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**THE PROCESS OF CARING:
NURSES' PERSPECTIVES ON CARING FOR WOMEN
WHO END PREGNANCIES FOR FETAL ANOMALY**

By

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THE PROCESS OF CARING: GT NURSING

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ABSTRACT

Grounded theory research was conducted with forty-one female, registered nurses from four Canadian hospitals who manage the genetic termination (GT) procedure for women who end a wanted pregnancy due to fetal anomaly. Based on the sociological concept of *dirty work*, interest focused on nurses' experiences with work that is viewed as unpleasant and undesirable, work that others would prefer not to do or even know about. The hospitals' inadequate organization and low priority of the GT procedure have largely contributed to the problems GT nurses face. These include lack of professional backup, lack of adequate procedures, protocols and policies, lack of specialized training, lack of choice and lack of support.

GT nurses readily discuss a working situation fraught with uncertainties, tensions, dilemmas and frustrations, yet they also describe this work as professionally rewarding and personally gratifying. They found two central strategies to respond to the *dirty work* dimensions of their job. First, nurses see GT patients as presenting a unique opportunity for them to put into practice the most fundamental and core values of their profession – patient-centered care. Second, nurses have created a routine that allows them to more efficiently manage their work, caring for patients the best way they can.

The exploration of these strategies led to a number of paradoxes experienced by the nurses. First, their isolation which is a part of the problem, also proved to be part of the solution as it afforded them a measure of professional and moral autonomy. Second, there is a built-in tension between the caring role and the routinization of the procedure that nurses managed by focusing on the unique aspects of GT work. Third, due to the intensely emotional aspects and ethically contentious nature of GTs, nurses care not only for their patients' emotional well being but their own as well. Fourth, nurses saw themselves as having two patients to care for, a mother at risk of needing emergency care and a stillborn baby. Fifth, a subtle degree of coerciveness exercised over the nurses made it clear that if they did not participate in GTs they may face possible disciplinary measures or risk losing camaraderie with their nursing colleagues.

The strategies illustrate that amidst professional and ethical constraints GT nurses do not acquiesce to institutional powerlessness. Instead by interacting and negotiating with nurse colleagues and challenging the structure of the hospital and physicians' views, GT nurses have taken advantage of situational circumstances to strengthen their professional influence and provide the best possible care for their patients.

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TABLE OF CONTENTS

INTRODUCTION TO THE RESEARCH	1
OUTLINE FOR THE DISSERTATION.....	6
CHAPTER 1: THE THEORETICAL FRAMEWORK	10
<i>DIRTY WORK</i>	11
APPLYING THE <i>DIRTY WORK</i> CONCEPT.....	14
SOCIAL ISOLATION AND <i>DIRTY WORK</i>	16
THE DEFINITION OF THE SITUATION.....	17
MEANINGS OF DEFINITIONS	18
THE NEGOTIATED ORDER PERSPECTIVE.....	21
SOCIAL ORGANIZATION AND THE NEGOTIATED ORDER.....	23
SUMMARY	26
CHAPTER 2: THE METHODOLOGICAL APPROACH	28
GROUNDED THEORY.....	28
RESEARCH METHODS	36
GAINING ENTRANCE TO THE HOSPITALS	37
MEETING WITH THE NURSES.....	40
THE SAMPLE.....	44
THE HOSPITAL SETTINGS.....	45
THE INTERVIEW METHOD.....	46
THE ANALYSIS OF THE DATA.....	49
CHAPTER 3: THE LITERATURE ON NURSING	53
INTRODUCTION.....	53
THE CARING FUNCTION OF THE NURSE	54
THE ORGANIZATIONAL CONTEXT OF HOSPITAL NURSING.....	57
NURSING AND PROFESSIONAL BURNOUT	59
DEATH AND DYING	61
NURSING AND LATE-TERM ABORTION	63
NURSING AND ETHICS	64
ETHICS AND PATIENT ADVOCACY.....	68

CHAPTER 4: GENETIC TERMINATION FOR FETAL ANOMALY.....	70
THE RISE OF PRENATAL TECHNOLOGY	71
HOW GENETIC TERMINATIONS ARE DONE	75
INFORMING PARENTS	75
THE GENETIC TERMINATION PROCEDURE.....	80
LABOUR INDUCTION	81
LABOUR AND DELIVERY	83
AFTER DELIVERY CARE.....	85
PATIENT SUPPORT	88
CHAPTER 5: GTS AS <i>DIRTY WORK</i>:	
THE INSTITUTIONAL CONTEXT OF GTS	90
INTRODUCTION.....	90
GTS ON SURGICAL/GYNECOLOGICAL WARDS.....	91
LACK OF PROFESSIONAL BACK-UP	100
LACK OF PROCEDURES, PROTOCOLS AND POLICIES	106
LACK OF SPECIALIZED TRAINING FOR GTS	114
LACK OF CHOICE.....	117
LACK OF SUPPORT	121
SUMMARY	127
CHAPTER 6: CARING AS A COPING STRATEGY	130
INTRODUCTION.....	130
PHYSICAL CARE	131
PAIN CONTROL	132
THE DELIVERY	135
SUMMARY.....	137
EMOTIONAL CARE	137
GIVING PATIENTS A SENSE OF EMOTIONAL CONTROL	138
PROVIDING REASSURANCE AND SUPPORT	141
EMOTIONAL ATTACHMENT	143
INCLUDING FAMILY MEMBERS.....	148
SPARING PARENTS' UNNECESSARY SUFFERING.....	150
PREPARING PATIENTS FOR GRIEF WORK.....	154
CONCLUSION	157

CHAPTER 7: ROUTINIZATION AS A COPING STRATEGY	160
ONE-TO-ONE NURSING	161
MOBILIZING THE WARD AROUND GTS.....	163
ESTABLISHING PROCEDURES AND PROTOCOLS.....	166
CREATING RESOURCES	174
CONCLUSION	178
CHAPTER 8: CONCLUSION.....	181
CONTRIBUTIONS OF THE THESIS	184
SUGGESTIONS FOR FURTHER RESEARCH.....	192
BIBLIOGRAPHY	197
APPENDIX A	
LETTER OF INTRODUCTION AND EXPLANATION (V.P.).....	A1
LETTER OF INTRODUCTION AND EXPLANATION (CHIEF).....	A2
LETTER OF INTRODUCTION AND EXPLANATION (ADMINISTRATOR).....	A3
LETTER FOR POTENTIAL RESPONDENTS	A4
INFORMATION FOR CONSENT FORM	A5
RESEARCH PROPOSAL	A6
APPENDIX B	
INTERVIEW GUIDE.....	B1
THANK-YOU LETTER.....	B2
APPENDIX C	
PERINATAL BEREAVEMENT CHECKLIST	C1
PERINATAL LOSS CHECKLIST	C2
CHECKLIST FOR GT PATIENTS	C3
PATIENT INFORMATION SHEET	C4
GLOSSARY OF TERMS	C5
APPENDIX D	
RECOMMENDATIONS	D1

**THE PROCESS OF CARING:
NURSES' PERSPECTIVES ON CARING FOR WOMEN
WHO END A PREGNANCY FOR FETAL ANOMALY**

INTRODUCTION

This dissertation presents the experiences of forty-one, female, registered nurses from four Canadian hospitals, who manage the genetic termination (GT) procedure for women who end a wanted pregnancy due to fetal anomaly. The genetic termination procedure is a result of prenatal diagnostic technology that was implemented in the 1960's. Prenatal technology was established in order to identify pregnancies considered to be at high risk of fetal abnormality. More and more the technology is becoming accepted by the medical profession and the public as routine prenatal practice. Medical tests that include ultrasonography, amniocentesis, maternal serum screening and chorionic villi sampling (see Appendix C, Glossary) are performed on women at the end of their first trimester of pregnancy. As results are typically not available until well into the second trimester, the decision to terminate requires that Canadian women undergo a late-term abortion.

The options for parents who receive a positive diagnosis are either to continue the pregnancy and knowingly give birth to a baby with an abnormality or to terminate the pregnancy. There are no cures for the more than four hundred detectable medical abnormalities. In the second trimester of pregnancy - between fourteen and twenty-four

weeks gestation - the most commonly used termination procedure in Canada is labour induction and delivery of a stillborn. This procedure which can take between one and three days is managed in hospital by registered nurses.

GT nursing is intense. It is one-to-one care across a range of extremely sensitive procedures, which are emotionally and morally charged for both patient and nurse. Typically, GT nurses are responsible for admitting patients, assessing patients' emotional status and level of understanding of the procedure, and preparing for labour and delivery - which in some cases patients are unaware they will undergo. The nurses also manage the delivery of the baby, assess patients for physical complications and decide whether a physician should be called in.

The nurses' work does not stop when the delivery is over. GT nurses aid parents in making decisions about burial and memorial services for their baby and prepare them and their families for the grieving process. Since the grieving process includes seeing and holding the baby, GT nurses prepare the baby for viewing, and the parents for seeing a baby, which although fully formed, is under two pounds and sometimes bears visible physical abnormalities. The nurses assess the emotional impact of the viewing on parents. Since it is not uncommon for parents to have difficulty giving up their baby, the nurses must often also decide how best to guide parents through the process.

Already arduous and complicated, GT nurses feel that their work is made even more difficult by a lack of institutional support. GT nurses have a far greater scope of responsibility than other nurses. They follow patients and often their families from the beginning to the end of their hospital experience either entirely on their own or with only

the minimal involvement of doctors and other hospital staff. They typically receive little training for this work. They are offered few explicit guidelines and procedures to follow. There is a lack of clarity about their professional role. There is also a shroud of secrecy that surrounds GTs, necessitated in part by the concern for the security and privacy of both patients and nurses. But the nurses feel that the secrecy reflects as well an institutional ambivalence about GTs. In almost every sense they work in isolation. Their experience working with GT patients is ignored, their calls for changes in how the procedure is handled generally go unheeded. They feel unacknowledged, unsupported and silenced in their work. Ironically, however, they love the work they do. They find it professionally fulfilling and personally rewarding.

This dissertation examines the work of these GT nurses. I am interested in the ways in which GT nurses experience their work as difficult and different from other types of nursing. A central concept in my analysis is that of *dirty work*. Sociologist Everett Hughes (1971) coined the term to describe work that is viewed in one way or another as tainted, unpleasant or undesirable. It is work that most people, given the choice, would prefer not to do. Though I am not completely comfortable with the use of the term *dirty work* to describe GT nursing, I have structured my analysis around it because in this case I believe it is apt. I want to stress, however, that I am using the term in its sociological sense. Neither I, nor certainly the nurses who do this work consider it to be *dirty* in the sense that some people may use that word. On the contrary, as this dissertation will show, GT nurses see their work as critically important precisely because others are loathe to do it.

In its sociological sense the concept of *dirty work* draws attention to outsiders' view of the work in question and the difficulties this raises for those who do it. GT nurses experience directly and indirectly the discomfort and ambivalence attached to GTs as a medical procedure. GTs are seen at their best as tragically unfortunate and at their worst as immoral and unconscionable. They are viewed by many as figuratively unclean not only because they violate social taboos against abortion but also because they deal with death and destruction. In a hospital structure where nurses are subordinate to physicians and administrators, GT nurses are expected to do the *dirty work* for others whose respectability keeps them above such tasks (Hughes, 1971). GT work in hospitals is organized in ways that allow higher status doctors to pass off the task of dealing with emotionally distraught patients and a messy abortion procedure, and to avoid being identified with a morally controversial procedure.

Beyond looking at how nurses experience their work, I am interested in how they respond to the physical, moral and emotional challenges inherent in this work. I suggest that there are two main strategies that nurses adopt. The first is to define their work in a way that focuses on the unique opportunity GT nursing presents to fulfill their primary mandate as nurses - to care for their patients. The nurses define the situation as one where their patients are perhaps more reliant on them than ever for their technical and caring skills. They prioritize above all else their responsibility to get their patients and their families through the physically and emotionally wrenching experience that GTs represent. That they need to do so under institutional conditions that are unsupportive affirms for them the value of the work they are doing. The effect of this redefinition is

that it is not *despite* its dirty work status but *because of* it that the nurses find GT nursing so rewarding and gratifying.

The second strategy the nurses adopt is to construct for themselves a routine that allows them to more easily manage the work they are required to do, filling in where they must for the lack of institutional support but at the same time giving themselves the flexibility to practice the unique style of nursing they are providing - a patient-centered nursing.

OUTLINE FOR THE DISSERTATION

The dissertation is organized in the following manner. In Chapter, 1 I describe symbolic interactionism, the theoretical framework that I used in approaching this research and in framing its results. Symbolic interactionism emphasizes the role that human beings play in constructing the meanings that make sense of their actions. What people say and do are the result of how they interpret the world around them. If social scientists seek to understand peoples' actions, they need to approach their subject matter from the perspective of these social actors. Chapter 1 explains this approach to research more fully. It also provides a more in-depth discussion of some of the theoretical concepts that have sprung from symbolic interactionism and that are key to my analysis. Foremost among these is E. C. Hughes' concept of *dirty work*. The chapter elaborates on Hughes' use of that concept and discusses how the concept has been used in various empirical studies. There are discussions as well in Chapter 1 on the concept of "definition of the situation" which I use in describing nurses' redefinition of their task in GTs, and the concept of "negotiated orders" which I argue is the product of their routinization strategy.

Symbolic interactionism represents not only a particular way of understanding social interaction but also a particular way of doing social research. The theoretical premises of symbolic interactionism suggest an inductive grounded methodology. Rather than beginning with a set of hypotheses, I as the inductive researcher began with data, the lived experience of nurses as social actors. From these data, I derived patterns, themes

and categories that may be used to generate hypotheses and theory. Theory emerges out of the data in a *ground up* manner rather than being imposed on the data prior to the collection and analysis of the data. In Chapter 2, my methodology chapter, I describe grounded theory, address the questions that have arisen about the validity, reliability and generalizability of such an approach and discuss how proponents of grounded theory have addressed these questions. I also provide an account of how this research came to be and the steps that I followed in conducting the interviews, and collecting and analyzing the data.

Chapters 3 and 4 are context-setting chapters. Chapter 3 reviews the academic literature on the nursing profession. It describes the evolution of the caring function as the core professional task in nursing and the organizational context for the work that nurses do in a hospital setting. It also addresses such themes as the high degree of professional burnout among nurses, how nurses deal with death and dying, nurses' attitudes towards late-term abortions, the development of nursing ethics and nursing's move into an advocacy role vis-a-vis their patients. In Chapter 4 I tell the story of genetic terminations. I begin by describing the rise of prenatal technology and the development of the procedure of genetic terminations as a part of that process. I then describe precisely what the procedure entails and what happens to a couple after they discover that there are problems with the pregnancy and that they are dealing with a fetal anomaly. To understand the nurses' perspectives on GTs, it is important to have as background some sense for what the process entails.

Chapters 5, 6 and 7 present the findings of my study. In Chapter 5 I discuss the ways in which nurses experience their work as "*dirty work*" - work that others would prefer not to do. I describe those features of the work that make it "*dirty work*." The discussion is organized around a variety of concerns that the nurses have about their work ranging from its location on the surgical/gynecological ward of hospitals to the lack of adequate procedures, materials and support. The way hospitals have organized the process of handling GTs suggests they attach a low priority to it and seems to reflect a moral ambivalence about GTs. As a result nurses experience their work as *dirty work*, work that most others prefer not to do or even to know about. This problematic work situation, fraught with uncertainties, dilemmas and frustrations is described around six themes. The first theme outlines the difficulties nurses encounter in doing GTs on the surgical/gynecological ward. It raises the question whether this is the most appropriate ward for handling this procedure since the ward is not organized to manage labour and delivery. The second describes the lack of professional back-up available from doctors, genetic counsellors, social workers and other medical professionals. The third theme addresses the lack of adequate procedures, protocols and policies in place for managing the GT procedure that has resulted in little standardization and guidance for nurses in how to do GTs. The fourth highlights the lack of specialized training offered to nurses which includes the absence of information pertaining to patients' cultural traditions and beliefs about death, abortion, burial and grief. The fifth theme discusses the nurses' lack of choice in deciding whether they will do GTs or not. The nurses who do not want to do GTs ostensibly do not have to, but in practice this choice is often compromised. The

sixth describes the lack of support the nurses receive in terms of acknowledgement and support for the work they do.

Chapter 6 then takes up the issue of how GT nurses respond to the difficulties that characterize their work. I look at how the nurses become focused on patient care. The chapter is divided into two main parts. The first deals with the concern for the physical care of the patient while the second deals with emotional care. Chapter 7 addresses the ways in which GT nurses routinize their work. It discusses, among other things, the one-to-one nursing model and both the formal and informal procedures that have been instituted to make GT work more manageable.

Chapter 8, the conclusion, summarizes the dissertation's main findings, highlights its main contributions and suggests avenues for future research.

CHAPTER 1

THE THEORETICAL FRAMEWORK

Symbolic interactionism is a social psychological perspective that rests on three root assumptions. First, “human beings act toward things on the basis of the meanings that the things have for them” (Blumer, 1969:2). Second, the meanings of things arise out of the process of social interaction. Third, meanings are modified through an interpretive process that involves individuals symbolically interacting with one another. Research using the symbolic interactionist approach has contributed significantly to the study of group dynamics, interpersonal relations, and socialization processes. In contrast to objectivist theories in sociology which focus on how individuals are acted upon by the social structures that surround them, the fundamental theoretical interest of symbolic interactionists is to acquire a greater understanding of how and why individuals interact with one another and attribute meaning to their interactions.

In this chapter I elaborate on the symbolic interactionist perspective by focusing on certain key concepts that have sprung from the perspective and that I have used to frame my dissertation. These include the concepts of “*dirty work*”, “the definition of the situation”, and “negotiated orders”.

DIRTY WORK

One of the key figures in the elaboration of a symbolic interactionist perspective was Everett Hughes. Hughes and his colleagues in what is known as the Chicago school of sociology created the foundations for symbolic interactionism. The Chicago school recognized the impact of social organization on people's lives but at the same time stressed that society is a dialectical process. Hughes argued that structural conditions themselves cannot be understood without understanding patterns of human action. The social organization of human life involves structural conditions as people collectively face problems of constructing and maintaining a viable environment. Those conditions sometimes make certain actions imperative; other times they require flexibility and creative adaptation (Hughes, 1971). The dialectical nature of this process is reflected in the assumption that social institutions can shape human behaviour within them while at the same time, human behaviour can shape and alter social institutions.

While Hughes applied this understanding of society and the place of individuals within it to various areas of human activity, he is perhaps best known for his contributions to the study of work and occupations. It was in exploring the work lives of individuals that Hughes developed the concept of *dirty work*. Hughes (1971:343) argued that:

Dirty work of some kind is found in all occupations. It is hard to imagine an occupation in which one does not appear, in certain repeated contingencies to be practically compelled to play a role of which he thinks he ought to be a little ashamed morally... it in some way goes counter to the more heroic of our moral conceptions.

Hughes focused on types of work that have low status within an occupation or profession, such as hospital workers who “perform the lowly tasks without being recognized among the miracle workers” (1971:307). Hughes also stressed that a profession itself can become connected in some way with work which is not considered respectable in the larger society; for example medicine’s negative connection to abortionists (Strauss et al., 1985:246).

In his essay *Good People and Dirty Work*, Hughes (1971) wrote of how the extermination of Jews in Nazi Germany could be considered *dirty work*. It was carried out by a small group of individuals so that the rest of German society, most of whom supported this work, could remain distant from it and maintain a conception of themselves as good (Davis, 1992). Hughes argued that there is an unwillingness to think about actually doing the *dirty work* that is being done. Further, he argued that there are complicated mechanisms by which individuals keep the unpleasant and intolerable knowledge that comes from doing this work away from consciousness. Given the use of this psychological mechanism, Davis (1992:531) argues that those who do *dirty work* can be considered to be no different from “good” people. They are good people doing *dirty work*.

In considering the concept of *dirty work* it is necessary to think about the people who do it and to understand how they do it. In this particular research, nurses are caring individuals working in a healing profession where they are also subordinate to the demands of physicians and administrators. These nurses too are good people expected to do *dirty work*. Similar in ways to Hughes’ dirty workers, this group of nurses do the

necessary but unacknowledged *dirty work* for those people- the physicians, scientists and administrators- whose respectability “must” keep them above such things.

Dirty work can be characterized as those jobs in society that most people prefer not to do or even to know about. Hughes (1971) made a distinction between work that is physically disgusting, for example, garbage-collecting by janitors, and work that is symbolically degrading, something that wounds dignity (Strauss et al., 1985). Genetic termination is work that is deemed undesirable and immoral by some. It is not so much that the work is literally unclean. Although labour and delivery can be very messy work, so too is the delivery of a live, healthy baby. Yet in normal deliveries, the work brings a high degree of prestige to physicians. Rather, genetic termination can be viewed as *figuratively* unclean because it violates social taboos against abortion and society’s negative view of working with the dead.

The connection between Hughes’ concept of *dirty work* and the work of those involved in genetic terminations has been observed by other sociologists. In 1992, sociologist Charles Bosk, in his book *All God’s Mistakes*, described the work of genetic counsellors as “a *mop-up service*”. Bosk argued that it was a way for higher status physicians to pass off the messy task of dealing with emotionally distraught patients. The hospital nurses who managed genetic termination for unwanted pregnancies were not only required to handle this *mop-up service* but also the emotionally charged, messy, clinical abortion procedure as well.

APPLYING THE *DIRTY WORK* CONCEPT

The concept of doing *dirty work* has proven to be a useful one for those who study work and occupations (Blau, 1982; Goldman, 1981; Killian, 1981; Saunders, 1981; Simoni & Ball, 1977; Jacobs & Retsky, 1975). Some authors have shown that the performance of what is perceived as *dirty work* plays a crucial part in an individual's self identity given that one's occupation has become the main determinant of status and prestige in North American society (Goldschalk, 1979; Hughes, 1951). As Ball (1970:329) has noted, "respectability is a central concern of actors in the problematic dramas of mundane life".

Ball (1970) found that those who do *dirty work* are in danger of being considered disrespectable if others in society were to become aware of what their work entails. Hence, he concluded that most of a *dirty worker's* responsibilities are kept secret. Ball also argued that *dirty workers* may sometimes internalize a perception of themselves as disrespectable and as a consequence may isolate themselves from others. They develop as well a low expectancy for social acceptance and inclusion in mainstream society.

The theme of social isolation among those who do *dirty work* appears in the work of others. Lemert (1953:148) in his study of solitary check forgers found that their lack of integration was reflected in self-attitudes where many referred to themselves as *black sheep* or as a kind of "Dr. Jeckyl-Mr. Hyde person" because of their belief that they would not be socially accepted because of the work they did. Schneider & Conrad (1980:42) in their qualitative study of epileptics presented their participants as being isolated from one another. The researchers argued that the wish of epilepsy sufferers to

lead conventional and stigma-free lives separated and isolated epileptics from one another. Schneider & Conrad claimed that a reason for this isolation was due to the epileptics' own beliefs and definitions that conventional society would view them differently if they knew of their illness.

Davis (1993) examined a group of bailbondsmen who felt socially isolated and stigmatized. The crucial element in their experiences were their own beliefs that they were being falsely accused and unjustly defined. While the actor's belief did not seem to necessarily result in social isolation, the presence of the belief appeared to have increased the probability that social isolation would occur. Most bondsmen saw themselves as falsely accused by conventional society. They justified their work as being valuable to society. Hence, Davis (1993) concluded as Hughes (1971) did that these individuals saw themselves as good people doing *dirty work*.

Furthermore, Davis argued that believing oneself to be falsely accused can result in social isolation without social support. Paradoxically, believing oneself to be correctly accused would likely result in individuals seeking out similar others where social support could be found. As a result Davis (1993:544) claimed, that actors who considered themselves to be correctly accused might find themselves in a more positive social position because it is easier to associate with like others as well as to organize and protest the attributions made against them. The point to be made is that *dirty workers'* definitions of the situation are pivotal to their social position and experience of social isolation and social support.

SOCIAL ISOLATION AND *DIRTY WORK*

Social isolation was also a problem faced by members of the funeral industry who make their living by doing work that is considered to be taboo by most North Americans. William Thompson (1993) did a qualitative study of how 19 funeral directors and morticians handled the social stigma of their work. He found that they were fully aware of the isolation associated with their work and as a result, continually strived to enhance their public image. They accomplished this by working on shifting the emphasis of their work from the dead to the living (Thompson, 1993:525).

To counter their isolation, morticians initially emphasized the scientific and technically complex aspects of their work, like embalming and preparation for burial. Thompson reported that they were viewed by society as strangers who 'chose' to work with dead bodies for financial compensation. When they realized that emphasizing this aspect of their work only served to increase their isolation, morticians shifted the social focus to working with the living (Thompson, 1993). They emphasized their roles as funeral directors and bereavement counsellors to the deceased's family and friends.

Sociologist Kathy Charmaz (1980:174-206) who studied the social reality of death, used the term *death work* to refer to those who dealt with human death. She examined the negative impact working with the dead had on self-image, arguing that "who they are should not be defined by what they do". Thompson also found this sentiment confirmed by all those in his study. As one funeral director noted;

I don't want to be thought of as somebody who likes working with the *dead*- that's morbid- I enjoy what I do because I like working with the *living*.

These researchers who have used Hughes' concept of *dirty work* in their studies have shown that their findings support the claims made by Hughes. In human interaction there is a retrospective and prospective interpretation of social situations. Those who considered themselves to be *dirty workers* in their occupation routinely saw themselves as being socially isolated. This definition became the basis for their response to and solutions for managing their situations.

Focusing on GT nurses' perceptions of their work experiences will shed some light on what was involved in their creation of the strategies that led to the process of caring for women who undergo the termination of a wanted pregnancy for fetal anomaly. In order to further understand how these GT nurses responded to and managed this *dirty work*, I also look at how they negotiated solutions to the problems and complications that arose, despite their many organizational constraints.

THE DEFINITION OF THE SITUATION

The *definition of the situation* is one of the most useful symbolic interactionist concepts for understanding human interaction generally. The concept of the definition of the situation was developed by W.I. Thomas (1951) who explored the powerful effects of societal and cultural views on individual behaviour. He claimed that human behaviour occurs in terms of what is thought to exist by members of a society. The definition of the situation is a process by which the individual explores the behavioural possibilities of a situation, particularly paying attention to the limits, which the situation imposes on

his/her behaviour. The final result is that the individual forms an attitude about how to behave 'in' that situation (Waller, 1961).

The concept of the definition of the situation has proven helpful for interpreting the social life of the hospital. The hospital may be viewed as an agency that imposes pre-formed definitions of situations. Increasing medicalization imposes upon a society the current definitions of situations. The hospital thus, can be seen as an agency of social control. The life of the hospital is a mass of situations to be defined by or for the persons involved in them.

MEANINGS OF DEFINITIONS

Since situations are defined in different ways and by different groups, a conflict of definitions often arises. A fundamental problem within the hospital organization is the struggle between nurses, patients, physicians, administrators and support staff to establish their own definitions of situations. There are many undefined situations facing hospital personnel. Nurses confront the introduction of new technology and new procedures wholly undefined for them. As a result, they will at first have little knowledge of the details that will aid them in defining what would be best from their own point of view.

Waller (1961) argued that there is a process by which individuals work out satisfactory definitions of situations, impose those definitions upon others, or adjust to the definitions put forward by others. It has become accepted practice that physicians establish and make secure their dominance in the hospital (Fox, 1989). There may be some conflict, but acceptance of and use of the situation makes physician dominance

bearable to the nurse (Chambliss, 1996). It is understood that the boundaries between nurses and doctors are rigid and quite firmly held, so that acceptance of physicians' definitions of the situation by nurses and patients becomes almost inevitable.

Defining a situation in hospital also has another meaning. It can be viewed as a means of imposing a particular definition such as to follow doctors' orders and where nurses and patients are expected to take little initiative on their own. However, all rules have limited utility, so a situation can never be so clearly defined and a procedure so rigidly routinized, that no spontaneous definition can ever arise. A situation will always contain subjective factors, thus an individual's behaviour reaction must be considered only in connection with the whole context (Thomas & Thomas, 1928:571). The Thomas' argued that individuals' immediate behaviour is closely related to their definition of the situation, which may be in terms of either the objective reality or in terms of a subjective appreciation – “*as if*” it were so. Very often then, it is the difference between the situation as it appears to others and the situation as it seems to the individual that brings about overt behavioural discrepancy. The consequence of this for Thomas & Thomas was that “if men define situations as real, they are real in their consequences”. Individuals use a number of strategies to define or redefine a situation. Some of the strategies that emerged in this research and will be discussed later are the nurses' caring role and routinization.

In another sense Thomas argued, we use the phrase *definition of the situation* to denote the actual situation as it has previously been defined, or to indicate certain products of group life which are the result of the definition of many situations. From past

experience, a consensus arises as to what is and what is not acceptable behaviour in a given situation. These generalized social beliefs become important conditions of behaviour within that group. These beliefs, such as norms, rules, laws, taboos and group attitudes affect individuals by virtue of the fact that while they are working out an attitude toward a situation, they are always influenced by certain preexisting definitions of situations (Waller,1961).

The process of defining a situation, exploring and considering possible behaviours in a situation, is a subjective process. It must be worked out anew in the mind of each individual. Yet, as individuals and social groups can greatly affect the definition of a situation, Thomas (1951) argued that it is assumed that an individual or group defines the situation for another. In the case of the GT nurse, who works under occupational constraints, she must define her work situation based largely on how other nurses and patients have defined the situation before her. As a result of the attitudes and actions of others, individuals may define a situation in one way and not in another.

Waller (1961) enhanced Thomas' theoretical construct by arguing the importance of self-activity in the process of defining the situation. An individual such as a hospital nurse, who faces a rigid social framework, makes a number of attempts to negotiate and adjust to a situation. Some attempts do not fit and are eliminated, those that fit are adapted and become a part of that final definition and the basis for action.

Important to the concept of defining the situation is the configurational element that is involved in the process. When a situation has been set in a particular configuration, it tends to be consistently viewed that way, thus creating routinization. It can often become

difficult to see it any other way. The process itself may be described as a series of definitions of situations whereby behaviour norms are established (Thomas & Thomas,1928). Certain cultures as well as an individual's place within the culture are more resistant to change than others. The hospital organization, can be considered to be a stable configuration that is resistant to change. For this reason, individuals tend to direct their attention and their actions toward elements, which they can change and do not often attempt to alter seemingly unchangeable things. Waller (1961:164) argued that one's behaviour is a result of how the situation is defined in the individual's mind, as well as a result of the individual's situation within the organization.

Clearly, definitions of situations are twofold. Objectively, they are a part of the social culture, accepted by the group and imposed upon an individual through group activity. On a subjective level, the definition of the situation is a process being worked out by an individual, either by creating a definition or assimilating the definition that the group has imposed on him/her. The symbolic interactionist concept of the definition of the situation is important to this study as it lends itself to the understanding of how social order and change can occur simultaneously in the hospital organization, making it possible for the nurse to manage the unprecedented GT procedure amidst many organizational constraints.

THE NEGOTIATED ORDER PERSPECTIVE

Symbolic interactionists, led by Anselm Strauss (1978) developed the negotiated order perspective, which presented concepts and arguments about how organizations

operate. Strauss, advocating a theoretical merging of social psychology and social organization, argued that all social orders are in some respect negotiated orders. From its inception, the negotiated order perspective has been firmly grounded in the underlying assumptions of symbolic interactionism. For example, the assumption that humans create their own environment even as they deal with the ways the social structure constrains them (Maines, 1977).

The negotiated order perspective is not only consistent with, but derivative from symbolic interactionism (Maines & Charlton, 1985). The negotiated order perspective recognizes and takes into account the importance of understanding interactional processes simultaneously with the constraining structural features of organizational life. One of the principal ways that things are accomplished in organizations is through people negotiating with one another. Thus, the theoretical stance is taken that both individual action and organizational constraint can be comprehended by understanding the nature and context of those negotiations. In *The Hospital and its Negotiated Order* Strauss and his colleagues (1963:373-4), based on empirical studies of the hospital organization established a general framework for this perspective. How order and change fit together they argued was through processes of negotiation. They stated that:

Rules and prescribed procedures cannot be either extensive or intensive enough to cover the fluid and ambiguous character of hospital work. New agreements must continually be worked out, and old agreements fade away. Negotiation is not "organized" in the sense that it lays down permanent expectations. Rather expectations are perpetually negotiated as new situations arise. The bases for working together are continually reconstituted through negotiation.

SOCIAL ORGANIZATION AND THE NEGOTIATED ORDER

Strauss (1978) advocated the merging of social psychology and social organization when he argued that identities cannot be understood independently of the organizational contexts in which they exist. He also argued that social organization can not be fully comprehended without an understanding of the interpersonal dimension of human conduct (Maines & Charlton, 1985:271).

This conceptualization recognizes that there are stable features in an organization. Those features though, such as rules, policies, work groups, hierarchies, divisions of labour, ideologies, career lines and organizational goals are regarded as the organizational background through which and within which people interact on a daily basis and attempt to get their work done. Strauss (1963) argued that there are always ambiguities inherent in the organization. These require negotiation, both explicit and implicit in order for organizational work to take place. Strauss also argued that not everything in an organization must always be negotiated. Instead, understanding negotiation processes and their bearing on social orders, provides important insights into how social orders are maintained, how they change, and how structural limitations interact with the capacity of humans to creatively reconstruct their social world (Maines, 1977).

