service(s), (2) frequency for delivering the service(s) and (3) start and end date of services. The CCAC office determines to whom the referral for services will be awarded from among a list of bidders for Home Care Providers. Thus, it is possible; as suggested earlier, that one Home Care Provider is chosen as the successful bidder for nursing services, while another is chosen for nutritional services. In this manner, the patient ends up receiving care from multiple
home care providers and health professionals who have no affiliation to each other; the significance of this is discussed later, in Chapter 5.

The CCAC faxes 1. the home care referral form, and 2. the HITC's Communication Form to the appropriate Home Care Provider. In the case of nursing services, The Home Care Provider schedules a primary home care nurse according to the number and frequency of visits authorized by the HITC and faxes the faxed version of the home care referral and HITC's communication form to an assigned home care nurse. This is supposed to provide her with the information she needs prior to the first home visit, and to inform her of the authorized start, number and duration of home visits. The Home Care Nurse determines the home care services required and goals for a home care patient based on the documented information on the faxed copy of a faxed version of the referral and the HITC's communication forms. In the patient's home, the home care nurse determines the patient's health status and MMSs requested from the referral; the other authorized home care services; and schedules hospital and community appointments. She performs her patient assessment by interviewing the patient and their informal caregivers to determine:

(1) the patient's physical, functional, clinical, and medication needs in the home environment;

(2) the patient's level of understanding of his or her medical and medication needs;

(3) accessibility to informal care providers and their role;

(4) any scheduled follow-up out-patient clinic, family physician, and physician specialist appointments; and,

(5) additional home care services from other providers, such as laboratory, nutritional, rehabilitation therapy, and speech therapy.
Finally, the home care nurse documents her assessment of the patient's needs and goals on the home care provider's records, communicates pertinent findings or questions to community providers on a communication form, contacts the patient's pharmacy to arrange medication renewal or delivery as well as "compliance" devices (e.g., medication blister packages), and completes CCAC documentation identifying the patient's ongoing home care needs (e.g., number and frequency of visits and services). When the home care nurse has assessed that the patient requires additional services, she communicates that information to the CCAC community-based intake coordinator (CITC) by leaving her a phone mail message as well as documenting the request on a CCAC form. Requests for changes are aimed at triggering an assessment or other response by a CCAC CITC to visit the home care patient.

4.2 Home Care Patient Demography

The study patient demography for the two groups of patients, those referred for home care nursing with a MMS and those referred for home nursing for other reasons, is given in Table 1.

As shown in Table 1, there was a similar proportion (46 percent) of male (16/35) as female patients (19/35). Patients were more likely to be referred for home care from the General Medicine Program (28/35 or 80%) than from the Cardiology Program (7/35 or 20%). Twenty-one or 60 percent of the referrals were made for home care with nursing for a MMS, and the majority of those referrals were from the General Medicine program (16/21 or 76%).
This table shows that some patients were more likely to be referred for home care with nursing for a MMS than others. First, female patients were more likely than male patients to be referred for MMSs (12/21 or 57%). Secondly, patients aged between 75 to 84 were more likely than younger patients to be referred for MMS (10/21, or 48 percent). Thirdly, patients with a medical diagnosis of either congestive heart failure (8/21 or 38%) or diabetes mellitus (5/21 or 24%) were more likely than patients with other diagnoses to be referred for a MMS. Fourth, patients receiving digoxin therapy (6/21 or 29%) or psychotropic medications (6/21 or 29%) were more likely to be referred for MMS that patients receiving other medications. Lastly, almost all patients with one or more hospitalizations within the past year (18/21; 86 percent) received a referral for nursing with MMS.

4.3 Medication Management Services Referred, Authorized, and Provided

The types of MMSs referred by the hospital’s physician/interdisciplinary team, authorized by the CCAC HITC, and provided by the home care nurse, were analyzed for each study patient, and are given in Table 2.

As shown in Table 2, in the column marked ‘referred,’ there were 21 referrals (or 60%) made for home care with MMS. The second column in Table 2 shows that there were actually 24 authorized MMS. The reasons that there is a discrepancy in the numbers in columns one and two is that the HITC, while disapproving some MMS referrals, actually approved an MMS in a few patients who did not originally get an MMS referral. The
difference between those disapproved and those newly approved was +3. Since I did not interview the HITCs, I can only speculate that the reason for this difference is that the HITC is authorizing an MMS in order to involve the nurse in the care of some patients who did not originally receive a referral for an MMS from the hospital team. In Chapter 5, I review nurses’ complaints about the HITCs ability to properly assess a patient’s home care requirements and make these changes.

Column 3 of Table 2 indicates that the home care nurse actually planned or provided a MMS in 29/35 (83%) cases. The reason that this number is larger than the number of referrals by the medical team is that the nurses assessed that most patients required an MMS. As I identified from my home visit observations and nurses' interviews, in addition to the referred services of medication administration, adherence monitoring, and/or medication education, nurses also conducted patient medication assessments. I had not previously included performing medication assessment in the study definition of "medication management services" as I had understood from the feasibility study that performing and documenting the patient's medical and medication assessment on the home care referral form was the responsibility of the hospital medical team. Further, I had understood that the HITC also performed her own assessment in order to verify that of the medical team's. It was the responsibility of the HITC to ensure the referral form contained complete and accurate contact, medical, and medication information. In addition, the HITC was also responsible for documenting the decisions that came out of her assessment, such as the patient's needs or potential problems in the home as well desired nurse's interventions for the patient, on the HITC's communication administration form.
Thus, the nurse is conducting work that should have been done by the hospital / CCAC HITC but which was not communicated or done. In performing the medication assessment, the nurse was trying to determine the medications that the patient should be taking home upon hospital discharge compared with the medications that the patient had been taking prior to hospitalization. As will be elaborated in the next chapter, this activity often took about half the time of a 30-minute home visit because it required that the nurse compare the each of the patient's medications at home against those listed on the referral (if listed) and the patient's medication discharge list (if provided). The table also gives some idea of the magnitude of services rendered by the home care nurses as compared to the services authorized by the CCAC, in that 107 MMSs were provided for 29 patients while only 24 had been authorized.

4.4 Home Care Nurse Education and Experience

Table 3 provides a description of the nurses who participated in the study by pseudonym, their home care provider affiliation, education and total years of experience with providing home health nursing. Since I followed one patient for each nurse, the table also shows which patients had a referred MMS as compared to a nurse provided MMS. Nurses in this Table are grouped first by education as an RN (majority of nurses) and the corresponding years of home care experience in descending order from the greatest number of years of experience (>11 years) to the least number of years of experience (1-5 years). Within this group, they are also listed in alphabetical order, so that the reader may locate them to provide a context when reading nurses' comments in Chapter 5. Secondly, I show nurses with B.Sc.N. degree and their corresponding years of home care experience
also in descending years of experience from those with 11 or more years to those with one to five years of home care experience. Lastly, I show nurses with an R.P.N. diploma and their years of experience. For the majority of the nurses (33/35 or 94 per cent) their total years of home care experience were with the same home care provider (not shown in the Table).

As shown by Table 3, of the 35 home care nurses in the study, the majority, 18 (51%) had an RN diploma, 9 (26%) had a Bachelors of Science in Nursing degree, and 8 (23%) had a registered practical nurse diploma. The majority of the nurses interviewed, 31 (86%), indicated that they were the patient's primary nurse.

Most of the nurses interviewed had 6 to 10 years of home care experience (43%), followed by those with one to five years of experience (34%), and lastly, those with 11 or more years of home care experience (23%).

When I examined the number of years of nurses' home care experience by their educational background, I found that it is reflective of the above distribution, I found few differences in the proportion of those with RNs, BScNs and RPNs who were novice, intermediate or senior in their years of experience. That is 6/18, or 33 percent of nurses with an RN diploma had five or less years of experience, 7/18 or 39 percent had six to 10 years of experience, and 5/18 or 28 percent had more than 11 years of experience.
5. ORDERED CARING, ASSIMILATED CARING AND EMPOWERMENT

Adeline Falk Rafael (1998), in her article entitled, 'Nurses who run with wolves: the power and caring dialectic revisited', describes the relationship between power and caring based on her work with public health nurses. She sees nurses having the "potential to transform health care through envisioning possibilities for meeting human health needs beyond the context of cure" (Rafael, 1998). Rafael proposes that the relationship between power and caring comprises at least three layers and that each form of power and caring may predominate in a particular nurse setting, or time. However, there is usually a dominant form that influences a nurse's feelings of power and powerlessness and her ability to envisage transformative change in her way of knowing and caring for patients' social, economic, and political needs. Rafael describes the three layers as "ordered caring," in which power and caring are polar opposites; "assimilated caring," in which caregivers assume dominant epistemologies, e.g., appropriate or co-opt androcentric and medical ways of knowing in order to gain a measure of power; and "empowered caring." In this third layer, "the conceptualization of power broadens to include an enabling power that is recognized as an intrinsic aspect of caring. It is in this layer, that the nurses' potential emerges to "transform health care through envisioning possibilities for meeting human health needs beyond the context of cure" (Rafael, 1998, page 30). Caring, in this context, "encompasses the social, economic, and political determinants of health" (Rafael, 1998, page 30).

In this chapter, I use Rafael's (1998) model of "caring" and Smith's (1997) ontology of power relations to critically interpret nurses' experiences with the home care referral
process for medical patients discharged from hospital with MMSs. Nurses' accounts of their experiences revealed that the referral process is fraught with difficulties for the nurses who attempted to implement it. I have attempted to illustrate the problems that they describe in Figure 3. When their accounts of frustration with trying to care for their patients are taken as a whole, the process can be seen as a struggle between power exerted by ruling relations, i.e., the hospital, CCAC and home care provider, and nurses' work of caring. I show how documents and documentation practices associated with the home care referral process "order" nurses' work. The goal of these ruling relations is social control or "order." Nurses' experiences suggest that they "cope" by adopting one of the positions described by Rafael (1998). Thus, I have entitled this chapter "ordered caring, resistance, and empowerment". The problems reported by the nurses in this study were so fundamental that even they tended to undercut home care's declared aim of preventing rehospitalization of acute care referred patients. Nurses, as the key link and resource between the hospital and community, were urging structural and organization changes so that they may continue to provide the health care needs of their patients.

This chapter consists of five sections. The first illustrates how nurses act as the key but powerless social actors in the patient's transition from hospital to home care and provides a glimpse of their struggles with this process. The second section describes how administrators of home care exert control over nurses' work of caring through text, and how nurses inadvertently silence patients' voices through their own constitution of text. In the third section, I discuss how accounting mechanisms promoted by ruling relations fail to "account for" the work of caring, thus disempowering nurses. In the fourth section, I
describe how "assimilated caring" occurs as nurses may unwittingly reproduce the power relations that they may be trying to resist in order to address patients' problems. In the fifth section, I illustrate how nurses' resistance to oppression exerted by ruling relations leads to "empowered caring". This leads into consideration of a more equitable model for home care based on my interpretation of nurses' suggestions for changes to the existing home care system if they are to provide what they believe necessary for their patients.

5.1 Nurses as the Key Link Between Hospital and Home Care

A primary objective of the nurses' work of caring for home care patients is to ensure that patients have the knowledge to participate in their self-care. Specifically, regarding MMSs, this assumes that patients can manage their own medication regimens. In aiming to encourage a patient's self-management with his or her medications, the home care nurse spends a great deal of time determining the medications that the patient should be taking at home, whether the patient has had all prescriptions filled, understands how to take them, is 'compliant' with therapy, and knows when to report potential unwanted effects of therapy. For patients discharged from hospital, the home care nurse is the key link between the patient's hospital care and community cares. The nurses' work of coordination, however, is problematic. Hospital staff and community health professionals do not routinely prepare the patient for taking medications. Thus, more often than not, the nurse is faced with the time-consuming task of figuring out what the referral agents intended without being able to communicate with them, and without accessibility to accurate information.
Shirley (a pseudonym) describes her frustrations with system fragmentation, lack of information between hospital and community providers, lack of hospital preparedness of the patient for self-management with medications, and a lack of services by community providers, in particular, pharmacies. Shirley's interview responses indicated that there is a great deal of what she termed "system fragmentation" and that there is a problem with the whole system. She provided a description of her frustrations with the system in the context of the patient we had just seen during the home visit. Shirley told me that this patient had experienced multiple hospital admissions and was seen by multiple physicians in hospital while his family physician was unaware of his patient's hospitalization or management. Undercutting the goals of restructuring, treating patients according to this silos of care model means much duplication of services. Duplication of activities can be due, for example, to lack of information sharing by the hospital and hospital-based intake coordinator with the home care nurse. Inconsistently performed patient assessments by the hospital team and hospital-based intake coordinator also required the assessments to be repeated by the home care nurse. If patient medication assessments were accurately performed and communicated by the hospital team and / or the HTIC, then the home care nurse would not need to spend as much time as she does on this role. Several nurses commented that a significant portion of an initial assessment is spent checking that the patient is taking the right medications and medication regimen. For example, nurses need to sort out variations between the medications listed on the referral with medications in the patient's home.
Medication inaccuracies on the referral form caused nurses a great deal of concern. Lee, for example, indicated that in the case of her patient, there was a need to check the accuracy of information on the medical referral form against the patient's medications at home, and the medication list received from the hospital. Often, as in this case, these were not the same. Lee went on to mention that sometimes the referral form, which has a section for the patient's medications on hospital discharge, will not list the medications that a patient is actually taking. Alternatively, a list of drugs that the patient was discharged on from hospital is sometimes attached to the referral form; however, this list, may be incomplete or outdated. Debbie complained that information from the hospital should be routinely passed on so that nurses have the same information (as other caregivers) instead of always having to ask the patient for it. She echoed Lee's concern that even when information is communicated from the hospital on a medication list, it is often inaccurate because medications are changed just prior to discharge, and the list is written in advance of a patient's hospital discharge. In Nancy's case, the home care referral form was prepared 48 hours before her patient had been discharged from hospital and medications changes made at the time of the patient's discharge were not included. In such instances, she said she would check to see if a medical discharge summary was also provided, and would obtain information from this form if it were available. However, even the patient's discharge summary form from the hospital often lacked an up-to-date list of the patient's medications.