The negotiated order perspective points to disjunctive careers, occupational segmentation, an incomplete rule structure, and differential professional training as factors that create situations in which negotiations must take place (Maines, 1977:243). Both organizations, and actors within organizations, use strategies and methods of

negotiation to resolve, alleviate and settle conflicts. When conflict is found to be present in social relations and social organizations, it is important to note Strauss (1963) argued, that it can be negotiated into a consensus, yet, the consensus is always temporary. Farberman & Perinbanayagan (1985) stated that in fact, all social orders are a result of such negotiated events from the past, and need to be established once again by negotiation, if the consensus breaks down. For example, when a new procedure like GTs is introduced on the ward, some reorganization is required.

Strauss (1963) also stated that in order to understand the negotiation process, researchers must focus closely on the degree of flux and change that is ever present within organizations. He maintained that order is not automatic but is instead 'reconstituted continually'. Negotiations can also occur when rules and policies are not inclusive, when there are disagreements, when there is uncertainty, and when changes are introduced (Maines & Charlton, 1985). Also, negotiations can breed further negotiations. Negotiative activity in turn reacts upon the previously created rules and procedures.

In light of the rapid advances in prenatal technology and the implications for medical professionals in hospital, unprecedented issues and dilemmas continue to arise which challenge the traditional ideas of medical practice. The creation and implementation of new technologies and medical procedures rely upon negotiative processes between medical professionals so that they may reach understandings about how work will be done. Strauss (1978) argued that the negotiated order is a stage in the ongoing life of an organization.

Strauss recognized that negotiations do not necessarily ensure one's intended or desired consequences, and that there is always routinization and rigidity of activity, and circumstance in organizational life (Maines & Charlton,1985:281). Strauss (1978:259-60) argued that:

Both the agreements made between respective parties and the situations involving seemingly absolute limits are open to being changed under certain kinds of conditions. The change can be the product of mutual agreement if it is not coerced, manipulated, and so forth but requires working through via negotiation. Both the limits and the agreements are potentially contingent. In the most general sense, there are no final agreements and no ultimate limits.

What is important to note in this perspective is that negotiated orders and their structural arrangements should be viewed as a temporal process that is continuously evolving. The consequences for the structure of an organization cannot be easily discerned without looking at it from an historical framework (Maines & Charlton,1985:299-300). Specifically, GT nurses' work will be understood by tracing the past structure of genetic termination and through an examination of the negative and positive processes that ensue, as they are negotiated and renegotiated.

A result of viewing social reality from the standpoint of the negotiated order perspective is that the observer will not only see orderly societies, but also societies that are in a constant process of change. The issue of limits and consequences of negotiation is one of the most critical aspects of the negotiated order perspective. It is at the heart of the structure and process dialectic and is an issue that any study of negotiated order needs to take into account. The process of negotiation not only accounts for organizational

elements, but the process also reveals the importance of individual actors who are in association with one another.

Particularly, utilizing the theory of the negotiated order will offer insight into how the nurses critically think about the kinds of service they offer, about the nature of their relationship with other medical professionals as providers, and with their patients as recipients. Framing GT nurses' own experiences and meanings of their work within the constraints of the hospital organization as an ongoing negotiated order, will shed light on the general understanding of the interaction process within a structured organization.

SUMMARY

Theoretically, it was important to review these three perspectives for the following reasons. (1) The theory of the definition of the situation is twofold. Subjectively it is a process that is being worked out by the individual, and one that is related to the actor's moral beliefs as well as to the work that needs to be done. However, definitions are also clearly situated within the culture, and as such, the individual is imposed upon by the group. This distinction is an important starting point in understanding how nurses create and/or assimilate definitions of the genetic termination procedure in a hospital setting. (2) The idea of doing *dirty work* assumes another relevance for nurses, given the greater responsibility that is being placed on them. Ethically, the fact that nurses are *expected* to do *dirty work* needs to be explored, particularly in terms of its impact on self-image and social isolation and the strategies nurses developed to deal with this impact. (3) Strauss' negotiated order theory stresses that the three dimensions of the perspective are integral

parts of the continuous process of an individual negotiating within a social organization. These, negotiation, negotiation context, and structural context, provide a link in grounding sociological theory to practical, real life experience. Where nurses face unprecedented issues arising from the new technologies and ethical dilemmas that challenge traditional ideas of medical practice, it is important to reexamine this theory empirically to ascertain whether these dimensions together do provide for changes in the institutional order, given the unique nature of this negotiative work.

Attention will now turn to the methodological approach taken in this research.

CHAPTER 2

THE METHODOLOGICAL APPROACH

This chapter discusses the relationship between the theoretical approach I have adopted (symbolic interactionism) and the methodological strategy it suggests (grounded theory). In the first part of the chapter I describe what grounded theory is and contrast the qualitative grounded approach to social research with deductive quantitative approaches. I also discuss some of the questions that have arisen with respect to the validity, reliability and generalizability of qualitative research and look at how symbolic interactionists have responded to each of these criticisms. In the second part of the chapter I discuss my methods for this study. I describe how I gained access to the hospitals and established contact with the nurses, I describe the sample of nurses I interviewed and the hospital settings. I also describe how the interviews were conducted and how I analyzed the data.

GROUNDED THEORY

Symbolic interactionism is a theoretical perspective with a concomitant methodological orientation that is qualitative. It is a paradigm that makes certain assumptions about the nature of social reality, specifies processes to be studied and offers directions about how they might be studied. Methodology represents ways in which the researcher acts upon observations of social phenomena. It also represents ways in which

the researcher can work with these observations making the research public and reproducible.

According to Denzin (1978:6):

The sociological discipline rests on these elements; theory, methodology, research activity and the sociological imagination.

Order is given to theory, methodology and research activity through the use of what nineteenth century philosopher John Stuart Mills termed the *sociological imagination*. Denzin argued that the sociological imagination demands that a researcher be open-minded to new ways in the research process. This is accomplished by acknowledging vague images and different ideas inherent in the research process and working them out as opposed to trying to fit the data into pre-existing forms. It is in these forms that original ideas appear and anomalies are noted.

Premising themselves on symbolic interactionist assumptions, Glaser and Strauss (1967) have developed a grounded theory approach to social research that combines two important strategies of inquiry. First, it emphasizes the theoretical aspects of social research, stressing that researchers have an obligation to contribute to the knowledge of their discipline. Second, it stresses that researchers have an obligation to the actors they study, to *give them a voice*. As Glaser and Strauss (1967:238-39) have stated:

A grounded theory that is faithful to the everyday realities of a substantive area is one that has been carefully induced from diverse data... Only in this way will the theory be closely related to the daily realities (what is actually going on) of substantive areas, and so be highly applicable to dealing with them.

As Glaser (1978:2) has noted, the use of the grounded theory approach involves generating theory and doing social research as two parts of the same process.

Most proponents of symbolic interactionism utilize a qualitative approach. Qualitative research methods are different from quantitative methods in that they yield different measures and data. Glaser & Strauss (1967) have identified a clash between qualitative and quantitative methods based on the primacy of emphasis on verification or generation of theory. Grounded theorists argue that in the past there has been an overemphasis on the need to test theories. As a result, quantitative methods have de-emphasized the prior step of discovering concepts and hypotheses that emerge from the data, a basic principle of grounded theory analysis. Conversely, qualitative methods focus on acquiring a greater understanding of how and why individuals act and interact the way they do. In order to achieve this it is necessary to study the actor's meanings of the situation. Denzin (1978:13) argued that:

It is often only after the act has occurred that sense is made of it. In retrospective ways then, persons explain their behaviours. . . most interactional studies must aim for the development of explanatory accounts of behaviour sequences. And these accounts must be grounded in the retrospective explanations people give for their behaviours.

A grounded approach to social research is characterized as inductive, subjective and process-oriented, while the quantitative research strategy is considered to be hypothetico-deductive, objective and outcome-oriented (Reichardt and Cook,1979:9). According to Patton (1980:306):

Inductive analysis means that the patterns, themes and categories of analysis come from the data, they emerge

out of the data rather than being imposed on them prior to data collection and analysis.

Kidder (1981:103) points out that the inductive researcher “. . .begins with data and generates hypotheses and a theory, from the ground up”, while with the hypothetico-deductive method; “the researcher begins with a theoretical framework, formulates an hypothesis, and logically deduces what the results of the experiment should be, if the hypothesis is correct.”

The inductive model, when compared to the hypothetico-deductive model, emphasizes the discovery of unique perspectives where the actors’ meanings are continually constructed as the research progresses. Glaser and Strauss’ (1967) grounded theory approach is an inductive method that maintains social theory is an ever-developing entity. By allowing substantive concepts and hypotheses to emerge first, grounded theorists argue this method is more *faithful* to the data. Rather than being guided by theoretical assumptions about the nature of reality, it allows the generation of new formal theory and the reformulation of existing theory. Qualitative methods are often used as Patton (1980:100) has noted:

... when one wants to learn something and come to understand something about certain select cases without needing to generalize to all such cases.

Qualitative research has been criticized for problems with the *validity* and *reliability* of the data it yields. There are those who have argued that the same criteria used by quantitative researchers must be applied to qualitative research, that all scientific criteria should be judged in this way (Hammersley,1992:57). The concepts of validity and

reliability were developed to evaluate quantitative methodologies and are considered by most qualitative researchers as inadequate criteria for assessing qualitative methodologies.

Validity in the quantitative context refers to the accuracy with which a set of descriptions represents the theoretical category that it was intended to represent. Hammersley (1992) has responded to this criticism by stating that qualitative researchers use the concept of *validity* as a synonym for *truth*. An account is valid or true if it accurately *represents*, rather than *reproduces* those features which it was intended to describe.

Validity can be challenged as we can never know with absolute certainty that an account is true as there is no reliable access to reality. The assessment of validity then, involves the process of accurately identifying and presenting the claims made in the study. In this research on GT nurses, as is often the case in qualitative studies, the study was selected because it was atypical. Dealing with original subject matter and the fact that there is no published research in the area of GT nursing, the goal of this study was to present the nurses' experiences as accurately as possible, based on their own claims.

Reliability has been referred to in quantitative terms as the replicability of observations (cf. Shaffir et al., 1980:11-12), or the mere consistency of results. Qualitative researchers argue that by its very nature most qualitative studies are not easily replicated, nor are they meant to be. The notion of reliability of data used in a quantitative analysis then is not useful for qualitative research. Schwartz and Jacobs (1979:308) have responded to the criticism that qualitative research lacks reliability by arguing that there

are reasonable and practical conventions for assuring the reliability of a study. First, it is important to avoid error in observation and inference, in other words do it right the first time. Second, the reward for *mere replication* of studies is low. Instead of replicating a study that has already been done, it is more practical to build on existing research by collecting counterexamples or by giving an alternate analysis of the same or comparable data. By offering alternate analysis, researchers promote further exploration and new discovery of the sociological issue.

A third criticism of qualitative research methodology has been that it offers a weaker basis for *generalization* of results to a larger population. Typically, a qualitative study is characterized by a small sample size, particularly as Becker (1970:49) has claimed, when the researcher is sampling *hidden universes of rare items*, such as in the study of GT nurses. Qualitative researchers have responded to this criticism in a variety of ways. They have pointed out that generalization in quantitative studies focuses on probability and statistical inference methods that are not useful in qualitative research. As qualitative researcher and theorist Hammersley (1992:189) has rightly argued:

It is very important not to think of generalisability as synonymous with the use of statistical sampling. The latter is one useful way of providing for generalisability to a finite population; but it is neither perfect nor the only way. If we cannot use it, we should not assume that our findings are therefore not generalisable, or that we cannot know whether they are representative.

Lincoln & Guba (1985) argued that criteria defined from one perspective may simply not be appropriate for judging actions taken from another perspective. Qualitative

and quantitative research perspectives each have their own set of assumptions and provide two different options for an investigator to consider.

Others have pointed out that while qualitative findings may not allow the researcher to generalize, they do provide a useful starting point for more quantitative research, the goal of which would be to establish generalizations. Reichardt and Cook (1979:16), for example, make the case that if questions arise in qualitative research about the generalizability of findings, they may be addressed by using a follow-up hypothetico-deductive study.

Denzin's(1978:9) response to the criticism takes a more forceful and offensive as opposed to a defensive tact. Denzin has suggested that there is a *fallacy of objectivism* in quantitative research. He defines this as a researcher's belief that: "... because his formulations are theoretically or methodologically sound they must have relevance in the empirical world". Denzin (1978) further argued that:

This may not be the case and in these situations a reliance on activities of exploration and inspection will be useful, indeed necessary.

Generalizability to a finite population was not a goal of this research. In looking at the unique issues that GT nurses presented I was able to compare these to other nursing studies to assess how the work of GT nurses is different from that of the traditional nursing model rather than to fit the GT nurses' work into an established nursing model.

Hammersley (1992) has also pointed out there are other issues of assessment criteria which require attention in qualitative studies, notably the question of *relevance*. He states that research must be judged in terms of its relevance, taking into account the

importance of the research topic to the chosen audience, as well as the contribution of knowledge made by the findings of the study to the chosen audience.

Besides providing a rationale for a grounded theory approach, Glaser and Strauss (1967) have also developed a way of assessing the plausibility, trustworthiness and the credibility of the theory generated that is consistent with that of Lincoln and Guba (1985). Glaser and Strauss argue that a successful data analysis should include three inter-related properties. The first is how closely the analysis fits the substantive area. The basis of grounded theory is that the substantive area be reflected in the emergent theory. If the data are general enough, and the resultant theory can be applied by sociologists and lay-people then the data and theory have arisen from it and can be considered to be credible.

The second property states that the grounded theory be understandable to those working in the area. Nurses should be able to recognize their own lives and work experiences in the data. Beyond this, however, the readers of the dissertation should be able to almost see and hear the nurses who are involved in managing these genetic terminations.

The third property argues that the categories generated by grounded theory be general enough to serve as a guide to the ever-changing, daily situations of social actors without ignoring their uniqueness (Strauss,1987:242). The theory should be flexible enough that it can be practically useful in a variety of organizational situations. The data analysis should also be general enough that it is applicable to the whole picture. Due to constantly changing conditions of everyday work situations, it is important to present

findings that will apply to diverse situations in the area. For example, conclusions about strategies for dealing with GTs should be sufficiently general to capture the strategies of nurses in different hospitals.

In the next section of this chapter I describe how I conducted my study and applied the principles of grounded theory research discussed generally above.

RESEARCH METHODS

Symbolic interactionists have developed a variety of methods for collecting grounded qualitative data including participant and field observation, focus group interviewing and content analysis. However, the most common technique, and the technique I employed in this study is the interview, a face-to-face verbal exchange in which an interviewer elicits views and information from a respondent (Strauss and Corbin,1990; Strauss,1987; Glaser,1978; Glaser and Strauss,1967). The interviews I conducted were semi-structured and open-ended. I did not create a formal interview schedule. Instead, I utilized a loose interview guide (Appendix B) that included general questions and areas I wanted to cover. My intention was to explore the impact of a number of issues based on the nurses' own meanings and experiences in managing genetic terminations. I asked the nurses about their interactions and experiences with physicians and with their nursing colleagues. I asked about their spiritual beliefs and views on ethical issues such as abortion. I also asked them to describe to me the process of managing genetic terminations and how they felt about doing this work. I explain the interviewing process more fully later in this section.

GAINING ENTRANCE TO THE HOSPITALS

As a researcher, I had prior knowledge of the prenatal technology that is involved in genetic termination as well as an understanding of the implications of this technology for women and their families. In 1995, I conducted a qualitative, participant observation study at a community hospital with parents, both mothers and fathers, who had experienced genetic termination.

My data for this earlier study were collected during sessions of a self-help group for parents who had ended a pregnancy for fetal anomaly. These parents had undergone prenatal testing, ultrasound, chorionic villi sampling or amniocentesis and were told that their babies had some form of genetic anomaly. The results of this study indicated that there are many issues connected to having to make 'the choice' as to whether to continue or end a wanted pregnancy in second trimester. As well, these parents described how some of their most difficult times were experienced while undergoing the hospital procedure. This led me to do further library research which revealed that the practice of genetic termination had not yet been studied from the perspective of the hospital nurses.

Additionally, I have done volunteer work with Bereaved Families of Ontario, Halton-Peel, an organization that offers self-help support to families who have lost children through death. I was also professionally involved in the creation of their self-help support groups that are now offered for GT families.

I approached a colleague from Bereaved Families of Ontario with my idea for this study. She had recently completed her Masters of Science in Nursing. Her research focused on mothers who had ended a pregnancy for fetal anomaly. As part of her degree

requirement, she had completed a placement at a major Canadian hospital where she was responsible for creating a proposal on standard protocol for medical professionals in hospitals who work with GT patients. As a result of this experience she was able to offer me insight into many of the problematic issues these professionals encountered. She also offered guidance as I began to think about approaching hospitals with my research idea.

I chose six hospitals in a large Metropolitan city and its surrounding areas with genetic centers. Hospital protocol required that I obtain permission from each hospital's ethics committee before entering the hospital to collect data. After I received approval from my own thesis committee, as well as from the McMaster University Ethics Committee, I prepared a letter for the hospitals requesting permission to conduct this study (Appendix A). This letter, along with a copy of my research proposal, the McMaster Ethics Committee approval letter, a sample letter of introduction to potential respondents, and a sample respondent consent form, (Appendix A) were mailed to the vice-president of nursing at each of the six hospitals. A letter explaining the nature and purpose of this study (Appendix A), as well as a package containing the above information were also mailed to the nursing director of the surgical/gynecological unit and/or labour and delivery unit, depending on how each hospital's GT procedure was organized.

I received telephone responses from the hospitals within two weeks. In two cases, the calls were from the vice-president of nursing. Both women expressed interest in this research. The other four responses were from the nursing director for the units where the GTs are handled. During these telephone conversations, I explained in detail how I

intended to conduct the study and answered all of the administrator's questions. They asked questions such as: how many hospitals would I be researching, how many nurses did I wish to speak with, what types of questions would I ask the nurses, and did I know of any other research that had been done in this area.

The nursing administrators were particularly interested in the previous research I had done with parents who had experienced GTs. They seemed eager to read about the results of both my past and current research. In all cases, I had lengthy conversations (between 20-30 minutes each) with these administrators who are themselves registered nurses. We talked about the concerns they had for their nurses and their departments with regard to managing genetic terminations. I was able to establish a rapport with each of these women during the initial telephone conversations.

Each of the administrators offered to send my proposal to their respective hospital ethics committees for acceptance. This began the longest part of the entrance process. The hospital ethics committees met once a month and proposals had to be reviewed and accepted by at least three members before receiving approval. I received a request from one committee for additional information. They wanted to see a detailed proposal of the grounded theory methodology that I intended to use. This I supplied for them within two days of the request. Another hospital committee requested an outline of potential interview questions, which I also immediately sent. It took two months to receive the approvals.

All six of the hospitals' ethics boards initially granted me permission to conduct the research. I received a letter from each committee informing me that my study had been

approved. Once I received the letters, I contacted the nursing directors at each hospital to arrange a meeting time. As I received acceptances at different times over the two-month waiting period, I was able to focus on working at only one or two hospitals at a time. This allowed me to be flexible with regards to interview and meeting times. While speaking personally with the nursing unit administrators in two of the hospitals, it became clear that the issue of genetic terminations on their wards had created a tension between the hospital administration and the clinical nurses at the hospital. At one hospital, a group of nurses had recently rallied at their City Hall in order to have this procedure removed from among the list of services the hospital offered. Not wanting to exacerbate an already sensitive situation the nursing directors at the two hospitals and I agreed that the timing for a study such as mine on their units was not optimal. The two hospitals were dropped from my study.

MEETING WITH THE NURSES

The first meeting at each of the four remaining hospitals was with the nursing director. In each case, we met for approximately one hour in order to establish how I might best proceed with the interviews. I was also able to interview these directors, asking questions that pertained to genetic termination from their perspective as administrators. Each of these nursing directors stressed that she felt this was a timely study. One of the major concerns in managing genetic terminations on the ward for each of these women was how best to care for the nurses as caregivers.

Two of the four directors expressed concern about the risk of certain recently resolved issues resurfacing as a result of this research. They explained that it had taken some time to reorganize many of the routines in order to incorporate GTs in the ward. For instance, there had been some difficulty in scheduling the procedure far enough in advance of the patient's arrival so that GT nurses could rotate the assignments fairly. The nursing directors confided that the reorganization was not without emotional issues. However, in both cases they decided that the study was an opportunity for them to reassess the status of GTs, how the procedure was working in their units and which outstanding issues still needed to be addressed. The directors felt that the data would be useful in furthering their understanding of how their own nurses experience the GT procedure. They were also eager to obtain information on how other hospitals managed genetic terminations. It was agreed, during these initial meetings that the findings would be made available to them in the form of a research summary, upon completion of the project. All responses would be anonymous.

At the end of these meetings I arranged with each director a time at which I might make a presentation to the GT nurses working in their units. The nurse manager of the unit and the clinical nurses were invited to attend, and in some cases clinical nurse specialists asked to be present. In all four of the hospitals, I made two presentations to each unit. The nurses worked twelve-hour shifts, so in order to reach as many of the nurses as possible, I presented the study on two different shifts.

Either the nursing director or the nursing unit manager accompanied me to most of these meetings. If she could not attend, she would personally ask each nurse on shift to

attend the meeting as a show of support for my research. These meetings took place in the nurse's lounge. There were between five and twelve nurses present at each meeting. Each presentation lasted approximately fifteen minutes. I began by introducing myself to the nurses, telling them about my interest in GTs, describing my past research with GT patients and explaining briefly that this was a sociological study. Many of the nurses felt more comfortable about the study once they knew that I was not a nurse and that this study was sociological. Also, I found my past research experience in the area of GTs allowed me to express myself knowledgeably about their work. I believe this helped to put the nurses at ease. They realized that I was aware of the sensitive and disturbing nature of GT work.

Some of the nurses expressed a concern that discussing the more controversial aspects of their work could jeopardize their jobs. Either the director or manager and I assured them that their participation in the study was completely voluntary and strictly confidential. I assured them that I was the only one who would know the identity of respondents, that in the report I would be using pseudonyms only and that any information that would allow them to be identified would be removed. I also assured them that the only people who knew which hospitals were participating in the study were the three members of my thesis committee at McMaster University.

In addition to the presentation, I handed a letter of introduction to the study (Appendix A) out to each nurse at the meeting. I was clear that my intention in doing this study was to give the nurses a voice, to give them the chance to tell their stories based on their own experiences of handling GTs. I explained to them that I was not going to use a

questionnaire, that instead I wanted them to tell me what it is like to be involved as a nurse in GTs. Some of the nurses commented that no one had ever asked them how they felt about their work or seemed interested in their work before. Many were excited about having the chance to speak openly.

After each presentation, I encouraged questions and found in all cases that there was great interest in the study. Often the group of nurses at the meeting would begin to share experiences and viewpoints with each other and with me on what it was like to do GTs. These became informative sessions which allowed me to hear about some of their past experiences, as well as to gain first hand knowledge of the aspects of their work that were particularly important to them. The information proved beneficial for me as I organized the interview guide. I did not take notes during these meetings, hoping this would help to put the nurses at ease. I wrote my impressions of each meeting after it had ended.

At the end of the meeting I invited nurses who were interested in participating to schedule an interview with me. I also left my phone number and a few copies of the letter of introduction with the nurse manager in case anyone wanted to contact me at a later time for an interview or to ask me any questions related to the study. The nurses were asked to consent to one interview, approximately one hour in length. Each time I made a presentation I was able to book one or two interviews for later that same week. Having the opportunity to focus on one hospital at a time allowed me to immerse myself in each individual ward, thus I got a feel for the ambiance and camaraderie of the nurses on each ward. This also allowed nurses to become comfortable with my presence as I

was there interviewing several times each week for 2-3 weeks. I conducted interviews at all times of the day and night, dependent upon the availability of the nurses. I often found after 11:00p.m. was a relatively quiet time for the nurses and they were more relaxed and eager to talk to me.

While I was at the hospital conducting the interviews other nurses approached me about booking an interview time. In a few instances, nurses who had not attended the meeting but had heard about the study from a nursing colleague, called me to request an interview.

I received strong support in all four of the hospitals, from the nursing administration as well as from the clinical nurses. In each hospital the nursing administrators and the nursing unit coordinators generously suggested that I conduct the interviews with the nurses while they were working their shift so they would not have to stay beyond their twelve-hour days.

THE SAMPLE

The data for this study were gathered between September and November of 1998. They were based on face-to-face interviews with 35 registered nurses, three nursing directors and three clinical nurse specialists who worked on the units in hospitals where genetic terminations for fetal anomaly were managed. All but one of the nurses were female. The male nurse I spoke with did not manage GTs as a primary nurse because of his gender. Of the 35 registered nurses interviewed, 31 were full-time and four were part-time. Three of the nurses had assisted with the procedure but had not taken on the

role of primary nurse. The primary nurse is responsible for managing the GT procedure. One nurse did not perform GTs for religious reasons. This group had been nursing between four and 25 years and ranged in age from late twenties to late fifties.

THE HOSPITAL SETTINGS

Three of the hospitals were teaching hospitals and the fourth was a community hospital. At the time of this study the hospitals were managing between one and six GTs per week. For three of the hospitals, the average was two and for the other, the average was four per week. The GTs were scheduled between Monday and Friday each week. The nurses worked twelve-hour shifts and GT patients were generally in hospital for 1 to 3 days. This required between two and six nursing shifts, and 2 primary care nurses to rotate the shifts. In each hospital, GTs were done on the short-stay, surgical/gynecological ward for pregnancies between 16 and 20 weeks gestation. Usually, but not always, terminations performed between 21 and 24 weeks were handled on the labour and delivery floor.

Thirty-nine of the interviews took place at the hospital, either on the ward or in the nursing director's or clinical nurse specialist's office. One interview took place at a local coffee shop while the other took place over the telephone from the nurse manager's home. In most cases, the nurse was working and was given permission by the nurse manager to take time for the interview. The location of the interview was either in the nurses' lounge or in a vacant hospital room. In many cases we conducted the interview in the room where the actual GTs took place. There were a few times when I arrived for

a scheduled interview and the nurse was busy with a patient, so I waited for her to finish. On a few occasions there was another nurse who wanted to talk to me, so I spoke with her first.

At the three teaching hospitals, the nurses had a choice as to whether or not they wanted to take the GT assignments. This was because there were enough nurses on the floor willing to take the assignments. Over the last ten years these hospitals have put into place one-on-one primary care for these patients. So when a GT patient was scheduled, a nurse volunteered for the assignment while another nurse was assigned to her other cases for that shift. The fourth hospital, a community hospital, had not been able to implement this type of scheduling due to the large number of patients that were cared for on the surgical/ gynecological unit. At this hospital, the nurses cared for the GT patient and managed approximately four other patients on their shift. These nurses were not given a choice to accept or refuse a GT assignment.

THE INTERVIEW METHOD

The interviews were unstructured, interactive and tape-recorded with the respondent's consent. At the beginning of each interview the nurses were again informed about the nature of the research. The confidentiality of the study was also discussed. I explained the procedures I intended to follow to ensure confidentiality including storing the taped interviews in a locked cabinet, making the hospitals unidentifiable, and using of pseudonyms for the nurses when presenting the data. Each nurse was invited to ask me

any questions at this time. They were then given an *Information For Consent* form to read and sign (Appendix A).

I asked each nurse if she would mind if I took notes during the interview. I explained that I wanted to jot down some key words and ideas that I could go back to later on after the interview was over. I also noted possible questions that I wanted to ask the nurse, so I would not forget them. I did not continually write notes throughout the interview as I wanted to create a relaxed atmosphere where we could freely talk back and forth. In fact, the note taking often allowed the nurses to take some time to think about what they wanted to say as well as an opportunity to collect themselves when they became teary or upset.

To begin the interviews, I asked each nurse how long she had been nursing and how long she had been working on the ward. This allowed her to talk about herself which helped to put her at ease. I then asked the question; 'Could you tell me what the experience of caring for women who end pregnancies for fetal anomaly is like for you?'

Each interview then followed the nurse's lead. The direction of the interview was to some extent determined by what the nurses said as I allowed myself to probe into areas they felt were important. Subsequent questions were often phrased in terms of the vocabulary that the nurses themselves used. I asked each nurse to tell me about her experiences, beginning with the time when patients were admitted to her care and to describe the entire procedure, until the time patients were discharged.

I used the interview guide (Appendix B) to steer the discussion only if the nurses omitted to talk about aspects of the process I wanted to address. In a few cases, the

nurses became visibly upset and tearful as they explained some of the more difficult aspects of their work. In these instances, I would turn off the tape-recorder and give the nurses a chance to regain their composure. There were also a few occasions when we were interrupted by a colleague who needed information about a patient. The interruptions generally lasted for only a couple of minutes at which point I was able to resume the interviews.

Those who do qualitative interviewing often recommend the use of theoretical memos (Strauss and Corbin,1990). Theoretical notes are notes about ideas and themes that are beginning to emerge in the study as the data is being collected which may influence the direction and content of further data gathering. I made theoretical notes throughout the study and also kept field notes containing demographic information for each respondent. This information included such data as (a) where the interview took place; (b) the nurse's apparent level of comfort; and (c) the nurse's support system as I was able to determine it through my observation on the wards and in the experiences the nurses related. Finally I kept personal memos which reflected my assumptions, questions, feelings about and reactions to each interview.

At the time of each interview, I substituted a number for the nurse's first name, both in my notes and on the tapes. After each interview, I asked if the nurse wished to receive a summary of the results. All expressed an interest in reading a summary.

THE ANALYSIS OF THE DATA

In contrast to more quantitative research methods, the analysis of grounded theory data occurs from the point where data begin to be collected and continues throughout the research project. The basic operations outlined by Strauss (1987) for the analysis of qualitative data are as follows: developing a concept-indicator model, theoretical sampling, coding, looking for theoretical saturation and process analysis.

As soon as I began my interviews I began the process of comparing the nurses' experiences and looking for common themes. Strauss (1987) referred to these as *concept-indicators*. The constant comparison of all the themes that emerged as the interviews progressed, allowed me to generate broad categories based on the similarities, differences and degrees of consistency of the nurses' meanings and responses. It became clear early on in the data collection stage that for all of the nurses their experiences of the work were connected to certain other factors. The organizational structure of the hospital, the medical profession, how the ward worked, the patients and society's cultural views all figured prominently in the way nurses talked about their work. These indicators gave me a starting point for the analysis. I built upon them to establish the nature of the interconnections.

Theoretical sampling is the means by which Strauss (1987) suggests qualitative data can be jointly collected, coded and analyzed. Theoretical sampling means looking for data to answer unanswered questions as they arise, to clarify meanings in the data that are not clear or to establish whether indeed the experience of some respondents on a particular point matches the experience of all respondents. The initial decisions in the

collection of data were based only on a general series of questions about GT nurses' work. As themes began to emerge, however, and as I constantly compared the data, I made decisions about the precise kind of data I needed, how to collect it next and where to find it. I developed new, more precise questions to use in my interviews. Subsequent interviews, while they continued to walk the nurses through their responsibilities in a GT procedure, at the same time became more focused on some of the themes that were emerging as critical. The process of data collection was controlled by the emerging theory (Glaser & Strauss,1967).

When I asked the nurses to explain the GT procedure to me during the interviews, all of the nurses described the clinical tasks that were involved in getting their patients to a safe delivery. While describing how they managed this work, the nurses discussed their responsibilities in terms of two separate concerns. The first was in terms of the clinical routine that was necessary to guide patients through the physical labour and delivery. Second, the nurses stressed the complexity of the emotional concerns they had for the patients and families, coupled with the ethical challenges they faced. It became clear that the nurses' role of caring for patients consisted of two sets of challenges that were closely related, the physical care and the emotional care of their patients.

Strauss (1987) referred to the operation by which categories are discovered and named as *coding*. The initial type of coding, referred to as *open coding*, is an unrestricted process of breaking down, examining, comparing, conceptualizing and categorizing the data. By scrutinizing the interview data verbatim, I was able to produce concepts that fit the data. Initially, these concepts were provisional and were intended to

open up the inquiry (Strauss,1987). The primary concern in this stage of the interpretation was to think in terms of explicit concepts and their relationship to each other such as the relationship between the physical and emotional care and the nurses' GT routine on the ward.

Coding was also used to link other data to the core categories as *sub-categories*. The sub-categories and relationships discovered during the open coding phase, became the focus for my continued data collection. This stage, known as *axial coding* (Strauss 1987), consisted of more intense analysis revolving around one category at a time. A second phase in the coding process, axial coding allowed me to create links which resulted in cumulative knowledge about relationships between categories and sub-categories. This linking of data assisted me in choosing categories that would eventually become core to the thesis.

The last coding phase described by Strauss (1987), *selective coding*, was the actual selection of the core categories. This was accomplished by systematically clustering codes into categories, relating categories to each other, and filling in categories that needed refinement and further development with more data. This eventually led to the integration of the theoretical ideas the data generated. In this dissertation there were three core analytical categories; (1) the problematic aspects of managing genetic terminations; (2) the nurses' caring role as a coping strategy; and (3) the routinization of GTs on the ward as a coping strategy.