Vera, Fiona and Marie all expressed concern about potential patient harm due to last minute changes in medications just prior to hospital discharge. Such changes leave no
time to monitor a patient's response to medication changes. Vera mentioned that there is a need for better coordination between the hospital and home, especially an older person whose medication doses are changed in hospital. Unnecessary anxiety can be the result for these patients if, when they get home, they experience light-headedness and cannot figure out if their side effects are due to the drug or change in dose. Vera was concerned about hospitals changing medication dosages but not evaluating the impact on the patient. This lack of follow-up could result in patient falls at home with the patient ending up back in the hospital; this is what had happened to her patient and it was in this context that she had expressed her concerns to me. Vera's concerns were supported by Fiona's experiences. Fiona indicated that in her patient's situation, medications were changed just prior to hospital discharge without time to monitor the patient's response to the changes in hospital, but the referral form had not been adjusted to reflect the medication changes. She too expressed concerns that changing medications just prior to discharge is bad timing for a patient because this creates too much confusion for them, especially the elderly. Fiona thought that this risk could be avoided by filling in the medical referral form as close to the time of hospital discharge as possible. Marie's patient went home with a new dose of a particular medication but also had the previous dose at home. She was frustrated by this because the problem is recurrent. She said that frequently, the change in dose is not explained to the patient at the time of discharge so that the patient at home is confused about which dose to take and may end up taking both unless this is caught and explained by the nurse. In general, if the referral form states medications and doses, these frequently differ from the medications that the patient has at home.
These concerns for safety add greatly to nurse workload. Stacey complained that nurses spend a great deal of time performing a complete patient medication assessment (checking patient's medication containers against the list of medications provided by the CCAC referral and hospital medication list). She stressed that it is really important for the nurse to see each medication vial, eye drop container, and every type of medication in the house (even those medications that the patient does not consider to be medications). She emphasized that this type of detective work is necessary to discover any potential discrepancies between what the patient is taking versus medications listed from the hospital on the hospital discharge list vs. the referral. She added, the more checks available the more likelihood of discovering errors because there is often large differences between these lists with the patient's medications at home. Stacey suggested that it would be optimal if there could be a standardized process of providing a list of medications with the CCAC referral from the hospital such that there is one current list that represents the patient's medications upon hospital discharge. A rational approach to referral would then be to give this list to both the patient and the nurse. Pat recalled situations in which she has called the patient's family physician to determine the medications the patient should be taking, only to discover that the family physician had not received the discharge note from the hospital physician yet. Her comments pointed to the need for receipt of timely patient information by additional community providers, such as the patient's family physician.

Several nurses indicated that neither the hospital team or community pharmacists consistently educated their patients on their medications. As a result, nurses were left with
the responsibility of providing medication information. Educating patients to fill their prescriptions prior to arriving at home is also often neglected by the hospital. For example, for Nancy's patient, did not have any of his medications available at the time of the home visit. She mentioned to me that patients might be confused or disoriented when they come home. If the nurse looks for the prescription in the home but doesn't find it, she inevitably has to make arrangements for the patient to get the prescription filled. This may take two to three days because sometimes the pharmacy does not have the medication in stock, meaning that the patient has been without therapy since leaving the hospital. During my home visit observations, I learned that, in fact, it is usually the home care nurse who makes arrangements with the patient's pharmacy to deliver medications if needed by her patient so as to ensure that the patient will have his or her medications with them at home.

Neither do patients receive much additional medication information beyond their medication dosages. There may be a good reason for this: if such information was given at the stressful time of hospital discharge when many people are seeing the patient, the patient may be overwhelmed with information. However, nurses expressed concerns about potential harm to home care patients resulting from the limited or non-existent education of patients regarding their medications. Especially lacking is education explaining changes to medications that were discontinued since hospitalization and information on new medications prescribed just prior to discharge. The failure to inform patients and their nurses about these important changes suggests a paternalistic system in which only the prescribers are "in the know."
Fiona emphasized the importance of educating patients on the trade and generic names of medications, because, as she pointed out, patients may get a prescription filled with the *brand* name while they have the same drug at home with the *generic* name on the label.

The patient may think that the drug filled and the drug at home are different ones and may end up taking both the old and new prescription. For example, her patient had a vial at home for 0.125 mg of digoxin, while a new prescription vial read, Lanoxin 0.25 mg. Not realizing that these are the same drugs, the patient could have resumed the old medication as well as taken the new one had the home care nurse not caught the problem and informed the patient. In general, the home care patient is usually self-administering his or her medications. Therefore, any lack of patient medication education on changes to medications upon hospital discharge places him at risk of experiencing a MRP. If nurses were not so vigilant about these details, harm and even death could result, since these patients are very ill.

Particularly problematic situations are ones in which it is difficult to communicate with the patient or the patient is taking a medication that has several side effects or a complex regimen. In such instances, it is even more critical for the hospital and community pharmacy to provide medication education. However, the home care nurse is often the one introducing the information for the first time to the patient. For example, Ruth’s patient had a mild degree of cognitive impairment, making it hard to communicate. When her patient drank too much, this further strained the communication. He had not received any information about his medication on hospital discharge. Ruth thus chose to spend the
time during the home visit to check that he understood the names of his medications and purpose of each one.

Problematic medications for patients to take without proper education include inhalers, or medications such as warfarin, which requires careful lab monitoring to ensure appropriate dosing and therapeutic effect while avoiding potentially dangerous side effects. A home care nurse may be referred specifically to provide medication education and monitoring for a patient who is prescribed warfarin. Lisa's patient was on both an inhaler and warfarin. But Ruth complained that patients are not told even simple information (on hospital discharge) such as the need to rinse their mouth when using certain inhalers, neither from the hospital nor at the community pharmacy. As a result of these oversights, Lisa pointed that the nurse must spend time teaching the patient about their medications even though this service was never requested. But general medication instructions at the hospital are not enough. Nurses stressed the need for individualized patient medication education. Audrey emphasized that one must judge how much information should be given to the patients about unwanted side effects. Unless education is tailored to the patient, he or she may become fearful and discontinue the medications. Nurses also expressed concerns regarding premature discontinuation from the home care program, which may place the patient at risk of experiencing a potential medication related problem or rehospitalization.

Although nurses are competent to perform MMSs, it would be helpful to have some assistance from pharmacists, especially since pharmacists are now advertising their
abilities to counsel patients on their medications. For example, the hospital or the community pharmacist could intervene to assess whether the patient should be using what is called a 'compliance device' in the home. This is designed to assist patients with multiple medications or medications with complex regimens. Because medication 'compliance' is not assessed by the hospital team prior to hospital discharge, it is often the home care nurse who takes the onus of ensuring that her patient's medications are dispensed in a 'compliance device' if she assesses that this will help the patient to remember to take these medications. The use of the term 'compliance' in connection with these types of services is a reflection of the paternalism in a system where orders are followed but not necessarily explained or understood. While the term 'adherence' is now preferred in the clinical literature, the idea is the same: the patient is to follow orders. Audrey suggested, for complex situations, such as when patients are on alternating dose schedules of a tapered dose medication, such as prednisone, then the 'compliance' device, such as a blister package, should be marked with the date and number of tablets that the patient should take with instructions on when to stop taking the medications. For example, Sydney's patient was on a "sliding scale" of prednisone for chronic obstructive pulmonary disease; however, the hospital did not provide a list indicating the date that the prednisone tapering had started or when it was to be completed, or the amount of prednisone that was reduced daily. Complete information, along with pharmacist intervention, would have been helpful in this case.

According to the nurses, a dosette is sometimes preferable to a blister package. For example, Fiona's patient's medications, other than prednisone, were filled in a dosette.
The prednisone had been dispensed by the pharmacy in the medication vial with instructions to "take as directed." Because this patient had a dosette, the nurse was able to access it and add the prednisone from the patient's medication vial. The dosette offers the advantage that the nurse could watch the patient to see that he would be able to retrieve the right medication at the right time from the dosette. If the pharmacy had provided a blister package, then the nurse would not have been able to add the prednisone to it, as the blister package is a tightly sealed container. As a result, without the dosette, Fiona's patient would have required daily visits to administer the prednisone in order to ensure that the medication dose was taken as prescribed. The matter of dosettes was so important that, as Lisa indicated, many nurses kept information on the pharmacies that supplied and arranged 'compliance' devices and referred their patients to those pharmacies to fill their prescriptions. Lorraine wished that Community pharmacies routinely assessed whether a patient needed a dosette or a blister package. She thought that it would be helpful if they were willing to preload dosettes and provide blister packages if these are required. Nadia went so far as to suggest that all seniors should be on a blister package to minimize confusion. This example emphasizes that nurses and patients are merely the agents of the prescriber in following orders. However, the vacuum surrounding the 'compliance' process makes 'compliance' very difficult.

It is clear from nurses' accounts that they are the key agents in the home medication management (though perhaps this role is more appropriate for the community pharmacist). The home care nurse becomes the key agent in determining whether a patient needs a medication compliance device. She provides recommendations to the
pharmacist regarding her assessment as well as the type of device to use (e.g., blister package or other device) rather than the other way around. Nurses have commented, however, that this function should occur at the time of hospital discharge or be performed by the community pharmacist at the time of dispensing the medication to the patient. If pharmacists were more intimately involved with home care MMSs, many problems might be circumvented. For example, nurses have found that oftentimes the patient (who may be illiterate) is unable to read or interpret the medication label because of the label font. Or that the patient may have difficulty opening the prescription vial. Again, nurses have indicated that it would be more appropriate for the community pharmacist to make such assessments at the time of prescription dispensing when the problem can be more easily corrected. Audrey went on to say that in her patient's case, the pharmacy label was faint; her patient wore eyeglasses and could read the label only with difficulty. The problem goes beyond whether a patient can read a label or whether the label is clear, but also includes the need for pharmacies to consistently use the same drug names on labels. For example, Nadia's patient had her medications filled at the same pharmacy but these were labeled sometimes by generic name and sometimes by the brand name. This situation became confusing for her patient and she had to call the pharmacy and ask them to use the same name on the label each time. Nadia indicated to me that pharmacies should have an internal policy and procedure as to how they label medications so that patients can be assured of consistency. As well, nurses ask that pharmacies consider whether a patient is able to open the medication vial lid. Nancy discussed her patient's challenges in opening the vial lid. She also pointed out that elderly patients have difficulty cutting doses in half; with fractionated doses, such as 1.5 tablets alternating with one tablet, patients may not be
able to cut tablets and it would be easier and safer if pharmacies precut the doses for patients who have issues with hand dexterity. It is as if no one is thinking about the patient in his or her unique situation except the nurse.

As the remote 'arm' of the medical 'team,' then nurses are often coordinating and ensuring the patient's understanding as well as following-up with their community providers. The nurse was the one who gathered the information about patients' ongoing care requirements in the home, taught patients about their follow-up appointments, explained about additional home care services and providers caring for the patient and activities that they would have to perform. In order to make this complex task easier, Linda suggested that the equivalent of a 'smart card' be given to each home care patient so that the patient could take it to each medical appointment or ambulatory visit. This could contain a 'medication chart' (i.e., an accurate list of medications) that indicates the drug and its purpose and when to take it. Such cards could be carried by patients, for example, when seeing the family physician. This medication chart could serve a number of purposes; it could help the nurse in the patient's home as well as those in the community (e.g., the patient’s family physician).

Overall, in addition to performing distinct MMSs, the nurse is constantly teaching, gathering information, coordinating care, and assessing the patient's health. However, the nurse performs this work of caring with minimal support by other health providers or information. Francis stressed the need to improve communication between the hospital physician and the patient's family physician in the community. Lack of communication
between hospital and community providers makes it difficult for either of them to have current information regarding the patient. The nurse in such a scenario is placed in a position of first gathering and then bridging information between providers. Francis suggested routine access to the hospital physician by not only the home care nurse but also the family physician, as it is the hospital physician who has pertinent patient information that community providers require in order to care for their home care patient. Often, as Manuela mentioned, the family physician does not even know the patient was in the hospital. For example, Debbie's patient had been seen by a cardiologist in the hospital; however, her patient's family physician had not received the hospital discharge summary notes from the hospital. She indicated that this put her (and other nurses) in the awkward position of telling the family physician the patient's discharge diagnosis and medications and asking the physician to assess the patient's medications. Nurses emphasized that, at a minimum, only when they and their patients have the correct information can they do their part of the work process. Other workers remote from them, for example, community pharmacies, and laboratories need the same kind of support if they are to accomplish their part of the process of home care.

5.2 Text Mediated Control

Gerald de Montigny, a social worker, describes how social control is exercised through the construction of text in social work in his article 'The power of being professional.' De Montigny (1995) describes how client contact by professionals during a home social work visit results in text entry as part of the construction of 'records' that exercise a social control function. An aggregate of text entries creates a file, which becomes a record of the
work performed. The routine textual construction activities of health providers are reduced to statistics by administrators for an organization such as the CCAC. In this case, the home care provider is required to conform with their requirements.

The views of the patient and the nature of the patient-provider relationship, as well as cooperation between providers in the act of caring, are disregarded in textual practices. Inherent in these texts are assumptions about, for example, social class. Interpretation of these texts and ultimately decisions about the care of the patient thus reflect these assumptions. Professional assessment of the patient becomes located inside a professionally-determined schema of documentary forms, in the process, silencing the patient's voice. For example, Shirley said that her patient is depressed. He has had a previous alcohol abuse problem. He was declared "demented" by the physician and his hospital record was labeled as such. However, she believed that he has enough abilities to get involved with activities. He had "home-making" approved, but did not want it because he had to wait around for the person to come. He hates waiting around. Shirley tried to get him connected with various community centers. Yet, this type of patient-oriented nursing work is rarely credited or recognized when buried among textual entries.

Nurses themselves, just as social workers and other professionals, create inequalities for their patients and for each other through the creation of documentation entries in the home record. For example, Debbie said that she questioned her patient's ability to understand the information she gave her on her medications. As a result, Debbie predicted that this would mean that the patient would forget to take her medication and experience
another anginal attack, which had resulted in her initial hospitalization. If this nurse has misjudged her patient's true abilities, her textual entry to this effect would label the patient as requiring intensified monitoring even if the patient was competent. In other words, it is possible that the same control being exerted over by the home care nurse herself, who feels powerless to pursue caring goals within the bio-medical model, is reproduced by the nurse in relation to her patient.

Policies and procedures regulate how and what nurses document, and how nurses spend time their time. It is important to recognize that such "accounting practices" not only regulate how nurses perform their work of caring, but also in essence reproduce the power relations in the health care system. For example, Vera described a situation in which her patient had to be hospitalized because of symptoms related to theophylline toxicity. Although Vera was the one who identified that the symptoms that the patient was having were due to his medication and who assessed the source of the problem, the complexity of this professional act of diagnosis would get reduced to a textual entry that would not sufficiently describe what she had done. Left out would be her role in relating the symptoms of drug toxicity and what she subsequently did, which was to ensure that the patient went to the emergency department for evaluation. The situation had added complexity because the patient's first language was not English. This case illustrates how the nurse's professional work is made invisible in the process of documentation. Documentation and documents thus direct the work of the nurse including performing or evolving issues that were not appropriately addressed by either the hospital or the community pharmacy at the time of the patient's hospital discharge. However, the records
do not indicate when she performs the work that was the responsibility of others. Perhaps the least regard is shown for the nurse when she cannot even decipher the orders. This pattern of carelessness on the part of the professionals in control is familiar from the example of the pharmacist who cannot read a prescribing physician's writing on a prescription. Nurses' accounts showed that there are similar problems with the legibility of the home care referral form, making it difficult to interpret what services are being requested by the CCAC. This reflects a lack of understanding on the part of individuals in control of the referral process about the health provider's needs in the home setting.

Several nurses indicated that it was difficult to read the handwriting of the hospital intake coordinator on the CCAC referral. Often a nurse receives a faxed copy of a fax sent to the home care provider agency from the CCAC. The double faxing makes it more difficult to read the referral form. Sydney was required to make many calls to his home care agency for the case we discussed, for example, to read out the information on their faxed version of the referral form because he could not decipher the information on his version of the double-faxed referral. Similarly, both Debbie and Linda indicated that medications listed on the referral forms that each of them had received could not be read because the handwriting could not be interpreted. Both also indicated that neater print or a typed referral would be preferable. Nancy thought that another solution to this situation would be to fax a list of medications directly to the home care nurse (instead of the to the home care provider who then faxes it to the nurse).

Significantly, the nurse is not involved with the beginning of the home care referral process. The form requesting services is often incomplete as it is filled out and assessed
by remote individuals involved with her patient who are not aware of the patient's needs in the home or the nurse's basic requirements for doing the job of coordination. Because the home care nurse does not have access to the medical record in order to obtain the missing information, when referral agents' forms were incomplete, nurses were dependent upon information possessed not by the prescriber but by the hospital, community agency or community CCAC coordinator. Nurses found this lack of access to the initiators of the home care process frustrating. In addition, missing contact information made it time consuming to determine who to call. Compounding this problem was the delayed response time to the home care nurse's call. Nurses found it frustrating spending time searching for this information, as it was valuable time that they could have better spent with their patients. As Debbie said, the incomplete referral affected her contact time with her patients because of time spent instead on trying to obtain pertinent patient information about hospitalization as well as searching for a contact phone number.

Frequently, the referral form and the hospital-based intake coordinator's communication form are missing contact information, the patient's diagnoses, course in hospital, and the desired home care goals. For example, in Debbie's case for her patient, the referral and the intake-coordinator's communication form lacked the goals for the patient at home. Marie indicated that for her patient, neither his course in hospital nor patient history were stated on any of the documentation. Contacting physicians for information could also be problematic. Because Stacey had received an incomplete referral and inaccurate medication list from the hospital, she was required to access the physician in order to clarify patient medication information. However, her patient had had been seen by
multiple physicians in the hospital. Thus, in addition to time wasted in determining which physician to contact, the physician she contacted was late in calling her back. Mary experienced similar frustrations. In her situation, there was a time lag in receiving the referral form as well as the time required to determine which physician, among the multiple providers caring for the patient, to contact. She said that it was very hard to check with the hospital physician to confirm medications because of numerous physicians being involved in a patient’s care. Even when contacted, a physician who did not have the patient’s chart in front of him or her could not immediately confirm the drug that the should be taking or previous medications. Nurses indicated that a 30-minute home visit does not provide time to conduct their nursing care for the patient as well as make the necessary phone calls to clarify information. Thus, nurses are frequently spending their own time, following completion of their home visits, to initiate calls to prescribers to obtain information as well as checking their phone mail for responses to their questions regarding their home care patients.

Despite the frustrations of “begging” for information, nurses felt that they had no choice but to contact physicians or the hospital because of their concerns about potential patient harm due to medication errors or lack of therapy associated with missing information on the forms. As reviewed in the previous section, nurses frequently complained that they did not receive any information from the hospital, including no medication list, or one that was outdated. Brenda told me that when the nurse is in doubt about the accuracy of the lists and the physician cannot be reached, she has no option but to ask the patient.
This places the person responsible for the care at the bottom of the professional hierarchy and interferes with her ability to make professional decisions.

Nancy indicated she experienced a delay of about two days before she received a response from the patient's physician to clarify the patient's medications on the referral form. This meant that the patient was without medication during this time and as a result might end up being readmitted to hospital. Thus, the need to improve response time from physicians to nurses in the community.

It was not just the hospital and prescriber's forms that were incomplete. Marie and Lee echoed other nurses' frustrations with inconsistently completed communication forms prepared by different intake coordinators. Lee indicated that the type and extent of information received from each intake hospital coordinator differs; she pointed out that "it is very subjective and depends on the intake coordinator doing the assessment." She went on to explain that it is stressful for the home care patient to have to repeat his or her whole hospital course to the home care nurse. Both Lee and Marie emphasized that one way to minimize this stress, would be for is for the hospital physician or the intake coordinator, who should be providing the information to the nurse, to provide consistent, extensive documentation about each patient's hospital course. They (the HITCs) should be aware that the home care nurse does not have access to the patient's medical record. In addition, since the form is prepared from the perspective of the CCAC's HITC, it does not necessarily consider the patient's needs in his or her home environment nor does it include information important to the home care nurse. The nurse is expected to be the
"arm" of the physician and CCAC intake coordinator, but does not have access to the medical record or decision-making autonomy by the hospital or CCAC to make decisions that may need to be made in adjusting therapy in the home. Neither are the community providers, such as the home care provider agency, the community family practitioners, and community pharmacists involved in the hospital team's assessment of the patient or have access to the patient's hospital record. All of them are thus rendered dependent upon the hospital providers to adequately perform their role. Notably, the community-based CCAC intake coordinator is not involved in either the hospital team's or the hospital-based CCAC intake coordinator's assessment of the patient. They too lack access to the patient's hospital medical record. Thus, the CCAC community-based intake coordinator is effective by just another layer of bureaucracy, merely serving to "broker" care within a capitalist model of health care.

The remoteness of these "brokers" from the professional work they hire is illustrated by nurses' difficulties in accessing the community-based intake coordinator as well as the long communication and response time of the community-based intake coordinator. Inga experienced a turnover of CCAC coordinators, leading to inconsistencies. As troubleshooters, Inga indicated that intake coordinators tend to be out in the community more often than before and hence, not available to respond to messages/calls. For example, as happened with Inga's patient, it was documented by the CCAC coordinator (in the community) that the patient was readmitted to hospital. It turned out that the patient was at home and not readmitted, but as a result, the home care nurse did not make the initial visit when it was scheduled, because her information was that the patient was
readmitted. When the home care nurse attempted to reach the CCAC coordinator, the coordinator was unavailable. She indicated that there seems to be no explanation for why the CCAC coordinator was unable to find the patient when she made the visit to the patient’s apartment. According to the patient, she was in her apartment on that day the whole time. These irregularities are problematic, since the nurse does not have information or "permission" to use her professional judgment when lapses occur. Ashley, for one, complained about how the slow response time from the CCAC community-based intake coordinator affected getting things done for her patients because she needs approval from intake coordinator.

As can be seen from this discussion, the fact that nurses lacked access to the initiators of the home care process and the patient’s medical record, was a recurring problem. At times, nurses were left with no option but to ask the patient him or herself to clarify the medication information that they may have received from the hospital. While this may serve the purpose of involving the patient in his or her care, it would be preferable when dealing with potentially dangerous medications to have the back-up of the "team" that is so often talked about in the hospital-health care literature.

Thus, serious problems can be seen in the production and implementation of the texts governing home care. Further, the nurses' record, as a text, is produced in compliance with CCAC, medical and other ruling policies. As a result, the nurses’ work of caring is reduced to performing the work of others in order to clarify documents, thereby, undercutting the autonomy and ultimately silencing the voice of the patient. Professional
activities are transformed into usable documentary forms that become bound to a course of action outlined in a policy and aggregated and summarized in a report. The authority of the professional accounts *silences both* the nurse and her patient.

In addition, while patients have the right to see their home care record, the power of the record is in its creation. For, by documenting their work, social workers (and other health professionals) display signs of professional practice, ability to use professional language, organize their daily activities into appropriate professional routines, incorporate professional understanding into practice, apply their clinical knowledge, and thereby, establish their professional location. Such work is organized by documents such as policies and directives.

My discussion with Inga is useful in illustrating how the home care nurse may perpetuate inequities through text entries. Inga indicated that different nurses may be seeing the same patient, such as when a nurse makes the initial assessment and another nurse subsequently sees the patient. If the nurse who did the initial assessment did not document her assessment, then the record appears as if it was never done and the nurse seeing the patient next must do a complete assessment. Inga indicated that this is a problem because the time for the first visit is one hour but time for subsequent visits is only 30 minutes.

How much of the professional's documentation is derived from the imperatives of the organizational directives versus the situation at hand? Theoretically, health professionals have some power over how they construct their accounts of their patients' lives. However,
the patient (and nurse) is made invisible as nurses appropriate for themselves the right to
tell the story and decide what gets counted as relevant in the health record. Text provides
a form of distance from the client. Power is also realized in everyday reactions between
health providers, as they mutually rely on each other and work together within their
organizations. Those creating the procedures and directives of activities exercise direct
control through those texts by binding health providers to what and how and how much to
document. Daily activities and clients' stories are reduced to statistical information.

5.3 Accounting Logic Oppressing Nurses' Work of Caring
Fran Gregor (2001), who has studied nurses' work, has argued that their teaching is
largely invisible despite the fact that they act within institutions to make the 'system' work
by virtue of their geographic work locations. For example, a nurse on the geographical
unit 3B is positioned to act on the institutional policies and procedures (i.e., the rules and
regulations) that patients and physicians must carry out while patients are hospitalized
(e.g., as a patient, giving up personal belongings). Nurses have an intermediary position
between administration of the institution (rules and regulations) and administration by the
physician (medical orders) so that if they did not do their work of caring and educating
others about hospital policies and procedures, such institutions would cease to function.
However, ruling relations submerge aspects of teaching, caring and other work that nurses
do through the use of documents (i.e., the referral forms that the CCAC requires, forms
that the Home Care Provider requires aligned to CCAC requirements, etc.).
Theoretically, these accountability mechanisms control the professionals. However, this study reveals the intense struggle between social control and caring in these institutional locations. Nurses gave many examples in which referral instructions were lacking, incomplete, or confusing. This included inconsistent and often vague documentation about expected nursing goals in institutions by the CCAC intake coordinator on her communication form, because, as indicated by Lee, documentation is very subjective and depends upon the skills of the intake coordinator doing the assessment. As was discussed in the above, the information received from each hospital team as well as the HITCs and CITCs differ. Given inaccurate and incomplete documentation, the home care nurse aims to circumvent potential harm to the patient as best she can. What this means is that instead of "letting the ball drop," nurses instead "absorbed" the additional work at their own expense, much as described by Broadbent and Laughlin (1997). "Absorbing" groups emphasize the needs of the patient, client or community against prevailing ideologies of those in powerful positions. Unfortunately, however, "absorbing" groups are at risk of burnout due to lack of recognition by regulatory groups and the excessive workload that they assume in the aim to care for their patient's needs. That is, they may try to reject the economic "business" model of home care with limited success.