It is difficult at the outset of any qualitative research to state how many participants will be sampled over the entire study. The criterion I used for judging when to stop

sampling participants was *theoretical saturation*. Strauss (1987) explains that a point of saturation is reached when no additional data are being found. As what I heard in the interviews, at least as far as the relationship of categories to sub-categories was concerned, became repetitive I was confident that I had reached a point of saturation for that category. The concerns and issues in each nurse's working life may have been coloured by her unique biography and the particularities of her local circumstances, but the essential concerns and how the nurse made sense of these paralleled the experiences of other nurses I had interviewed.

Finally, I was able to link the data from the categories together to form a meaningful analysis. The goal of this final operation, known as *process analysis*, was to clarify the process and order that occurred with the passage of time (Strauss & Corbin, 1990:147). Thus, in linking the categories I have created a *story* that describes the process of genetic termination based on the GT nurses' understandings of their work.

In the next two chapters I cover some of the literature that provides the context for this story. I review two bodies of literature - the academic and sociological literature on nursing and the literature on prenatal technology. I also describe in detail what precisely is entailed in doing a GT.

CHAPTER 3
THE LITERATURE ON NURSING
INTRODUCTION

There is a large nursing and social science literature that describes some of the difficulties connected to the nurses' role, especially within the hospital setting. Much of this research, however, focuses on nurses' work from the perspective of authoritative others concerned with what nurses ought to be doing and what role they ought to be playing. Much less research has been done on the perspectives and experiences of the nurses themselves. A review of the literature also indicates that the role of GT nurses in particular and their experiences in caring for women who end pregnancies for fetal anomaly has largely been neglected.

This chapter presents an overview of the parts of the literature on nursing relevant to my dissertation. To fully understand the predicament of GT nurses, it is necessary first to understand how nurses define themselves and their professional task. I start, therefore, by discussing the caring function within nursing. It is also critical to situate nursing in the broader context of the hospital organization. Nursing is deeply embedded within a hierarchy of authority in which nurses are subordinate. In important ways, it is this structural organization that makes nursing work generally, and GT nursing more specifically, problematic.

After discussing the organizational context of nursing I present a brief overview of the other themes that have emerged in the literature on nursing and which I feel are relevant to my thesis. Though my review of this literature is hardly comprehensive, it does fill out the picture of contemporary nursing that I want to paint in this chapter and which serves as the backdrop for my study. These themes include professional burnout among nurses, the nurses' experience of death and dying, nurses' feelings about late-term abortion, the development of nursing ethics and the patient advocacy role that nurses are moving into.

THE CARING FUNCTION OF THE NURSE

Nursing is considered to be among the most noble of professions. Nurses care for patients in their most vulnerable and difficult moments, sharing an intimacy that is found in few other human relationships. Sociologist Daniel Chambliss (1996) in one of the most illuminating books about contemporary nursing, *Beyond Caring*, highlights the centrality of caring in how nurses think of their work:

Care is the key term in nursing's definition of itself and it defines what nurses believe their job to be. Many nurses say that "care" is what distinguishes nursing from medicine: nurses care, doctors cure.

The commitment of nurses to their caring function has long historical roots and ties with assumptions about the nature of female identity. In the 19th century, Florence Nightingale had a major influence on training nurses in hospitals. She envisioned nursing as an art rather than a science for which women needed to be trained. Nursing was built on a model that relied on the concept of duty to physicians. But Nightingale thought

medical therapeutics and 'curing' were less important to patient outcome than was caring. She left the realm of therapeutics to the physician. Focusing on caring, nurse training emphasized discipline, order, and practical skills (Conrad & Kern, 1990:188).

Unwittingly, Nightingale's beliefs about the role of women provided much of the ideological justification for the dilemmas that North American nurses face today. While caring may be thought of as a universal element in female identity, for nurses it is also work. Policy analyst Hillary Graham has argued that 'caring touches simultaneously on who you are and what you do' (Finch & Groves, 1983:13). Given this duality, it has become difficult for nurses to define caring solely in the context of their work and even more difficult for nurses to control the caring aspects of their work. Circumstances, ideologies and power relations create the conditions under which caring occurs, the forms it will take, and the consequences it will have for those who do it (Conrad & Kern, 1990:185).

Caring as an historically created experience was premised on the expectation that nurses would accept a duty to care rather than demand the right to determine how they would satisfy this duty. Nurses were expected to act out of a gendered obligation to care, thus taking on caring more as an identity than as work. Nursing exemplifies the nature of historically feminine occupations: an emphasis on caring for others, especially dependents; menial cleaning and housekeeping tasks; relatively low pay and prestige; and an emphasis on helping those (typically men) who are in charge rather than making substantive policy decisions themselves (Chambliss, 1996:80). Consequently, much like others who perform what is considered to be "*women's work*" in North American society,

nurses contend with a dichotomy between their duty to care for others and their right to control their own activities within their own work. They are expected to act as if altruism (assumed to be the basis for caring) and autonomy (assumed to be the basis for rights) are separate ways of being (Conrad & Kern, 1990).

But it has also been argued that the *nature* of the nurses' job, more than their natural gender-based propensity to care or *women's view* of morality, has shaped their attitudes towards their professional role (Clarke, 1994; Williams, 1989; Miller, 1986). Nurses spend twelve hours each day in close contact with patients. They are the ones who witness patients' cries, see patients' pain, and are often in the room when patients die (Chambliss, 1996). Their proximity and intimate contact with patients makes it more likely that they, rather than physicians, would be concerned with care and aspects of the patients' experiences beyond the treatment of their diseases.

These different views of the source of nurses' concern for patient care are hard to test because the effect of female gender on the nursing occupation is hard to distinguish. The two features of nursing, its character as an essentially female occupation and the nature of its relationship to patients have always been highly correlated. These features have shaped many of the nurses' views of what their professional task entails.

It would be a mistake though to view the nursing experience as being essentially one of exploitation. The authoritarian model, influenced by Florence Nightingale, instilled in nurses much idealism and pride in their skills. It has served to differentiate the trained nurse from the untrained nurse and has protected and aided the sick and dying. Chambliss (1996:18) has noted that an appeal of nursing as a profession is the intensity

that the job demands; 'People don't become nurses to avoid seeing suffering or to have a quiet day'. Nursing is meaningful work.

THE ORGANIZATIONAL CONTEXT OF HOSPITAL NURSING

As committed as nurses may be to their caring function, the fact that hospital nurses are fundamentally members of a large organization profoundly affects their work. The occupation of nursing is scarcely autonomous. It is embedded within a hierarchy of authority. Chambliss' analysis of nursing shows that nurses are subordinate to hospital authority in numerous ways. They are subject to hospital policies that are applied by head nurses, supervisors and administrators. They are subordinate to physicians and their orders. They are expected to work within the doctor's view of patient needs and doctor's plans for patient care (Chambliss, 1996:3). Yet, as the previous section showed, nurses are medical professionals with their own set of responsibilities and values. As a result of their training and experiences doctors and nurses have very different perspectives on what humane patient care in hospitals entails.

From a physician's perspective, a patient may be viewed simply as the object of a technical process. This occurs, for example, in abortion procedures. Generally, physicians are not interested in what they term non-viable 'cases', where they know the pregnancy will not result in a live baby. Cooke (1975), in looking at the moral perspectives of physicians and nurses towards their patients found that many physicians viewed their responsibility to patients as best being served by concentrating on the

technical procedure rather than caring for the whole person, which they believed was the nurses' concern.

The nursing mandate is to care for the whole patient. Smith (1966:135), an American nurse who studied the barriers nurses face in giving quality care, argued that nursing must involve an identification of the nurse with the patient and with the patient's family. She also stressed an acceptance of the high moral value placed on the health and the preservation of life. But, much nurses' work is determined by others (1966:81). Embedded in the organization, nurses typically work on a tight schedule with a long list of mandated tasks to be accomplished in a limited time. The tasks must be done according to various defined standards that are often legally sanctioned. These tasks include medication doses and standards of care.

Nurses, Chambliss claims, understand their work as governed by often conflicting imperatives of caring for patients, behaving as professionals, and working as subordinates in the hospital organization. When there is time, nurses do have the option to talk with patients and their families or to help other nurses with their work. Yet he argues, "given the degree to which nursing work is dictated in advance and controlled in execution, it is a wonder that they have time for any decision-making at all."

Nurses then, face at least three difficult and sometimes contradictory missions. Hospital nurses are expected to be simultaneously a) caring individuals; b) professionals; and c) relatively subordinate members of the organization (1996:62). These three directives clearly conflict, as nurses are to be both caring and yet professional, a typical conflict of interest in the organization of the hospital. Nurses are to be subordinate and

yet responsible, and they are expected to be accountable for a patient's total well being and yet oriented to the hospital as an economic employer.

There is a tension built into this organization where the hospital with its specialized technologies, highly specialized staff and administrative duties has become the focus of health care. A barrier is created for nurses who wish to do their job of caring for the total individual (Smith, 1966: 137).

NURSING AND PROFESSIONAL BURNOUT

Although there are certainly satisfactions and personal rewards in nursing, the tensions and frustrations associated with the context within which nursing is practiced take their toll. Nurses appear to have a disproportionate share of stress-related difficulties, including heart disease, drug abuse, suicide, and high rates of attrition (Clarke, 1994). By definition, nursing involves a great deal of contact with people—patients, their families and friends as well as medical personnel. Often this interaction is emotionally charged, with feelings of tension, anxiety, embarrassment, fear and hostility. This chronic emotional stress, it is argued, can lead to *burnout*, a syndrome which can include; a) emotional exhaustion; b) depersonalization and c) reduced personal accomplishment (Leininger, 1990; Handy, 1990; Maslach & Jackson, 1982).

Emotional exhaustion refers to a depletion of one's emotional resources and the feeling that there is nothing left to give patients. The more time spent in direct patient care, the greater the risk of emotional exhaustion. The *depersonalization phase* is reached with the development of negative and callous attitudes about those with whom

one works. This perception may lead one to judge others as somehow deserving of their troubles (Handy,1990; Lerner, 1980). The third aspect of burnout is *reduced personal accomplishment*, the perception that one's accomplishments on the job fall short of personal expectation. This aspect also involves a negative self-evaluation. As a consequence, burnout may lead to a decline in the quality of care that is provided to the patient (Leininger,1990; Smith,1992).

Direct patient care, a key aspect of nursing work, can be emotionally demanding in a number of ways. Patients may be anxious, frightened, angry, or rude. They may misinterpret what they have been told or have trouble articulating their thoughts and fears. The nature of the patients' health problems is also a factor in the stress related to direct patient care (Clarke,1994; Smith,1992). Working with dying patients poses its own unique emotional risks for health practitioners. Death is usually viewed as an adversary to be fought and overcome. Indeed, death can be experienced by nurses as a visible sign of their powerlessness and inability to help patients.

Communication problems are another source of emotional stress (Clarke,1994; Handy,1990; Maslach & Jackson,1982). Not only patients, but nurses may have difficulty in communicating directly with patients, particularly about emotionally laden problems. 'Bad news' is an example of this. Few people feel comfortable having to tell another that the treatment will be painful or risky (Chambliss,1996; Smith,1992). GT nurses, as a result of the lack of standard protocol, are often the ones left to tell patients the "bad news" about the procedure they will have to endure.

The relative lack of control over their work described earlier in this chapter can add to feelings of ambiguity and uncertainty about their professional role. Ambiguity about one's own career choice has been found to be a major cause of psychological stress and burnout (Handy, 1990; Leininger, 1990). Where there is a perceived lack of relevant information or training, nurses are more likely to experience feelings of tension and anxiety. As a result of role ambiguity, Handy (1990) has argued, nurses may experience higher blood pressure, physical signs of stress, high job turnover, and poor job performance, all of which are characteristics of professional burnout.

Other factors connected to professional burnout among nurses are the mismatch between the ideals they bring to their work and the reality that confronts them once they are actually on the wards, ambiguities about what defines appropriate job behaviour, a lack of recognition and feedback about the value of their work, as well as the continuous, intense, direct contact with patients (Smith, 1992; Clarke, 1994; Maslach & Jackson, 1982; Hughes, 1994; Svensson, 1996).

DEATH AND DYING

Death as an ever present and inevitable part of nurses' work lives is another factor to consider. Nurse researcher Jean Quint (1967) has studied the role of nurses in caring for dying patients. She reports that the constant presence of death as a feature of their work creates serious difficulties for nurses. Besides their personal reactions to death nurses have to contend with the general uncomfortableness of others towards death and a health care system that values lifesaving activity and technological achievement. The

terminal care that nurses are often called upon to provide is viewed essentially by many as a form of low-status work.

As Glaser and Strauss (1965) have shown, death represents a failure for most medical professionals whose central goal is the preservation of life. When patients are seen as dying, staff visits will fall off and the attention paid to patients declines (Hackett & Weisman, 1964:308). Mauksch (1975:14) has suggested that death is especially disruptive on wards where death is uncommon. This would be the case for example, on surgical/gynecological wards where GTs are managed.

From the nurses' perspective, there are two kinds of death encounters (Quint,1967). First, there are those in which death is medically accepted and is recognized as inevitable. Second, there are encounters where the possibility of death occurs suddenly. In these emergencies, heroic measures are used to prevent death. Quint has argued that the standards and expectations that govern acceptable nurse performance when death is expected are different from those where the prospect of death arises unexpectedly.

When a patient's death is inevitable, nurses are responsible for the provision of care and comfort for the patient, and support for the grieving family. The emergency situation provides a sharp contrast to this inevitable death. Successful performance in emergencies depends on recognizing the urgency, calling for a physician's help, performing appropriate emergency actions until help arrives, collecting and organizing the necessary equipment, and assisting the physician until the crisis is averted. These assignments require different performances by the nurse, yet in both instances she has considerable responsibility (Quint,1967:23).

NURSING AND LATE-TERM ABORTION

It has only been in the last thirty years that researchers have begun to provide insight in to the attitudes and experiences of dealing with abortion. The research on nursing and abortion has focused mainly on nurses' attitudes towards working with patients who end an *unwanted* pregnancy. The data show that the organization and administration of abortion services and the social environment in which abortions occur including the attitude toward abortion in the general community and among health professional peers, has a significant impact on the attitudes of nurses (Rudy, 1996; Callahan, 1995).

Kane and colleagues (1973), sampling the attitudes of physicians and nurses who had participated in large numbers of abortions, indicated an ambivalence on the part of some nurses about their participation in the procedure. This ambivalence was exacerbated by the fact that nurses perceived physician's involvement beyond the clinic and operating room to be minimal and perfunctory. The nurses felt that this added to their feelings of anxiety, depression and even anger towards patients (Kane et al., 1973).

A study done by Kaltreider (1981) on second trimester abortions for *unwanted pregnancies* focused on the psychological attitudes and experiences of both patients and abortion providers. Kaltreider found that the experience of a medical care provider participating in any abortion procedure is in direct contradiction to the medical profession's focus on the preservation of life. However providers may feel personally about the procedure, this is a fact with which they must come to terms. Second trimester,

induced abortions were viewed by nurses not only as upsetting experiences, but also as symbols of abandonment of nurses by the medical staff. Much like in Kane et al's study, the ward nurses' comments reflected frustration at being left to cope with emotional patients who most often delivered late at night due to the timing of the induction which was scheduled at physicians' convenience. Physicians were not available at night and the house staff, although technically available, were quite clear about preferring to be in the delivery rooms where *live births* occur.

The nurses found physical contact with the fetus particularly difficult, reminding them of the preemies just down the hall. This also made them feel uncomfortable as they thought about their own potential, future pregnancies. Light staffing on the night shift also made a total voluntary system of participation impossible. Late-term abortions required intense nursing care, and physician involvement took place only in emergencies. It was the ward nurses' role to care for the expelled fetus. Kaltreider (1981) noted that even nurses in favour of abortion found this a lonely and difficult task.

NURSING AND ETHICS

Over the past decade, there has emerged within nursing a discussion about the unique ethical responsibilities of nurses and the role of nurses in the bioethical decisions that are made as a part of practice. Nursing bioethics, a variant of bioethics, rejects the notion that ethical positions developed by physicians and scientists can simply be applied to nursing situations without recognizing that nurses' situations may be profoundly

different from those faced by the physicians. The voice of nurses and their distinctive moral issues need to be taken into consideration (Chambliss,1996).

The earlier writings on nursing ethics focused on frameworks from bioethical theory more generally (Beauchamp & Childress, 1983), theologically-based contract theory (Veatch,1981), pluralistic secular-based theory of human rights (Engelhardt,1986), and a liberal theory of justice (Rawls,1971). Seen by some writers to be a 'masculine' medical ethics, it has been argued that this ethical theorizing is governed by an implicit, logical necessity between hierarchically arranged levels of principles, rules and actions (Fry,1992; Asch & Geller,1996).

These models have been criticized by many feminist bioethicists for focusing on an ordering of principles rather than on the context within which decision-making takes place (Noddings, 1984; Holmes & Purdy, 1992). Applied to nursing ethics, the argument is that insufficient attention is being paid to the role of nurses in health care, the social significance of nursing in contemporary society, and the value standards for nursing practice (Fry,1992).

A feminist approach to nursing ethics argues that *caring* ought to be the foundational value for any theory of nursing ethics. This value of caring must be grounded within a moral-point-of-view of persons rather than an idealized conception of moral action, moral behaviour, or a system of moral justification. A few nurse researchers have attempted to articulate the value of caring in the moral practice of nursing (Leininger,1990; Clarke, 1994; Chambliss,1996). Nurse ethicist Sally Gadow (1985) has argued in her research on the ethics of caring in nursing, that the value of

caring provides nursing with an ethic that will protect and enhance the human dignity of patients. She has analyzed caring in nursing actions as *truth telling* and *touch*.

In truth telling, nurses assist patients by first assessing the subjective as well as the objective realities in illness and second by making decisions based on the unique meaning of the illness experience. Through touch, the nurse assists the patient in overcoming the *objectification* that often characterizes a patient's experience in the health care setting. To touch patients, Gadow (1985) has argued, is to affirm patients as people rather than as objects, and to communicate the value of caring as the basis for nursing actions. This approach is supported by others who articulate caring as the foundation of the nurse/patient relationship and its meaning (Griffin, 1983; Huggins & Scalzi, 1988; Packard & Ferrara, 1988; Yeo, 1991; Fry, 1992; Holmes & Purdy, 1992; Chambliss, 1996).

Any discussion of nursing ethics must also take into account the multicultural context in which nursing is practiced, where diverse cultures are encouraged to emphasize their own identity, special needs and ethical values. This complicates ethical and moral decision-making. Nurses, particularly, face these ethical issues in the most intense and continuous way because of their intimate contact with patients in providing direct care (Leininger, 1990). Leininger has argued that trans-cultural ethical and moral knowledge of Western and non-Western cultures is greatly needed to help nurses function effectively with people of different cultural backgrounds. It is essential in assisting nurses to make meaningful care judgments and decisions and to take appropriate actions (Leininger, 1978, 1983, 1988).

As society becomes increasingly multicultural, it is argued that patients will expect that their ethical values and moral beliefs will be respected and acted upon appropriately by health personnel. If the nurses' ethical care judgments are not reasonably congruent with the clients', unfavourable problems may occur (Leininger,1988; Horn,1978). Some clients do not comply with professional decisions that are against their ethical or moral values. Others may comply under duress in an emergency, but their well being, recovery or healing may be affected. Still other clients may press legal suits when their cultural values are not respected (Leininger,1990).

An unusual and provocative perspective on nursing ethics has been provided by Chambliss (1996:88). Chambliss argues that nursing ethics is the ethics of powerless people, of witnesses not decision-makers, of implementers not choosers, the ethics of those whose work goes unnoticed.

Nursing ethics is the ethics of most of us: not in charge; carrying out the commands of others, trying within imposed limits, to do the job.

Since the ethic that has been traditionally applied to nursing has focused more on the job of the physician, rather than on the work of the nurse, a number of important ethical issues have been disregarded. Chambliss (1996) offers three suggestions which may shift the bioethic debate to a more empirical and feminist oriented approach, focusing specifically on nurses and nursing. 1) Move ethical discussions from the hypothetical scenarios to real, practical settings. The social and psychological aspects of hospital life are just now beginning to be noticed. 2) Ethics should shift from a formal

individualism to a broader awareness of organizational contexts. Nursing issues reflect the hospital's organizational structure. Nurses' ethical issues and concerns are situated within life in an organization. 3) Empirical study should move from speaking only with those who are autonomous, to speaking with the nurses who work in the organization. The *real* problems, those experienced by the nurses in their daily work routines, can then be dealt with on a more practical level (Chambliss, 1996:6-7).

ETHICS AND PATIENT ADVOCACY

Since the 1970's, there has been much discussion in the nursing literature devoted to the view that nurses should be "patient advocates", whose primary responsibility it is to protect patient rights and interests in the health care setting (Winslow,1984; Pence & Cantrell,1990; Yeo,1991). Advocacy includes informing patients about their rights, providing facts about their health care situation, and supporting them in the decisions they make (Kohnke, 1982). This obligation to patients, it is argued, is an ideal. In actual practice, institutional and hierarchical constraints often prevent nurses from acting as patient advocates (Bernal,1995).

The central idea of patient advocacy is that the primary obligation of nurses is to patients, rather than to physicians or others within the hospital hierarchy. The patient advocacy literature presents symbolic images of nurses as individuals who identify ethical concerns, yet because of institutional constraints, must either set these concerns aside, or take unusually forceful action. Bernal (1995:183) has argued that this is problematic because if nurses set their moral concerns aside, they compromise personal

integrity and adequacy of patient care. If they take action, they may risk personal and professional harm. Bernal further argues that a solution to the nurses' dilemma may be to consider setting aside the idea that nurses are powerless within hospitals. It seems more productive to identify and extend currently available resources for action, rather than to seek an idealized version of autonomy that Bernal claimed does not exist for *anyone* working in a hospital. Those who espouse the concept of patient advocacy argue that nurses must achieve greater professional autonomy before patients' rights can be fully protected in hospitals (Baylis et al., 1995; Tong, 1995).

The work of the hospital nurse is clearly difficult. It is rooted in the structural organization of a hospital and within a hierarchy of authority in which physicians are dominant and in which hospital administration, regulatory agencies, business and scientific interests, and the general public all play key roles. Each player has differing conceptions of how the nurses' work should be done. These quite often interfere with what nurses themselves feel they need to do in order to meet the best interests of their patients. As a result, many nurses feel frustrated and devalued. As a group they tend to experience high levels of stress and professional burnout.

As this review of the nursing literature has shown there are many features of nurses' work that need to be appreciated if one wants to understand the work of any particular group of nurses. The organizational, interactional and ethical system within which nurses work and attempt to fulfill their professional mandate is critical to any analysis of nursing.

The next chapter tells the story of genetic termination.

CHAPTER 4

GENETIC TERMINATION FOR FETAL ANOMALY

This chapter focuses on genetic termination. In the first part of the chapter I describe the rise of prenatal testing and a major outcome of this technology; genetic termination. There are two parts to the chapter. In the first I discuss some of the broader social issues surrounding the emergence of this technology. These issues and the controversy that continues to exist around genetic terminations cannot be separated from nurses' experience doing this work. Though not often discussed openly on the wards in which the nurses work, the debates about the procedure loom large as a feature of their work.

In the second part of the chapter I lay out precisely what happens when a pregnancy is terminated for fetal anomaly. I start from the point where parents are faced with the news that there is trouble in the pregnancy and end with the patient's discharge from hospital. Essentially, I tell the story of genetic termination. To my knowledge this information has not been presented in quite this way before. While there is an abundance of technical information about the procedures, there is virtually nothing that describes in simple, descriptive terms for a lay person, who has no knowledge of the procedure, what precisely is entailed, and what happens to a couple when they discover they are dealing with a fetal anomaly. This background understanding is pivotal to my analysis of the GT nurses' experience of their work. The chapter is based on my past research with parents who have experienced genetic termination, interviews with GT nurses, and on information pamphlets written for GT patients.

THE RISE OF PRENATAL TECHNOLOGY

Before the 1960's, genetic counselling consisted almost exclusively of advising couples who already had a child with an abnormality about their chances of having another affected child. By calculating the odds from a pattern of occurrence over family generations, geneticists could offer a diagnosis. Until the 1960's, there was no way to tell before birth if a baby would be affected by a genetic abnormality.

However, as techniques became available for detecting problems with the fetus, prenatal testing for these problems began. At first prenatal testing was reserved for women deemed to be at high risk for fetal abnormality either because of a family history of hereditary disorder or because of maternal age. The use of prenatal tests is rapidly increasing, however, as more women seek, or are persuaded to undergo such screening. The increased use of prenatal testing is driven partly by the availability of the technology. It is driven as well as by the medical profession's desire to reduce the suffering and anxiety caused by the occurrence of genetic disorders and other conditions present at birth (Royal Commission Report on NRTs,1993: Volume 12). Prenatal technology is regarded by medical and scientific groups as breakthrough science.

It has been largely professional medical organizations and the research and scientific communities that have determined the direction that the practice of human genetics is taking. It bears repeating that nurses have played at best a minor role in this process, as has the public. Professional concern has focused on specific techniques and the implementation of services such as genetic termination. Research revolves around

large-scale studies meant to establish the safety and accuracy of the techniques, and to monitor the practice of the techniques.

More recently, however, a public debate about these technologies has arisen in Canada. The debates have been initiated by groups who represent women's interests, people with disabilities, and both pro-choice and pro-life movements. During the last fifteen years, these special interest groups have raised a variety of issues. These have included concerns over:

- (a) the morality of using abortion as a means of avoiding the birth of babies with congenital disorders (Royal Commission Report on NRTs, 1993:Volume 12).
- (b) whether programs to eliminate fetuses with certain disorders will adversely affect society's attitudes towards persons living with disabilities.
- (c) whether the increasingly routine use of PND and prenatal screening alters women's perceptions and experience of pregnancy.
- (d) whether, when an abnormality is diagnosed, women are subtly or overtly pressured into ending the pregnancy and that such pressure impinges on women's rights to make personal choices in pregnancy.
- (e) whether, as a result of the fact that genetic conditions vary in severity and that PND can not predict the degree to which a fetus will be affected, many near normal fetuses are being aborted
- (f) whether the notion that human disability as being costly to society should be considered justification for the use of prenatal testing.

Scholars as well are raising questions about prenatal technologies and genetic termination. Some have linked medical advances in prenatal technology to the routinization of prenatal, medical intervention. They have suggested that women may lose the freedom to choose not to use prenatal tests or the information these tests provide (Gregg, 1993; Clarke, 1994). Prenatal testing is often presented merely as an option for women who desire such testing. Research indicates however, that the fear of producing a child that would not be considered *normal* by society compels many parents to seek diagnostic information so that they can determine the health status of their unborn baby (Rothman, 1986; Kolker and Burke, 1994; Rudy, 1996). Rudy (1996:11) explains that prenatal diagnosis began with the goal of producing healthier babies but has progressed to a point where testing is considered a social obligation for many parents. He (1996:4) suggests that given the intolerant attitude within society towards physical and mental disability, many parents feel that they have no choice but to abort their less-than perfect fetuses.

I do not believe that Americans willingly and happily choose to abort fetuses that are diagnosed as disabled, abnormal or non-rational. Americans for the most part have compassionate attitudes towards children with disabilities. Rather, physically and mentally disabled fetuses are aborted at increasing rates because the contained and isolated nuclear family is often unable to organize the social and economic resources necessary to sustain this life.

Rothman (1986), Callahan (1995) and Clarke (1994) argued that a problem with technology is that society has come to believe that these tests are necessary. As a result of medical advances, society has become more aware of the risks of producing unhealthy

babies and has become more focused on these risks. The data does indeed show that the numbers of parents seeking prenatal testing, and the number of physicians routinely recommending it is increasing yearly (SATFA,1995). The age at which mothers begin to be considered as *high risk* has declined from 40 to 35 and that decline appears to be continuing (Rothman,1986).

Conrad (1997) has suggested that there is an interplay between professional and public conceptions of prenatal technology. Although professional definitions are just one source of information, often they are the only source and therefore shape the way the problem is framed. How problems are defined by professionals influences in profound ways how they are acted on by individuals in society. Rothman (1986:xii) insists that when making a decision as to whether to continue or terminate a pregnancy it is never enough to look at genetic and medical information. Parents must look also at what society offers in the way of services, support and institutions. The decision to continue or end a pregnancy is never just a medical one. It is always social.

What cannot be disputed is the impact that fetal anomaly and the GTs have on women who undergo them. Numerous studies have documented the effect. Most women describe GTs as 'the hardest thing I have ever done; a nightmare; saying hello and goodbye; and a double-edged sword' (Gregg,1993; Bryar,1997; Bishop,1996). GTs provoke the grief of bereavement for women and their partners (White-Van Mourik et al., 1994; Seller et al., 1993; Kolker and Burke, 1993). Many couples report that they felt pressured to undergo the procedure (Elder and Laurence,1991; Dallaire et al.,1995)

The impact of prenatal technologies extends beyond the couple however. Its effects are far reaching. Rothman (1986) suggests that it has consequences for women and their families who must consider it, but also for those health care workers who manage the technology and for the society that has developed it. This technology Rothman explains, encourages society to think differently about pregnancy as well as the ethics and value of human life. Scientific developments are introduced to the public mainly through the media in simplistic ways. The long-range social implications of the developments are not fully appreciated nor are they fully discussed (Rothman,1986; Basen et al.,1993; Kolker and Burke,1993; Nelkin and Lindee,1995; Hubbard and Wald,1997).

Consequently, as the conditions and behaviours that are believed to be genetically grounded grows, so too will the list of *abnormalities* for which fetuses can be tested. The social scientists cited above argue that there is a need to broaden the debate to include the many social, political and environmental implications of prenatal technology. An investigation of the effects that genetic terminations have on parents who experience it, and the nurses who manage it is a beginning.

HOW GENETIC TERMINATIONS ARE DONE

INFORMING PARENTS

After the conception of a child, genetic screening and prenatal testing can discern the existence of several hundred medically determined genetic disorders. If an abnormality is identified through testing, it is typically detected in the second trimester of pregnancy. Thus, most genetic terminations occur between the seventeenth and twenty-

fourth week of gestation. Parents' options are to continue the pregnancy or have a second trimester abortion, a procedure that requires an induced labour and delivery.

Presently, prenatal screening can reveal only problems or abnormalities for which limited treatment, and no cures exist. The available tests include ultrasonography and maternal serum alpha-fetoprotein (AFP) screening, which in the last decade have become routine tests in pregnancy (For a description of these tests, see Appendix C). Amniocentesis and chorionic villi sampling are commonly used for pregnancies that are considered to be high risk; either because there are hereditary disorders in the couple's history or because the mother is over 30 years of age.

Typically, pregnant women are informed about prenatal testing during early prenatal visits with a physician. Most physicians now recommend ultrasound screening as a routine prenatal test. Ultrasound is a useful tool for dating the pregnancy before sixteen weeks gestation and for detailed scanning between eighteen and twenty-one weeks to detect any major and some minor anomalies (Spallone and Steinberg,1987).

There is no standard protocol in the health care profession for deciding who should have testing and which prenatal tests to have. It is left to the discretion of the physician and to a lesser extent, the parents. Once a decision to consider prenatal testing has been made, mothers are referred to a hospital or clinic with a genetic center. They visit with a genetic counsellor who informs them of the procedure, explaining the risks and benefits. Genetic counsellors book the tests and also make appointments with the geneticist to discuss the test results. The results are also sent to the patients' physician.

Parents may be informed of an abnormal test result in a number of ways. The news may be given to mothers by telephone, at work or at home, with or without their partners present. The family physician, gynecologist or medical geneticist may inform parents during an arranged appointment. Regardless of how the news is presented, parents most often find themselves in a state of shock and disbelief (Swanson,1995; SATFA,1995).

There is a risk that initial test results may be inconclusive. Further testing would then be recommended by a physician to confirm suspected diagnoses. For instance, an abnormality first detected through ultrasound may be followed by an amniocentesis. Consequently, initial disclosure of test results is often followed by a delay in the decision-making process for parents. This waiting causes parents heightened anxiety yet also provides some time for parents to discuss options regarding the outcome of the pregnancy.

After a final medical diagnosis is made, genetic counsellors schedule one or two counselling sessions to review the findings with parents (Clarke,1994). These sessions generally include the medical geneticist, a genetic counsellor and perhaps a social worker involved with the hospital's prenatal diagnosis program. This is the time for parents to ask questions that will aid them in making the decision. Some of the commonly asked questions include: a) are you absolutely sure of the results? b) can this condition be cured after birth? c) can prenatal surgery be performed to correct the problem? d) what are the baby's chances of survival? e) will there be physical and/or mental handicaps? f) will the baby face multiple surgeries in her/his lifetime? g) what will my child's level of

functioning be? and h) what are the chances this could happen in a future pregnancy? (SATFA,1995).

Parents' responses to finding out their child has a fetal anomaly vary a great deal. Likely, they will experience a mixture of emotions including anger, fear, frustration, guilt and sadness at the loss of the normal baby parents expect, and sadness for the abnormal baby the mother is carrying. As a result of public debate, it has becoming more common for parents to consider the possibility of genetic abnormality even before they become pregnant. Many prospective parents consider the difficult choices they might have to make without knowing whether or not there is a problem.