One problem already discussed that nurses "absorbed" by their labor was in taking the time to clarify medication inconsistencies. This work is complicated with the challenge of who to access to clarify information, as well as delayed response times by hospital providers and the community based CCAC coordinator. When the nurse has several
patients to see in one day, and each case involves medication inconsistencies, such extra labour, not documented in the records, greatly adds to her workload.

In the following examples, nurses describe their patient's needs and how these affected their time commitments above what had been scheduled. For example, Brenda was concerned about the potential harm to her patient due to inaccurate assessment of the patient’s insulin dose prior to hospital discharge. She also worried about the patient's lack of accessibility to medical specialists in hospital. Her patient was discharged from hospital on what is called a “sliding scale” of insulin doses. Her diabetes and insulin were difficult to manage because she had been discharged from hospital without being stabilized on an insulin dose. Brenda's attempts to reach the patient's hospital physician to get insulin orders were frustrating. In addition, Brenda had to expend some effort in verifying the accuracy of the drugs in the patient’s blister package against those on the list from the hospital. Her patient, who was blind, read out what was in Braille and the nurse read out was on the hospital discharge list. As a result, Brenda spent a longer time with the patient than scheduled in order to resolve all of the issues she had identified. Even though home care does not always "allow" the time per visit to do all of the work required, Brenda commented that it is really important to take this time in the initial visit and insisted on performing it.

In fact, although the time "allotted" per patient visit to perform a patient assessment needs to be flexible as determined by the nurse and according to the complexity of the assessment, currently, nurses explained that only one hour is allotted for the initial patient
assessment. Taking more time results in fewer funded visits. Shirley went on to say that
the home care agency allots only this one-hour for the initial assessment although they
know it takes longer. This is thought to be because the agency receives funding from the
CCAC for a certain number of visits and those have to be allotted as economically as
possible. Shirley pointed out the contrast between being in the hospital with being in the
home in that the home care worker has the opportunity to better assess the patient in their
home. In her view, being able to provide the care needed in the home is all a time issue
because we (nurses) are dealing with people, and "people need time."

Another example of the time that is required and thus "absorbed" by the home care nurse
involves situations the patients cannot communicate in English, as with Mary's patient. In
spite of the fact that her patient could not read English, this was not noted by the
pharmacist, who typed the patient's medication instructions in English on the vial label. It
was the nurse who identified that the patient could not understand the medication label
instructions when she made the home visit. Mary had asked for her patient's daughter to
be present to act as a translator. The daughter interpreted the medication instructions for
her father who in turn described them to his wife in their mother tongue. After this, Mary
called the pharmacy and asked them to type the label instructions in Spanish. Mary
described another situation in which her patient was so concerned about finances that
Mary decided that this might affect the patient's ability to perform what we assume to be
routine acts. In addition, her patient lacked the finances to have a phone. As Mary pointed
out, not every patient has a phone and this has its own set of challenges. To confirm the
patient's availability for an appointment, she would go out of her way to go to the
patient's home to determine her availability. While nurses may be frustrated in carrying out their practices, it was clear in this study, as in Gregor's, that the work that they do for the home care patient is significant in creating courses of action for patients, such as the action associated with clarifying the medications that they should take following hospital discharge. In fact, these interactions between the nurse and the patient's family are critical, but they are not adequately represented by the "time is money" type of workload measure. At the same time, the "ordered caring" implicit in the system would not be possible without this "extra" work of nurses.

In many home visits and interviews, I saw that nurses possessed both professional skills and a valuable body of knowledge; however, consciously or unconsciously, they reported being cautious about the use of their knowledge, imparting it without negatively affecting those in power. Thus even in reflecting on their work, some nurses hesitated somewhat to challenge the whole system. I would like to argue following, Gregor (2001), that the work done by the home care nurse needs to be contextualized and recognized. Home care work remains largely invisible to the CCAC or health providers, and possibly, to other nurses. Nurses did not have very many opportunities, given the current referral system, to make their work explicit in order to show physicians and others upon whom they are dependent what they needed them to do. If they had, for example, expressed their views via strike action or by talking to the press, such action would be seen as subversion of the system. Even the act of asking for medication information involves a conditional display of knowledge, thus subverting the social order.
It needs to be clarified that in their interviews with me, nurses were not objecting to a system created to translate their activities into output indicators. They seemed to accept its inevitability. Instead, they expressed frustration at the fast-paced environment within which they had to care for patients with little support from the hospital, the CCAC, home care provider and community providers. They made innumerable suggestions about how those in authority could make their work easier with such little effort. For example, the hospital could provide a legibly written referral containing accurate patient, medication, and contact information; the home care provider could provide a source of support by scheduling a nurse who speaks her assigned patient's mother tongue; the community-based intake coordinator could take the time to ask the nurses' opinion to determine her assessment of the patient's ongoing home care needs before discontinuing services; and the community pharmacist could take the time to assess that the patient is able to read and understand the instructions on the medication label. In that manner, the nurse may be more able to assess her patient's medication needs as well as carry out the referral request of medication 'compliance.' The fact that those in authority did not facilitate the process in these ways suggests that the work of caring is not important in either the old paternalistic or the new privatized model of home care.

The CCACs attempt to 'account' for the work of caring by using an economic model. However, this fails to adequately define output measures that capture the complete picture of nurses' work. In particular, it fails to recognize the gifts of care which cannot be "encompassed by maximization of outputs" (Broadbent and Laughlin, 1997).
5.4 Assimilated Caring and Relations of Ruling

To this point, it has been argued that power is reproduced through relations of ruling and text. Nurses' accounts have been used to illustrate how CCAC's and nurse employers exert an "accounting logic" and how this suppresses the work of caring. In this section, I will discuss how, despite their best intentions, nurses are complicit in the maintenance of power relations as part of fulfilling their mandate as professionals. That is, in order to be able to function, they often feel that they have no choice but to reproduce dominant ideologies that marginalize caring.

Rafael's (1998) description of "assimilated caring" provides a way to understand how non-for-profit home care providers are under pressure to assimilate the bio-medical model in order to survive in the government-generated, competitive bidding process of home care. Federal and provincial government reports present a dominant ideology based on economics without connecting the economic ideology to a nursing paradigm or articulating how nursing care is consistent with the ideology. Using these texts, government, allied with those who wish to privatize the health care system, render invisible nurses' experiential knowledge and skills.

Again and again in my study, the home care nurses themselves identified their problem as misuse of their time and underutilization of their skills, as they are required to perform numerous administrative tasks (documentation). They knew that the extensive work required to clarify incomplete CCAC documents produced by the hospital-based intake coordinator was disruptive to their time with his or her patient. But they were
themselves powerless not to perform these documentation-related activities. In addition, the CCAC itself directly intervened and made sure that ordered caring occurred through the 'surveillance' (however inadequate) of the community-based intake coordinator's activities. For example, Lisa said that monitoring medications has always been a frustration for nurses in the community because of the number of errors, discontinued medications on discharge, and changes to medication doses on discharge. Nurses are left in the position of sorting through all of these changes in order to construct the 'correct' list of medications for the patient. Nurses are frustrated and feel anxious because of medication discrepancies between the referral form and the "bags of medications" that the patient has at home. Shirley complained that the time that the nurse spends dealing with a patient's medications at home could be the whole visit. Because of the amount of paper work that the home care agency and the CCAC require of the nurse, the important activity, patient assessment, is difficult to keep in focus.

As well, because of CCAC community coordinator practices and funding, the frequency of home visits authorized are at times inconsistent with the nurses' assessments of required services for her patient. This is an example of how CCAC managerial control over nurses' decision-making autonomy limits nurses' flexibility to make decisions regarding additional or continued services that their patient may require in the home. The CCAC is thus a "gatekeeper", and "care" is effectively truncated. Nurses were concerned that CCAC intake coordinators had the power to discontinue patients' home care services. The CCAC often exercised such authority based on a limited understanding of the home care patient's needs because such decisions were made following a single home visit.
assessment with the patient. Thus, regulatory control worked towards limiting nurse-determined decisions about ongoing services that might be required to adequately assess a patient's medication "compliance" or understanding of his or her therapy (e.g., a new insulin regimen). Ironically, by discontinuing services prematurely, in some cases, this regulatory control may be giving rise to situations that result in the very health consequences that the services were initially authorized to avoid, possibly leading to recurrence of a patient's problems and inability to self-manage or become independent living at home. In a case discussed in my study, Claudine expressed concerns about the community-based intake coordinator's decision to discontinue home care services prematurely. She said that the CCAC would likely decrease her patient's visits, although she felt that her patient would need extended nursing to ensure that he takes his medications. According to Claudine's assessment, this patient is ill and needs care. Adrian similarly expressed concerns regarding CCAC assessment of patients' home care needs leading to discontinuation from the home care program. In his words, "the CCAC has no idea" how his client lives. Before making such decisions, either they do not visit or they make an assessment based on a single visit. Nurses thought many patients needed more home visits, but their CCAC refused to increase home visits or discharged patients without ever seeing them or understanding their needs.

In some cases, the nurses I interviewed thought that the community coordinators lacked the skills necessary for performing home care patient assessment, which would in turn influence authorization of continued funding for nursing services. Frieda worried that the CCAC puts a great deal of responsibility on inexperienced personnel. For example, she
indicated that the person delivering medications from a pharmacy or providing support services funded by the CCAC (e.g., home making) is, at times, expected to administer medications. Such agreements can be seen to reflect the priority of saving money over ensuring safety. Nurses, however, did not conceptualize the problem as an issue of hierarchy and power. They instead suggested that it could be solved by strengthening relationships between the nurse and community coordinator and the health care team. Debbie advocated a closer relationship between the home care nurse and the referral agents. She told me that she thought that a closer relationship between the home care nurse and the hospital team would alleviate problems and duplication of information gathering. Importantly, nurses thought that a "closer relationship" would encourage trust between the community-based coordinator and the nurse, such that the coordinator would be able to accept the nurse's assessment of and approve her patient's home care services. This, in turn, would allow less paperwork and more time for nurses to spend with client. However, it is unclear in the nurse accounts how "closer relationships" would come about. In terms of reproducing power relations, while nurses may occasionally find ways to circumvent issues they face, in general, it was unclear how they could avoid complicity given the inherent power relations in the system. Nurses, possibly fearful for their jobs, did not speak out when CCACs introduced more regulations that the home care provider must implement in order to be awarded a bid for a contract.

The reality of the home care situation in Ontario, in which economics is valued over care, is hidden through the use of "approved" terminology, which to nurses, is also "vague." For example, the term "monitoring services," accurately reflects what nurses do.
However, since this is a term that can be applied to a number of situations, and thus cannot be controlled by the CCAC, it can no longer be used. Frieda explained that it is, therefore, difficult to get the CCAC to cover visits for medication, including "support" services, or "monitoring" (although that term was formerly approved used to be used by the CCAC). The only support service that is currently available is for "medications." As a result, the term "medications" is required to get nursing services authorized into the patient's home. In fact, this is the convention behind the use of the hospital-based intake coordinator to get a nursing visit authorized. Ashley described how the term "monitoring", although important, has come to be disempowering to nurses. She said that because the term "monitoring" is no longer a "good" term for the CCAC, nurses try to avoid using this term, although it is a good word to describe the function that they perform. She has suggested that the CCAC provide a list of terms and what they mean by those terms. Her comments might be considered as a challenge to the relations of ruling. However, while nurses, like Ashley, may have an opinion or recommendations regarding many of the practices, I found that they did not openly challenge the practices. One reason for this, as mentioned by Vera, was the concern that they would be perceived as being resistant to change.

The economic ideology behind the CCAC's use of the competitive bidding model for awarding home care services to a provider is consistent with the bio-medical model. Home care providers who work within a bio-medical model, however, are likely to pay a high price for doing so. In the hope of gaining a measure of power and "respect" by "assimilating" perceived values of those in dominant positions, home care providers are
distancing themselves from the possibility of performing as the professionals they feel they should be. That is, by agreeing to requirements of government regarding community agency roles, or by supporting CCAC regulations on documentation practices, without contesting how those disempower nurses to provide their role of caring. It can be argued that nurses contribute to their own disempowerment. Their actions lead nurses to internalize dominant ideologies and values, and cause them to feel pressured to devalue and reject a part of who they are and the work of caring they perform. Ultimately, the price is that nurses may abandon their professionalism as they become trapped in the dominant paradigm to the point that they lose the vision of who they can become and possibilities beyond the biomedical / market paradigm. As I noted above, many nurses seem to know this but feel powerless to act. Similar risks exist for other professions in the hierarchy. By practicing "assimilated caring", the hierarchy of power is reproduced.