Among those parents who do face the difficult decision, some decide immediately to end the pregnancy. A few decide immediately that they will continue the pregnancy. For most the decision is much less clear. In the midst of emotional upheaval, couples are forced to make a decision that they say is very different from any they have ever made before (Swanson,1995). This life-changing decision is also made under time constraints, generally between a few days and a few weeks because of the medical limit of 24 weeks gestation.

Factors in the parents' decision-making process generally include:

- 1) the prognosis: Some conditions are incompatible with life; other diagnoses such as Tay Sachs disease and spina bifida (see Appendix C) may not be lethal at birth, but may mean a shortened life expectancy and a physically painful life. Quality of life issues are also a major consideration. Conditions like Down syndrome or other

trisomies (occurrences of an extra chromosome) can be detected prenatally, yet the severity of the disorder cannot be known until after birth.

- 2) **past reproductive history:** Couples with a history of infertility may view the pregnancy as their only hope for parenthood.
- 3) **availability of financial resources:** Parents' generally take into account their current income level, projected future earnings, and medical benefits. They sometimes also feel they need to investigate government, community and social resources available to them.
- 4) **social impact:** Parents also consider the social impact of bringing a special needs child into the family when there are other children to consider. They know that a special needs child requires more time and emotional resources.
- 5) **their own emotional reactions:** Parents consider the impact of physical and emotional suffering of their child not only on the child but on themselves as well. They may not feel capable of watching their child in pain.
- 6) **religious beliefs:** Parents also consider their religious beliefs in this type of decision. Often parents keep much of the information about their decision-making private, finding it difficult to anticipate others' responses and not wanting to deal with a negative response at an already difficult time. Even after the decision has been made, many parents report that they spend agonizing hours vacillating about that decision. (Swanson,1995; SATFA,1995).

Once the decision has been made, hospitals try to admit the women as soon as possible, usually within two days, recognizing that the waiting time can be emotionally

draining for parents. If a bed is unavailable mothers wait for up to five days. Hospitals generally have one room reserved for GTs. GTs are usually managed on the short-stay surgical/ gynecological ward for pregnancies up to 20 weeks gestation or on the labour and delivery ward for 21 to 24 weeks gestation. Patients are told to expect a one to three day hospital stay since it is not possible to predict how long labour will take or whether medical complications will arise.

THE GENETIC TERMINATION PROCEDURE

Each woman responds differently both physically and emotionally to a genetic termination. There is also variability in routines between medical centers. However, a description of the general sequence of events and responses will help in understanding the termination procedure and the situation nurses face. Patients are generally admitted at approximately 9 a.m. After checking in at the hospital's admitting desk they proceed to the ward. There, parents meet the GT nurse who will be their primary care-giver. Over the last decade, many hospitals have changed their policy to allow for one-on-one nursing care. This is seen as necessary because of the emotional and physical demands of the procedure. When patients are scheduled for a genetic termination, an additional nurse is typically scheduled on the floor so that the GT nurse can be available to provide constant care.

Once settled in the hospital room, patients change into a hospital gown. Nurses then chart their medical history and have mothers sign a medical consent form. They also

provide information for women regarding pain medication, which is typically Demerol, morphine or, if they are on the labour and delivery ward, an epidural.

Nurses also assess the patients' knowledge of the procedure so they can be sure patients are fully informed. Nurses ask parents to think about their wishes for the baby after delivery. They will ask if parents want to see and hold the baby, and whether they want a burial or prefer to have the hospital take care of the baby's remains. Most often nurses are unaware of what information patients have been given prior to being admitted to the hospital because there is no standardized procedure in Canada for informing parents about genetic termination. In many cases, it is the GT nurse's responsibility to explain the physical and emotional aspects of the procedure to patients who are about to go through it.

LABOUR INDUCTION

Once nurses have recorded the necessary information, they take the patients' vital signs and begin an IV (a small catheter placed into a vein in the arm) so that the patient can receive fluids and medication. Patients are then taken to a treatment room on the ward where a doctor and another nurse will induce labour. In most cases mothers are supported by a partner or close friend throughout the procedure. GT nurses usually accompany the couple to the treatment room and stay with them during the induction to offer emotional support.

The most commonly used induction procedure is a prostaglandin induction. The drug prostaglandin can be administered in the form of a vaginal suppository or by

injection into the amniotic sac through the mothers' stomach muscle. Injection through the amniotic sac requires a procedure similar to amniocentesis where the needle is guided by ultrasound. The doctor and nurse who handle the induction will usually position the ultrasound screen so that only they, and not the parents, are able to see the image of the baby.

If prostaglandin suppositories are used, they are placed in the vagina every 3-4 hours until the time of delivery. There may be flu-like side effects associated with prostaglandin which can be minimized with medication (SATFA,1995). Prostaglandin initiates uterine contractions in order to bring on labour and delivery of the baby. Babies in utero will usually stop breathing during the labour process because they are not strong enough to tolerate the process at this gestational stage (SATFA,1995).

The second part of the induction procedure is the insertion of laminara (SATFA,1995). These are small, tapered sticks of seaweed that are placed into the woman's cervical opening to absorb moisture in the cervix, slowly expanding it in preparation for delivery. Often, more than one laminara at a time are placed to speed up the dilation. The laminara help to reduce the delivery time and also to decrease the incidence of cervical injuries. The body is not prepared at this stage of pregnancy for delivery and thus must be forced. There is often cramping and pain associated with the laminara placement. This too can usually be controlled with pain medication. The induction procedure can take from 20-30 minutes.

LABOUR AND DELIVERY

After the induction is complete, parents return to their hospital room. An IV containing oxytocin, is started on the woman. Oxytocin is a drug that prevents excessive bleeding. The termination procedure, from the time of induction to the delivery, can take 24 - 48 hours. To stimulate the onset of labour, nurses may suggest that mothers walk around the ward. But most patients feel uncomfortable leaving the room because they are not eager to explain their situation to others. Usually they decide to stay in the room for their entire stay.

After ensuring that patients are as comfortable as possible and that questions have been answered, the nurses will leave the room. This gives parents some time alone before labour begins. At the same time it gives nurses an opportunity to attend to the paperwork they need to do and to prepare for the clinical part of the delivery. This process includes preparing medications, setting up the cart and equipment for delivery and, in some cases, preparing an informational package to give to parents when they are discharged.

Over the last five years, it has become more common for mothers to have family members as well as their partner present at the genetic termination. Mothers, mothers-in-law, sisters and close friends may also be present. The GT nurse is responsible for tending to the emotional needs of not just the patient, but family members as well. This can include answering questions, keeping them calm and suggesting ways they can be supportive to parents. It is a time consuming task for nurses and can be difficult especially when the mothers' labour is progressing, the pain is increasing and the patient

requires the nurse's undivided attention. Nurses report that because it is difficult to watch a loved one in intense pain, family members often rely on nurses to reassure them and provide emotional support. Occasionally a geneticist or genetic counsellor will visit patients to see how they are progressing and to answer questions. However, this is not standard procedure and is left to the discretion of the geneticist or counsellor.

As labour progresses nurses spend more time in the room coaching patients in breathing and coaching partners in how to support mothers both emotionally and physically. Nurses may suggest holding the mother's hand or administering back rubs to her. As with any labour, every woman's experience is different. Some experience more pain than others and some labour longer. Induced labours are generally longer and more painful than non-induced labour as the body is not naturally ready for delivery (Clarke,1994).

Women generally labour through the night and deliver in early morning. If they have not delivered by morning, the laminara are usually extracted to check how far the cervix has dilated. Nurses may then contact the physician to order a pitocin drip that further induces labour. On the surgical-gynecological wards where most GTs take place, the nurses are not trained in labour and delivery procedures. Thus, they are not trained to start an epidural or do a vaginal examination to assess delivery time. This means that nurses must rely on their experience with GTs and on the mothers' feedback to determine their progress. Experienced nurses know that if there is an urgency to urinate, this can be a sign that delivery is close. In most cases, physicians are not present for the delivery. Nurses are left to manage the procedure on their own.

Once delivery begins, it happens quickly. The nurse guides the delivery of the baby, instructs the mother to push and assesses for any complications that may be arising such as a breach delivery, hemorrhaging, or the mother going into shock. Once the baby has been delivered, nurses cover the baby with a sterile pad, and cut and clamp the umbilical cord. They then immediately take the baby from the room. In most cases the baby is dead. In rare cases it is still breathing. Unless nurses are assisted by a colleague, parents are left alone at this time. In most hospitals the location designated for the handling of the babies' remains is the *dirty utility room*.

AFTER DELIVERY CARE

If parents choose to see their baby, nurses wash and dress the baby in a blanket and tiny hat. Nurses then return to the room to present the baby to parents. The nurses may stay with the parents for a short time to emotionally support them. How long they stay and how they handle the situation depends on the individual nurse, her comfort level and her personal style. As far as possible, nurses will honour parents' wishes. Parents are always given some private time with their baby. The amount of time varies greatly. Some parents spend twenty minutes while others may spend hours. In the latter case, it is necessary for the nurse to inform the parents that due to immaturity, the baby's appearance will begin to change within a few hours. The skin will darken to a bluish colour and begin to wrinkle.

Once parents have spent time with the baby, the body is returned to the *dirty utility room* and preserved in a container of saline solution for routine autopsy. Confirming the

abnormality is essential for future genetic counselling. The container is stored either on the counter or in the refrigerator of the *dirty utility room* until patients are discharged. This saves the nurse the task of retrieving the container from the morgue and once again preparing the baby in cases where the parents want to see their baby again. It is not uncommon for parents to ask to see the baby a second time during the day.

The nurse calls the doctor soon after delivery to let him/her know the termination is complete. However, notification of terminations completed in the middle of the night are left until morning. If there are complications the doctor or resident on call is paged immediately. At this time nurses also watch for the delivery of the placenta. If not expelled within 6 hours, the physician would then proceed with a dilation and curettage (D&C) (Appendix C) to surgically remove it. The nurses are responsible for informing patients about the need for this procedure and preparing them for surgery. In cases where a D&C is required, there is also usually a huge amount of paperwork that nurses must complete. After a D&C, patients stay in hospital another night for observation.

If the placenta expels itself, patients can be released after the doctor has examined them. However, it can often take several hours for doctors to arrive. During this time nurses try to keep patients comfortable, offering them a meal and spending time with them talking about the physical healing and emotional grief.

Parents have a number of choices as to how they would like the baby handled. There are no legal requirements to bury or cremate a stillborn baby before 24 weeks gestation. Hospitals have different policies concerning the handling of a baby's remains. If requested, the hospital chaplain will visit parents after the delivery to discuss their

plans. Some parents request that the chaplain baptize the baby in the room with the parents present. Others ask the GT nurse to accompany the chaplain to another room to bless the baby. If the parents decide on a burial, they will make the arrangements with a funeral home themselves. The chaplain or nurse will have the name of a funeral home that is familiar with these special circumstances. If parents want the hospital to keep the baby's remains, the body is handled as human waste. A few hospitals have burial plots where the babies can be buried. The hospital chaplain invites the parents to attend a group memorial service.

In certain religions and cultures, it is the parents' responsibility to take the baby with them when they leave the hospital for immediate burial. In these cases, the baby is swaddled in a blanket and carried out of the hospital by the parents either through the main or rear entrance. Some parents prefer to leave through the front door as a matter of dignity. Other parents prefer to leave discreetly through a back exit.

When they are discharged, parents are given a memento package, which includes photographs, footprints, fingerprints, weight, height, and perhaps a baby bonnet, and blanket. Photographs are usually placed in a sealed envelope as some parents are not ready to look at them. Most parents express gratitude for these mementos. Studies have shown that such packages help the parents through the grieving process (Gregg,1993; Ilse,1993; SATFA, 1995; Swanson,1995).

PATIENT SUPPORT

Once patients have been discharged, nurses generally have no further contact with them. For many nurses this is unfortunate. They would like to know how patients are managing. In some cases however, mothers have sent thank-you cards and some have even visited after a successful pregnancy to show off their new babies. It is routine for patients to visit their physician for a six-week check-up as would be the case for any labour and delivery. The genetic counsellor or the clinical nurse specialist will also telephone patients a few weeks later to follow-up and see how they are coping and if they have any questions or concerns. When autopsy results are available, typically within two months, geneticists meet with parents to discuss the results and their future family plans.

A few hospitals offer a support group for parents. Groups are generally organized as a drop-in, once a week and are facilitated by a hospital social worker. In September 1998, a chapter of Bereaved Families of Ontario created a self-help support group for parents who have experienced a genetic termination. This group, the first of its kind, is facilitated by parents who have also terminated a pregnancy for genetic anomaly.

Through the support groups, parents are introduced to the little literature that exists about understanding and coping with pregnancy termination due to fetal anomaly. There is a monthly newsletter published in the United States, entitled *A Heartbreaking Choice* (Pineapple Press) which focuses on pregnancy termination. There are also a few books that parents may be referred to. These include; *A Handbook for parents when an abnormality is diagnosed in their baby: Support after termination for abnormality,*

published by SATFA; and *A time to decide, a time to heal: For parents making difficult decisions about babies they love*, published by Pineapple Press.

CHAPTER 5

GTS AS DIRTY WORK: THE INSTITUTIONAL CONTEXT OF GTS

INTRODUCTION

This chapter focuses on the problems that GT nurses experience in doing their work. There are specific features of this work that make GT nursing different from all other types of nursing. Dealing with women who are terminating wanted pregnancies because of fetal anomalies is, under the best of circumstances, difficult and emotionally charged work. Instead of acknowledging this and providing nurses with an environment that supports and assists them in their task, however, hospitals have organized the process of performing GTs in a way that suggests they attach a low priority to them. Further, a troublesome moral ambivalence about GTs is reflected in this organizational processing. As a result, nurses face a working situation that is fraught with uncertainties, tension, dilemmas and frustrations. They experience their work as *dirty work*, work that others would prefer not to do or even to know about. In fact, it is not uncommon for nurses to use that very term to describe various features of their work. In this chapter I discuss those features and describe the precise ways in which the nurses experience their work as *dirty work*. The discussion is organized around the following six themes: 1) GTs as a surgical/gynecological procedure, 2) the lack of professional back-up, 3) the lack of adequate procedures, protocols and policies, 4) the lack of specialized training, 5) the lack of choice and 6) the lack of support.

GTS ON SURGICAL/GYNECOLOGICAL WARDS

At the root of many of the nurses' most pressing complaints about their work are the issues of where, how and by whom GTs are done. As a result of organizational restructuring in most hospitals, the GT procedure was relocated from the labour and delivery (L and D) ward to the surgical/gynecological ward. The rationale behind this decision in most cases was that while surgical/gynecological wards are generally busier than L and D wards, they are also more stable and have a greater degree of predictability to their schedules and routines. Surgical/gynecological wards, therefore, were seen as better able to accommodate the demands of the GT procedure, especially the constancy of care required. Nurses in the surgical/gynecological ward were seen as being better positioned to provide the continuous one-on-one care that GT patients need.

There were concerns as well for the GT patients and the emotional impact of undergoing the procedure on an L and D ward where they would be in close proximity to women giving birth to healthy children. Hospital administrators felt that by keeping GT patients separated from other delivering women, they would be sparing these patients unnecessary distress.

Since the mid-1990's, some hospitals, including the four that were studied in this research, have modified their procedures so that more advanced pregnancies - those beyond 20 weeks gestation - may be handled on the L and D ward. Technically, patients may be admitted directly on to the L and D ward. Alternatively, patients may start in the room typically designated for GTs on the surgical/gynecological ward, and may then be transferred to L and D if the nurse feels that the situation warrants the move. In practice,

in the four hospitals I studied, most patients were admitted to and stayed on the surgical/gynecological ward until their discharge. This was true even for the late stage pregnancies. It is taken for granted in the four hospitals that "GTs happen" in the room specially designated for them. Both doctors and the admitting offices of the hospitals tend to direct most GT patients to the surgical/gynecological ward.

From the perspective of the GT nurses, there are a number of problems connected to managing GTs on surgical/gynecological wards. First, they complain that they were not consulted about the hospital's initial decision. GTs were added to the responsibilities of nurses on the surgical/gynecological ward with little regard for how they felt about their new duties or their preparedness to take on the new task. I discuss later how the lack of choice is experienced at the individual level by nurses working on these wards. Here I am concerned with how surgical/gynecological nurses reacted collectively to the expansion of their duties. Maryanne, a clinical nurse specialist, complained about the unilateral way in which the hospital administration introduced and implemented GTs, arguing:

These nurses need to be consulted, not dictated to. They feel like victims. They have no voice. Generally nurses are not politically active.

The decision rankles because of the hospitals' blatant disregard for the views of those who were expected to be working most directly with GT patients. It rankles as well because the nurses feel that they were not allowed to provide any input into the decision-making process, input based on their knowledge and experience. From the nurses' point

of view, both their moral views about a controversial and ethically sensitive procedure, and their expertise as nurses were ignored in the process.

More significantly, many GT nurses question whether, as surgical/gynecological nurses, they have the skills and expertise it takes to guide women safely through a termination procedure that involves labour and delivery. As I explained in Chapter 4, the most common method used for terminating pregnancies is a labour induction method. Women are artificially induced and give birth to babies who usually, though not always, die as a result of the trauma of birth. There are two other methods, which may be used, both requiring surgery and both unpopular among hospital administrators and the doctors who would be required to perform the procedures. The first, known as dilation and evacuation (D and E) starts, as does the labour induction method, with the insertion of laminara tents into the cervical opening to dilate the cervix. Rather than waiting for birth to occur, however, the products of conception are removed with gynecological forceps. The technique is faster and less painful for the patient. Since the procedure is carried out by a doctor, it also means a less central role for the nurse.

Studies have shown that patients fare better both physically and emotionally after a D and E, in comparison to a labour and induction procedure (Callahan,1995:275; Kaltreider et al.,1979). But there are risks. D and Es work well only when the fetus can be removed intact. When fetal tissue becomes separated during the procedure, the consequences for the patient may be serious. One of the more common complications of this type of termination is septicemia, an infection that can occur due to retention of fetal tissue in the patient's body.

Though doctors typically point to this risk when explaining why they tend to shy away from D and Es as a termination technique, there is literature to suggest that there may be other reasons. Callahan (1995) found that many doctors view D and E's as repugnant because the fetus is often crushed during the removal. This is consistent with how the nurses in this study understand doctors' reluctance to use the D and E technique. GT nurses believe that D and Es transfer at least some of the emotional burden for overseeing terminations from patients and nurses to doctors. Most doctors, as they see it, are not prepared to carry that burden. Nurses also point out that beyond the 15th week of pregnancy, experiencing labour is as risky for patients as undergoing a D and E. The preference for labour then, the nurses reason, has little to do with the safety of the patient and more to do with the convenience and lack of compassion and/or fortitude of doctors. For hospital administrators, the fact that doctors are not as involved, also means that there are cost benefits to be realized.

The second method of surgical intervention is a Cesarean section, which involves an incision across the abdomen and external removal of the fetus. The reasons given by hospitals and doctors for not performing Cesarean sections in cases of GTs is that, as major surgery, the procedure entails too many unnecessary health risks for patients and involves a prolonged period of recuperation afterwards. For the nurses however, this argument fails to consider the pain involved in delivering a stillborn child. They point out that the decision as to which pain is easier to endure should reside ultimately with the patient. It is not a decision that doctors nor hospitals should be making on women's behalf.

The decision to avoid Cesarean sections is understood by the nurses, again, as more of a question of cost. Surgery requires the time and resources of an entire surgical team - doctors, nurses and anesthesiologists. Labour induction is far more cost effective. At a time when hospital administrators are constantly on the lookout for ways to cut back on costs, labour inductions are seen as more attractive. There is little regard on the part of both administrators and doctors for what is actually best for the patient.

From the nurses' perspective, both of the alternative methods are seen as preferable to labour induction because they minimize the degree of pain that patients must suffer. The nurses understand that for many of the patients, the pain is not purely physical, and that it becomes confounded with the emotional pain and guilt that the patients are experiencing. Some patients believe that they deserve to suffer as a punishment for their decision to end their pregnancies. The concern for GT nurses is to get the patients through the procedure as quickly and as painlessly as possible so that the healing process can begin. They have difficulty accepting that patients are being forced to endure the added pain of labour when other, less painful techniques for termination are available.

As Amy stated:

These women are going through enough. They shouldn't have to go through so much physical pain too.

Moreover, unlike L and D nurses, surgical/gynecological nurses are simply not trained to guide women through the birthing process. They generally do not know how to do pelvic examinations as a way of assessing how the birth is progressing, nor are they allowed to do them on this ward. They do not understand the stages of delivery in the

same way that L and D nurses do. With the benefit of more experience in labour and delivery, they feel they would be in a better position to monitor the situation and safeguard the physical well-being of their patients. The nurses also feel that they would be in a better position to reassure and guide their patients through the experience, giving them an idea of the progression of the birth and some sense for when the process might be coming to an end. As Donna, a nurse at Eastern Hospital explained:

We are expected to treat this like we would any other surgical procedure and it's not. We are not labour and delivery nurses, we are surgical nurses. We are fortunate that we have had a few midwives join our team... We can't physically examine them as they do in L and D, so we can't give them a progress report. We also don't know ourselves when delivery will happen.

Nor are nurses in the surgical/gynecological ward able to give spinal epidurals - a technique available to nurses on the L and D ward to control labour pain. An epidural procedure involves the placement of a needle inserted into the epidural space outside the spine so that local anesthetic may be injected. Only L and D nurses are allowed to perform the procedure. The only thing that GT nurses can do to offer relief for birthing women is to administer oral analgesics - pain controlling medication such as Demerol or morphine. The problem with analgesics is that first, while they may offer partial relief, they also make the patient groggy and inhibit her ability to participate in the process, thereby prolonging labour. Epidurals allow mothers to be more alert during the delivery, making it easier to push the baby out. With analgesics, patients labour longer and while their physical pain may be slightly diminished, their emotional pain is prolonged. The

frustration and sense of powerlessness this creates for GT nurses is captured by Sarah who stated:

Analgesics can often slow things down. The waiting is an issue. All you can tell patients is 'yes, it will happen, but I don't know when'.

Another problem with analgesics as a method of pain control is that they require a doctor's order and doctors are often not available to provide those orders in a timely fashion. Connie explains:

Nurses feel it is their responsibility to help and care for the patient. But they are unable to take the pain away. It is uncomfortable to watch patients suffering and you can't give them pain relief. If the doctor is called to ask for a(nother) prescription they often can't come right away.

At a time, then, when nurses feel they should be attending to the emotional needs of their patients, they find themselves preoccupied with simply getting themselves safely through a procedure they have little training for. Many are unsure of themselves and worry that their inexperience or lack of knowledge will compromise both the patient's physical and emotional health.

Some GT nurses are also skeptical about the argument that it is better emotionally for women to undergo GTs in surgical/gynecological wards because they need not witness other women giving birth to healthy babies. They wonder whether by shielding women from other delivering mothers, they are diminishing the patient's experience of the birth as a *real* birth. They wonder if they are depriving their patients of the kinds of contact with other women and their babies that, though painful, can also be healing. Who

better to comfort and console a woman who has lost her baby than someone who has just given birth and appreciates the magnitude of the loss? How better to communicate to patients the hopeful possibilities of new life than through the presence of a newborn?

Not all GT nurses are of the same mind on this question. Debates among the nurses about the advantages and disadvantages of each ward in relation to the emotional health of GT patients are common. As the following quotation from Elaine makes clear, not all nurses have completely resolved the issue for themselves.

I'm of two schools of thought. Do we shield them from all babies or do we recognize the loss and hope that women (on the L and D ward) would be more empathetic because they can appreciate their loss? I can appreciate that it would be difficult to hear other babies crying. Maybe other babies would help the healing begin.

The nurses strongly feel that the question is an important one to ask and that decisions about where the procedure will be provided ought to be made on the basis of what is best for the patient, rather than what best suits the interests of the hospital and those who work in it.

For all these reasons it is not uncommon for GT nurses to at least try to transfer their patients to the L and D ward for the actual birth. But these attempts at transfers are often resisted by L and D nurses, even when they involve patients who are beyond 21 weeks gestation. There is always a good reason. "The L and D ward is too full". "The L and D nurses are too busy". "They would not be able to devote the time required to the patient". "It is not a good day". "The patient would be better off on the surgical/gynecological ward". But the pattern is such that the nurses on the

surgical/gynecological ward are often left with the feeling that the L and D nurses simply do not want GT patients.

Exacerbating the whole situation is the lack of information that patients often have when they enter the hospital. It is not uncommon for women to arrive at the hospital ill-informed and unprepared for what is about to happen to them. When a fetal anomaly is detected, the focus in most discussions with patients and their families is on *whether* to terminate the pregnancy, not on the particulars of *how* it will be done. Additionally, there is the time constraint to be considered. Once the patient makes the decision to end her pregnancy, things move quickly. As noted earlier, admissions are usually arranged within two to three days. There is not much time for discussion. Time, however, is not the only constraint. Many GT nurses believe that doctors and counsellors prefer to avoid the difficult and unpleasant discussions that would be involved in explaining in a detailed way what the GT procedure entails. It is a task, they believe, that other health care workers prefer to leave to the GT nurses. Audrey explained:

Patient's expectations are high. They expect to be on the maternity ward and have an epidural. Most of the time they are not.

On the other hand, some patients come into hospital not realizing that they will actually have to give birth to their babies. Those that do may not understand fully why they need to experience the trauma of a birthing process when they are there to end their pregnancy, and why other termination techniques cannot be used. GT nurses who themselves have difficulty understanding the rationale for using a labour and delivery method, are left to try to persuade distressed mothers that this is the "best thing for them".

In the absence of information about what will happen to them once they enter the hospital, patients sometimes develop their own mental picture of how the process will unfold. Even if they know that they will be giving birth to their babies, they are often surprised to discover that they will not be doing so with other women on the L and D ward, but in the surgical/gynecological ward. They may also be surprised to discover that the birth will be overseen by a nurse, rather than a doctor (an issue I address in the next section). As Alice's experience with patients shows:

When patients are told (by the nurses) that they will be staying in the room to deliver and not going to L&D some are alarmed. Also, when they realize that there won't be a Doc present.

As a result, patients may become upset, distracted and even more emotional than might otherwise be the case, complicating for the GT nurses a job that is already highly complicated. In these cases, the GT nurses find themselves both having to break the news and being left to pick up the emotional pieces.

LACK OF PROFESSIONAL BACK-UP

As the previous section suggests, a major source of frustration for GT nurses is that they are left to manage the terminations more or less on their own. The normal division of labour that characterizes the patient care function in hospitals tends to disappear in GT cases. There is little back-up from doctors, genetic counsellors, social workers, chaplains and even other nurses who could conceivably be playing a more significant role in assisting patients through the difficult experience. As a group, these professionals rarely show any initiative in involving themselves in GT cases, needing to be called in by GT

nurses in instances where the nurses feel their assistance is really needed. Even when called, many of these other workers will either refuse to come or do so reluctantly, minimally or not in time to do any real good. One nurse, Carrie, described a procedural strategy used by the genetics department in her hospital to resist involvement in GT cases:

The genetics department won't come to see the patient if they have not counselled her before the genetic termination. Sometimes a patient will just arrive on the ward having come directly from her doctor's office. In this case the nurses must do everything.

Renee's complaint suggests that when other professionals do involve themselves, they do so in quick and sporadic ways and in a manner that reflects their eagerness to leave.

It's a difficult day. We're the ones in there all day long. The geneticist may give the most eloquent, profound speech that they (the patients) only hear a third of and you are left to pick up the pieces again. They are not here all the time.

Melanie complained about the lack of support on the part of the hospital's bereavement team. Her comments also suggest that GT nurses have learned they cannot count on the support and back-up of others. They will make requests for consultations only in the most extreme cases, but often without any real expectation that they will get the assistance they need.

We used to have a bereavement team, the Chaplain and the CNS (clinical nurse specialist). someone was always on call. now, I will assess the patient and if I feel she needs him, I will call the Chaplain.

The difference that the professional back-up of their colleagues could potentially make to GT nurses as they struggle to do their jobs is illustrated in the few examples of experiences GT nurses had where their colleagues were in fact supportive. Fran talked about her experiences with a particular geneticist at her hospital:

One woman, a female doc is so excellent. She helped me through an incident. The baby was very abnormal. She showed me how to wrap the baby so the baby's normal features were showing. I took her aside and said this is what I've said to the couple. I don't know if its appropriate or not. She was so reassuring. She explained how its important to see the baby for closure and to say to the patient 'it often helps - maybe not today, but weeks down the road when you are struggling you will know that you made the right decision'.

Renee as well had had a positive relationship with a hospital geneticist:

The geneticist is really helpful. She will tell us what she sees when she is examining the baby, which she comes and does shortly after the delivery. She'll say 'see this, it's...' and you don't feel stupid asking questions... I want to know what the anomaly is so I am prepared for the patient.

As both these experiences illustrate, professional back-up serves more than one function. On the one hand, it relieves nurses of the pressure to handle everything on their own and provides them with the technical assistance they may need. On the other hand, it serves an important educational function. Nurses can be learning from their colleagues how best to manage particular situations and how best to provide their patients with the care they need. In the absence of that back-up, nurses are left scrambling to figure things out on their own.

GT nurses are particularly incensed by the almost complete absence of doctors at GTs. As they see it, the technical aspects of performing a genetic termination fall properly under the purview of medicine and should therefore be performed by doctors. They, as nurses, should be assisting doctors through the procedure. This would leave them free to perform what they see as their primary function - attending to the emotional needs of their patients. As Melanie put it: "We are not doctors. We are nurses. We should not be expected to do a doctor's job".

Like other professionals in the hospital, however, doctors involve themselves grudgingly and minimally. They typically oversee the induction procedure. But they are generally not present during labour and delivery. Nor do they participate in the aftercare of the patient, including the cutting of the umbilical cord, the delivery of the placenta or the critical assessment for complications, such as hemorrhaging or the patient going into shock. The release of the patient technically requires a final examination by a doctor. But doctors may or may not show up when called by nurses to authorize the release.

The nurses' understanding of this recalcitrance is that it reflects the moral and sometimes religious objections that doctors have to the termination of genetically compromised fetuses. The nurses resent that, while doctors can act on their moral impulses in these situations, nurses cannot. The nurses also recognize that, apart from any moral questions doctors may have about the procedure, it is a difficult and uncomfortable situation that doctors are simply not prepared to deal with. Most are looking for ways to make a quick getaway. The nurses resent this because it means they are left to muddle through as best they can, making tricky clinical decisions they were

never trained to make. Further, they feel this behaviour has a negative emotional impact on their patients. Jeanette highlights the need for more physician involvement for the benefit of both nurses and patient:

If a doc comes for a delivery he or she only delivers the baby and placenta then leaves right away, often not even talking to the patient! We need the docs involved. We need to see them more often, talking with patients, not at them. And the docs need to support the nurses more - we are not doctors.

Mary provided an account of a specific incident where a patient, eager to leave the hospital after the termination, was left waiting by a doctor who simply “forgot” about her:

One patient after delivery wanted to get out! She wanted to leave so badly by morning. I called the doctor finally by 11a.m. The doctor said ‘Oh yeah, has she started labour yet?’ I said she delivered, she’s dressed and wants to go home. She’s waiting for you! You know there are both sides of the spectrum here. Usually the doctor comes in first thing in the morning but this particular doctor had a cesarean that morning and she forgot about this patient!

Similarly, Corey described doctors’ attitudes towards GT patients as fundamentally disrespectful and reveals the extent to which nurses are prepared to go, including violating standard hospital procedures, to meet their patient’s needs:

Some docs are disrespectful. When you call they don’t come. The time and emotional energy needed to wait for the doc is difficult. You phone the doc, they say ‘I want to see her before she goes’, I ask ‘When will you come’ they say ‘I’ll be there when I get there’. Well, I can’t make her stay, this isn’t a happy place for her right now. Sometimes I will take the heat from the doctor, but the patient will go.

The degree of physician disinterest in GTs has resulted in an ironic situation where GT nurses now generally know more about what is involved in performing the procedure than most doctors. The following series of quotes speak to the fact that when doctors do involve themselves, though they project an image of being “in charge”, most need to be guided carefully through the process by the nurses. The quotes conjure up an image reminiscent of the doctor-nurse game first described in the literature by Stein (1967) where nurses are in fact educating and directing doctors, but in a way that does not challenge the physician’s authority or destroy the illusion that the nurses are simply following the doctor’s lead. Daria commented:

Docs expect us to know what to do. They breeze in for five minutes and they think they know everything. The doctors aren’t a part of it. The nurses feel that docs don’t have an interest in what they are doing. The doctors need to be educated and they need to be more sympathetic to the patients as well.

Lina added:

Sometimes we have to insist that the resident come and help, especially if there is an emergency. They are not trained to do GTs or abortions for that matter. They often ask us what they should do.

Fran agreed when she pointed out:

Many residents have not had any exposure to GTs and the nurses have to walk them through it. They need more education and exposure. Also, they haven’t been there for the delivery or seen what you’ve done with the patient for the last six hours. They could use more sensitivity training to nurses and patients. L and D is their priority. ‘What’s the routine’ they ask the nurses!

While they are eager for more physician involvement, nurses feel strongly that this involvement will only be beneficial if it is accompanied by a major change in attitude, much greater sensitivity to the physical and emotional needs of these patients and more rigorous training on the part of doctors.

LACK OF PROCEDURES, PROTOCOLS AND POLICIES

In addition to the issues discussed above, there are a series of other problems that GT nurses face in their work. Among these is the lack of clear standards and protocols for both nurses and non-nurses to follow in managing GT cases. In an institution notorious for its bureaucracy and rigid adherence to standard procedure, there is remarkably little standardization and guidance in how to do GTs. Particularly in the early years when GTs were first introduced into the hospitals, the nurses feel that little attention was paid to figuring out how best to integrate the procedure into the routine on the ward and to clarifying the role of various health care professionals. The sense among many of the nurses is that GTs were simply “dumped” into the surgical/gynecological ward.

Patients sometimes simply arrived on the ward. Nurses were not given any advance notice that they were coming. Nurses often had no idea of what unique clinical or personal circumstances they would be confronting. They did not know for example how much information the patient had been given about the procedure, unique features such as which fetal anomaly the baby had been diagnosed with, and perhaps unique cultural traditions the patient followed. Without this knowledge, the nurses had no time to

prepare either clinically or emotionally for the patient's arrival. Sharon, who has worked as a GT nurse since the inception of GTs at her hospital, recalls:

Years ago, the patient's history, the orders and consent were not given before the patient arrived. The patient would just show up!

Nurses soon discovered that the routines that worked for other patients were completely unworkable for GT patients. For example, it quickly became clear that while other cases could be managed collectively by the nursing team on duty, GT patients needed one-to-one nursing. This allows nurses to come to know the patient and allows for the kind of rapport needed to effectively manage the case. Nurses also quickly realized that patients experiencing a GT could not be part of the nurses' daily routine where nurses would administer clinical care or medications to their surgical patients at specific times during the day. GT patients require constant care on demand.

Eventually the nurses re-structured the organization of tasks on their ward to allow for one-to-one nursing. Until that point, however, they struggled with great difficulty to accommodate GTs into their work routines. For example, the nurses explained how complicated their daily routine became when they had a GT patient who needed their immediate attention while at the same time they were tending to another patient who they could not just leave. This meant that often a different nurse would be caring for the GT patient each time she called. This was difficult for both nurses and patients as they did not have enough time together to establish a relationship. Another common problem the nurses expressed was the experience of the emotional extremes of going back and forth between caring for patients who were either in a positive state of mind or critically ill,

then to a GT patient who was emotionally distressed. The outcome of this disorganization was that, in most cases, nurses felt that they had little control over the procedure or the outcome for the patient. Mary's comments are revealing:

It was a surgical floor. Other patients were screaming and dying, it was very awkward. Genetic terminations just became part of the patient population. There was no thought for the nurses.

Another issue that arose was the confusion that nurses experienced about what role they were expected to play in the procedure. Before it became apparent to them that they were essentially expected to "carry the GT ball", the nurses struggled to figure out where to draw the lines for their part in the process. In particular, they worried about their clinical involvement. Who was responsible for presenting patients with the procedural and clinical information? Who was responsible for making decisions about the administration of drugs? What were the expectations with respect to who handled various aspects of the birth? Who was to handle the baby's aftercare? Their dilemmas in this regard were exacerbated by the fact that again, as surgical/gynecological nurses, they did not feel equipped to take on the kinds of clinical responsibilities associated with doing GTs.

A particularly revealing and heart-wrenching example of the degree to which nurses are left on their own to muddle through situations that could be expected to arise in connection to GTs concerns the birth of a live baby. As previously mentioned, in most cases babies at this early stage of gestation cannot withstand the trauma of birth and are stillborn. It is not uncommon, however, for some babies to survive the birth.

Approximately half of the nurses in this study experienced this situation at least once over the course of their careers. Melanie remembers her first experience this way:

The first time I had a baby born alive I didn't realize it at first. You could see the baby take breaths when I was in the treatment room. I hoped that the mother didn't see it.

Babies born live cannot survive long. They may continue to breathe between five and twenty minutes after birth. Their birth creates a host of difficulties, not the least of which is how to care for the baby. Another nurse recalled her first experience with such a birth. Completely unprepared for it, she panicked and called the doctor with a plea for guidance. As much at a loss as she was, the doctor simply replied: "just drop it into the saline solution". While it is easy to focus here on the insensitivity of the doctor's response, the more telling point is how little thought had been given by the hospital to developing standard care programs that anticipated this situation and assisted staff - nurses and doctors - in dealing with it.

The birth of a live baby also raises questions about how to handle patients. Should nurses let parents know that their child is breathing? If so, when should nurses inform the parents? In such circumstances should they give the baby to the parents right away before the baby stops breathing? At a time when nurses may be expected to be dealing with their own emotional reaction to the situation, there is little to guide them, except their instincts, through these difficult decisions.

Even in terms of the physical set-up of the ward for GTs, little regard seems to have been given to the space that nurses need to do this work. There is one patient room on the surgical/gynecological ward in which GTs are done. In most cases, the room is

located in an “out-of-the-way” section of the ward, ostensibly for reasons of security and to offer both patient and nurse some degree of privacy. While labour and the birth itself take place in that room, the aftercare - the bathing, wrapping and preparation of the baby for viewing by the parents and after they have viewed it, the preparation of the baby’s remains for testing, release or disposal - all need to be done elsewhere. In each hospital this work is done in the ward’s *dirty utility room*. The room is a small, multi-purpose space containing a large utility basin, a refrigerator and cupboards for medical supplies and cleaning supplies such as mops, brooms and pails. It is often used by the other nurses on the ward for “messy clean-ups”.

For a variety of reasons, the GT nurses find these arrangements completely unsatisfactory. From a purely practical point of view, it is not a suitable space for the washing, wrapping and bundling of the baby they need to do. There is no clear work area for them to use as the room was not set up for the purposes for which they must use it. Nor are the nurses provided with the supplies they need. For example, the nurses do not have a baby bassinet, baby bath or soap to properly wash the baby. As well, they are not supplied with baby blankets and bonnets to dress the babies for presentation to parents.

Also of serious concern to GT nurses is the lack of suitable containers necessary for safe keeping as well as safe transport of the body to the morgue. There is no “standard” container used for this task. Either the morgue sends up containers, usually whatever is handy or the nurses themselves must scramble to find something on the ward that they can use. A number of different shapes and sizes of containers have been used. The nurses have complaints about all of them. Sarah explains the difficulty she

encounters in having to place the body into a bucket or jar of saline solution. "I cringe when putting the baby in the saline bucket." Not only is this an emotionally distressing task for the nurses, there is a moral implication that arises as to the humanity of the act.

As Daria explains:

The fetal container is a peanut butter jar. Where is the dignity? Because of the shape of the container you have to drop the fetus in - it's like a plop!

As if this task was not difficult enough, the nurses also recount "accidents" that commonly occur as they are transporting the body to the morgue. Donna describes the ongoing problem this way:

Oh, the peanut butter jar! The problem is we used to have a 24 hour urine bottle that was great. Then they changed it to this small neck jar that was useless. Then we got this plastic tupperware jar... a spill waiting to happen. I had one that flooded the elevator. I had it double bagged, I was walking it down to pathology myself. It (the jar) was wrapped in two green garbage bags and wrapped in a blue pad. I was walking on egg shells and it still flooded pathology.

Jean explains her experience:

I was walking to the elevator to go to the morgue. In front of the nursing station I dropped the container which was in a green plastic bag. It shattered all over the floor. Thank goodness it was late at night so there weren't a lot of patients and visitors around. All of us just rushed around to clean it up.

Even more disturbing for the nurses however, is the symbolism of the *dirty utility room* and the message it sends about how the hospitals regard GTs. Even though patients

never see where the work of dealing with their babies' remains is done - making the room in a sense one of the hospital's "backrooms", - they nevertheless feel that the arrangements show a fundamental lack of concern if not disrespect both for the fetus and for them.

Nurses have done what they can about the lack of standardized procedures for dealing with GTs, and as I discuss in Chapter 7, have constructed a routine for themselves that at least begins to fill the void and get the job done. Yet, problems connected to the lack of policies and standard care programs remain. One problem continues to be the lines of authority between nurses and doctors. As the nurses have come to better appreciate the demands of their GT work and the needs of their patients, they have acquired a certain confidence in their decision-making capabilities. In many cases they feel that they know best what their patients need. For the most part, the nurses' isolation means they can act on their best instincts.

But occasions do arise when disagreements emerge between nurses and doctors over how work should be done and how certain cases should be managed. A disturbing example of this described earlier by Lorraine dealt with her first delivery of a live born baby:

I was shocked! I didn't know what to do so I called doctor and asked him what to do. He simply said 'drop it in the saline solution'. There was no way I was going to do that. These babies are human beings that deserve to be treated with dignity and caring.

In cases such as this nurses find themselves in a position where they must decide whether they are going to follow orders or exercise their own professional judgment and

do what is best for the patient. What Lorraine did was to wash and dress the baby, wrap him in a blanket and carry him around with her until he stopped breathing. She then took him to his parents. This example illustrates how the nurses' definition of the situation often differs from that of the doctors' and the institution. The absence of a doctor in this situation allowed this nurse to exercise free agency.

Another problem that remains for nurses has to do with how little information comes with the patient's file when she is admitted to hospital. In particular, nurses are still in the dark about just how much their patient knows about what will be happening to her. They do not know how much information has been provided to the patient, by whom it was presented, the patient's level of understanding of the procedure or the patient's reaction to the situation. They do not know whether explaining the procedure to the patient and/or dealing with an exceptionally distraught patient will be a major or minor part of their job. Simply put, they never quite know what to expect and this creates an uncertainty that complicates their task. In rare instances, notes written by the doctor will be attached to the clinical file that arrives with the patient. These notes may just state that the procedure has been explained to the patient. But the information is usually limited and not particularly helpful to the nurses.

A related problem has to do with the meager resources that nurses are given. If it is left to nurses to educate patients about the procedure - and it usually is - the nurses feel that it would be helpful to have pamphlets and other written materials that they can give to patients. Even in cases where the patient has had the opportunity to go through several counselling sessions, the nurses recognize that there is a lot of verbal information to

process at a time when the patient is usually in a state of shock and disbelief. Patients need time to absorb the news, but they also need materials that answer the many questions they have.

The nurses also feel that it would be useful to have bereavement information on hand for patients. The hospitals provide booklets and pamphlets written for families who have experienced a miscarriage. But the nurses point out that these pamphlets are of limited use to their patients because the circumstances of the loss are so different.

The need for progress in developing clearer protocols and policies for handling GTs is recognized not only by the nurses but by their nursing directors as well. In each of the four hospitals studied, the nursing directors have taken on the task of advocating beyond the surgical/gynecological ward for changes that will facilitate the work of the nurses.

One nursing director put it this way:

It is very important for all involved hospital personnel including RNs, RNAs, business clerks and environmental staff to be prepared to work with these patients.

In recognizing the importance that all employees involved with GT patients be aware of the situation, this nursing director advocates training to prepare the staff members to work with GT patients.

LACK OF SPECIALIZED TRAINING FOR GTS

Closely related to the lack of clear procedures, protocols and policies is the issue of the lack of specialized training to do GTs. Whether they like it or not, nurses recognize that they carry the burden of caring for GT patients and that they do so largely on their

own, without the back-up of their professional colleagues and with little in the way of protocols to guide them. They accept the enormous responsibility of looking after GT patients and look for ways to equip themselves to do so effectively. Most are inclined to at least try to make the best of a less than ideal working situation. But in doing so, the nurses would like to be given the opportunity to learn and develop the special skills they need to perform the tasks asked of them. These include not only labour and delivery skills, but also a broad range of skills specific to the needs of GT patients. The nurses would like better training in how to counsel and comfort patients. They would like to have a better understanding of the grief and bereavement process. As Mary Anne, a clinical nurses specialist sums up:

There are physical care issues such as the nurses not being able to assess when delivery will happen and also the issues of pain control. I recommend that the staff need more educational sessions in providing care. They want to know more about labour and delivery procedures. They also need more in-services on grief and bereavement. There is not a lot of communication between professionals, nurses feel abandoned, isolated and unsupported.

Many of the nurses also mentioned the critical importance of understanding the cultural backgrounds of their patients. The nurses routinely deal with patients from a myriad of racial, religious, linguistic and ethnic backgrounds. They know that cultures have a powerful impact on the meanings that individuals attach to life, death, abortion, burial and grief. They know how important cultural traditions surrounding death are and how integrally tied these traditions are to the healing process. They know that they need this knowledge in order to make informed clinical decisions and to guide their actions.

Yet the nurses receive little of the training they ask for, either informally through their colleagues or more formally through the in-service programs that hospitals sometimes provide to inform and educate hospital personnel in new procedures or skills.

One of the nurses, Renee, commented:

We have in-service, but you only learn so much from an in-service. But they don't tell you what to say when you go in there (to the patient's room). We buddy up, but it doesn't always work out.

With respect specifically to multicultural training, virtually all of the nurses in this study admitted that they had little grasp of the cultural values and customs so pivotal to understanding their patients' experiences. Kerri commented:

Some cultures need too much support. They are constantly crying and moaning. Some, like the Asian culture are very quiet. The nurses don't know what to do for them.

The lack of preparation and training for working in a multicultural environment means that nurses have to make assumptions, process information and make judgments arbitrarily and without a framework to guide them. They know that in many cases their lack of understanding probably results in care that, from the patient's perspective, may be seen as inadequate or insensitive, and that this only adds to their stress and pain. As badly as they may want to avoid such situations, without the proper training they are limited in what they can do.

LACK OF CHOICE

Another aspect of their work that concerns GT nurses has to do with the degree of choice they have as individuals. At three of the four hospitals included in this study, Eastern, Central and South Side, nurses on the surgical/gynecological ward, in principle, volunteer to do GTs. Those nurses who prefer not to do them ostensibly do not have to. In practice however, this choice is often compromised. If the delivery happens at night, as it frequently does, and the ward is particularly short staffed, nurses will be called on to at least assist even though they morally object to GTs. At Eastern General, for example, a busy community hospital, nurses routinely work in teams of four. GTs will be assigned to teams that include at least one nurse willing to perform them. But at the same time those teams will also have other patients assigned to them. Though the teams try to fashion a division of labour for themselves that respects a team member's preference to avoid GTs, this is not always possible. If it is a busy shift with several crises to attend to, the team members have to be prepared to do the best they can to support each other and to get themselves through. The preferences of individual nurses become irrelevant if a GT nurse needs the back-up of a fellow team member and no one else is available.

When GTs were introduced at the fourth hospital, St. John's, the nurses on the surgical/gynecological ward were told that they had no choice. All of the nurses were expected to provide care and support for GT patients, and if asked, could not refuse. In response, the nurses hired a lawyer to defend their right to refuse on moral grounds. The result was an agreement negotiated with hospital administration whereby the nurses on the ward could specify precisely which aspects of the GT procedure they were prepared

to deal with - preparing a room for an incoming patient, attending to a labouring mother, delivering the baby etc. Nurses could also request no involvement at all. A list of nurses and their preferences was drawn up for the nurse manager so that staff could be scheduled accordingly. However, this situation has caused complications for the nurse manager who does the scheduling. As one nurse, Sarah commented:

Two members of my team do more of the *dirty work*. There are two members of my team that don't do them. Management screwed up. Instead of placing one to a team of four, there are some teams who have two who won't do it. This could lead to burnout.

Though the agreement had the support of all parties involved, it has not proven to be easy to implement. As it is at the other hospitals, it is not always possible to anticipate the situations that may arise and to organize tasks so that nurses who object to them are not pulled into participating in GTs. When their colleagues and team members need them, nurses feel compelled to respond, whether they object to the procedure or not. They also feel guilty about letting their colleagues carry the burden for doing this work alone. Melanie described her feelings:

I feel troubled that my coworkers must pick up the duties because I refuse to do GTs for religious reasons. I feel that my team does more of the *dirty work* and the emotional work... The hospital is doing more and more terminations all the time.

There are additional pressures to participate. Nurses know that refusal comes with a price. They worry that their refusal will have career consequences and will be detrimental to their advancement. Those who are determined to act on the basis of their beliefs will look for ways to compensate for their refusal, either by extending themselves

to be supportive to those nurses who *are* doing GTs or by volunteering to take on other difficult or less desirable tasks on the ward. Sarah explained:

I worry about my job in the future because I say no now. But I play a significant support role. I don't refuse any other assignments or requests from others to take on any other jobs because I won't do the GTs. What's fair is fair

However compromised their choice may be now, at least the option of choosing currently exists in principle for nurses. It is not clear for how long that will be the case. All of the hospitals in this study are moving rapidly towards a policy of eliminating choice. GTs are becoming much more frequent. Whereas in the past a GT might be scheduled once a week, the trend now is moving in the direction of five per week and often two per day in some hospitals. The relatively small number of nurses prepared to do GTs simply cannot carry the load. The nursing directors in these hospitals fear that with the steady increase in the numbers of GTs and the demand for a full complement of nurses prepared to provide service, it is only a question of time until the choice option is eliminated. In fact, in each of these hospitals, nurses who interview for jobs on the surgical/gynecological ward are now informed that handling GTs is among the requirements. Candidates are also asked to consider their ethical and religious beliefs on abortion before taking the position.

The nurses' greatest fear is that they may soon lose even the minimal degree of choice they now have. They can see what is happening on the wards in terms of the rising demand for GTs. They are also aware that all incoming nurses will have been screened for their preparedness to take on the task of doing GTs. They recognize that

over time those who refuse will become a minority and that the pressures to conform will become greater than they are now.

Virtually none of the nurses - neither those who refuse nor those who do not - regard the trend towards elimination of any effective choice as a positive one. They are deeply resentful that nurses, but not doctors and hospital administrators, are being forced to do work that they find morally objectionable. The decisions to do GTs in hospitals and to locate them in the surgical/gynecological ward were made by doctors and administrators without consultation with nurses. But the task of actually performing GTs has fallen to nurses, including some nurses who are against GTs on moral grounds. That these nurses should now be losing their individual right to do GTs represents, for most nurses, a glaring example of their relative powerlessness. Sally comments:

It's not our choice that they (GT patients) are here. But we have to resign ourselves that they are and care for the patient. Nurses are powerless.

Referring specifically, to the contrast with doctors' prerogatives, Angela states:

I deal with anger towards the docs who won't do GT procedures for religious reasons but will get information for the hospital and support the program. They don't have to worry about making the choice not to do GTs...

Apart from the reservations they have about coercing nurses to do work that they find morally repugnant, nurses have concerns about the effects that a lack of choice will have on patients. Recalling situations where nurses found themselves involved in GTs, despite their objections to them, Jackie insisted:

There should be a choice for nurses. They should do it wholeheartedly. There were problems with some nurses who did not want to do it. Their patients were aware of this.

Although it is not an overt reaction on the nurses' part, those who have moral or religious objections often find it difficult to wholeheartedly support and care for the GT patients. Patients who are experiencing guilt and feeling troubled over their decision are quite attuned to the reactions of others around them. Similarly Celia, an experienced nurse who was involved in presenting in-services to nurses for GTs, emphasized the importance of unbiased care:

I emphasize to the nurses that what is right for us isn't always right for others. I believe it is a disservice to put in there who has ethical issues with this procedure.

LACK OF SUPPORT

Finally, there is the issue of how little acknowledgment and emotional support there are for GT nurses. The nurses realize that there is a great deal of unease and ambivalence on the part of the public about GTs. They know that there are not many people outside of the hospital that they can talk to about their work. Tellingly, however, there are very few people even within the hospital that they feel they can confide in. Every hospital has its institutionalized mechanisms of support for hospital staff. There are special programs specifically designed to deal with the personnel and emotional problems of those who work within the hospital, and counsellors specifically trained to provide support and assistance. But GT nurses do not feel - given the stigma surrounding GTs - that they can

avail themselves of these services. None of the nurses interviewed had ever consulted with a hospital social worker. Sarah summed up the common response:

A support group for nurses would not be helpful in this situation. She (social worker) would not understand.

Fran echoed this sentiment, stating "You can't call on a lot of people for support. They wouldn't understand." Another nurse, Daria, admitted that even with members of her own family who are in the nursing profession, she does not feel she could talk openly to them about her work as a GT nurse. GT nursing, she insisted, is not like any other kind of nursing.

My mom and my two sisters are nurses. I don't think I have ever told them. Just to bring it up in Saturday night conversation, you don't.

A seemingly promising initiative adopted by one of the hospitals, Eastern General, that was meant to provide GT nurses with some modicum of support, was the creation of a perinatal group. The perinatal group was formed for nurses who work in departments that deal in one way or another with mothers and babies. The group which consists of only a few representatives from each department meets regularly to discuss any difficulties or procedural problems that arise as well as ways to improve on their work. The group has helped the GT nurses in the sense that they are beginning to feel included. However, at the same time it serves to highlight just how different their work is from the work of other nurses and in doing so accentuates their sense of isolation. As Lina explained:

We are the forgotten group. We are now involved in the hospital's perinatal group. This helps us to be included. It consolidates the women's health group. We don't have the warm, fuzzy feelings, we don't have the baby pictures on the wall.

Though GT nurses may meet with the group, they do not feel comfortable sharing their experiences openly with others. They view their concerns and issues as entirely different and do not feel that they can discuss them with the expectation that they would be understood and supported.

The nurses' isolation is heightened further by the security concerns about GTs. All four hospitals in the study have experienced difficulties in the past with pro-life groups. The hospitals also stress the need to maintain a low profile for GTs. Although they do not expressly forbid staff from talking about GTs outside of the ward, there is an expectation that, both for security reasons and in order to maintain the patient's privacy there should be little open discussion about them.

GT nurses are well aware of the personal risk they are vulnerable to as a function of what they do. They recognize the need for tight security and are largely in favour of the hospital's arrangements in this regard. Linda, one of the nursing directors, argued:

Security measures are very important for nurses and patients. The idea of abortion draws out the radical groups. There can be violence, there is a risk involved. Society still goes back to the old way of thinking of abortion as a birth control method. We keep a low profile on this procedure.

The nurses acknowledge that the strategy of maintaining a low profile has benefits and that it works. Most had not experienced serious problems. But their security comes

with a price. As Lily put it: "We don't have a lot of trouble because no one talks about genetic terminations". GTs are shrouded in a veil of secrecy. This means that nurses get little recognition for their work and its unique problems. It means as well that they get little emotional support.

In the absence of outside support, GT nurses turn to each other. As a group, the nurses recognize that doing GTs affects all the nurses on the ward in one way or another, whether they are individually involved in caring for GT patients or not. They recognize too the need to acknowledge and somehow deal with the intensity of the work they do and the emotional impact it has on them. The nurses routinely "debrief". They encourage each other to talk about their frustrations and reactions not only while they are overseeing a GT, but afterwards as well.

But there are restraints on their ability to do such debriefing. One constraint is space. There are few places on the ward where nurses can talk. The nurses' station, which on most other wards serves as a central spot where nurses can meet and converse, in this case is too open. GT nurses cannot risk having their conversations overheard by patients and visitors. Mary lamented:

We talk between each other, but it's difficult because there is no privacy. At the nurse's desk the set up is very open.

There is a staff room that could be used to debrief, but the nurses rarely have time to retreat to it. The ward is a busy place. There are always jobs still waiting to be done, patients waiting for attention, paperwork waiting to be completed and new cases to attend

to. Finding the time for the kind of discussion it takes to deal with deeply personal and emotional experiences is not easy, yet it is necessary.

The nursing directors in each of the hospitals are well aware of the problem. Of all the huge responsibilities they carry, from staffing the ward to managing its budget, from dealing with the day-to-day practical needs of the ward to ensuring the security of their nurses, the responsibility they feel most acutely is the nurses' emotional well-being. As one of the nursing directors put it:

My biggest issue is how do we care for these nurses. I check in on the ward and with the nurses regularly. If I sense a problem I will talk with them one-to-one.

The nursing directors worry in particular about professional burnout among their nurses. As I discussed previously, as much as possible, nursing directors try to respect nurses' preferences *not* to deal with GT cases. But this means that the same few nurses are called on again and again to manage GTs. The combination of the frequency with which GTs are now being done and the intense nature of the work makes professional burnout almost inevitable.

Several nursing directors seemed eager to find ways to provide support for the nurses. Sue mused about the possibility of arranging, even on a one-time basis, a gathering of GT nurses from all the area hospitals for a discussion of their unique problems and concerns:

There is such a stigma attached to GTs for whatever reason. As soon as the word *abortion* is said attitudes change. So these nurses have to be selective in the support they choose. I would like to see if maybe we could form an education group or support group for the nurses. It would be nice if

we could pull together all the providers even if its just once (from all area hospitals that manage GTs).

Lorna too saw the need for support work geared specifically to the emotional needs of

GT nurses:

We need to talk about emotional support with the nurses. The family dynamics that they are dealing with is very intense and variable. I would like to provide staff meetings to talk about it and for them to have an outlet. It would be nice if they could do more self-assessment after the patient leaves.

Yet, none of the directors has as yet succeeded in establishing specialized support programmes for their nurses. In this regard it is important to remember that nursing directors too operate within a larger set of institutional constraints. While they may wish to do more for their nurses, without the support of the hospital administration, there is often little they can do. The nursing directors are reduced, then, to encouraging nurses to share their problems, concerns and frustrations with them and with each other.

From the nurses' perspective, the acknowledgment and respect they get from the nursing directors of their wards is appreciated. It means a lot to them to know that their supervisors understand the complexities of their task and the unique dilemmas they face. Most of them feel that they have a sympathetic ear in their nursing directors. But even with their nursing directors, there is a limit to how open nurses feel they can be. As sympathetic as nursing directors may be, they are still supervisors. As one nurse commented: "We worry that administration would question us as to whether we can handle the work or not". As a result, some of the nurses think that because of this

relationship, it is not in their best career interest to be completely forthright about their problems in managing GTs. In the end, then, nurses feel that they can only really count on each other.

SUMMARY

This chapter has covered a range of themes, including administrative and organizational decisions made about GTs, training issues and working relationships within the hospital. Yet, a common overall theme emerges. The consistent message received by GT nurses is that most people, including those in positions of authority within the hospital, those who made the decision to accept responsibility for performing GTs on women who are carrying babies with fetal anomalies, want as little as possible to do with GTs, the patients who need them and the nurses who manage them. Genetic termination is messy work. It is morally controversial and raises a host of difficult ethical questions. It involves death and destruction, not life. It is a potential *new* life that is coming to an end, not the life of someone who has enjoyed a full and rewarding existence. GTs can be clinically complicated, as any birth can be. Genetic termination is emotionally intense. Is it possible to imagine a more heart-wrenching situation than the termination of a wanted pregnancy? Who would not be reticent to involve themselves in such work?

Most hospital workers and administrators have successfully distanced themselves from GTs, both literally and figuratively. GTs are done in small, isolated rooms in the back wards of the hospital. They are done in a way that does not necessitate the

extensive involvement of doctors. Social workers and bereavement counsellors find ways not to be around. Little thought is given to the special needs of those who do them - the need for a proper work area and proper materials, the need for special training, the need for educational materials they can share with patients, the need for a clear set of procedures and policies, and the need for specialized support programs. There are always "good" organizational, administrative and clinical explanations - security concerns, the good of the patient, lack of resources, lack of time. But the message to GT nurses is clear.

As this chapter has shown, the nurses feel that the responsibility for GTs has been "dumped" on them with little regard for how they feel about doing them, how they feel they should be done or what they need to do the job properly. Often feeling morally ambivalent and ill-prepared themselves to do GTs, these nurses have no choice but to accept almost full and exclusive responsibility. They can count on little back-up from their health care colleagues. Their calls for more dignified conditions of work, more dignified both for themselves and for their patients, go unheeded. In a gesture that could not more graphically capture how their work is viewed, they continue to make do with the *dirty utility room* assigned to them. They do so without the specialized training, the specialized materials and the specialized resources they feel they need. Moreover, they do so quietly. There are few with whom the nurses feel they can share the unique difficulties of their jobs. They work in isolation and their contributions remain unacknowledged and unsupported.

It is difficult to understand how, given this situation, GT nurses can still find this work rewarding. Yet they do. Themes of personal satisfaction, gratification, professional challenge and commitment are prevalent in the ways GT nurses talk about their work as are the themes of unacknowledgment and stigmatization. In the following chapters I describe how GT nurses respond to the *dirty work* features of their jobs.

CHAPTER 6

CARING AS A COPING STRATEGY

INTRODUCTION

Despite the overwhelming practical and emotional difficulties attached to GT nursing, difficulties that nurses readily discuss and complain about, the work of a GT nurse is also described as professionally rewarding and personally gratifying. GT nurses may decry the lack of institutional support, yet they constantly refer to GT nursing as “what nursing is really all about,” and “nursing as it should be practiced.” Indeed, some nurses see the opportunity to do GT nursing as a privilege. They are charged by the intensity of their work and the clinical and emotional challenges it offers. Their patients have physical needs that are tricky and emotional needs that are great. They are patients who, like all patients, need expert and sensitive care. Perhaps more than any other group of patients, however, they are reliant on their nurses since most others in the hospital setting seem to want to have little to do with them. The nurses see GT patients as presenting a unique opportunity for them to put into practice the most fundamental and core values of their profession – patient-centered care.

In this chapter, I describe the various ways that GT nurses prioritize and become focused on caring for their patients, constantly looking for ways to ease their patients through their hospital experience. I suggest that – powerless to change the institutional context within which GTs are done and to escape the *dirty work* aspects of their job – nurses work hard to redirect their attention to those aspects of the work that make it

meaningful and rewarding for them. Their focus on patients involves attending to both their clinical and emotional needs. They need to get their patients safely through a medical procedure in which any of a number of things can go wrong. At the same time, however, they are dealing with patients who are extremely fragile and vulnerable emotionally. Nurses need to ensure that their patients get through the experience in a way that allows a process of on-going healing to begin. I begin by describing the approach that the GT nurses take towards the physical care of their patients. I then turn to the emotional care they provide.

PHYSICAL CARE

While it is easy to focus on the emotional intensity of the GT procedure and patients needs in this area, GT nurses are well aware that the physical well-being of their patients is also on the line and that there are points through the process where these physical needs must take precedence. There are a variety of things that can go wrong. For instance, during delivery women can experience a breach birth, hemorrhage or go into shock. When they do, the life and physical health of the mother may be compromised.

In Chapter 5 I described how GT nurses quite often feel ill prepared to handle the physical aspects of the procedure. They are not labour and delivery nurses. They are not as adept at judging how the labour is proceeding and how close to giving birth the mother is. Nor are they doctors. They do not have the experience that others have in handling complications that may arise such as a breach birth delivery or excessive bleeding

immediately afterwards. Yet it is their job to get mothers safely through the procedure. It is a responsibility that weighs heavily on their shoulders. While the emotional reactions of their patients, therefore, are never far from their minds, there are moments during which the nurses are concentrated on the technical aspects of their task.

In relation to the physical care of their patients, there are two areas that are particularly important for the nurses. The first is pain control; the second is the delivery itself, which also includes the aftercare of the baby.

PAIN CONTROL

In their efforts to try to help patients deal with the pain of childbirth, the nurses on the surgical/gynecological ward are at a distinct disadvantage. Without epidurals, which only L and D nurses are trained to administer, GT nurses are limited in their options. However, they have learned to make effective use of the techniques they do have available to them. The nurses make extensive use of analgesics. When a patient is admitted the physician will write a prescription for Demerol or morphine, usually enough to last through the labour and delivery.

Within the last few years, two hospitals in this study introduced patient controlled analgesics (PCA) as a result of the nurses' persistent claims that it would be beneficial to patients. PCA is a pain medication pump designed to release a preset amount of medication within a certain time period as ordered by the doctor. Patients press a button when they are in need of pain relief. Most nurses agreed that PCAs were an improvement in helping ease their patient's pain. In some cases they found it was still

inadequate for controlling pain. Patients were able to activate the pump when they needed pain relief, relying on their own sensations. Thus, they were not dependent upon nurses to provide relief. The PCA is also seen as an effective time-saver, freeing up valuable time for nurses to be performing other duties. GT nurses, like all nurses whose patients use PCAs, recognize this advantage.

In the two hospitals that did not use pain pumps, pain control was a pressing problem. The nurses described a number of strategies and hints that they have picked up from their colleagues in the labour and delivery department. They have learned to use massage, breathing techniques and reassuring words to soothe and encourage. They have learned that getting patients up and walking facilitates labour, sucking on ice chips and resting in certain positions is also helpful for easing patients' pain. In addition to using these techniques themselves, nurses coach their patient's partners and families in their use, just as they might in a normal delivery situation.

A key feature of the nurses' pain control function in some cases is persuading patients to take advantage of those pain management options that exist. The nurses have learned from experience that some patients will resist their efforts in this area because they feel they deserve to suffer. Racked with guilt, patients are prepared to accept the pain as a price for their actions. In these cases, the nurses patiently and sensitively try to get patients to come around, reassuring them that they are not to blame for what is happening and gently urging them to avail themselves of the pain management options that are available. Describing how she handled such situations, Lina offered these words:

There is nothing that you are being punished for. This is not a perseverance test. Take the medication to ease the pain.

In the worst cases, there is a final option for the nurses – transferring their patients to the L and D ward so that an epidural can be administered. As one nurse explained:

Sometimes the mother comes here (to L & D) from the surgi/gyni unit at the end of her labour. They come for pain relief or because the other nurses don't want to do the delivery.