For those who remain committed, caring occurs at a high price, exacerbating the nurse's ethical dilemmas, stress, and finances. On a recurring basis, such feelings are likely to lead to feelings of inadequacy and dissatisfaction with nursing work (Rafael, 1998). Thus constructed, caring remains invisible and undervalued. Because of regulatory control as well as pressures on home care providers to live out a medical model, nurses are stripped of their autonomy and power to advocate for themselves or their patients. Unless a patient's well-being is immediately at stake, in which case a nurse would likely find a way to circumvent a particular order in order to care for her patient, everyday nursing follows the path of least resistance to powerful authorities. When the referral process does not truly reflect the types of required intervention, but instead follows impersonal guidelines,
it actually services to be a "gatekeeping" or "social control" purpose instituted by regulatory powers for obtaining home care nursing services. The irony of the situation is that, on the one hand, nurses are expected to document all of their home care activities in order to provide information to the CCAC yet they themselves are given very little information when initiating their care for the home care patient. This situation can be contrasted to the situation that Rafael (1998) calls "empowered caring." In "empowered caring," nurses recognize that inequities are brought about by social and cultural practices that maintain power imbalances and require political action. With "empowered caring," they find methods to effect change. I discuss "empowered caring" in the next section, giving examples of how, in spite of the "state of oppression" in living out the regime of "ordered caring", nurses, especially those with several years of experience in home care, knew ways to subvert the "system" so as to continue to provide the work of caring for their patient.

5.5 Empowered Caring: A New Model of Home Care

In the previous sections, the role of accounting logic and accounting text in suppressing nurses' autonomy was described. In this section, their ideas for a more patient-centered model of care are presented. Nurses described practices that would empower them for the many aspects of their work of caring for home care patients. Their holistic vision goes beyond medication management. Instead of "ordered caring", it is "empowered caring".

According to Rafael, empowered caring affects all aspects of a nurse's practice, strengthens her role in promoting health and gives her power in her decision-making for
her patients (1998). Empowered nurses recognize their expertise and are empowered by it. They take action, such as constructively opposing change that they consider to be harmful; they have the knowledge to make decisions and confidence and authority and personal power to act. They place an emphasis on relationships among each other and patients instead of with those in power. There is also an emphasis on relationships that develop alliances that facilitate promoting health, such as with politicians, journalists, and health professionals from other disciplines who will support nurses and patients when hardships occur.

The nurses' model, summarized in Figure 3, emerged as I read and reread nurses' interview responses and my interview notes. I discovered that they were describing a model that allows the nurse, who is closest to the home care patient and who is the one coordinating all of the patient's home care services, to become recognized as the patient's "case manager." For example, Manuela said that the hospital team is unaware of the patient's home environment and housing conditions. Conversely, the nurse in the home does not see the patient's hospital course. This means that neither has a complete picture. However, the home care nurse is currently dependent on services being ordered by the hospital team because they may not be authorized by her. In addition to determining the patient's course in hospital, because such information is frequently lacking on the hospital referral form, the nurse at home ends up coordinating additional services, e.g., wheel trans, or nutrition services, based on her assessment once patients return to their own environment. As Inga said, sometimes, the home care coordinator who is in the hospital, requests too many or inappropriate types of services. In other cases, the number of visits
contracted for is not enough to meet the patient's needs. As Inga described it, the home

care nurse is in the best position to determine the number of visits and types of services

that the patient needs. She can also work out requirements, including an accurate and

complete medication list, and authorize services in terminology and language she

understands.

Figure 3 summarizes the scenario nurses described for empowering them. In this model

of home care, the nurse would be in a position of autonomy with the support that they

need from the hospital, home care provider and CCAC to in turn support their patients' home care needs. In drawing this model, I recognized that textual practices administered through the CCAC referral had to be reconstructed. Their present orientation only serves to extend control over nurses' actions and devalues their skills, knowledge and time.

Nurses also advocated expanded roles for community providers with the home care patient. When the surgeon and specialists in the hospital who cared for the patient discharge him or her, in Fiona's opinion, the family physician is the key person to carry on community-based care. As shown in Figure 3, the family physician should be the one others rely on for information and should take on a greater role in knowing more about the home care patient. Nurses in this study wanted to see improvements in communication between hospital and community providers. This includes hospital physician communication with the family physician and hospital physician access to the nurse in the home. Also, in this model, the pharmacist would take on more of an active role with providing patient medication assessment as well as education for the home care patient. Nurses also suggested more effectively using information technology. This would
enable the home care nurse, when in the community and patient's home, to be able to quickly and directly access the health record through a computer link or authorization by the CCAC and hospital, provide another means of information sharing with other community providers, and obtain quick access to drug information. As Sydney said, providers do not often know all of the new drugs and do not have the time to call to find out what each medication is for. Lee suggested the use of information technology such as that used by pharmacists between the hospital, CCAC, and home care nurse, in order to share patient information.

The new model of home care given in Figure 3 begins with sharing CCAC span of control with professionals working in the community. In this model, the CCAC appoints the home care nurses as the case manager. A crucial step in a new model of home care in this Figure occurs at hospital discharge. Ideally, the home care agency providing the primary nurse should coordinate this transition. Being involved as a member of the hospital team at the outset of the home care referral process would provide many advantages for improving the process for home care referral, authorization, and delivery. As shown in Figure 3, the nurse would have the authority and autonomy to access the patient's hospital health record information and authorize home care services (e.g., type, duration, increased or decreased frequency of home visits, medication devices, etc.). In dialogue with the hospital team and patient, the nurse would determine what was necessary for meeting the objectives of encouraging patient self-management with medications and independence in their home. By participating in hospital discharge planning for the patient, the home care nurse begins to act as the patient's case manager.
This would include checking that the patient has been stabilized on his or her medications prior to discharge, has received medication education and information on medication changes, new medications, and related prescription information, and has assessed the patient's need for a medication compliance device. Since she intimately knows the home care patient's environment, it makes sense that she is the one who completes the patient assessment and home care referral form (thereby avoiding illegibility and inaccuracies and delays associated with sending the referral to the CCAC who then fax it to the home care provider and then to the nurse). Among the nurse's responsibilities would be clarifying medications on discharge as well as times for visiting with the patient. The home care nurse can work out and document home care referral requirements, including an accurate and complete medication list. She can authorize services in terminology and language she understands for meeting the objective of encouraging patient self-management with medications and independence in the home. The nurse and patient as well as the patient's informal care-givers can jointly determine the patient's needs based on recognition of the patient's cultural and socio-economic situation as well as medical and medication needs, thereby preparing the patient for their transition from the hospital setting, in which they were recipients of 'care' to the home setting in which they will predominantly be assuming their own care. The nurse case manager, as liaison from the home care provider agency meets with the hospital team and the patient in the hospital to coordinate the patient's transition from hospital to home.

Authority for determining ongoing home care services is another area that the home care nurse is in a better position to assess than the hospital team. Giving the home care nurse
responsibility for making these decisions will avoid the problem of discharging a patient too soon from the home care program before the patient is ready to be discharged. As Adrian pointed out, many patients need more home visits but the CCAC often refuses to increase home visits, or will discharge a patient from the program before the patient is ready to be discharged, without ever seeing the client. Giving the home care nurse such authority might actually prove beneficial to funding of home care services, as nurses have commented that the CCAC community based coordinators frequently increase services when these are unwarranted. Stacey indicated that one method that might make this process work more efficiently is by giving the nurse the authority to increase time at the initial visit to establish a routine, for example, such as setting up medications in a dosette for patients who require this type of 'compliance device' to assist them to 'comply' with their medication regime. In Stacey's example, after the nurse has set up such a routine and verified that it was working, it would be possible to decrease the frequency of visits to monitor the patient's ability to take their medications. The family physician would be notified of any changes so that the physician could call the pharmacy with any changes to medication prescriptions. It could be argued that the ideal situation would be for the community pharmacist to establish such a routine for the patient at the outset, when dispensing the patient's prescription, although the pharmacist would not be aware of the patient's other medications at home. Therefore, a good argument could be made that it is to the CCAC's advantage to provide nurses with the time to set up this routine. The CCAC is not in the position to make the decision regarding the patient's ongoing needs and frequency of home visits based on their one visit with the patient.
Through implementing these changes, nurses would be empowered to care. In empowered caring, power is no longer a central value that is pursued for itself but rather is used as a means for effecting structural, social and cultural change (Rafael, 1998). Thus, the ‘restructured’ version of home care would be one that gives the home care nurse the autonomy to use her knowledge, expertise, and values to guide home care; patients would have the nurse as an agent or advocate to assist with their economic, social, political, and medical as well as medication decisions. As well, access to patient confidential information, such as the hospital health record, would be extended to the home care nurse so that she may perform her assessment of the patient's needs when at home. The new model assumes that the nurse case manager would have the authority to document the referral so that it accurately portrays information on the patient's medications as well as contact information of members in the hospital and community.

This vision implies a need to create a structure that supports the power of professionals at the bottom of the health care hierarchy. It also requires developing relationships of mutuality among the CCAC, home care provider, hospital, and nurse in caring for the home care patient discharged from hospital. Ultimately, unless the recommendations of nurses are adopted, we risk losing not only their invisible work of caring in the home but also patient safety with medications.
6. CONCLUSIONS

6.1 Summary of Main Findings and Their Practical Implications

The stated goal for which home care with MMSs is prescribed and authorized is to encourage patient self-management and autonomy in the home. To achieve this goal, the hospital team prescribes and the CCAC authorizes MMSs such as medication education, medication administration, and medication "compliance" monitoring by the home care nurse, with the intention of promoting patient independence with medications. When seen within the framework of Smith's (1987) and de Montigny's (1998) analysis of professional power and relations of ruling, this process is a way to have patients carry out biomedical orders. That this is the intent of the process can be seen from the authoritarian word "compliance". True autonomy would involve a patient-driven process rather than one driven by a biomedical provider system.

At the same time that attempts are made to "control" care, the literature suggests areas of system failures that may occur upon hospital discharge. Of significance, nurses whom I interviewed identified concerns, which they perceived, could result in potential MRPs or patient harm. The hospital, CCAC, and health care providers, though ostensibly part of the relations of home care "rule", seem to jeopardize the entire system by not recognizing and responding to the regulatory, financial, and professional concerns identified by frontline nurses. Two different threats to the integrity to this system can be seen in this study. The first, identified by nurses, has to do with danger to the patient. The literature suggests that system failures in the hospital discharge process may result in MRPs due to (a) last minute changes to the patient's medications and regimen; (b) medication teaching
conducted just prior to discharge, at a time when the patient is unable to concentrate on or absorb the information received; and (c) insufficient transfer of patient information and medication-use needs between the hospital and the home care providers in the community. These issues have already been identified in the literature, but nurses' accounts provided additional insight into exactly where the process breaks down and how medication errors might occur. Their accounts of their daily work also make it clear how they daily "save" the system by working to circumvent these medication errors from occurring. The second threat, to be discussed below, is that nurses will refuse to continue to be part of this system if their concerns are not heard.

In the nurses' ideal world, home care for MMSs would appear as described in Figure 3, the hospital team and HITC would document the type of professional services referred and authorized (e.g., nursing). The diagnoses and desired intervention (e.g., medication compliance monitoring) is also documented for the home care patient on hospital discharge. A brief description of the patient's course in hospital appearing on the referral form and Communication Administration Form completed by the HITC would also be useful to home care nurses and family physicians. These texts, were they accurate and accessible, could alert the primary caregivers of unique patient information (e.g., 'patient is blind', 'patient is diabetic', 'patient requires a glucometer and one has been ordered') as well as reiterate the specific intervention and desired outcome (e.g., 'patient can self-manage').
The lack of standards and consistency in documenting required and accurate information in the system is not only dangerous, but interferes with what I have called "ordered caring" (discussed in section 5.1). Nurses' narratives repeatedly indicated that both the referral as well as the intake coordinator's communication forms are inaccurate and lack information regarding the patient's clinical course in hospital, current medications, and required services. They identified a need for patient demographic, medication, and contact information on the medical referral, which is currently not consistently documented by either the hospital or the HITC. Of significance, nurses expressed the need for the hospital and CCAC coordinators to document from the nurse's perspective. However, it is doubtful that those in regulatory positions can appreciate how the world looks from the nurse's perspective. Nevertheless, the nurse's need for accurate and complete patient and contact information is made necessary by the fact that the home care nurse does not have access to the patient's hospital medical record. Nurses' narratives indicated that the hospital and intake coordinator frequently do not really understand the types of home care services the patient needs because they do not see the patient in his or her home environment. Hence, the referral does not truly reflect the types of required intervention, content of information, or pertinent patient information required by the home care nurse. Instead, it serves the purpose of a "gateway" maintained by regulatory powers for obtaining home care nursing services, and the nurse is cast as a frustrated and unwilling "gatekeeper", affecting the nurses' provision of MMSs in the community (medication administration, "compliance" monitoring, and education.)
The first threat to the system, that it will fail in its biomedical aims, is addressed daily by nurses. Nurses circumvent problems by "absorbing" the extra work of finding alternate methods for resolving the unplanned issues that they confront with their home care patients. In their accounts, nurses emphasize the relationship with their patients and care in following up problems encountered with them. Irregardless of the time and frustration they face in accessing information and health professionals, they present themselves as responsive to unspoken health and social problems faced by their clients, and as resisting an oppressive workplace pressure that is aimed at controlling their autonomy and decision-making.

Gregor (2000), among others, has expressed concern that nurses do not more directly confront the system in which they are embedded. In fact, the second potential threat to the system, that frustrated nurses will sabotage it, seemed remote in this study. Nurses' responses raise the concern that nurses may have settled into a 'false-consciousness' or a general inability to 'see' their oppression in its larger context. Their responses represent the nurses' voice within their particular location, but their voice is being silenced by organizations that aim instead to promote the ideology of caring for profit. Nurses' need for decision-making autonomy to practice ethical decisions for their patients is suppressed by a more powerful group that, on the surface, indicates a support for caring practice. While that has some basis, when seen as a system of ruling (Smith, 1987) it is over-ridden by the competitive nature that has been set up by the Ministry of Health for CCACs, which in turn has influenced the practice patterns of not-for-profit home care providers competing for survival in the competitive bid process. Nurses' options or choices are
overridden by accounting logic that aims instead to control and account for their workload and a bottom line. The result is the exploitation of ill health and caring for profit.

Nurses have a long history of using labor actions to draw attention to their work situations. In the recent nurses' strike Hamilton, Ontario, they began to resist the latest initiatives of the Ontario government towards privatizing home care. Even if they do not strike, they may just abandon the system (Armstrong 1993). Thus, a good argument can be made that unless the community and the home care system begins to value nurses' work by recognizing their need for decision-making autonomy, nurses will make other choices. Given their militance, it could be imagined that a time will come when they will not only resist but also refuse to continue to allow their philosophy of care to be subjugated by powerful hierarchies. In my account, it is clear that these relations of ruling silence the voice of caring as part of the pursuit of power and profit. Ultimately, I believe the powerful hierarchies that aimed to control the work habits of nurses through "accounting logic" will find that they have lost.

6.2 Theoretical Implications and Ideas for Future Research

Nurses' model for improving the home care system (that I have discussed in this thesis) addresses principles of the collaboration between hospital and community providers and timely access to patient information from the hospital setting. The model also calls for ongoing information exchange and communication between the hospital and community providers. However, these principles do not address the powerful political organizations that control nurses' work at home. From my perspective, this 'new' model of care does not
address issues of power. I am, therefore, skeptical that it can be successful. Real change, I feel, cannot occur without addressing the devaluation of nurses' work and the inappropriateness of privatizing home care.

To my knowledge, this research is the first time a study has addressed the home care referral process for hospital-referred home care patients. As well, it is the first time that a critical feminist framework has been used to highlight the importance of textual mediation of power exerted by medicine, hospitals, government, and its contractors on the home care process. I believe that this research has demonstrated many significant findings from the perspective of the home care nurse. The shift in perspective that this view of the home care process provides suggests many future areas of research. Much is still to be learned about how the privatization agenda is played out in home care. Therefore, there is opportunity for future research to apply institutional ethnography to do extensive field study in which the research could observe and report the daily interactions between the hospital medical team, the CCAC, hospital and community based intake coordinators, home care nurses, the home care patients, and community providers. Such research could explain the structural aspects of how each of these players are involved in the "production of their everyday world, examined with respect to how that world is organized by and sustains the institutional process" (Smith, 1987, page 166).
REFERENCES


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Meyer, K.A. An educational program to prepare acute care nurses for a transition to home health care nursing. The Journal of Continuing Education in Nursing, 28 (3), 124-129.


**Table 1: Patient Demography**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>With 'MMS' Referral (n=21)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>- male</td>
<td>9 (43%)</td>
</tr>
<tr>
<td>- female</td>
<td>12 (57%)</td>
</tr>
<tr>
<td><strong>Medical Program</strong></td>
<td></td>
</tr>
<tr>
<td>- general medicine</td>
<td>21 (60%)</td>
</tr>
<tr>
<td>- cardiology</td>
<td>16 (76%)</td>
</tr>
<tr>
<td>- cardiology</td>
<td>5 (24%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>- 45-64</td>
<td>4 (19%)</td>
</tr>
<tr>
<td>- 65-74</td>
<td>7 (33%)</td>
</tr>
<tr>
<td>- 75-84</td>
<td>10 (48%)</td>
</tr>
<tr>
<td><strong>Living arrangement</strong></td>
<td></td>
</tr>
<tr>
<td>- lives alone</td>
<td>8 (38%)</td>
</tr>
<tr>
<td>- lives with someone</td>
<td>13 (62%)</td>
</tr>
<tr>
<td><strong>Impaired cognition</strong></td>
<td></td>
</tr>
<tr>
<td>- impaired cognition^a</td>
<td>4 (19%)</td>
</tr>
<tr>
<td><strong>Impaired vision</strong></td>
<td></td>
</tr>
<tr>
<td>- impaired vision^b</td>
<td>5 (24%)</td>
</tr>
<tr>
<td><strong>Impaired hearing</strong></td>
<td></td>
</tr>
<tr>
<td>- impaired hearing^c</td>
<td>1 (5.0%)</td>
</tr>
<tr>
<td><strong>Medical condition on admission^d</strong></td>
<td></td>
</tr>
<tr>
<td>- congestive heart failure</td>
<td>8 (38%)</td>
</tr>
<tr>
<td>- diabetes mellitus</td>
<td>5 (24%)</td>
</tr>
<tr>
<td>- chronic obstructive pulmonary disease</td>
<td>3 (14%)</td>
</tr>
<tr>
<td>- coronary artery disease</td>
<td>3 (14%)</td>
</tr>
<tr>
<td>- inability to cope (e.g. chronic alcoholism)</td>
<td>1 (5.0%)</td>
</tr>
<tr>
<td>- other</td>
<td>1 (5.0%)</td>
</tr>
<tr>
<td><strong>Number of Medications</strong></td>
<td></td>
</tr>
<tr>
<td>- 1-3</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>- 4-7</td>
<td>8 (38%)</td>
</tr>
<tr>
<td>- 8-11</td>
<td>7 (33%)</td>
</tr>
<tr>
<td>- ≥ 12</td>
<td>4 (19%)</td>
</tr>
<tr>
<td>Characteristic</td>
<td>Number of Patients</td>
</tr>
<tr>
<td>----------------</td>
<td>--------------------</td>
</tr>
<tr>
<td></td>
<td>With 'MMS' Referral (n=21)</td>
</tr>
<tr>
<td>High Risk Medications&lt;sup&gt;e&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>corticosteroids</td>
</tr>
<tr>
<td></td>
<td>theophylline</td>
</tr>
<tr>
<td></td>
<td>warfarin</td>
</tr>
<tr>
<td></td>
<td>digoxin</td>
</tr>
<tr>
<td></td>
<td>psychotropics</td>
</tr>
<tr>
<td></td>
<td>insulin</td>
</tr>
<tr>
<td>Number of Medication Changes Prior to Discharge</td>
<td></td>
</tr>
<tr>
<td>New medications started</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 - 2</td>
</tr>
<tr>
<td></td>
<td>3 - 4</td>
</tr>
<tr>
<td></td>
<td>≥ 5</td>
</tr>
<tr>
<td>Changes to medication dosage</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 - 2</td>
</tr>
<tr>
<td></td>
<td>≥ 5</td>
</tr>
<tr>
<td>Discontinued medications</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 - 2</td>
</tr>
<tr>
<td></td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>4</td>
</tr>
<tr>
<td>One or more hospitalization(s) / past year</td>
<td></td>
</tr>
<tr>
<td></td>
<td>18 (86%)</td>
</tr>
</tbody>
</table>

a. Impaired cognition — MMSE ≥ 21 or community care coordinator assessment
b. Impaired vision — unable to read prescription vial label / similar size of print even when using a corrective device (i.e. glasses). Based on home visit observations.
c. Impaired hearing — difficulty hearing conversational tone even when using a corrective hearing aid. Based on home visit observations.
d. Represents the primary reason for hospitalization.
e. A patient may be represented more than once if taking more that one of these medications'
### Table 2: Home Care MMSs Referred, Authorized, & Provided

<table>
<thead>
<tr>
<th>Medication-Management Service(s)</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Referred (n=21)</td>
</tr>
<tr>
<td>Medication administration</td>
<td></td>
</tr>
<tr>
<td>• administers medications (from</td>
<td>3</td>
</tr>
<tr>
<td>medication vials)</td>
<td></td>
</tr>
<tr>
<td>• administers medications (from</td>
<td></td>
</tr>
<tr>
<td>dosette / blister package)</td>
<td></td>
</tr>
<tr>
<td>• checks medication administration</td>
<td></td>
</tr>
<tr>
<td>technique</td>
<td></td>
</tr>
<tr>
<td>Medication compliance monitoring</td>
<td>6</td>
</tr>
<tr>
<td>± compliance intervention</td>
<td></td>
</tr>
<tr>
<td>• checks / uses a compliance device (e.g. dosette)</td>
<td>3</td>
</tr>
<tr>
<td>• asks the patient how or if taking medications</td>
<td>18</td>
</tr>
<tr>
<td>Medication education</td>
<td>1</td>
</tr>
<tr>
<td>Medication review/ assessment / monitoring</td>
<td>3</td>
</tr>
<tr>
<td>• compares medications at home against those listed on the referral and patient’s discharge list</td>
<td>14</td>
</tr>
<tr>
<td>• contacts hospital physician / community pharmacist to clarify medication regimen</td>
<td>5</td>
</tr>
<tr>
<td>Non-specific request</td>
<td></td>
</tr>
<tr>
<td>• ‘medications’</td>
<td>8</td>
</tr>
</tbody>
</table>

* A patient may have received more than one MMS from his/her home care nurse.
<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Agency 1</th>
<th>Agency 2</th>
<th>MMSSs</th>
<th>Education</th>
<th>Years Providing Home Health Nursing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Hospital Referred</td>
<td>Nurse Provided</td>
</tr>
<tr>
<td>Audrey</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Linda</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Lisa</td>
<td>X</td>
<td></td>
<td>No</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Marie</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Stacey</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Francis</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Manuela</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Mary</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Frieda</td>
<td></td>
<td>X</td>
<td>No</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Inga</td>
<td></td>
<td>X</td>
<td>No</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Nadia</td>
<td></td>
<td>X</td>
<td>No</td>
<td>No</td>
<td>X</td>
</tr>
<tr>
<td>Shirley</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td>Vera</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Ingrid</td>
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<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Lary</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Ashley</td>
<td></td>
<td>X</td>
<td>No</td>
<td>No</td>
<td>X</td>
</tr>
<tr>
<td>Karla</td>
<td></td>
<td>X</td>
<td>No</td>
<td>No</td>
<td>X</td>
</tr>
<tr>
<td>Pat</td>
<td></td>
<td>X</td>
<td>No</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Fiona</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Nancy</td>
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The above Figure is adapted from the reference by Hutchinson et al (1990, page 634). In their article, the authors describe their Figure 1 as "a system's approach to rational drug therapy: steps of the drug use process". They describe areas in which this process is presently "disjointed and inefficient in manpower use" as physicians, nurses and pharmacists perform many "technical tasks without added professional value" (page 633).
Figure 2: The Home Care Referral, Authorization, and Delivery Process for Patients Discharged from Hospital

Hospital Physician / Interdisciplinary Team:
- Assess patient's need for post hospital discharge care and types of services: initiate referral form; may provide medication list; may provide medication education.

Home Care Nurse:
- Determines services requested by the referral.
- Assesses patient's medical and medication needs.
- Clarifies referral with hospital team and intake coordinators.
- Creates a nursing plan and provides nursing services.
- Coordinates all patient's post-

Patient and Informal Caregivers

Community Services:
- Family physician
- Laboratories
- Pharmacies
- Ambulatory Clinics

Community Services:
- Family physician
- Laboratories
- Pharmacies
- Ambulatory Clinics

CCAC Community-Based Intake Coordinators:
- Audit and assess continued need for home care / new services ('gatekeeper')

CCAC Hospital based Intake Coordinator:
- Audits the referral.
- Assesses patient's need for home care.
- Authorizes services/orders additional types of services.

CCAC office (geographically based):
- Awards 'contract' for authorized services to successful home care 'bidder'
- Faxes referral to the home care provider.

Home Care Provider (successful bidder for nursing services)
- Assigns resources.
- Faxes referral to home care nurse's home.
- Provides procedures on documentation in the home.
Figure 3: A New Model of Home Care

Community Providers
(Family Physicians, Pharmacists, and Laboratories)

Hospital Providers
Hospital-Initiated Home Care Referral

Communicates back information to the Hospital & Community Providers.

Triggers Notice to Home Care Provider to Assign a Home Care Nurse

Access the medical record via technology link with the hospital.

Hospital-Initial Assessment PATIENT

HOME CARE NURSE
Home Care Nurse as Case Manager liaises with the Patient, the Hospital and Community Providers.