This option, though it is always in the back of the nurses' minds, has serious problems connected with it. One problem has to do with timing. To be wheeled from one ward to another while they are labouring is difficult on patients. If the patient is close to giving birth, the baby may actually be born en route. Apart from the health risks involved, this can be extremely distressing for patients. Since the nurses on the surgical/gynecological ward are not trained to determine just how close to birth the labouring mother is coming, they do not trust themselves to make wise decisions about a transfer. Jackie, an L and D nurse complaining about the occasions on which this has happened, pointed out:

There is a need to better assess the patient, but of course surgi/gyni nurses are not trained to do pelvics so they cannot be sure how close delivery actually is... Sometimes if they wait too long to transport the patient the baby is delivered on the way to L and D.

A second problem has to do with breaking the continuity in care for the patient. A transfer to the L and D ward means responsibility for the patient passes from one nurse to another. The L and D nurses are not eager to accept GT patients, especially at the eleventh hour. They have not had a chance to develop rapport or trust with these patients.

“This is hard for the patient because we then are the stranger” is how one L and D nurse put it. The GT nurses can understand the reluctance of the L and D nurses and can also appreciate what it must be like for patients, at the height of their labour, to be passed on to someone else.

For all of these reasons, GT nurses prefer to keep patients on their own ward to manage their pain as best as they can. It is only in the most extreme circumstances, where they feel the health of their patient is at risk or where the pain is excessive, that they will consider a transfer. GT nurses care enough for their patients to take actions that may jeopardize their relationship with colleagues. To mitigate at least some of the negative consequences of a transfer, at Central Hospital the GT nurses have worked out an arrangement with the L and D nurses which allows them to accompany their patients to the L and D ward, stay with them through the birth and then return with them to the surgical/ gynecological ward afterwards.

THE DELIVERY

The most critical part of the GT procedure in technical terms, is the actual delivery. Almost all of the nurses had stories to tell about difficult, complicated and messy deliveries. Among the most dramatic was the following situation, described by Cynthia:

One patient got up to go to the bathroom and she started bleeding all over the place. She was going to deliver in the toilet. That was the icing on the cake for me that day. Here I was on my knees, we were running around like chickens with our heads cut off. I called the doc who said it would take a half hour to get there. It was an emergency! She needed a D & C! So I called the OR and told them to get ready. We were trying to manage her so she wouldn't go

into shock. Her boyfriend was acting like a bodyguard. We asked him to wait outside the room. Every time we went out the door he was asking us a lot of questions. It was hard.

Not surprisingly, then, once it is clear the baby is on its way the nurses move into a high state of alert. They ready themselves for any eventuality and concentrate on getting the job done. Daria explained it well:

At the point of delivery you're very detached – it's very clinical. You want to make sure the fetus passes and you get the clamps on and hopefully it passes in one piece. I am trying to be supportive to the patient, I'll say "you're doing a good job, but this is what we have to focus on right now (getting the baby out)."

Jackie put it this way:

During delivery you just do it and treat it as an emergency situation. Things can go wrong. There is a chance of infection and bleeding.

As with the management of pain, if the nurses feel the situation is getting beyond them, they will consider a transfer to the L and D ward. But they know that emotionally, it is in the best interest for patients to stay with their original GT nurses. As long as it is not compromising the patient's physical health, they will make every effort to handle the birth on their own ward.

The passing of the placenta or afterbirth marks the end of the most critical stage of GTs as a clinical procedure. If, after four hours, the placenta has not been expelled, the nurses know that it will need to be removed surgically. It is their responsibility to book the operating room and to prepare the patient for surgery. But in cases where the

placenta has been expelled uneventfully, the nurses know that they can relax, though only momentarily, and re-focus on the difficult emotional work that still lies ahead.

SUMMARY

Nurses view physical patient care as an important part of the GT procedure. In trying to make their patients as comfortable as possible they used pain pumps wherever possible to help with the physical pain. The nurses recognize, however, that the pain pump also serves to give patients back a measure of control over their situation. Those nurses who did not have access to pain pumps developed other ways to help patients control the pain. They enlisted the assistance of the patients' partners and also sought advice from trained labour and delivery nurses.

The nurses also urged patients to take advantage of the various techniques that were available to them even when they were reluctant to do so because of notions that they somehow *deserved* to suffer. To address this common patient response, nurses get patients through delivery as quickly and as safely as possible. This includes asking for assistance from another nurse or transferring patients to L and D when they do not feel they can manage the delivery. The nurses argued that this was a particularly difficult situation as they had to prioritize physical care over emotional care.

EMOTIONAL CARE

There are several dimensions to the emotional care that GT nurses see themselves as providing. They strive to give patients the feeling that they have some measure of

control – however small – over what is happening to them; they try to be as reassuring and supportive as they can be; they empathize with the patients and their loss; they involve family members; they look for ways to minimize the emotional suffering of their patients and finally, they do their best to put patients on the path to recovery and to prepare them for the grief work they must do. In the remainder of the chapter, I discuss each of these in turn.

GIVING PATIENTS A SENSE OF EMOTIONAL CONTROL

A goal that figures prominently in the kind of care GT nurses seek to provide is control. Frustrated by how little influence they themselves have over decisions about how GTs are done, the nurses are particularly sensitive to their patients' sense of utter powerlessness. They empathize with their patient's experience of the situation as one where things are happening *to* them, which they barely have time to grasp, let alone react. Most feel desperate, helpless and overwhelmed. Just as the nurses respond by finding ways to exercise agency, they look for ways to give their patients that same option. The opportunities are few, but the nurses are alert to them and eagerly take advantage of them when they present themselves.

The process begins from the moment patients first arrive. An important aspect of the nurses' task at this stage is to do a proper assessment – to inform the patients about the procedure, to answer any questions they might have and to get all the necessary paperwork signed. However, the assessment is as much about information gathering as it is about information giving. It is at this stage that the nurses try to gauge the emotional

state of their patients and to ascertain among other things how they would like the situation handled. Are the patients approaching the procedure as an abortion or a birth? Would they prefer to have the situation framed in clinical medical terms, referring for example to the “fetus”, or are they thinking in terms of the loss of their “baby?” Do they want to know the medical particulars as the process unfolds or do they simply want to get through the experience as quickly as possible? Do they want a greater or less degree of involvement on the part of the nurse? While some patients seem to want and need a great degree of talk and emotional support from their nurses, others prefer as much quiet time and privacy as is possible under the circumstances. Is it important for patients to see and spend time with the baby afterwards? How would they want that situation framed – again in more clinical terms as an opportunity to talk about the anomalies that precipitated the termination or as quiet time with their babies? Are there any cultural considerations that the nurse needs to know about in order to respect their patients’ sensibilities and that they could use to ease their patients more smoothly through the experience?

This information is critical to the nurses in providing the kind of care they are striving to provide. The more they know about the patient and her expectations and needs, the better able they will be to handle the situation. At the same time, however, they are trying to give patients some sense of control over the situation. The nurses are prepared to let patients define the situation in a way that makes them feel most comfortable and are prepared as well to take their cues from what their patients tell them. Getting patients to do this is not always easy. Some patients are uncommunicative either

because of a language barrier or because they are too unsure about what is happening. The nurses work particularly hard in these cases to elicit feelings and information. Their techniques vary. Sally uses the technique of asking patients how they would like to remember the experience:

I tell the patients that however you want to remember this experience is fine. I ask mom "what's most helpful for you at this stage?" We see patients at their most vulnerable.

Melanie is more direct:

I tell them "I'll do whatever you want, you call the shots."
At least they know they have some control over it.

Another nurse, Sandra, explains that she simply asks questions, trying to draw her patients out as much as possible:

I take clues from my patient on how to respond. I ask a lot of questions to start conversations. I find the beginning patients don't talk very much. Often they are calm until the labour begins.

Most patients view GTs as births and experience the procedure as the loss of a baby. The nurses respond, then, by treating them as they would any birthing mother. In those situations where patients prefer to see it as an abortion or in terms of a medical procedure, the nurses will treat it as such, keeping their references more technical and referring the patient for post-abortion counselling afterwards. The nurses set aside their own definition of the situation in favour of their patients'.

Another example of the effort that nurses put into giving their patients a sense of control concerns pain management. As discussed earlier, the introduction of patient

controlled analgesics (PCA's) was supported by the nurses. Notwithstanding their benefits in easing pain, the greater appeal for GT nurses has to do with the sense of control that PCAs provide for patients. The fact of the matter is that, at best, medication can only slightly reduce the pain connected to labour. In most cases, as a pain controlling device, PCAs work minimally. Their real value, from the perspective of most GT nurses, is psychological. However minor their effect, they allow patients to assume responsibility for at least one aspect of their care and in doing so give them some small measure of control.

PROVIDING REASSURANCE AND SUPPORT

The nurses also seek to provide unconditional reassurance and support for their patients, meeting their emotional needs however patients may define them. This process too begins as soon as the patient walks on to the ward. It is not uncommon for patients to arrive feeling confused and unsure of their decision. The nurses are careful not to rush them. They give them the space and time they need to get used to the situation, answering questions, allowing them to tell their stories and express their fears, reassuring them that they have made the right decision and comforting them. It is not always easy for the nurses to find the right words. It is something that the nurses worry and anguish over, as Renee's comments suggest:

All of a sudden I have to come into the room and know what to say to someone who has to sign papers to terminate a wanted pregnancy. "Oh, I'm really sorry but can you sign on the dotted line?" Sometimes I just don't know what to say.

Each nurse has to find her own way to reach out and provide support for her patients. This is especially so for those nurses who may have moral reservations about GTs. While most of the nurses in this study held pro-choice views on abortion, there were some who tended to move in the direction of a pro-life position. There were also nurses who, while they accepted the rationale for GTs, felt that the procedure was being used too liberally to terminate pregnancies for conditions that they did not consider to be severe disorders. Whether nurses approved of the procedure or not, however, was seen as less important than their ability to set aside their own personal points of view in the interests of their patients. The test for most nurses is whether they can devote themselves to their patients' needs unreservedly, non-judgmentally and wholeheartedly. Cecile, a nurse with a Down syndrome child, expressed this view on abortion:

To terminate is to get rid of the unfit. It is like planting flowers. You don't just plant roses But society decides on perfection.

In spite of these views, Cecile was completely devoted to her work as a GT nurse, arguing that while it might not be a decision she would ever have made for herself, she respected the right of her patients to decide for themselves and was prepared to support them fully through their experience.

To be a caring nurse, then, means grappling with one's own moral views and reconciling those views with the demands of the job. The nurses know that they cannot provide the kind of reassurance and unconditional, non-judgmental emotional support their patients need unless they are constantly reassessing their own beliefs about GTs.

The nurses were asked whether the gestational age at which the pregnancy was terminated made a difference to them from an ethical perspective. Donna explained:

It doesn't make a difference to me apart from the extra paper work after 20 weeks gestation, what stage she is at. It's easier for the patient if the baby is smaller. To me, we're still past the miscarriage stage, it's not a blood clot, it's a formed baby.

And Monica stated:

Life is tough, an abnormality is tougher. It's society that's the problem. There is not enough support.

The nurses believe that patients easily pick up on the discomfort and ambivalence of their health care providers. At a time when they need to be concentrating on getting themselves through the experience, patients should not have to deal with the moral reservations of their caregivers. The nurses do a lot of soul-searching in order to prepare themselves to care for GT patients. Debbie summed up nicely a sentiment that many of the nurses expressed:

I have no judgement of the patient whatsoever. It's something I have worked on, the moral stuff. It's not my job to judge. Oh yes, they pick up on your attitude. This day is not about me.

EMOTIONAL ATTACHMENT

Supportive care means empathetic care. Empathetic care means relating to – and crying with patients. A recurrent theme in the sociological literature on health care professions is the notion of emotional attachment. Sociologists of health have pointed out that perhaps the central professional norm in health care, at least for doctors, is to

maintain an emotional detachment from one's patients (Hafferty, 1991). Health care workers confront illness, trauma and death on a regular basis. If they are to function effectively over the long term in such situations they need to learn how to distance themselves emotionally from their patients. Emotional involvement is seen as a sign of weakness. Emotional detachment is seen as a necessary and indispensable coping mechanism and for this reason is stressed in professional training programs (Klass, 1987). In his study of nurses, Chambliss (1996:71) pointed out that when their emotions overtook them nurses retreated into a washroom, had a good cry, cleaned up and then came back out to continue working their shift as if nothing had happened.

There is something about the situation of GT nursing, however, that makes it easier for nurses to feel that they need not be bound by the norm of professional detachment. Most GT nurses have come to see it as acceptable, even desirable, to acknowledge and share their patients' suffering and heartache, and to cry right along with them. Sarah recalled a particularly emotional situation for both nurse and patient:

At delivery, they often let out a deep pitted cry or scream. That last push when the baby comes out. It's a deep pit scream that comes from deep in their stomach. I don't know what to say to them at this time. Sometimes I cry with them.

Many of the nurses admitted to trying at least initially, to keep their emotions in check. But to do so was too much of a struggle and eventually most had come to see it as appropriate to express their feelings. Lorraine said:

Every family is so different. Certain patients it's like you are part of their family. There are families that seem to latch on, they look for you, and they seek you out. I tend to

feel the loss more with them. It wouldn't be uncommon for me to cry. I don't apologize for that. It's how I feel. I say to them "I feel this way because you are feeling this way."

A factor that may be contributing to the relaxation of the professional detachment norm in this situation is the closeness of the relationship that nurses build up with their patients. In order to provide the emotional support their patients need, there has to be a bond of trust. The nurses work hard to establish that bond. The one-to-one nature of the nursing facilitates this process as does the timing of the GTs. Most patients come into the hospital early in the morning, but it is quite often late at night by the time they give birth. With the day's work done, there is more time during the evenings for the nurses to be with their patients and to talk to them. They learn about their families and their lives. It becomes harder for the nurses to think of the GT simply as a clinical procedure. They come to understand it in the same way their patients do – in the context of their lives.

For some nurses the temptation to empathize so completely with the patient is a liability. Apart from the fact that it flies in the face of a professional norm that they have been trained to observe, an emotional connection to their patients makes it just too hard for them to do their work. Consistent with how most other health care workers think about professional detachment, these nurses feel that they need to maintain their composure. Michelle, for example, argued that if she were ever to "let her guard down," she would never be able to "get it together again." Much like Chambliss' (1996) nurses who retreated to the washroom to cry, these nurses will wait until after the patient leaves to deal with their emotional reactions. "Sometimes it's better not to stop" Michelle argued, "or to pull away until after they (the patient) have left."

But most nurses in this situation feel differently. They recognize how unreasonable it is, given the situation, to expect nurses to maintain emotional distance from their patients. An intense involvement with their patients is seen as unavoidable. Beyond this, however, they see it as undesirable. Professional detachment may facilitate the physical aspects of their work. But in order to provide the emotional support that patients need, the nurses feel they must have a certain degree of empathy for, and emotional connection to their patients. As Lorraine said, the degree of rapport they establish with their patients is nothing they feel they need to apologize for. On the contrary, they are proud of their commitment to their patients and their ability to share fully in their grief and sorrow. It is perhaps their greatest source of pride. It represents for many what nursing ought to be about, total commitment and devotion to one's patient. Sue, a nursing director at one of the hospitals claimed:

What personifies nursing is when she takes the fetus, cleans it up and presents it to mom and puts her arm around her and there are tears in the nurse's eyes.

Providing empathetic care has the effect of reducing the social distance between nurses and patients. Rather than assuming the role of the "expert", the nurses often related to patients on the level of one human being to another. They did not presume to tell patients what they should be feeling and did not pretend to have all the answers. They offered themselves primarily as listeners and comforters. They recognized their ability to empathize with their patients as one of the most valuable services they could provide. Barbara said:

Patients always ask 'why me?' I always say "I don't know - things happen." You can't give an answer.

The degree to which nurses are able to empathize with their patients is demonstrated not only in those cases where they are able to establish a strong rapport, but also in those cases where they are dealing with angry patients. Though they are rare, there are occasions when patients take out their frustration, fear and pain on the nurses who are treating them, lashing out verbally at them. These outbursts are never easy for the nurses to deal with. But they are able to put themselves in their patients' places. They recognize that patients sometimes need someone to lash out at, accept it as part of their job and adopt a forgiving attitude. If the situation becomes too tense, they will simply leave the room and ask a colleague to replace them temporarily. Amanda explained:

Sometimes I will have another nurse take over for a while. Especially if the patient is angry and lashes out at me. And, I will offer relief for another nurse who is in that situation.

Providing empathetic care also has emotional consequences for the nurses after the GT is all over and the patient has gone home. Sarah described it this way:

After the patient leaves I feel like a balloon being released. Afterwards we are so tired... the whole mental thing, lots of pain, lots of bleeding.

Marie also explained:

Sometimes you go home and cry and cry and cry.

and Linda admitted:

Some of us don't sleep afterwards, sometimes for day.

INCLUDING FAMILY MEMBERS

Prioritizing as they have, the need to provide patients with as much support as possible, GT nurses have been willing to expand the parameters of their responsibilities to include caring not only for the patients, but for their partners and families. Over the last eight years, it has become commonplace for families to accompany patients to the hospital and in some cases for family members to be present for the entire procedure. The presence of a partner or family member can be useful. Particularly at those moments when things are happening quickly and when the nurses are concentrating on the physical needs of the patient, it is helpful to have an extra pair of hands in the room, holding the patient, helping her to push, helping her to drink, massaging her back or wiping her brow. If the nurse needs to leave the room momentarily, it is helpful to have a family member to stay with the patient.

But, for the most part family members add to, rather than reduce the complexity of the GT nurses' task. In addition to managing the patient, nurses have to contend with their families, finding tasks to keep them busy or distracted and dealing with the emotional reactions that they bring to the situation. Arli admitted:

It is difficult to deal with many family members. The husbands are upset seeing their wives in pain. Most don't expect they will be in so much pain. It's awful to see a man cry.

Several nurses described the atmosphere of chaos that the presence of family can create.

Carrie for example said:

Having family members there can create a lot of emotion. They will say to the mother, 'Are you sure you aren't

having any pain?' They are at us a lot and demanding. They will say, 'What are you going to do now?' 'What if this doesn't work?' 'Don't you use this or that?'

Daria commented:

Often family members panic when they realize the pain the mother is in. They don't understand that it is a labour, that the pains are fast and furious and mom has to push.

In an emergency situation described earlier in the chapter, Cynthia recounted the story of a patient who began to give birth while in the washroom. As the nurses scrambled to assist the patient, while at the same time making arrangements for a D and C, the patient's boyfriend stood at the door panicking and acting like a bodyguard, firing questions at everyone as they entered and left the room.

It would be perfectly understandable if the nurses looked for ways to minimize family involvement. In cases where they feel the presence of family is compromising either the physical or emotional health of their patients, they will indeed ask families to leave the room. But in the vast majority of cases, they will tolerate and even encourage family involvement even though it adds to their already heavy burden. As Lorraine explained:

I always involve the partner. I'll say 'can you get this or do this?' So, this way they are not bumping into things. They often don't know what their role is.

The nurses feel that in whatever ways it may add to their workload, the presence of their families is of benefit to their patients. They recognize that most patients do not want to be alone and that the presence of a family member can be comforting and

reassuring. They know that patients will feel less isolated and frightened. In this instance, as in so many others, the nurses are prepared to put their patients' emotional needs ahead of their preferences for a less encumbered and demanding work situation.

SPARING PARENTS' UNNECESSARY SUFFERING

Another dimension of nurses' caring involves their efforts to spare their patients any unnecessary suffering. Both collectively and as individuals, the nurses look for ways to protect their patients and to make the experience less traumatic and painful for them. There are many examples, but perhaps the most poignant relate to patients' viewing their babies' bodies. Recognizing the significance of the moment, the nurses go out of their way to make it meaningful for their patients. They take great care in preparing the babies for presentation to their patients. The hospitals provide them with few supplies to work with, so the nurses have had to be creative. They seek out from L and D wards such items as baby soap, baby blankets and even handmade sweaters and hats that have been provided by volunteers for premature babies. Some of the nurses will sprinkle baby powder on the babies before taking them to their parents. The nurses will let patients spend as much time as they need with their babies, never rushing or pressuring them.

Typically, once patients have had a chance to view their babies, the babies' remains are placed in a saline solution and sent to the hospital's pathology department for an autopsy. From there they are transported to the hospital morgue. It is not uncommon for patients to ask to see their baby again before they are discharged from the hospital. The nurses do what they must to retrieve the bodies. Marie described a situation in her

hospital where a confused labeling system in the pathology department made it difficult to find the body she was looking for. In an effort to comply with her patient's desire to see the baby again, she persisted in her search:

I'm on a first name basis with half of the lab. I've been down there so often. One couple wanted to see the baby again. I had to go to the lab to get it and I couldn't find it! These things happen because things aren't labeled properly or not in the right containers. Needless to say there went my supper hour looking for it. I found it.

The nurses must once again prepare the bodies to be viewed. The baby must be removed from the saline solution, washed and redressed. This is done patiently and without complaint.

In one hospital, members of the pathology department suggested that the babies' remains be kept in the refrigerator in the *dirty utility room*. The reason they explained is that cold air slows down the deterioration process so the baby can be kept on the ward until the patient is discharged. For the nurses in this hospital, there is the task of not only re-dressing the baby but also warming it before it is presented to the parents.

In order to carry out this task, the body is wrapped in a blue sterile pad and placed inside the refrigerator. Anticipating the distress that a cold body might provoke in parents the nurses developed a range of solutions. Some nurses will bathe the baby in warm water or swaddle it in blankets and cuddle it in their arms until it is warm. These moments are not easy for nurses. It requires them to treat the baby alternately as a human being to be respected and treated with dignity and as a specimen to be preserved. Such

moments take an emotional toll on the nurses, a toll that they are prepared to pay if it will comfort and ease the suffering of their patients.

Just how far the nurses are prepared to go in meeting their patients' emotional needs is illustrated in another incident recounted by Lina. The incident involved a patient who based on cultural tradition, had made arrangements for the burial of her baby the day after her release from hospital. Hospital policy requires patients to specify in advance how they would like their baby's remains handled and, if the remains are to be removed from the hospital, to whom they should be released. In this case, someone claiming to be a family member simply appeared the day after the patient had been released and requested the body for burial. Lina explained:

One woman had someone come to pick up the fetus after she was discharged and she didn't tell me who this would be. I couldn't just sign this fetus out to just anyone. How did I know who this was?

This put Lina in a delicate situation. To comply with the request meant retrieving the body from the pathology department without the proper documentation. "Pathology isn't going to like this" she recalls thinking. She was also uncomfortable releasing the body to someone she did not know. On the other hand, in refusing to release the body she knew she would be disrupting the planned funeral. Not wanting to add further to her patient's emotional burden, she signed the necessary papers and released the body, putting her job on the line in the process.

There are other examples. Sally recalled a couple who wanted to have their baby blessed by the hospital chaplain, but could not bear to be there. They asked her to attend the blessing on their behalf. She agreed:

It was touching – one day the patient wanted to have the baby blessed and the parents did not want to be present. But they asked me to be there with the chaplain. It was so nice, the chaplain said “Oh you poor little lamb.” It was one of the nicest things I have experienced.

Renee has discovered that patients who may not be religious nevertheless appreciate having some way to mark the passing of their baby. She offers to say a simple blessing before she takes the baby away:

Sometimes I will bless the baby. I ask if they want the baby blessed. If so, I say “in the name of the father, son and holy spirit. God bless (baby’s name). I use water in a glass to make a cross on the baby’s forehead.

The nurses at all four hospitals anguished over the question of how the photographs of the baby should be presented to parents. The nurses took photos of the babies with a polaroid camera right after they had been washed and dressed. These photos were often the only ones parents would have to remember their baby. They found that the poor quality of the camera coupled with the immaturity of the baby and the visible anomalies resulted in less than adequate photographs. The nurses said that the photographs often did not resemble the baby that parents held in their arms. Parents often found these pictures disturbing at first. On the other hand most parents find these pictures assist them through their grieving process. At one hospital, the nurses decided to put the photographs in a sealed envelope so parents could look at them when they felt ready. At another

hospital, they decided to provide patients with an undeveloped roll of film so that parents could make up their own minds, and if they decided they wanted the photos, had the option of developing them when they felt emotionally ready to look at them. In big ways and small, the nurses try to anticipate their patients' needs and reactions and wherever possible, do what they must to make the experience just a little easier for them.

PREPARING PATIENTS FOR GRIEF WORK

This Chapter has stressed the extent to which GT nurses blur some of the traditional lines between health care providers and patients. I have described how rather than imposing their definition of the situation on their patients, the nurses allow patients to determine how the process will be framed and what approach will be taken. I have also described how nurses set aside the norms of professional detachment and put themselves on the same level as patients, crying and responding emotionally with them as they go through the experience and readily admitting that they do not have all the answers.

At the same time, the nurses do have a sense for how the healing process should work. As they acquire experience with GTs, the nurses learn where their patients may be particularly vulnerable and how best to guide them through the crisis. While they are prepared to relinquish a good deal of control over the situation to their patients, there are areas where they feel they have a responsibility to be more interventionist. Though they do it in subtle and non-directive ways, they feel it is their responsibility to counsel their patients and prepare them for the grief work they will need to do.

The nurses feel it is important, for example, for patients to accept the reality of what is happening to them right from the beginning. Patients come into hospital hoping against hope that there will be a reprieve, that some error will be discovered or that someone will tell them that it has all been a big mistake and that they can go home. Theresa mused: "None of the mothers accept it until it's done. They all have hope until the end (the delivery)." Gently, the nurses urge patients to accept what is happening. Sharon said:

I ask them what they know. I try to bring out the reality for the patients. It's a death. I tell mom she should cry and grieve.

Emily took a similar approach:

I am very honest with them about what they are going to experience and what they can expect afterwards.

The nurses also feel that it is critical for parents to see their babies, even though this is for the majority of patients, the most difficult part of the procedure. For the nurses it represents the "beginning of the end," the point from which their patients can begin to experience some closure. Fran tell her patients:

It helps to see the baby. Maybe not today, but weeks down the road when you are struggling you will know that you made the right decision.

In particular, the nurses feel it is important for patients to come to grips with the anomalies that have precipitated the GT. They will make the effort, therefore, even when patients are eager to simply put the whole experience behind them, to explain the

problem. In cases where the anomaly is visible, they encourage patients to actually look at their babies. This is done carefully, as in some cases the malformations are severe and dramatic. Nurses wrap the baby in such a way that only the normal features are visible. Once the baby has been presented to the parents and the parents have adjusted to holding the baby, the nurses encourage them to slowly pull back the blanket and look at the baby's other features.

In other cases the anomalies are not visible. The babies look perfectly formed, though tiny and underdeveloped. As Alice explained:

It's often hard to tell. A lot of these anomalies are tied together. You can't always see all of the baby's problems. A cleft palette may be tied to a kidney problem. There are so many different problems.

In these cases the nurses feel it is even more important to carefully explain the nature of the problem. They know how easy it is for their patients to look at the baby and to be plagued with lingering doubts about whether the procedure had in fact been necessary at all. The nurses want to spare them that anguish.

The task of helping patients to fully grasp both what is happening to them and the nature of their babies' problems is not an easy one for nurses, especially when patients are reticent. Another difficulty the nurses face is that they themselves are not expert in the range of medical problems that precipitate GTs. They are putting themselves in the position of explaining problems to patients that they themselves do not fully understand. They work hard to pick up whatever information they can from the geneticist involved in the case. As a way of compensating for their lack of expertise, in some of the hospitals

the nurses have begun to keep a binder of articles on genetic anomalies that they can refer back to when they need information to relay to patients. These may be articles suggested to them by geneticists or literature that the nurses themselves have come across in the hospital library, medical journals, popular press or elsewhere.

It would be easy for nurses to avoid these conversations with parents. In many cases it would certainly be the path of least resistance. But from the nurses' perspective it would also be an abrogation of their responsibility for the emotional well being of their patients. In gentle ways they try to get patients to accept what has happened and to get them started on a path towards healing.

CONCLUSION

Reflecting on her experiences as a GT nurse Melanie concluded: "We know it's not the best day's work you're going to do, but it's rewarding." That short phrase succinctly sums up the juxtaposition of nurses' reactions to GT nursing. The work is difficult and unpleasant in so many respects. The conditions under which it must be done are deplorable. In both a literal and figurative sense, it is truly *dirty work*. Yet it is rewarding and the nurses derive tremendous satisfaction from doing it.

While it may be difficult to reconcile the two reactions, in important ways they are linked. The nurses see themselves as overcoming overwhelming obstacles to provide their patients with the best possible care. But in terms of the physical and more complicated emotional needs of their patients, they feel they have risen to the challenge. Both physically and emotionally they prepare their patients for the ordeal they are about

to face, they support them through their labour and the birth of their babies, they guide them through the beginning of their healing process, they shield and protect them, they talk to them, cry with them, grieve with them and in every way, care for them. In doing so they are doing the work that brought many of them into nursing in the first place. They are practicing nursing as they feel it should be practiced. From their perspective their work involves the essence of what nursing should be – caring for and meeting the needs of their patients.

The nurses take great pride in what they are able to accomplish. That they are able to bring their patients safely through the procedure and get them started on the path to physical and emotional recovery is a source of great satisfaction. The rewards are both tangible and intangible. For most nurses, the greatest reward is the sense of a difficult job well done. Explaining what she enjoyed most about her job, Carli said:

The patient feels safe after it is all over. They know we're taking really good care of them, that if they have any problems we're there.

The nurses proudly describe the embraces, the cards and letters and in some cases, even the gifts of thanks they receive from grateful patients. They treasure these. Anna explains:

One patient came back and gave me a cherub holding a baby cherub. I keep it where I can see it everyday. It means a lot to me.

The nurses also describe instances where patients have returned one or two years after their GTs to proudly introduce their healthy newborn babies. They are pleased to

see their patients doing well and proud of the strength of the bonds they continue to share with them.

The intensity of the satisfaction that GT nurses get from their work is critical to their on-going management of the problems connected with doing that work. Were it not for the rewards described above, few nurses would last as long as GT nurses. For some, in fact, the rewards are insufficient. They transfer out of the ward if they can or quit. But for those who stay, the emphasis on the patient care and the rewards connected to it act to sustain them and allow them to continue doing what they do. It may be *dirty work* but it is also gratifying work. Much of the satisfaction comes from doing it well despite the obstacles.

The centrality of patient care as a coping strategy for GT nurses makes it important for the nurses to restructure their work to allow them to care for their patients in the way they feel they should be cared for. The nurses need a routine that efficiently systemizes their work, but also gives them the flexibility to do the kind of nursing they feel is critical both for the patient and for themselves. This issue is taken up in the next chapter.

CHAPTER 7

ROUTINIZATION AS A COPING STRATEGY

In the previous chapter I described one way that GT nurses manage the *dirty work* they do. They turn their task into an opportunity to practice a more idealized kind of nursing where patients and their families become the center of care. The nurses take a situation rife with tensions and dilemmas and redefine it as a chance to practice nursing as it should be practiced – a patient-centered care. In this chapter I describe another central strategy that the nurses use to cope – the development of a routine that standardizes their work in some way and compensates for the lack of institutional support, but at the same time gives them the flexibility to practice the kind of nursing that makes their work so rewarding and meaningful. My discussion of the routine is organized in the following way. I begin by describing the unique one-to-one nursing model that nurses have implemented when dealing with GT cases. This is followed by a discussion of the ways in which the entire surgical/gynecological ward is mobilized to provide GT nurses with the support and assistance they might need. Next, I turn to the procedures, both formal and informal, that the nurses have implemented to deal with various aspects of their work. This includes patient assessment, bereavement counselling, dealing with the lack of appropriate working spaces and materials and dealing with the birth of a live-born baby. Finally I explain how nurses have

compensated for the lack of information and educational resources for both themselves and their patients.

ONE-TO-ONE NURSING

At the heart of the nurses' routinization strategy is a division of labour that allows the nurses to devote their full attention to their GT patients and to meet their needs in a prompt and timely fashion. In three of the four hospitals studied, this has meant instituting a one-to-one nursing model. Normally nurses work in teams. On each shift, each nursing team is assigned a roster of patients for which the team is collectively responsible. The nurses on each team work out amongst themselves how to respond to their patients needs. While one nurse may be assigned the task of taking blood pressures and another will look after distributing medications, the others make themselves available to respond to calls from patients.

When GTs were first introduced in these hospitals, it was assumed that the procedure would find its place within the established routine of the ward. It quickly became apparent that this was not going to be easy. Mary stated: "We were expected to treat it like any other treatment. It's not." The nurses recall trying to treat GTs as "business as usual." Patients would arrive with little warning and had a nursing team assigned to them. The nurses would try to fit GT patients into their normal round of activities, but found that they could not. The patients' uncertain emotional status and the uncertainty surrounding the progress and length of labour and delivery defied an orderly scheduling of care for them. The nurses discovered that GT patients had needs that

demanded immediate attention. They upset the normal scheduled routine of the nurses' work. A different structure was necessary.

Working with their nursing directors, the ward nurses eventually implemented one-to-one care. According to this model, a single nurse is assigned to each GT patient before she is admitted. The benefits have been significant and numerous. This model gives nurses greater control over the scheduling of GTs. Since arrangements need to be made in advance to have a nurse available to care for a GT patient, the ward needs to be notified a day or two in advance. This allows nurses the opportunity to volunteer for the assignment. As Cecile said:

There should be a choice for nurses. So they are doing this work whole-heartedly. There have been problems with some nurses who haven't felt comfortable with this work.