Utilizes her or his knowledge of the patient's home situation, problems, needs, and treatments to document the patient's social, financial, medical, medications, and treatment needs. Determines, communicates, and documents the goals of home care with the patient.
Appendix A: University of Toronto Research Ethics Approval
University of Toronto

OFFICE OF RESEARCH SERVICES

PROTOCOL REFERENCE #3783

August 31, 1998

Dr. L. MacKeigan
Faculty of Pharmacy
17 Russell Street
University of Toronto

Dear Dr. MacKeigan:

Re: "An Assessment of 'Medication-Management Services' Provided to Home Care Patients on Hospital Discharge" by Dr. L. MacKeigan (Ms. Doris Nessim)

We are writing to advise you that a Review Committee composed of Drs. S. Bowles, D. Irvine, L. O'Brien-Pallas and Professor M. Kelner has granted approval to the above-named research study.

The approved revised information letters and consent forms are attached. Subjects should receive a copy of their consent form.

During the course of the research, any significant deviations from the approved protocol (that is, any deviation which would lead to an increase in risk or a decrease in benefit to human subjects) and/or any unanticipated developments within the research should be brought to the attention of the Office of Research Services.

Best wishes for the successful completion of your project.

Yours sincerely,

[Signature]

Susan Pilon
Executive Officer
Human Subjects Review Committee

SP/mr Enclosures
cc: Dean D. G. Perrier, Ms. D. Nessim
Appendix B: Hospital Research Ethics Approval
Dear Ms Nessim:

Your research proposal and consent forms have been reviewed by The Wellesley Central Research Ethics Board and are approved from an ethical standpoint.

The approval of this board is valid for a period of one year from this date provided there are no substantial changes to the approved protocol nor any new information or developments which must be considered with respect to the study. If, during the course of the research, any unanticipated developments should occur, these should be brought to the attention of The Wellesley Central Research Ethics Board.

Your protocol will now be forwarded to the Medical Advisory Committee and Research Advisory Committee for their approval.

Ronald J. Heslegrave, Ph.D.
Chair, The Wellesley Central Research Ethics Board

June 29, 1995
Appendix C: Letters of Endorsement from the Toronto Community Care Access Centre, and Home Care Providers
July 6, 1998

Ms Doris Nessim,
Director of Pharmacy,
St. Michael's Hospital,
Wellesley Site,
160 Wellesley Street East,
Toronto, Ontario M4Y 1J3

Dear Ms Nessim:

The Toronto Community Care Access Centre agrees to participate in the M.Sc. research thesis project to be conducted by you, a graduate student with the Faculty of Pharmacy, University of Toronto, for the purpose of conducting the research project entitled: "An assessment of medication-management services' provided to home care patients on hospital discharge".

We understand that the activities which we agreed to include involving the hospital-based home care co-ordinator to forward the names of hospitalized patients who have been authorized to receive home care upon hospital discharge and have verbally consented to participate/learn more about the study. You will contact the Toronto Community Care Access Centre in order to determine authorized referrals contracted to the Victorian Order of Nurses or St. Elizabeth Health Care. Field research will be conducted to fulfill the requirements of the master's degree, which would necessitate approximately 30 visits to patients' homes in the Toronto area, in the company of a home care nurse. The purposes of the field research are to (a) observe the visit, (b) review the home care record, as well as (c) interview the nurse following the visit, and not for the purpose of providing care. We understand that visits will likely occur over the months of June to August 1998.

The Toronto Community Care Access Centre will be given a copy of the outcome of this study.

Yours sincerely,

[Signature]

Camille Orridge,
Executive Director

Community care for people of all ages. Soins communautaires pour gens de tout âge
March 20, 1998

Doris Nessim, B.Sc.Phm. & M.Sc.Student
34 Poplar Heights Drive
Etobicoke, Ontario M9A 5A2

Dear Doris,

Re: Letter of Authorization to conduct home visits with nurses of Saint Elizabeth Health Care

Saint Elizabeth Health Care, Markham, Ontario, agrees to participate in the M.Sc. research thesis project to be conducted by you as a graduate student with the Faculty of Pharmacy, University of Toronto, for the purpose of conducting the research project entitled: “An assessment of ‘medication-management services’ provided to home care patients on hospital discharge”, pending approval from the University of Toronto’s Research Ethics Committee.

We understand that the activities which we agree to include:
(1) contacting the Toronto Community Care Access Centre in order to determine authorized referrals contracted to Saint Elizabeth Health Care,
(2) field research conducted to fulfill the requirements of the master’s degree, which would necessitate approximately 30 visits to patients’ homes in the Toronto area, in the company of a home care nurse, for the purposes of:
   (a) observing the visit,
   (b) reviewing the home care record, as well as
   (c) interviewing the nurse following the visit,
and not for the purpose of providing care.

We understand that visits will also occur with a second home care agency, the Victorian Order of Nurses, Metropolitan Toronto Branch, and that the visits will likely take place over the months of June to August 1998.

Sincerely,

Susan Munro, R.N., B.Sc.N., M.Sc., C.H.E.
V.P. Health Services

90 ALLSTATE PARKWAY SUITE 300 MARKHAM ONTARIO L3R 6H3 (905) 940-9655 FAX (905) 940 9934

Saint Elizabeth
HEALTH CARE

Dear Doris,

Saint Elizabeth Health Care, Markham, Ontario, agrees to participate in the M.Sc. research thesis project to be conducted by you as a graduate student with the Faculty of Pharmacy, University of Toronto, for the purpose of conducting the research project entitled: “An assessment of ‘medication-management services’ provided to home care patients on hospital discharge”, pending approval from the University of Toronto’s Research Ethics Committee.

We understand that the activities which we agree to include:
(1) contacting the Toronto Community Care Access Centre in order to determine authorized referrals contracted to Saint Elizabeth Health Care,
(2) field research conducted to fulfill the requirements of the master’s degree, which would necessitate approximately 30 visits to patients’ homes in the Toronto area, in the company of a home care nurse, for the purposes of:
   (a) observing the visit,
   (b) reviewing the home care record, as well as
   (c) interviewing the nurse following the visit,
and not for the purpose of providing care.

We understand that visits will also occur with a second home care agency, the Victorian Order of Nurses, Metropolitan Toronto Branch, and that the visits will likely take place over the months of June to August 1998.

Sincerely,

Susan Munro, R.N., B.Sc.N., M.Sc., C.H.E.
V.P. Health Services

90 ALLSTATE PARKWAY SUITE 300 MARKHAM ONTARIO L3R 6H3 (905) 940-9655 FAX (905) 940 9934

Saint Elizabeth
HEALTH CARE
March 20, 1998

Ms. Donim Nessim
34 Poplar Heights Drive
Etobicoke, Ontario
M9A 5A2

To Whom It May Concern:

The Victorian Order of Nurses, Metropolitan Toronto Branch, agree to participate in the M.Sc. research thesis project to be conducted by Doris Nessim, graduate student with the Faculty of Pharmacy, University of Toronto. The research project is entitled "An assessment of medication-management services provided to home care patients on hospital discharge."

We understand that the activities which we agree to include 1 contacting the Toronto Community Care Access Centre in order to determine authorized referrals contracted to the Victorian Order of Nurses, 2 field research conducted to fulfill the requirements of the master's degree, which would necessitate approximately 30 visits to patients' homes in the Toronto area, in the company of a VON-nurse; for the purposes of (a) observing the visit, (b) reviewing the home care record, as well as (c) interviewing the nurse following the visit, and not for the purpose of providing care.

We understand that a similar project is occurring simultaneously with a second contracted agency, St. Elizabeth Health Care, and that the visits will likely take place between the months of June to August, 1998.

If there are any questions or concerns about this involvement, please do not hesitate to contact myself.

Sincerely,

Susan Cockburn-Gillespie, RN, BscN
Manager of Education and Development
Appendix D: Patient Information Letter and Consent Form
Study Information Sheet for Patients

"An assessment of 'medication-management services' provided to home care patients on hospital discharge"

Study Coordinator: Doris Nessim, Master's Student, Faculty of Pharmacy, University of Toronto

About the study: This study aims to learn about which types of patients receive home care services for purposes of helping them with their medications and how these services are provided. This information will be helpful to home care agencies in improving their services. The study is being conducted through the University of Toronto, by Doris Nessim, a graduate student under the supervision of Professor Linda MacKeigan at the Faculty of Pharmacy.

Patients who are discharged from St. Michael's Hospital, General Medicine unit, are being asked to participate in the study. In addition, the home care program and home care nursing agencies (Victorian Order of Nurses, and St. Elizabeth Health Care) have agreed to participate in this study.

What the study will involve: If you and your home care nurse both agree to participate, then the study coordinator, Doris Nessim, will come to your home with your home care nurse on her 3rd or 4th visit. During this home visit, the study coordinator will read your home chart and observe the nurse. She will not be asking you any questions or interfering with the services provided by the nurse.

Prior to the home visit, she will need to review your hospital chart in order to obtain information about your medications, medical condition(s), and the types of home care services your doctor requested for you. After the home visit, she will interview your nurse about the services she provided to you and her suggestions for improving use of medications in home care.
**About the Study Coordinator:** The study coordinator is a pharmacist who is conducting this study as a graduate student with the University of Toronto. She will not be providing care to you.

**How you can participate:** To learn more about the study, or to express your interest to participate in it, please call the study coordinator, Doris Nessim at 416-926-5053 ext. 3031, and leave a message which includes your name and phone number. Ms. Nessim will arrange a time to visit you in the hospital to answer any of your questions and to obtain your written consent to participate in the study. If it is not possible to meet with you while you are in the hospital, she will discuss the study with you over the telephone.

**Thank you.**
Patient Consent Form

"An assessment of 'medication-management services' provided to home care patients on hospital discharge"

Study Coordinator: Doris Nessim, Master's Student, Faculty of Pharmacy, University of Toronto

The purpose of this study is to learn about what types of patients receive home care services to help them with their medications and to know how these services are provided. This information will be helpful to home care agencies in improving their services. The study is being conducted through the University of Toronto, by Doris Nessim, a graduate student under the supervision of Professor Linda MacKeigan at the Faculty of Pharmacy.

Patients who are discharged from St. Michael's Hospital, the Bond St. site, General Medicine unit, are being asked to participate in the study. In addition, the home care program and home care nursing agencies (Victorian Order of Nurses, and St. Elizabeth Health Care) have agreed to participate in this study. While participation in the study is not expected to benefit you directly, it may benefit future users of home care services.

If you and your home care nurse both agree to participate, the study coordinator, Doris Nessim, will come to your home with your home care nurse on either her 3rd or 4th visit. During this home visit, the study coordinator will read your home chart and observe the nurse. She will not be asking you any questions or interfering with the services provided by the nurse. She will also have reviewed your hospital chart in order to obtain information about your medications, medical condition(s), and the types of home care services your doctor requested for you. After the home visit, the study coordinator will interview your nurse about the services she provided to you and her suggestions for improving the use of medications in home care. If you agree to participate in the study, but your home care nurse is unable to do so, the study coordinator will call you to inform you that it will not be necessary for you to participate in the study.
Your identity and participation in the study will be kept confidential. The study records, which will include your name and address, will be seen only by members of the study team, and will be stored securely in a locked cabinet at the Faculty of Pharmacy, University of Toronto, in order to ensure confidentiality. The report on the study will only include information about groups of people who participated; it will not be possible to identify individual people.

Your decision to participate in the study is entirely voluntary. The quality of care and services that will be provided to you by St. Michael's Hospital, the home care program, and the home care nursing agencies (Victorian Order of Nurses and St. Elizabeth Health Care) will not be affected in any way by your decision if you chose not to participate. Even after you decide to participate, you have the right to withdraw at any time, without affecting your present or future care in the hospital or from the home care agency.

If you have any questions about the study, please call the study coordinator, Doris Nessim at 416-926-5053 ext. 3031 between 8:00 a.m. and 5:00 p.m.

If you agree to participate in this study, please sign this form, which will also be signed by the study coordinator. A copy of this information will be given to you for your records.

By signing this consent, I (print your name) ______________________ acknowledge that I have been informed of the purpose and methods of this study as well as my role as a participant in it.

I voluntarily consent to participate in the study. I confirm that I have received a signed copy of this form.

______________________________  ________________________________
Patient's Signature and Date     Study Coordinator's Signature and Date
Appendix E: Nurse Information Letter and Consent Form
Patients discharged from hospital in Ontario are frequently prescribed home care services including some type of medication-related service. The anticipated increase in the demand for home care services is motivating the need to learn more about how these services are provided.

I am a pharmacist and a Masters of Science student in the Faculty of Pharmacy, University of Toronto, conducting a study under the supervision of Professor Linda MacKeigan. This study aims to understand the characteristics and medical needs of patients prescribed medication-related services upon hospital discharge, what these services are, and nurse perceptions of patients’ home care medication support needs and required services. The information gained from the study will benefit future users and providers of home care services, by determining the most effective way to assist home care patients with medication use.

The study involves a review of the processes linking the hospital, Toronto CCAC, and home care providers (either the Victorian Order of Nurses or St. Elizabeth Health Care) for a sample of patients discharged from St. Michael’s Hospital. This project has been endorsed by St. Elizabeth Health and the Victorian Order of Nurses (see letters attached) as well as the Toronto CCAC.