Nurses who do not want to do GTs then are not put in the situation of having to take the assignment because their team happened to be working that day. This model also gives both the ward and individual nurses time to prepare. The nurse assigned to the case can set up the treatment room with the necessary equipment. She also has a chance to prepare emotionally, something the nurses claim is important in doing this work over the long-term.

But perhaps the greatest benefit from the nurses' perspective is the quality of care it allows them to provide for their patients. The nurses feel that working directly with patients in such an individualized way allows them to better assess what their patients' needs are. There is much to sort out – the patients' physical status, their emotional state, their cultural and religious beliefs and so on. The sporadic and discontinuous contact

with any given nurse in a team nursing approach would not allow for a proper assessment. Nor would it allow for the development of the close bonds that nurses feel is so critical to dealing with patients' emotional needs. Sarah talked about some of the issues her patients face:

Patients have a lot of complications and pressures. There are social issues and religious issues. There are differences between partners.

The experience of the nurses at Eastern General, the one hospital in this study that had not instituted a one-to-one nursing model, bears this out. A common complaint among the nurses at Eastern was that they are not able to get close enough to their patients to do a proper job of caring for them. Melanie explained:

GTs affect all workers on the floor. It also affects the patients. We don't get the chance to get to know them because it is not always the same nurse in and out of the room.

Another nurse from Eastern General, Susan said:

Often we are so busy here on this floor, we greet them with a wave and say "be there in a minute. It's hardly the ideal ward for GTs.

MOBILIZING THE WARD AROUND GTS

While, according to the one-to-one nursing model, the primary responsibility for a GT patient falls on the shoulders of one nurse, the entire ward has an important supportive role to play. Whether they are directly involved in them or not, most nurses see GT cases as the ward's top priority. Leanne explains:

These patients are the priority. Their needs are to be met...
So, when they have a request everything else goes on hold.
You can't just say "Oh, I'll get you that in a few minutes."
You want to meet that request quickly.

As a response to the lack of backup and support from doctors and other health care workers in the hospital, the nurses feel they need to support each other. In other cases as crises arise, physicians are called in immediately and emergency treatment is provided until the doctor arrives. The nurses' role after the doctor is there is to assist. In GT emergencies too, nurses will immediately alert the physician and perform whatever emergency procedures are appropriate. The difference is that the nurses know that the doctors are likely to come late, if at all, and do not always know what needs to be done.

Lorna said:

Some docs are disrespectful. When you call they don't come right away. The time and emotional energy needed to wait for a doc is difficult.

All of the nurses on the surgical/gynecological ward know that the GT nurse is on her own and they will do whatever it takes to provide her with assistance.

When a GT is happening, all of the nurses on the ward keep themselves apprised of the patient's progress and status. Alert to the possibility of an emergency they are prepared at a moment's notice to assist the nurse handling the GT. Sally describes one of her experiences where she immediately called another nurse for assistance:

A breach birth is difficult. I'll help guide the baby's head out. But for me, looking and seeing a foot – you don't want to see a foot. Then you know they (the patient) are in for a tough time.

In some of the hospitals, the nurses have created “help” codes as a way of letting their colleagues know that the delivery time is drawing near or that they need help. When a “help” code is sounded, the response on the part of the other nurses is immediate. The nurses at St. John’s Hospital also created a strategy that they found helpful:

We will sometimes alert the resident and FYI. They will sometimes come in and check-up. This allows us to be more prepared if an emergency occurs.

The support that the nurses provide is more than merely technical. Besides supporting their colleagues through any clinical difficulty or emergency that might arise, the nurses see themselves as offering moral or emotional support. Daria commented:

They (the nurses) are all there for a shoulder. They all say “Oh you’re doing a good job”, “Are you OK?” “Do you need help?” “Should I do this...?”

The nurses make themselves available to fill in, not only at times when the patient is in distress, but also at times when the assigned nurse is having difficulty coping emotionally. The most tense emotional moments for many nurses involves the baby’s aftercare. The actual task of washing the baby, taking weight and height measurements and dressing the baby is too much for some nurses to bear. These nurses commented that just having another nurse standing beside them in the *dirty utility room* while they completed this task provided invaluable support. At moments such as these, the other nurses are especially attuned to when they will be happening and they reorganize their tasks so that someone is available if needed to assist the GT nurse.

For their part, GT nurses feel they can count on their nursing colleagues and do not hesitate to ask for assistance. Many had stories of circumstances where assistance had been sought and provided. Gina recalled:

I had a couple, nothing you said was getting through to them. Nothing the geneticist would say was getting through. They were going to do it their way. She screamed for six hours straight. I had to call another nurse in to help me.

Marie shared this difficult experience:

I've had one where I was splashed with blood. I didn't react at the time. I went into the treatment room and closed the door. She (the mother) had such a difficult time, it seemed so traumatic. It wasn't what I had wanted for her and with the astonishment of all the blood – I just broke down. It wasn't that I had blood all over me, but it was that it was more frightening for her to see this. Another nurse went in and took over from there.

Angela admitted:

I seek support from the nurses on my ward continuously. I share with my colleagues every time I leave the room.

ESTABLISHING PROCEDURES AND PROTOCOLS

In the absence of established procedures and standardized protocols for dealing with GT patients, the nurses have created their own. One area that has drawn particular attention is the lack of an adequate way for health care workers to exchange information about patients. The nurses have been disturbed by how little advance knowledge they have about the patients who will be coming on to their wards and what their unique

circumstances and problems might be. They have often been unaware of both their patients' health status and their understanding of the GT procedure prior to being admitted to hospital. This has made the initial contact with patients when they arrive needlessly complicated as nurses try to gather the information they need in order to proceed with their care. Sharon describes the strategy that the nurses at Northern Hospital began to use to correct this problem:

The nurses went to a meeting with the administration and we argued that paperwork needed to be done before the patient was admitted. It's better for all involved.

At Northern Hospital a procedure was instituted whereby a file is kept for all GT patients that includes information about past appointments, medical information, prenatal diagnostic information and concerns about the patient. The implementation of this procedure has slowed the admission process by a day so that the paperwork may be prepared. But the nurses feel the preparation time is valuable for them as well as for their patients. Amy pointed out:

There is a difference between this loss and a stillbirth, as with a stillbirth the parents ask a lot of "whys." with ending a pregnancy for fetal anomaly parents are already in mourning when they arrive. They don't know the answers, they are going through a nightmare.

To deal with the problem of how to assess the patients' level of knowledge about the procedure the nurses at both Northern and Central Hospitals have introduced information assessment forms into their routines. At Northern Hospital a perinatal bereavement checklist has been introduced (see Appendix C). This two-page form lists

eighteen questions that serve to ensure that the pertinent issues have been dealt with. In completing the checklist, nurses record progress notes that reflect their assessment of the patient, actions taken, patient and family responses and an evaluation. The checklist ensures that all patient issues have been discussed with patients including whether the labour and delivery has been discussed, the possible appearance of the baby, whether parents want to see or hold their baby, will the baby be named, has a memory package been prepared, will parents consent to an autopsy, what burial arrangements will be made and who will be providing follow-up care. The checklist also records the date, time and name of the nurse who presents the information.

The nurses at Central hospital use a two-page, perinatal loss checklist that is completed in triplicate so that documentation can be sent to the physician and the genetics department (Appendix C). Nurses record when issues such as pain control, seeing baby, burial arrangements and autopsy has been discussed with patients. This form has been modeled on a form typically used for patients who experience the loss of a baby through miscarriage or stillbirth. GT nurses have used the form as a guide to create their own form. The nurses also designed a separate form to accompany this checklist which charts information specific to the GT clinical induction (Appendix C). This *Checklist for GT Patients* records the time that each step of the induction procedure takes place such as the insertion of the laminara, delivery of the fetus, delivery of the placenta and administration of medication. The use of these forms also serves to include doctors and genetic counsellors in the routine as the nurses send a copy of the forms to each of these.

Thus far, this section has dealt with the formal protocols that nurses have developed in relation to their work. In addition to these, however, there are informal routines that have evolved as a way of easing the burden of doing this kind of work. For example, the nurses have developed a way to work around the lack of proper facilities and basic materials. At one time, South Side Hospital had a “baby room” that was used only for caring for these babies. The room contained a baby bassinet, a sink and the necessary supplies for doing genetic terminations. Suggestive of the low priority assigned to GTs by hospital administration, the room was taken away during a reorganization of the ward. It was at this time that baby care was relocated to the *dirty utility room*.

Though they are stuck with the *dirty utility room* as a place for dealing with the babies' remains and preparing them for presentation to their parents, they have made the best of it by reorganizing the room to best suit their needs. The *dirty utility room* is well used, staff are in and out of there often. Sally from South Side Hospital explained that whenever someone walked into the room, unaware that a baby was in there, it was shocking and discomfoting. In order to protect others from this experience, the nurses created a signal to alert others that a baby was in the room. Daria explained:

Now that we must use the *dirty utility room*, when the door is closed it is a signal to others that the baby is in there.

The difficulties that GT nurses have run into in relation to the lack of proper materials are resolved in a number of creative ways. The nurses described having only cleaning rags with which to wash the babies and having to lay the babies in a metal sink and on a cold, bare counter. Finding this unacceptable they took it upon themselves to

remedy the situation. As discussed in the last chapter, the nurses go to L and D and get supplies such as baby blankets, bathtubs, towels, baby soap and even clothes like sweaters and hats that were handmade by volunteers for the tiny, premature babies. Some of the nurses said that they even sprinkle baby powder on the babies before they wrap them in their blankets so they will smell nice for their parents.

Nurses also reorganized the *dirty utility room*, setting up a special area just for these babies. They have draped a curtain around for privacy as well as to separate their “caring” work from the other jobs that are handled in this room. Proud of the ways they have found to manage this problem, the nurses considered this to be a temporary solution. They stressed that a more reasonable, permanent solution needs to be negotiated with hospital administration. The nurses at south Side would like to have their “baby room” back again while others suggested that a small, two-room ward created just for GTs could include a “baby room.”

The nurses also experienced difficulties in relation to the lack of proper materials for preserving the baby’s remains. As discussed in Chapter 5, one of the most difficult parts of the GT procedure for nurses is placing the body in the container of saline solution. The lack of suitable containers was a concern that nurses raised with their nursing supervisors and members of the pathology department. Having experimented with a number of different containers they had in their ward, the nurses at Central Hospital found a suitable container that they described as a rectangular Tupperware container. Due to its length and narrow depth, the nurses were able to gently place the body in the solution without having to drop it in with a “plop.” This solution not only

made the physical task better, it also solved the ethical issue for nurses with regard to the questionable humanity of the act.

As well, the container has a more secure seal that means less spillage and accidents for nurses as they transport the container to pathology. The nurses did not have a supply of these containers on the ward so they would go to pick one up when pathology was finished with it. The nurses at the other three hospitals had still not found a suitable container. They did say that they have not given up their search.

Built into the routine is a consideration for the emotion work that nurses need to do for themselves. A significant dimension of how nurses deal emotionally with the work they are doing has to do with how they treat and handle the baby. The nurses feel that it is important in the midst of all of the activity surrounding GTs and with all the pressures mitigating against it, to treat the baby with dignity and respect. Many of the procedures they have developed for handling the baby are a reflection of the significance they attach to this. The routine accommodates the time it takes for the nurses to prepare the baby carefully and respectfully. It can accommodate as well the time that the nurses need with the babies. Melanie said that when she took the baby to the *dirty utility room* to do the after care she would spend a few minutes quietly with the baby. She explained:

I always bless my babies – it's peaceful. This is what nursing is all about.

If the nurses needed to spend time with the baby, they would build it into the routine.

The nurses have also developed a routine to deal with the even more difficult experience of delivering a live-born baby. This situation does not happen often, and although the nurses know it is a possibility, they are always shocked when it happens. Often their instinct is to think about taking heroic measures to save the baby and to keep it alive. Wanda admitted:

It's difficult to do this because your instinct as a nurse says "save the baby, take it to ICU." But that's not the parent's wishes. I used to work on OB High Risk and we delivered 24-week babies and kept them alive. You did everything you could to save the baby. It's the complete opposite.

Accepting then that these babies will eventually die, the question becomes what to do in the interim and whether or not to inform patients. Chapter 5 describes the case of the nurse who found herself at a complete loss when she first confronted the situation of a live-born baby. In a panic, she called a physician who instructed her to put the baby immediately into a saline solution. She rejected the advice, opting instead to call in another nurse to look after the patient while she walked the baby up and down the hallway until he stopped breathing. This is, in fact, what most nurses will do. At birth the babies are quickly wrapped in a blue sterile pad. The nurses whisk the baby out of the room and into the *dirty utility room*. They will wrap the baby in a blanket to keep it warm. Then they will cradle the baby and either wait in the utility room or walk the ward until breathing ceases.

In terms of informing parents, GT nurses have opted not to tell parents that the baby is breathing. They know that the babies will not live long. They are too immature to live and are only able to breathe for a short time. The nurses feel that it is unnecessarily cruel

to aggravate the emotional burden patients are already carrying by letting them see their live babies. Interestingly, when these babies are born on the labour and delivery ward, and are delivered by an L and D nurse, there is another routine that is observed. L and D nurses will normally give the baby to the mother immediately after birth just as they would in a normal delivery. The nurses stay in the room with the parents to support them through this emotional time. When the baby has stopped breathing the nurse will take the baby away and do the aftercare. These different approaches clearly illustrate the relevance of the organizational context and nurses' definitions of the situation in shaping the procedures followed.

Finally, the nurses have developed a routine around ensuring patients' privacy and security as well as their own. They have arranged for confidential admission of patients to the ward. This means that the patients' reason for admission is not recorded at the main admission desk. The nurses screen inquiring phone calls about GT patients. They refrain from discussing GT patients at the nursing station or anywhere else on the ward where they might be overheard. When they do talk among themselves about GTs, they are careful and selective in the language they use, camouflaging in many cases what they are talking about. The term "GT" itself, because it is still relatively new and not commonly understood, is a handy acronym. The nurses might also make reference to "the fetal anomaly," a term sufficiently ambiguous to be unproblematic. Doors to the rooms in which GTs are being done are kept closed at all times. If patients need to be transported on stretchers to or from the labour and delivery ward, back corridors are used.

Particularly, if patients are moved after delivery with their babies, the babies are discreetly swaddled and placed on the mother's abdomen so as not to draw attention.

CREATING RESOURCES

In Chapter 5, I discussed the difficulties that GT nurses have had as a result of the lack of resources both for themselves and their patients. In response, and as their experience in handling GTs builds, the nurses have created their own materials. For example, the nurses have developed a *Patient Information Sheet* (see Appendix C). This sheet briefly outlines admission procedure, the GT procedure and expectations after discharge. As a result of negotiation between nurses, nursing directors and genetic counsellors, this information sheet is given to patients by the genetic counsellor at their last appointment before they are admitted to hospital. The sheet tells patients precisely what will happen to them and how the process will unfold. It tells them, for example, where they are to report once they arrive at the hospital. It tells them what will happen once they are admitted – that the procedure will be explained to them, that they will be asked about what they would like done with their babies' remains and that they will be asked if they would prefer the term "baby" or "fetus". The sheet tells patients how long they can expect to stay in hospital, what the induction procedure entails and what they can expect physically afterwards.

The nurses have also felt that there is inadequate information about GTs themselves and about bereavement for patients to use. They have stressed the need for information

sheets that answer patients' questions about the GT procedure. Dorothy made the following suggestion:

It would be nice to have a video for the parents to view before the delivery. It could include expectations and other information they need to know.

In response, the nurses from South Side Hospital worked together with the nursing director and the clinical nurse specialist to create a support package for patients to take home with them. The package contains a covering letter signed by the nursing director that expresses her sympathy to the family; a comprehensive reading list from *Parentbooks*, a unique bookstore that specializes in pregnancy and infant loss issues; an information sheet called mourning an unborn child; practical information on early pregnancy loss and references for support; and a two page feedback form that patients are asked to complete.

Initially, the package contained a booklet on grief. The booklet was prepared by the hospital's perinatal program in the early 1990's and was designed to help patients cope with miscarriage. It dealt with the physical changes that patients might expect to see after a miscarriage, how they might explain the loss to others, considering future pregnancies and carrying on after the loss. Although helpful in a number of ways, the GT nurses felt that the booklet did not sufficiently address the unique issues related to GTs. In fact, they felt that its inclusion was detrimental to the patients' emotional health as it denied the full reality of their loss. They have opted to eliminate the booklet from the package.

Another example of where the GT nurses have made decisions about materials *not* to use rather than what materials to present to parents was offered at South Side Hospital.

Without consulting GT nurses, hospital administrators at South Side made available for distribution to patients a booklet entitled *Difficult Decisions*. The booklet focuses on how to make the choice whether or not to terminate a pregnancy for fetal anomaly. The nurses argued that this booklet would be more appropriately distributed by the doctor or genetic counsellor before the decision is made, not after the decision has been made and the patient is ready to have the procedure. The inappropriate timing in presenting this literature resulted in situations where patients were set back in their treatment, emotionally and physically. Maria explained:

The patients are handed a copy of the *Difficult Decisions* booklet when they are admitted. We feel that this is inappropriate because it discusses making the choice. We don't want patients to have to further torture themselves. They are already second guessing their decision.

Beyond the technical and clinical information, the nurses think it is important for patients to have materials that they feel are an important part of the grieving work they must do after they are discharged. At each of the four hospitals, the nurses have created memento packages for their patients. These packages include photographs of the baby, handprints, footprints, weight and height descriptions and also the bonnet and blanket the baby was wrapped in. These memento packages are a relatively new service that nurses have for GT patients. The idea originated from nurses who care for families who have had a baby or young child die in hospital.

In three of the hospitals, the nurses took photographs with a Polaroid camera right after they had washed and dressed the baby. As already discussed, taking these photographs was a point of contention for the nurses. They argued that due to the poor

quality of the camera they could not take good pictures. A combination of the camera problem, the immaturity of the baby and the visible anomalies often resulted in photographs that were upsetting for parents to look at. The nurses were anxious about this since these were often the only pictures parents would have to remember their baby by. They argued that the pictures often did not resemble the baby that parents held in their arms.

The nurses at Central Hospital created a temporary solution to this problem. Whenever possible, they borrow a 35mm camera from another department in the hospital, take the photographs and give the roll of undeveloped film to parents. This serves a dual purpose. First, it ensures a better quality print and second, parents who are not emotionally ready to look at baby photos can develop the film when they are ready to do so. The nurses at Eastern Hospital did not have this concern because a social worker from the genetics department was responsible for taking these photographs.

Nurses at each of the four hospitals have had to create their own memento package. Many nurses also add their own special touches to these packages. For instance Sally said:

I put a rattle beside the baby when I take the picture. This gives an indication of the size of the baby. Usually, we just place a ruler or a surgical instrument there for measure, but that is so clinical. Then, when I prepare the memento package for the parents I will include the rattle as well.

For themselves as well, the nurses have created materials and educational resources designed to help them in the work they are doing. They do their own research collecting articles and information from nursing journals and other professional sources. They have

collected information on different types of anomalies, induction procedures, the latest research on prenatal technology and any information they can gather about the needs of GT patients and how they manage the procedure. All of this information is compiled in a manual that the nurses keep at the nursing station for easy reference. The GT nurses routinely go through the manual to keep abreast of new additions and they also refer to it when they have specific queries. The nurses have said that there is not a lot of information available on GTs in the journals particularly from the nursing perspective and the search for information can be very time intensive. Realizing the value of their own experiences in doing GTs, the nurses also record professional experiences and compile these as well in the manual. They may include a difficult experience they had encountered and how they managed it. They may also record information relayed to them by a helpful geneticist and cultural or religious information given to them by a patient.

CONCLUSION

It would be a mistake to assume that because nurses have developed ways to compensate for and deal with the many difficulties associated with doing GTs that they have given up on the possibility of institutional change. As Maryanne, a clinical nurse specialist stated:

There is a need for a standardization of care, a continuity of care. This must include a lot of communication between professionals.

Collectively the nurses continue to advocate at an institutional level for clearer procedures, more humane protocols and better ways of doing GTs. I have described some of their successes in this regard – particularly in relation to the implementation of protocols – in this chapter. But in their day-to-day work the nurses begin from the assumption that the large-scale changes are not going to happen quickly. One of the nurses, Sally said: “Nurses don't' expect change. They just deal with what's thrown at them” That, fundamentally, is what this chapter is about, how nurses deal with what is thrown at them. The nurses realize that they are on their own and that they must rely on their own devices and each other. Though they complain about their isolation, they have in fact taken advantage of it to create a routine for themselves that makes their work manageable and helps them to cope. By reworking their schedules and the normal division of labour on the ward, creating ways of dealing with various aspects of their tasks and developing the materials and resources they need to accomplish these tasks, GT nurses cleverly utilize their expanded responsibilities and their isolation from other medical professionals to establish a more successful working situation for themselves and for their patients.

The routines they have created serve multiple functions. They allow the nurses to look after their patients the way they want to do it, with personalized, individualized and continuous care; they allow the nurses to do their own emotion work. Finally, in important ways, they allow nurses to compensate for all the obstacles that exist in GT nursing. The routines fill in the gaps and allow the nurses to provide for each other what

they know they cannot expect any time soon from the institutions within which they work.

CHAPTER 8

CONCLUSION

This dissertation has looked at the various ways in which GT nurses experience their work as "*dirty work*" and at their responses to it. I began by describing the range of problems connected to doing GTs from the perspective of the nurses who are responsible for them. The problems are in many ways a function of how hospitals have chosen to structure the procedure and the negative institutional attitudes they display towards GTs. Though the hospitals have introduced GTs for fetal anomaly as part of an effort to be responsive to women's health care needs, their approach to GTs in fact suggests that there is a good deal of moral ambivalence about GTs at an institutional level. As a consequence the service receives low priority. It is work that most would prefer not to do or even to know about.

The task of managing GTs is left to a small group of nurses - nurses, ironically, who at least when they started doing GTs had only the most rudimentary of skills in overseeing the birth and delivery of babies. These nurses work with little training, few guidelines and procedures to guide their actions, little professional back-up and virtually no institutional support. Their calls for large-scale change in how GTs are done have gone, for the most part, unheard and unheeded. It is little wonder that they feel silenced, unacknowledged and unsupported.

Yet, as bleak as the conditions may be, the nurses have responded in a way that makes their work not only manageable, but for most, gratifying. First, rather than

dwelling on the "dirty work" aspects of their job, the nurses redefine GT nursing as a unique opportunity to practice nursing as they believe it should be practiced. GT nurses focus not on their problems, but first and foremost on their patients. In doing so, they are concerned with both the physical and emotional well-being of their patients. They try to ensure that their patients come through labour and delivery safely. They also try to deal with the emotional trauma that GTs represent in the lives of most patients and do what they can to ensure that a process of healing emotionally from the experience begins.

This caring strategy allows the nurses to constantly affirm for themselves the value of the work they are doing, even if the institution does not. The nurses respond to institutional indifference by redefining their work in a way that makes it important and valuable. GT work becomes the most noble of callings - a chance to deal with patients whose needs are great but who most hospital workers prefer to avoid.

Second, the nurses have developed routines that allow them to get the job done safely, effectively, and efficiently despite the lack of institutional support. They work around the many obstacles they face to provide the quality of care that they feel patients deserve and from which they derive so much professional satisfaction. There are routines for admitting patients and informing them about the procedure they are about to undergo, dealing with the crises that may arise during labour and delivery, responding to the birth of a live-born baby, dealing with the after-care of the babies, ensuring the privacy and security of their patients and so on. Combined, these routines allow nurses to successfully manage GTs without the presence of a doctor.

Looking more broadly at the experiences of GT nurses, there are two particularly interesting paradoxes. The first concerns the caring function. I have described how focused GT nurses become on caring for their patients and on seeing them through their hospital experience in a way that minimizes to whatever extent possible the physical and emotional pain that they must endure. But I have also described this caring function as a coping strategy for the nurses. In other words, to the extent that the nurses are looking after their patients, they are also looking after themselves. In being of service to their patients, protecting them, advocating for them, looking after them, crying with them, ministering to them and extending themselves in whatever way they can on their behalf, the nurses derive a sense of satisfaction that makes their job manageable. It is the quality of the care that they provide to patients that transforms their job from "*dirty work*" to "nursing as its best" and "nursing as it should be practiced." Put differently, while patients certainly benefit from the kind of care that GT nurses provide, the nurses derive benefits as well, benefits that are critical in terms of sustaining their commitment to their work. The nurses, as much as the patients, depend on the high quality of care connected to GT nursing.

The other interesting paradox concerns the relative isolation of GT nurses. The nurses recognize their isolation as a problem. They complain about being set apart both figuratively and literally from the rest of hospital life. They complain about being relegated to the back wards of the hospital where they are unseen and unheard. They complain about not being able even to talk to others about the work that they do.

What the nurses do not often appreciate is how their isolation is also a solution. It is their relative isolation that has given the nurses the latitude to redefine their task in a way that they find professionally rewarding and to develop routines that support those redefinitions. Knowing, for example, that a physician will not likely be present for a delivery puts nurses in the position of making clinical and ethical decisions based on their own professional sense of what is best for the patient. While acknowledging the stress that they experience as a result of their isolation, most GT nurses welcome the additional responsibility and the opportunity to exercise independent professional judgement. GT nursing provides them with many opportunities to do so. This was most apparent when nurses made decisions about caring for live-born babies, exercising their own clinical and ethical judgements.

CONTRIBUTIONS OF THE THESIS

This analysis of GT nursing contributes to knowledge on several levels, substantive, theoretical and methodological. At a substantive level, I have stressed in earlier chapters just how little attention GTs have attracted. Partly because GTs as a procedure are relatively new, but also because of the mystery and secrecy that surround GTs, there has not been much written about them or the health care professionals who do them. In focusing on the work of GT nurses, this dissertation sheds light on this much neglected development in health care.

More specifically, it provides a glimpse of GTs from the perspective of those health care workers most directly involved - the GT nurse. Up until now, to the extent that GTs

have been written about at all, they have been addressed from the point of view of the scientists and medical professionals who are responsible for implementing the technology, or the parents who have experienced them. This dissertation adds the voice of a group of central players. It presents a detailed picture of how this work is experienced by the nurses who do it. It describes the unique practical and ethical problems and dilemmas these nurses face. It provides an understanding of how these nurses see themselves and experience their work. It uncovers the strategies that they have developed for coping. It brings out into the open what has up until now remained largely hidden. In this sense the dissertation adds to the substantive literature in the sociology of health, the story of a group of health care workers that we have thus far known little about.

This information is useful, however, to more than simply sociologists. While a dissertation may not be the appropriate place to elaborate on them, there are many practical lessons and insights here about how GTs ought and ought not to be done. This is information that would be valuable to anyone involved in providing GTs and perhaps even to those going through the procedure. In Appendix D, I address the practical implications of this research in the form of a series of recommendations. The recommendations address such questions as how to reduce the possibility of professional burnout in this area of work, what sort of training - practical, cultural and ethical - to supply for nurses who will be involved in doing GTs, and how other professionals might be incorporated in a supportive way into the work of providing GTs.

Theoretically, the study contributes to many of the conceptual areas I outlined at the beginning of my dissertation. I began by describing symbolic interactionism - a perspective that in contrast to more structural approaches in sociology emphasizes the view of social actors and the role that they play in creating the meanings that become the contexts for their actions. In this instance, there is no denying the structural context within which GT nurses work. The institutional arrangements that have been made for the provision of GTs in hospitals and that determine the conditions under which GT nurses work have been largely out of the nurses' hands. In an important sense, these are the "givens" of the nurses' situation. The nurses have not played a major role in the decision-making about whether and how GTs would be incorporated into the hospital routine. Nor have the nurses had the power that other groups of professionals within the hospital setting seem to have to delegate to others work they prefer not to do themselves.

While the influence that the nurses have been able to exert at the institutional level may be minimal to this point, however, they have certainly not been passive or powerless. The story in this dissertation has not been about oppression and submission, but about resistance and agency. The nurses have resisted societal and institutional definitions of the work they do as "dirty" and morally suspect, and through their active caring have reconstituted it as work that is challenging and satisfying. The redefinition becomes an important element in the professional identity they develop. They see themselves not as "*dirty workers*" but as individuals in the privileged position of practicing nursing in its purest form. They see their careers as encapsulating "what nursing should be all about."

Nor have the nurses passively acquiesced to the circumstances of their work, particularly the institutional indifference that surrounds it. They continue to advocate at an institutional level for change. More importantly, in their day-to-day work they are constantly exercising agency. Amid the many obstacles and difficulties, the nurses have developed a number of creative and successful strategies to manage their work. The dissertation shows, then, how even under the most constraining of circumstances social actors find ways, through their definitions of the situation and their actions, to act back against the structures and forces that constrain them. Though they may not be able to change the objective conditions of their work, they have the power to subjectively redefine the work in a way that renders it meaningful and rewarding.

This dissertation also contributes to our understanding of "*dirty work*," filling out our appreciation of both what it is that makes work "dirty" and how those who do it respond to it. First, it underlines the importance of asking "dirty for whom?" and "why dirty?" While others may see GTs as *dirty work* because it involves a procedure that is morally suspect and involves death, for nurses the moral dimensions of GTs do not stand out as paramount. In fact, there was remarkably little talk from the nurses about the moral aspects of their work. Most of the nurses had separated how they felt about GTs from their responsibility as GT nurses. They had reconciled their moral views with their professional activities. This in itself can be viewed as an adaptive strategy. But the point here is that for the nurses the work was "dirty" because of the conditions under which they were required to do it - the lack of training, the lack of resources, and the lack of

support. These obstacles, as far as they were concerned, reflected their devalued and subordinate place as nurses within the hospital organization.

Work may be "dirty," then, because of its organizational context and the status hierarchy among workers that it reflects. Its negative features, for those who do it, may have less to do with its literal or figurative uncleanness than it does with the fact that the work is devalued by others and sloughed off to those who do not have the power to refuse it. The thesis links dirty work and organizational politics in a way it has not been linked before.

To the literature on adaptations to *dirty work* (Davis, 1993; Schneider-Conrad, 1980), this study adds insight about the strategies that workers in such situations use to manage the work. When it is institutional *dirty work* that is involved and when the workers to whom it is delegated are relatively powerless in organizational terms, how is such work managed? The dissertation suggests that workers' powerlessness does not extend as far as their capacity to define the work - if not the conditions under which it is done - on their own terms. Like other "*dirty workers*" (Thompson, 1993), these workers always have the power to redefine their tasks and themselves in more positive and valued ways. This study shows that they will make every effort to do so.

The dissertation also suggests that organizational *dirty work* comes with certain benefits that workers can use to their advantage. The more devalued the work, the more isolated the workers. While this social and organizational isolation certainly has its drawbacks, it also has a liberating quality, giving workers greater freedom to do the task as they see fit and to develop or alter routines accordingly. The isolation of GT nurses

has allowed them to create for themselves an opportunity to practice a more idealized form of nursing - to care as they feel nurses ought to care. In a profession that is for many an exemplar of a subordinated occupational group, they have taken the most challenging and difficult of circumstances and transformed them into a rarefied opportunity to practice nursing as they feel it should be practiced. Perhaps more than any other group of nurses in the hospital they have the freedom to practice independently and autonomously.

The usefulness of the concept of *dirty work* is also evident in that it has allowed for the identification of the problematic aspects of this work for nurses. The difficulties these nurses experience in doing this work can be viewed as expressions of the hospital system and its features, with a clear lack of regard for the role of the nurse.

This research, which has focused on a specific group of GT nurses, also has theoretical implications for nurses in general. Specifically, all nurses, on all hospital wards share a similar subordinate position in the hierarchy. They are compelled to do the work that physicians instruct them to do or themselves do not want to do. The ethical challenges of GT nurses may also intimate the ethical challenges of any caring, subordinate person who does *dirty work* in a large organization. As Chambliss (1996) stated, in trying to understand the ethics of nursing, we can begin to understand the ethical problems of many other low status workers as well.

Theoretically, this research contributes to the concept of *dirty work* by demonstrating that workers can acknowledge and accept their position as *dirty workers* in an organization. As a result of this realization, they are able to utilize that information in

a positive way to identify the problematic issues and create strategies to successfully manage their work.

Finally, the dissertation contributes to a more nuanced understanding of the negotiated order within organizations and links the literature on dirty work with the negotiated order perspective. In Chapter 1, I described the view of organizations not as rigid structures within which individuals play predefined roles in carefully prescribed and predictable ways, but as collectivities of workers negotiation their roles within the organization and constantly constituting and reconstituting the order that characterizes organizations (Strauss, 1978). The negotiated character of organizational orders is certainly demonstrated in this study which has had as its subtext the introduction of GTs in the hospital setting and the re-configuration of hospital organization and routines around the new procedure. To the extent that GTs are done in an orderly and routinized way in hospitals, it is because GT nurses have constructed or constituted that order.