I am writing to request your participation in the study. Your opinion and expertise are crucial. Approximately 30 patients and their nurses who provide informed consent will be enrolled in the study (please note, I have already conducted a feasibility assessment for this aspect of the study.) If you consent to participate, I will contact you only if a consenting patient from the hospital has been assigned to your care. I will arrange to join you on either the 3rd or 4th home visit to that patient for the purpose of observing the visit, reviewing the care record, and interviewing you following the visit. The interview would be approximately 10 minutes. The purpose of the interview is to obtain your perspective on the home care services requested and planned or provided to the patient, as well as possible system-related issues which interfere with the care process. If you are not available for this interview immediately after the visit, then we would do it over the telephone later that day or on the next day. You will be requested to participate in this process for only one patient.

Your decision to participate in the study is entirely voluntary. Your employer will not be informed of your decision. Should you choose to participate, your identity will be kept confidential. The anonymity of your response will be safeguarded by identifying your data collection form only with a reference number. Your name, address, and phone number, will be on a separate cover page which will be removed from the data collection form and destroyed once the home visit and interview have been completed. Data collection forms will be kept in a locked cabinet accessible only to the research team, and will be shredded upon completion of the data analyses. From that point on data will be in electronic format, only with no personal identifiers. Reports on the study will include information related only the groups of people who participate; individuals will not be identifiable.
To indicate whether you consent to participate in the study, please complete and fax the attached CONFIDENTIAL NURSE'S CONSENT FORM before the client receives their 3rd home visit. I will follow-up with you by phone if I do not receive a response from you.

I would be glad to answer any questions you might have. Please leave a message for me at (416) 926-5053, ext. 3031 to leave me a message including your name and phone number as well as the most suitable time for reaching you. Thank you for taking the time to consider my request.

Sincerely,

Doris Nessim B.Sc.Phm.
Graduate Student
Faculty of Pharmacy
University of Toronto

Linda MacKeigan, Ph.D
Assistant Professor
Faculty of Pharmacy
University of Toronto
CONFIDENTIAL NURSE'S CONSENT FORM

"An assessment of 'medication-management services' provided to home care patients on discharge from hospital"
Study Coordinator: Doris Nessim, Master's Student, Faculty of Pharmacy, University of Toronto

From: ____________________________ (please print your name)  ____________________________ (please print your agency)

To: Doris Nessim, Study Coordinator

Fax: (416) 245-0713

Mailing Address:
Doris Nessim, Faculty of Pharmacy,
University of Toronto
19 Russell St., Toronto, ON M5S 2S2

Please select one of the following two options:

☐ I agree to participate in the study: 'an assessment of medication-management services provided to home care patients on hospital discharge'

I agree to participate in this study. I understand that this means that the study coordinator will accompany me on either the 3rd or 4th visit, as well as conduct a personal / telephone interview with me. I understand that my participation in this study and any information I provide will be held in confidence by the research team.

(Signature) ____________________________ (Date) ________________

or

☐ I do not wish to participate in the study: 'an assessment of medication-management services provided to home care patients on hospital discharge'

I understand that my refusal to participate will be kept in strictest confidence by the research team.

(Signature) ____________________________ (Date) ________________

19 Russell Street  Toronto Ontario Canada M5S 2S2  Telephone (416) 978-2889/2873  Fax (416) 978-8511
Appendix F: Study Patient Recruitment Form
Steps:

1) Determine if the patient meets each of the following eligibility criteria:

- has been prescribed one or more medications on discharge.
- does not have a terminal illness which requires palliative care.
- does not have a diagnosis of HIV/AIDS.
- is capable of providing informed consent, in your opinion.

2) If the response to each of the above criteria is ‘yes’, then the patient is eligible to participate in the study.

Obtain the patient’s verbal permission to forward their name to the study coordinator, who will explain the study to the patient and obtain their consent to participate in it.

To obtain the patient’s verbal permission, please read the patient the following information: and also provide them with the ‘patient information sheet’:

“A study is being conducted on our unit to learn more about home care services provided to patients. The study coordinator would be interested in talking to you about the study while you are here in the hospital or calling you at home after you have left the hospital to ask you about the possibility of being part of this study. Would it be alright if I give her your name so that she can come to see you to tell you what being part of the study would involve? You can decide whether you want to participate once she talks with you.” We would also like to provide you with this ‘patient information sheet’ about the study.

3) Provide the patient with a copy of the Patient Information Sheet for those patients who (a) have agreed to see the study coordinator to obtain more information about the study in order to determine if they would like to participate, or (b) are undecided and would like more time to consider whether to participate.

4) List the Patient’s Name:

Patient’s Name: ___________________________ J# (medical record number): ____________

Unit (location in the hospital): ____________________________

Consented to see the study coordinator?: Yes ____ Undecided ____ No ____

Completed by: __________________________________ Date: _______________________

Please note: for confidentiality reasons, this form will be destroyed once it is reviewed by the study coordinator. Only the name and J# number of those patients who consented to see the study coordinator will be retained on a separate form, entitled ‘patient recruitment form’.

Thank YOU.

Doris Nessim. (pager: 1-800-580-4428; phone mail:926-5053; fax: 245-8801)
Appendix G: Data Collection Forms
CONFIDENTIAL
An Assessment of ‘Medication-Management Services’ provided to home care
patients on hospital discharge
Study Coordinator: Doris Nessim, M.Sc.Student

PATIENT DISCHARGE SUMMARY DATA COLLECTION FORM

PATIENT IDENTIFICATION #    DATE COMPLETED:

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<td>Most Responsible Diagnosis for Hospital Stay’ (this visit)</td>
<td>Doctor’s Discharge Summary</td>
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<td>Other Diagnoses (medical conditions)</td>
<td>Doctor’s Discharge Summary</td>
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<td>Medications (name and regimen) on hospital discharge vs. admission—medical notes on adm; &amp; doctor’s DC</td>
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1 The ‘Discharge Summary Data Collection Form’ will be used to document the patient’s risk factors, and the home care services referred and authorized for the patient. It uses data sources from the sections of the medical record as well as the CCAC forms. The medical record is the patient’s medical record. The CCAC forms include the medical referral form and the CCC’s Communication Administration Form (CAF).
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</tr>
<tr>
<td>VISION&lt;sup&gt;3&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### LAST HOSPITALIZATION (within the past year)

<table>
<thead>
<tr>
<th>Date</th>
<th>Medical record</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Most Responsible Diagnosis for Hospital Stay</td>
<td></td>
</tr>
</tbody>
</table>

---

<sup>2</sup> Hearing Deficit—Difficulty with hearing will be assessed by observation during the home visit.

<sup>3</sup> Vision — Documentation of whether a patient wears prescription lenses (documented on nurse's assessment form in the medical record). Difficulty with vision will be observed during the home visit. Observations will determine if the patient is able to see their menu or prescription vial with prescription lenses.
<table>
<thead>
<tr>
<th>CCAC HOME CARE SERVICES REQUESTED or AUTHORIZED</th>
<th>SOURCE USED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing Services Requested by the hospital</td>
<td>Medical Referral</td>
</tr>
<tr>
<td>Nursing</td>
<td>Communication Administration Record</td>
</tr>
<tr>
<td>Nursing Services Authorized by the CCC for a New Home Care Admission</td>
<td>Medical Confirmation Form</td>
</tr>
<tr>
<td>Home Care Provider Agency</td>
<td>VON</td>
</tr>
<tr>
<td>Frequency of Nursing Visits Scheduled by the CCC</td>
<td></td>
</tr>
</tbody>
</table>

**Other:**
**HOME VISIT OBSERVATIONS DATA COLLECTION FORM**

**AVAILABILITY OF INFORMATION TO THE HOME CARE NURSE**

<table>
<thead>
<tr>
<th>RESULT</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>What were the services that were transcribed by the nurse from the CCAC 'referral form' to the 'client assessment form' (VON)/ 'professional services ordered' form (STE) of the home chart?</td>
<td></td>
</tr>
<tr>
<td>What was documented as the nursing diagnosis (diagnoses) on the 'client assessment form' (VON), 'client's care plan' (STE) of the home chart?</td>
<td></td>
</tr>
<tr>
<td>What was documented as the nursing approach/plan?</td>
<td></td>
</tr>
<tr>
<td>Did the patient raise questions about his/her medications during the home visit? If so, state issue(s) raised.</td>
<td></td>
</tr>
<tr>
<td>What did the nurse say / do in response to the questions raised by the patient about their medication(s)?</td>
<td></td>
</tr>
<tr>
<td>Did the nurse raise questions about the medications the patient is taking since the patient's discharge from hospital? If so, state the issues raised.</td>
<td></td>
</tr>
</tbody>
</table>
### OBSERVATION CHECK-LIST OF POTENTIAL 'MEDICATION-SUPPORT' SERVICES:

<table>
<thead>
<tr>
<th>'MMS'</th>
<th>Check-List of Items to Observe</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Assistance with Medication Administration</strong></td>
<td>- uses a medication compliance device (e.g. unit dose blister package; dosette; other – state)</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>- provides assistance (<em>describe what kind</em>) to the patient’s caregiver or other persons who may be involved in the patient’s care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- administers a drug (<em>note which drug and dosage form</em>)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- helps the patient or a caregiver to obtain a method to help them to remember to take/administer medications as prescribed; <em>describe method:</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- checks medication administration technique (e.g. inhalers)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- other:</td>
<td></td>
</tr>
<tr>
<td><strong>Medication Compliance Monitoring</strong></td>
<td>- if a dosette/blister package is used as a compliance aid, checks that the medications have been taken on the right day and time by checking the dosette/blister package.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- asks the patient if they have been taking their medications</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- other:</td>
<td></td>
</tr>
<tr>
<td><strong>Medication Education</strong></td>
<td>- For the drug in which the CCC has authorized ‘medication education’, indicate if the nurse:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(1) Reviews drug’s prescription label with the patient</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(2) Informs the patient of indication of use</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(3) Informs the patient of frequency of administration (‘when to take’)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(4) Informs the patient of potential unwanted effects</td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Other:</em></td>
<td></td>
</tr>
<tr>
<td><strong>Other ‘MMS’</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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NURSE INTERVIEW QUESTIONS

NURSE IDENTIFICATION NUMBER: DATE OF INTERVIEW: MODE:

PATIENT IDENTIFICATION NUMBER: PATIENT'S PRIMARY NURSE?

Yes ___ No ___

Script:
The interview will take about 10 minutes to conduct. Please feel free to request clarification to a question at any time.

Questions

1. Have you seen the Community Care Access Center 'referral form' for this patient?

___ YES if yes:

What were the services authorized?

How did you use the information provided by the CCAC?

Interviewer, if the answer to question #1 is 'yes', then go to question #3.

___ NO if no, then ask, is it because you:

___ ARE UNAWARE OF SUCH A FORM

___ RECEIVED ALTERNATE DOCUMENTATION SPECIFYING SERVICES REQUIRED (specify documentation: ___________________________ )

___ DON'T REMEMBER

___ DIDN'T LOOK FOR IT

___ DIDN’T ‘OPEN’ THE CASE/PERFORM THE INITIAL ASSESSMENT VISIT FOR THIS CLIENT interviewer, go to question #2

___ OTHER: ___________________________

Interviewer, if the answer to #1 is ‘no’ (exception: if the response was ‘didn’t open the case’) then go to question #4

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^ Mode = face-to-face (F), or, by telephone (T)
2. If someone other than yourself made the initial assessment for this patient, do you recall what was documented in the home chart as her/his assessment (if a nurse with VON) or diagnosis (if a nurse with STE) of the services referred by the CCAC?

__ NO, if ‘no’, then ask is it because:

___ THE NURSE WHO MADE THE INITIAL ASSESSMENT DID NOT DOCUMENT THE SERVICES REQUESTED
___ I DON'T RECALL WHAT WAS DOCUMENTED
___ I DON'T KNOW WHAT WAS DOCUMENTED
___ OTHER REASON, STATE REASON: __________________

Interviewer: if the answer to question #2 is ‘no’, go to question #4.

___ YES, if ‘yes’, then:

What were the CCAC services transcribed by the nurse who made the initial assessment?

3. Home care patients are frequently on a number of medications and some receive a referral for some type of medication support, such as assistance with medication administration, compliance monitoring, or providing medication counseling.

Did this patient have a CCAC ‘referral’ or documentation in the home chart for some type of medication-management service?

__ NO

___ YES if yes:

What was the service requested? __________________
4. In your assessment, what are this patient’s medication-related needs (i.e. actual or potential problems)?

*Interviewer: if the nurse’s response to #4 indicates that she does not think this patient has any medication-related needs/potential problems, then go to question # 8.*

5. Since I’m only doing one home visit with you, I will not have the chance to observe or read about the various activities you have planned/ are planning for this patient. In addition to those activities you provided during this visit, are there other medication-management activities which you have already provided or would be planning for a future visit?

   ____ NO

   ____ YES if yes, what are these?
6. In your opinion, what are the barriers (e.g. system barriers) to delivering medication management services for this patient?

7. In your opinion, what would help you to meet the medication-management needs of this patient?
8. What suggestions would you make to improve medication-management services for home care patients?

Now, I just have 2 questions to ask you about yourself:

9. What is your level of nursing education or training?

   ___ B.Sc.N. from a University / College
   ___ R. N. diploma
   ___ R.P.N.

10. How long have you been providing home care services?

    With this agency? ____
    With any agency? ____
    TOTAL Years providing home care services: ____

This concludes my list of questions. You may have comments that you would like to make which were not addressed by these questions.

11. Are there any additional comments that you would like to make?
    List comments:

    __________________________________________