Beyond demonstrating how organizational orders are constituted and how an institution and its worker adapt to change, however, the dissertation says something about the factors in an organization that may precipitate negotiation (Maines, 1977). Among the issues that workers may be negotiating is the doing of organizational dirty work. In any organization the more powerful players will have certain advantages in the process. Dirty work is likely to be delegated down the organizational ladder. Those to whom it is delegated will find ways to do the work and ways in which to make it meaningful for themselves. They will create new routines and re-create order. At the same time, however, they will be involved in a constant effort to re-negotiate current work

arrangements. While GT nurses have certainly adapted to the introduction of GTs on to their wards, at the institutional level they continue to advocate for changes including greater involvement on the part of others such as doctors, geneticists, social workers and bereavement counselors. To the extent that they have been successful in this regard, they have been precipitators of organizational change. Even disadvantaged workers, then, have negotiating power.

Negotiation was evident in that the nurses, as a result of their limitations have created strategies such as the 'help' code which they negotiate amongst themselves. By taking advantage of the realization that they are unsupported by other medical professionals, the nurses have devised their own support system in order to successfully care for their patients and manage the GT procedure. The nurses also continuously re-negotiate amongst themselves in order to continue to create the best possible GT procedure under limited circumstances.

Finally, methodologically, the dissertation demonstrates the merits of using a qualitative, grounded theory approach. As Glaser and Strauss (1967) have argued, researchers have an obligation to the actors they study, to give them a voice. As a group who have been little recognized or studied, as many said, "no one ever things to ask the nurses", the qualitative approach has allowed nurses to give a voice to their experiences. It was these experiences and the meanings that the nurses gave their experiences that allowed me to discover a number of relevant theoretical concepts and hypotheses as they emerged from the data, not by testing predetermined theories. These concepts and hypotheses uncovered a greater understanding of how and why these GT nurses act and

interact the way they do. As a result, qualitative, grounded theory analysis allowed for the generation of new knowledge as well as a contribution to existing knowledge of nursing and the social organization of work.

SUGGESTIONS FOR FUTURE RESEARCH

There are a variety of directions in which this research might lead. The qualitative approach taken in this research has yielded a rich data base essential to an understanding of how GT nurses manage their work. The dissertation has been useful in identifying both some of the key problems and some of the key coping strategies used by a particular set of nurses. This exploratory research should now give way to a broader sampling base. The four hospitals in this study were selected primarily for their geographic accessibility. There are eighteen other locations in Canada where GTs are being done. It would be interesting to see if nurses in other institutions face similar sorts of problems, and if so, if their adaptive strategies are similar to or different from those that I have uncovered. How generalizable across hospitals are the findings of this study? Have other hospitals found ways to introduce GTs that have avoided the difficulties confronted by the nurses in this study, and if so, have those nurses responded differently to their work? Are other nurses involved in doing this type of work as successful in accommodating themselves to the challenges and dilemmas that it presents?

Second, it would be interesting to follow nurses' experience of GT work over time. The whole area of reproductive technologies generally, and GTs specifically, is growing extremely rapidly. There were indications even over the course of this study of changing

patterns and trends. Perhaps the most significant of these is the steady increase in the number of GTs being performed and the range of genetic/medical problems for which GTs are being recommended. How nurses respond as GTs become more common and the advancement in this technology continues is worth tracking in a longitudinal study. How would the elimination of even the little degree of choice that nurses are now able to exercise in doing this work, affect their experience of their work?

It would be particularly valuable to go back at some future point to the same wards studied in this research to see if their conditions of work have changed and their strategies for dealing with their work have evolved. A specific question worth looking at would be how the process of routinization is unfolding and whether this process is compromising in any way the individualized care that nurses have sought to provide for their GT patients. To the extent that specific procedures are developed to deal with the range of eventualities that may arise in GT work, one would think that the nurses' capacity to see, and respond to, the unique needs of different patients would be limited. To the extent that this occurs, the nurses may feel more directed and less autonomous in their work. This in turn might result in less job satisfaction. In other words, the two coping strategies that the GT nurses have developed - individualized patient care and routinization - may eventually work at cross-purposes with each other. What impact would this have on how GT nurses experience their work?

A third possibility for future research that suggests itself as a result of this study has to do with how to approach the question of nurses' experience of their work. This study was based on intensive interviews. While there is no basis for suspecting that the nurses

were anything but open and honest in their responses - often remarkably so - their responses did often depend on retroactive interpretations of events and after-the-fact reflections. As rich as the data was, one wonders how much more detailed a picture might be gleaned from actually following the nurses around as they do their work and catching their responses *in situ*. A participant observation study of a GT ward has exciting possibilities. Of course, the problems connected to doing such a study would be daunting. There is first the issue of entry and the significant security concerns surrounding GTs. With the appreciation that this study has provided for the intensity of this work and the crises that can so easily arise, there is also the question of the appropriateness of intruding and perhaps adding to an already tense and harried situation. Assuming, however, that these barriers could be overcome, the payoffs in terms of the richness of the data would be great and would provide an opportunity to triangulate the results of this study.

A fourth direction would involve broadening the study not across settings or time, but across the social actors involved in the drama that GTs represent. This study has presented the story of GTs as seen through the lense of the nurses involved. It would be interesting to explore the perspectives of others, particularly geneticists, genetic counselors, social workers, chaplains and other support staff. It would appear from this study that these groups have the option in many instances of distancing themselves from the actual performance of GTs and direct contact with GT patients while they are at their most vulnerable. But it would be unfair to assume that they all do and that this is their intention. Looking at GTs, the issues they present and useful strategies for coping with

these issues from the perspective of these professionals would help to fill out our picture of the management of GT cases by health care workers.

There is also the perspective of the patient to consider. Much of this research has dealt with the goals that nurses strive for vis-a-vis their patients and with the kind of hospital experience they are trying to create for them. It would be interesting to see how GT nurses are viewed by their patients and whether from the perspective of their patients, the nurses are accomplishing what they set out to accomplish in terms of the quality of care they seek to provide.

A fifth, and related, possibility is to examine the broader social environment or context within which GTs are done. The nurses in this study assumed an ambivalent, if not openly hostile, institutional attitude towards GTs. They understood these attitudes to be a reflection of a more general societal ambivalence about GTs. It would be useful, therefore, in future research to explore public views of the procedure and to trace in more careful terms the impact that these views have on how GT work is done. This includes looking at institutional decision-making about GTs, and the factors that impinge on these decisions.

Thinking in more theoretical terms, comparative studies of a different type suggest themselves. This study has examined "*dirty work*" in one context. There are a variety of other contexts in which *dirty work* is done, both within nursing and beyond it. By looking for a comparable work situation - one where workers are seemingly powerless to resist certain difficult tasks and yet find ways to accomplish those tasks in efficient and rewarding ways - one could explore further the possibilities and limitations of the

adaptive strategies I have described here. One might find these and a range of other adaptive strategies that workers have developed in response. This would allow us to begin to build a series of generalizations about the kinds of strategies that may be used under different conditions and why they may or may not work. Rather than talking in terms of specific workers and specific job situations, we could begin to talk more generically about problematic work situations and workers accommodations and responses to them. In doing so we would be moving in the direction of ever higher levels of generalization and abstraction that grounded theory calls for.

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APPENDIX A

A1

Letter of Introduction and Explanation to the Study Presented to the Vice-President of Nursing of the Hospital

Dear.....

My name is Catherine Swanson. I am a Doctoral Candidate presently enrolled in the Ph.D. programme in Sociology at McMaster University in Hamilton, Ontario. As a requirement of the programme, I am planning a research study under the supervision of Dr. Dorothy Pawluch, professor of Sociology at McMaster University. The study is titled; The Process of Caring: Nurse's Perspectives On Caring For Women Who End Pregnancies For Fetal Anomaly. I am writing to request your permission to conduct a qualitative, grounded theory study in the Gynecological Unit and the Obstetrics Unit at the Hospital. The study will focus on talking with the nurses who care for women who end their pregnancies due to fetal anomalies.

The purpose of this study is to gain an understanding of the experiences of the Head Nurse and the clinical nurses in the units who care for these women. As I am sure you are well aware, ending pregnancies for fetal genetic abnormalities are no longer rare occurrences. Presently, little is known about how women experience a perinatal loss due to a genetic termination. Even less is known about the nurses perspectives and experiences as the primary care-givers. The information gained from this study may assist the health care team to intervene more effectively pre, during and post-termination. It is also hoped that this information will help to fill an important gap in the professional literature for the purposes of future social policy.

With your approval I would like to contact the appropriate unit(s) at the Hospital and arrange a time with the Nursing unit administrator to give a short presentation to this specific group of nurses. This will include an explanation of the nature and purpose of the study. At this time I will assure the nurses that participation is voluntary and completely confidential. My plan is to contact six hospitals in Toronto and surrounding areas who perform this procedure. Therefore it will be very difficult to identify respondents.

The nurses' participation will require one interview which will take place in a setting of the nurse's choosing.

The interview will be 1 to 2 hours in length. I will follow-up with a phone call one week later to clarify what they have shared with me and to allow them to share further comments if they wish to.

A brief, standardized introduction to the study will be provided for the nurses. With your approval, data collection will begin as soon as possible.

Enclosed please find a copy of my approved research proposal for your reference, a copy of the ethics committee approval from McMaster University, a copy of the standardized introduction to the study and a copy of the respondent consent form. In advance, I would like to thank-you for your time and consideration. I look forward to speaking with you at your earliest convenience.

Sincerely,

Catherine A. Swanson M.A.
Ph.D. Candidate
(905) 238-2658

June 3, 1998

A2

Chief of Genetics

Dear Dr.

My name is Catherine Swanson. I am a Doctoral Candidate presently enrolled in the Ph.D. programme in Sociology at McMaster University in Hamilton, Ontario. As a requirement of the programme, I am planning a research study under the supervision of Dr. Dorothy Pawluch, professor of Sociology at McMaster University. Dr. Pawluch may be reached at (905) 525-9140, ex. 23618.

The study is titled; The Process of Caring: Nurse's Perspectives On Caring For Women Who End Pregnancies For Fetal Anomaly. I am writing to request your permission to conduct a qualitative, grounded theory study on the Ward or Wards where this procedure is performed. The study will focus on speaking with the nurses who care for women who end their pregnancies due to fetal anomalies.

The purpose of this study is to gain an understanding of the experiences of the Head Nurse and the clinical nurses who care for these women. As you are well aware, ending pregnancies for fetal genetic abnormalities are no longer rare occurrences. Presently, little is known about how women experience a perinatal loss due to a genetic termination. Even less is known about the nurses perspectives and experiences as the primary care-givers. The information gained from this study may assist the health care team to intervene more effectively pre, during and post-termination. It is also hoped that this information will help to fill an important gap in the professional literature for the purposes of future social policy.

I have received approval from my thesis committee to proceed with this research and I have also obtained approval from the President's Committee On Ethics Of Research On Human Subjects from McMaster University.

With hospital approval I would like to contact the Nursing Unit Administrator of the Ward and arrange a time to give a short presentation to this specific group of nurses. This will include an explanation of the nature and purpose of the study. At this time I will assure the nurses that participation is voluntary, anonymous and completely confidential. A brief, standardized introduction to the study will be provided for the nurses at this time. I have contacted six hospitals in Toronto and surrounding areas who perform this procedure. Each respondent and hospital will be

assigned a number, no names will be used. In the final thesis only pseudonyms will be used.

The nurses' participation will require one interview which will take place in a setting of the nurse's choosing. The interview will be 1 to 2 hours in length. I will follow-up with a phone call one week later to allow the nurses to share further comments if they wish to. Data collection will begin as soon as possible.

I have spoken with Ms. _____ and I have sent her a copy of my research package to be presented at the Nursing Education and Research Council meeting this month. I understand that the hospital wide Research Committee will also be meeting in June. If the Committee requires additional copies of the proposal please do not hesitate to contact me at the number below. Enclosed, please find a copy of my approved research proposal, the approval letter from the President's Committee on Ethical considerations from McMaster University, a copy of the standardized introduction to the study and a copy of the respondent consent form for your perusal. In advance, I would like to thank-you for your time and consideration.

Sincerely,

Catherine A. Swanson M.A.
Ph.D. Candidate
(905) 238-2658

Letter of Introduction and Explanation to the Study
Presented to the Unit Administrator
of the Hospital

Dear.....

My name is Catherine Swanson. I am a Doctoral Candidate presently enrolled in the Ph.D. programme in Sociology at McMaster University in Hamilton, Ontario. As a requirement of the programme, I am doing a research study under the supervision of Dr. Dorothy Pawluch, professor of Sociology at McMaster University. The study is titled; The Process of Caring: Nurse's Perspectives On Caring For Women Who End Pregnancies For Fetal Anomaly.

The purpose of this study is to gain an understanding of the experiences of the nurses who care for these women. Professional literature addresses issues and concerns involved with prenatal diagnosis from the perspective of Canadian physicians, patient's, genetic counselors and of Canadians in general. What is not addressed in the literature are the perspectives of the clinical nurses who provide primary care to women who end pregnancies due to fetal anomaly. The goal of my research is to fill this void by including the voices of the nurses in the debate.

I have spoken with and she has given me approval to speak with the nurses in your unit. I would like to ask for your assistance in arranging to give a short presentation to the nursing staff who work with women in this capacity. At this meeting I will explain my study and give the nurses a chance to ask any questions or discuss any concerns they may have with regard to the research. I will also assure the nurses that participation is voluntary and completely confidential. My plan is to contact six hospitals in Toronto and surrounding areas who perform this procedure. Also, no one other than myself need know who has agreed or not to participate in this study. Therefore, it will be very difficult to identify respondents. I will also have a brief, written, introduction to the study available for the nurses to peruse. At this meeting I would like to begin to arrange interview times with those nurses interested in participating.

The nurses' participation will require one interview which will take place in a setting of the nurse's choosing. The interview will be 1 to 2 hours in length. I will follow-up with a phone call one week later to clarify what they have shared with me and to give them an opportunity to share further comments if they wish to.

Enclosed please find a copy of the standardized introduction to the study and a copy of the respondent consent form. Thank-you for your time and consideration.

Sincerely,

Catherine A. Swanson M.A.
Ph.D. Candidate
(905) 238-2658

**Sample of the
Letter of Introduction to the Study
to be Given to Potential Respondents**

My name is Catherine Swanson. I am a Doctoral Candidate presently enrolled in the Ph.D. programme in Sociology at McMaster University in Hamilton, Ontario. I am doing a research study under the supervision of Dr. Dorothy Pawluch, professor of Sociology at McMaster University. My study is titled;

**The Process of Caring:
Nurses' Perspectives On Caring For Women
Who End Pregnancies For Fetal Anomaly**

The purpose of this study is to gain an understanding of your experiences and perspectives as a medical professional caring for women who enter hospital to end a pregnancy due to fetal anomaly. In doing my research I have found professional literature which addresses issues and concerns about prenatal diagnosis from the perspective of Canadian physicians, patient's, genetic counselors and Canadians in general. It has become quite clear that your voice as the clinical nurse who provides primary care to these women is absent.

The goal of my research is to fill this void by including the voices of the nurses in the debate. I hope that the information gained in this study may assist the health care team to intervene more effectively pre, during and post-termination as well as to address some of the professional issues and concerns around a relatively new medical procedure.

If you would agree to participate in this study, I will talk with you in a confidential interview that will take between 1 and 2 hours of your time. Since to my knowledge, there has not been any research devoted to your particular nursing experience, the interview will be loosely structured in order to gather the information that is important to you as the nursing professional. I will begin by asking what your experiences of caring for women who have ended pregnancies due to fetal anomalies is like for you. The interview will then focus on these experiences in order to gather your views and concerns. The interview may take place in a setting of your choice, inside or outside of the hospital. One week after our interview I will contact you by telephone to give you an opportunity to share further comments with me if you wish to.

Please be assured that you are under no obligation to participate in this study by your supervisors or your place of employment. Your anonymity will be protected. Your interview will be assigned a number, no names will be used. In my thesis only pseudonyms will be used. I will be talking

with nurses from a number of hospitals in and around the Toronto area, hospitals also will be made unidentifiable. I will take notes during the interview and, if you agree, I would like to tape record the interview for purposes of clarity. The tapes will be kept in a locked cabinet and I will be the only one with access to them.

If you have any questions or concerns I may be reached by telephone anytime before or after the interview. I thank you in advance for your time and consideration in this important project.

Sincerely,

Catherine A. Swanson M.A.
Ph.D. Candidate
(905) 238-2658

INFORMATION FOR CONSENT FORM

You are being asked to consent to be interviewed with regard to a Ph.D. dissertation regarding nurses' perspectives on caring for women who end pregnancies for fetal anomalies. The interview will be between one and two hours.

There are a number of provisions which have been set in place to protect the confidentiality of your responses. First, the only identifying mark on this interview schedule is an identification number. This number is used to link together, for the purpose of analyzing the data. Second, the data that are obtained will be treated with utmost confidentiality and will be stored in a locked cabinet. Third, the results of this study may be reported in academic journals. In these reports, no individual or institution will be identified, only pseudonyms will be used and the data will be presented in a non-identifying, summary form.

Therefore, in consenting to participate in this study, you understand that:

- * You are entering into this study voluntarily.
- * You are guaranteed a pseudonym and a change of any identifying details.
- * The data will be kept in a secure place, and only the interviewer will have access.
- * There is no known risk anticipated, there may be potential discomfort due to the emotional nature of the topic.
- * Support will be offered by the investigator if needed.
- * There are no immediate benefits in participating, but benefits may result from the completed study.
- * You are free to refuse to answer any questions.
- * You are free to withdraw from the study at any time, even after the interview has been completed.
- * The study is being conducted independently from your institution of employment, except for the request to you for your participation.

CONSENT FORM

I have read the information sheet regarding the research on Nurses' perspectives on caring for women who end pregnancies for fetal anomalies, and I consent to participate in this study.

Signature:

Date:

**THE PROCESS OF CARING:
NURSES' PERSPECTIVES ON CARING FOR WOMEN
WHO END PREGNANCIES FOR FETAL ANOMALY**

Ph.D DISSERTATION PROPOSAL

**CATHERINE A. SWANSON M.A.
DEPARTMENT OF SOCIOLOGY
MC MASTER UNIVERSITY
HAMILTON, ONTARIO
APRIL 1998**

**THE PROCESS OF CARING:
NURSE'S PERSPECTIVES ON CARING FOR WOMEN
WHO END PREGNANCIES FOR FETAL ANOMALY**

STATEMENT OF THE SUBSTANTIVE PROBLEM

Prenatal diagnosis has transformed pregnancy and parenthood and has given rise to ethical and personal dilemmas that parents, medical professionals and society are only beginning to confront (Kolker & Burke,1994). The ability of prenatal tests like ultrasound, amniocentesis and chorionic villi sampling (CVS) to reveal information about a fetus means that women face unprecedented "choices" about the continuation of their pregnancies. Prenatal testing and genetic screening have aggressively extended beyond the ability of modern medicine to attempt therapeutic interventions for most of the conditions that testing can reveal (Kolker & Burke,1994;xiv).

After the conception of a child, genetic screening can discern the existence of several hundred genetic disorders. There are presently very few conditions for which in-utero treatment exists and there are no known cures available for the vast majority of abnormalities that are detectable prenatally. Thus, if an anomaly is identified, the most available options are to continue or to end a pregnancy, often in the second trimester. As well, social research indicates that the major focus is placed on these technologies as medical and scientific advances while much less importance is being placed on the social meanings and implications of these technologies for individuals in society.

Genetic knowledge, like all knowledge, is a social product which reflects the needs, desires and interests of a particular culture. The knowledge thus constructed meets the needs and desires of prominent groups in society. With

regard to prenatal technology, these dominant groups are within the scientific and medical professions. Medical discourse assumes that these genetic conditions are undesirable and thereby argues that pregnancy termination of certain prenatal conditions is a health benefit to individuals and a social benefit to society.

It is essential to recognize that the debate over prenatal testing and diagnosis; how it should be developed, used and regulated is much more than simply the appropriate use of the science and technology involved. The breadth of the debate extends from the nature of individual human identity to ethical and social issues which inform our society's values, attitudes, beliefs, commitments and myths, thus informing collective life and individual meanings.

A review of the literature indicates that the majority of research to date focuses on prenatal technology from the scientific and medical perspectives, particularly that of the physician. Much less, but a steadily growing number of studies, describe the perspectives of the women who use the technology, with a focus on the process involved in prenatal testing and of ending a pregnancy. Many of these studies focus on the ethical and social issues of informed consent and choice.

To date there has been no published literature which focuses on the nurse's perspectives and experiences surrounding care-giving to women who end pregnancies for genetic anomalies. These women are the medical professionals who are responsible for the primary health care of women as they undergo the lengthy, physically and emotionally painful procedure in hospital to end a wanted pregnancy. This analysis is intended to provide a comprehensive examination of meanings from the perspectives of these clinical nurses.

During the last two decades, prenatal screening and diagnostic procedures have become a widely accepted routine for "at-risk" women. Research has indicated that prenatal testing which indicates a fetal abnormality leads the

majority of women to end their pregnancies (Rayburn & LaFerla,1982; Faulkner,1990; Kolker & Burke,1994). The emotional impact of ending a pregnancy for fetal anomalies is thought by most professionals to be particularly significant as the woman may have developed a relationship with the "baby" when she learns of a fetal abnormality (Hall,1990; Clarke,1994; Kolker & Burke,1994), as fetal movements have been felt, and as the pregnancy is already apparent to others (Rothman,1993).

The role of the clinical nurse in prenatal technology is a critical one. These nurses are responsible, in many cases, for obtaining informed consent for screening tests in pregnancy, measuring patients' understanding of procedures and implications involved in the choice to undergo testing and possibly ending a pregnancy, and they are the primary practitioners during labour and delivery. It is argued in the sociology of professions literature that the performance of professionals generally and the professional work of nurses particularly, is greatly influenced by organizational and structural elements, as well as by social and cultural features in the society at large (Davis et al.,1975; Strauss, 1975; Roy et al.,1994).

Due to structural features characteristic of the profession of nursing, the work performance of the nurse would seem to be highly vulnerable to the influence of external elements. In the clinical situation of nursing, multiple relationships are formed among individuals of differing levels of authority, expertise and status (Davis et al., 1975:ix). These relationships constantly influence each other and consequently can often change the nurse's perspective in a clinical situation. For instance, the relationship between nurse and patient can easily affect the one between nurse and doctor; in turn, the doctor-family interaction is bound to affect the nurse-patient relationship. These complex relations are but one dimension in the work context. Other factors that particularly

influence the clinical nurse relative to prenatal technology, are the interactions with other practitioners such as the clinical geneticist, the genetic counselor, the Ob/Gyn and the Chaplain. These interactions in turn will influence work performance.

Presently, there is no formal education program for nurses who assist women in ending pregnancies for genetic anomalies. Neither is there a standard care program for other professionals involved. Consequently, when women enter hospital for a pregnancy termination due to genetic anomalies, nurses may be unaware of how much information has been presented to the patient, by whom it was presented, the patient's level of understanding of the implications and procedures, as well as the patient's own perspective of the situation. Furthermore, there is no standard procedure for visits from professionals such as the clinical geneticist, genetic counselor or Chaplain during the patient's hospital stay. Hospital stays can vary, generally between one and three days, dependent upon the length of labour, whether a woman needs a D & C after delivery or if there are any other medical complications. Some M.D.'s or genetic counselors may visit and possibly assist the nurse with emotional care of the patient, others may 'pop in for a moment' and still others may not visit the patient or may telephone the nursing station for an update on the patient.

The nature of the fetus's abnormality and the advancement of the pregnancy are also important dimensions which may impact the nurse's performance. A more advanced pregnancy (pregnancy termination's can legally be performed until the 24th week) can lead to a more difficult and possibly a more lengthy labour. The fetus as well is more developed the further along the pregnancy is. The fetus later in second trimester very much resembles a premature newborn (Overall,1993). The nurses are responsible for delivering the fetus, an M.D. need not be present as the fetus is not born alive. It can occur though, in rare

instances where the fetus is delivered live and dies shortly after birth. This is a potential situation which would be emotionally charged for parents and the nurse.

Cultural features such as social views regarding abortion may also influence the nurses' perspectives on their professional role. Many groups in society such as disability advocates, feminist scholars and bioethicists argue that these prenatal technologies carry social, moral and ethical implications that remain unaddressed within the scientific and medical framework. The ethical implications of abortion for abnormality is the subject of heated public debate, yet the ethical and psychological implications for the nurses who care for the women during labour and delivery are absent in the debate. Abortions are morally unacceptable to some and, in the wake of political and legal challenges and attacks on clinics and providers, abortion is increasingly unavailable and more risky for providers.

An examination of the literature on prenatal technology has clearly shown that there are a number of issues raised by critics of the dominant medical approach to prenatal technology which need to be addressed, particularly with regard to policy debate. These issues include (1) the meanings of informed consent, (2) the meanings of choice and (3) the social construction of the needs of women and families who are affected by this technology. Public policy questions are now being prepared to present to Parliament and may soon after be implemented. These future policies will have a dramatic effect on the lives of women, their families, caregivers and the future of Canadian society. It is necessary that before legislative policies are implemented in Canada that the technology and its implications are investigated, questioned, and analyzed from the many different viewpoints, including that of the clinical nurse. The nurse's viewpoint is important because nurses develop a set of beliefs about their work and the patients they care for. These beliefs may include notions

about the nature of the medical problem, the moral character of the patients presenting these problems, the kinds of help to give, and the conditions under which help may be given or withheld (Strauss,1975; Davis et al.,1975). This research hopes to show that not only do agency demands and goals shape the nurse's definitions of their patients and the kind of help they dispense, but that nurses may also be influenced by other social factors. An increased understanding of the nurses' experiences may enable not only the nursing professional, but all involved professionals to intervene more effectively throughout this medical procedure.

The education of nurses is viewed as a significant route to the improvement of providing health care (Davis et al., 1975). Thus, an examination of their primary position as providers of clinical care is an important route towards change. Speaking with nurses directly could initiate implementation of realistic guidelines based in part on nurses' own perspectives and needs in their clinical environment. This could possibly lead to changes in nursing education and subsequently to improvement in health care for patients.

THEORETICAL ORIENTATION

Within the discipline of sociology, symbolic interactionism is viewed as a theoretical perspective with a concomitant methodological orientation. Symbolic interaction is a paradigm which makes certain assumptions about the nature of reality, specifies concepts to be studied, interrelationships between concepts and suggests a methodological approach that is qualitative. Theory functions as a body of presuppositions which lead to an explanation of observable social phenomena.

Generally, qualitative research methods are utilized in exploratory studies to discover actors' perceptions and subjective meanings. This is in keeping with the symbolic

interactionist perspective, which rests on the assumptions that (1) interacting individuals produce their own definitions of situations; (2) individuals are capable of shaping and guiding their own and others behaviour and; (3) interaction is negotiated and often unpredictable. This perspective is considered to be symbolic because, in interaction it involves the manipulation of symbols, meanings and language (Denzin,1978:7).

The fundamental theoretical interest of symbolic interactionists is in acquiring a greater understanding of how and why individuals interact. In order to acquire this understanding, it is necessary to study the actors' meanings. Denzin (1978:13) argues that the research subject's perspective must be penetrated.

It is often only after the act has occurred that sense is made of it. In retrospective ways then, persons explain their behaviours...most interactional studies must aim for the development of explanatory accounts of behaviour sequences. And these accounts must be grounded in the retrospective explanations people give for their behaviours.

METHODOLOGY

As the symbolic interactionist perspective will be utilized in this research, qualitative methodology will be employed. The research will be designed using grounded theory methodology to gather in-depth, qualitatively rich data. The intent is to capture the social world as experienced by clinical nurses who provide care to women ending a pregnancy due to genetic anomalies.

Since, to my knowledge there has as yet been no research devoted to this particular nursing experience, it seems that a qualitative approach is the best way to begin, as it will allow me to gather descriptive data, rich in detail with which to hypothesize for further study. The

strategy used in qualitative research is characterized as inductive, subjective and process-oriented, while the strategy used in quantitative research is considered to be hypothetico-deductive, objective and outcome oriented (Reichardt & Cook, 1979:9). According to Kidder (1981:103) the inductive researcher "...begins with data and generates hypotheses and a theory, from the ground up", while with the hypothetico-deductive method, "the researcher begins with a theoretical framework, formulates an hypothesis, and logically deduces what the results of the experiment should be if the hypothesis is correct." From these definitions, we can construe that different techniques offer different types of social explanations. In most research questions an argument can be made that there is a need for both.

As the focus of this inductive approach is to generate hypotheses from data for more rigorous testing, the observations made in this study can be addressed in future research, using a more hypothetico-deductive research approach. The method of inductive research emphasizes the discovery of individual perspectives wherein meanings are constructed as the research progresses. Glaser and Strauss (1967) argue that the perspective of grounded theory maintains that social theory is an ever developing entity involving a progressive mounting of empirical facts into a grounded formal theory. By allowing substantive concepts and hypotheses to emerge first, the researcher is then able to ascertain whether there is an existing theory that may assist in generating new substantive theory. Glaser and Strauss further claim that this results in a method which is more "faithful" to the data. Rather than forcing the data to fit an existing theory, it allows the generation of new formal theories and the reformulation of existing sociological theories.

Gaining Entrance To The Organization

After thesis committee approval and acceptance by the McMaster University Ethics Committee, a letter requesting permission to conduct this research study and a copy of the research proposal will be sent to the the appropriate administrators and/or committees at a number of hospitals in Toronto and surrounding areas with genetic centres. A letter explaining the nature and purpose of this study will also be sent with copies of the research proposal to the nursing unit administrator of the gynecological unit and/or the labour and delivery unit dependent upon how each hospital is organized. Upon approval, I will make a presentation to each nursing unit, inviting the head nurse and the clinical nurses to participate. During this presentation I will assure the nurses that their participation is voluntary and confidential. I will assure them that the head nurse/supervisor will not know whether they participate or not in this study. This is to help ensure that the nurses feel no actual or perceived coercion to participate or not in the research. At this time I hope to be able to schedule interviews for those nurses who are interested in talking with me.

Interview Method

Data will be gathered through intensive, non-directive interviewing. The interviews will be unstructured, interactive and tape-recorded with the respondent's consent in order to gain in-depth information. This format will offer the participants the most control over the interaction with the researcher (Kirby & McKenna, 1989). Participants will be informed about the nature of the research, and they will be able to ask questions before they consent to an interview and sign the consent form. The planned uses of the information and issues of confidentiality will also be explained.

I will ask the nurses to consent to one interview of approximately one to two hours in length, and a follow-up phone call two weeks later in case there is anything else they would like to share. The interviews will take place at a spot designated by the respondent as the hospital may not be the most comfortable place for the women to discuss such sensitive issues. The interview will begin with the open-ended question; "Could you tell me what the experience of caring for women who end pregnancies for fetal anomalies is like for you?" This interview will follow the lead of the participants in order to gather their major viewpoints and concerns. A loose interview guide will be utilized containing general questions which may be useful for categorizing the data as the research progresses.

The second interview will also begin with an open-ended question; "Since our last interview, have you thought more about any of the things we discussed or do you have any other ideas you would like to share about your experiences?" This interview will be modified in order to address emerging concepts and themes as the study progresses.

IMPLICATIONS FOR THIS RESEARCH

This study will have implications for both a further understanding of the consequences of medicalization and nurses' work. Those studying medicalization typically focus on how medical professionals readily define emerging concerns as medical problems that belong within their professional domain (Conrad & Schneider, 1980; Zola, 1972, 1975). To date this has not included definitions from the nursing professionals.

The research will also have implications for the practice of members of the health care team involved with prenatal technology, particularly nurses working in prenatal diagnosis units, labour and delivery suites, and on gynecological units. Nurses may find that they can play a

vital role in the physical and psychological care of both women and their families during the genetic termination procedure.

This research will have further implications for social policy. The issues and concerns involved with prenatal technology are being prepared to go before the Canadian legislature. It is important to analyze the many issues and perspectives with a view to possibly correcting the present imbalance and ensure that the social and moral implications are clearly understood from the perspective of all involved in the technology. The Royal Commission Report on Reproductive Technologies(1993) addresses issues involved in prenatal diagnosis from the perspective of Canadian physicians, patient's perspectives, genetic counseling as well as from the perspective of Canadians in general. What is not addressed in the report are the perspectives of the clinical nurses who provide the primary care to women who terminate a pregnancy for genetic anomalies. Until this important group is included in the literature, the research can be considered incomplete.

APPENDIX B

BI

THE PROCESS OF CARING: NURSES' PERSPECTIVES ON CARING FOR WOMEN WHO END PREGNANCIES FOR FETAL ANOMALY

INTERVIEW GUIDE
CATHERINE SWANSON
JUNE 1998

Opening Question: Can you tell me what the experience of caring for women who end pregnancies for fetal anomalies is like for you?

This study will explore the impact of the following:

1. Organizational and structural elements.

Potential questions:

a) Would you explain to me the details of the procedure that you follow upon admitting a woman to hospital for a pregnancy termination?

b) What types of support are offered to these parents through the hospital?

c) How would you define the professional code of nursing ethics?

2. The nature of the termination and its impact.

a) Have your experiences in doing this work influenced how you feel about this procedure?

b) Would you say that the way you relate to your patients varies with each situation and the individual people you are caring for?

c) Do you feel you receive professional support in doing this type of work?

3. Relationships with other professionals.

a) Are there other professionals that you are in contact with before, during and after the patient's hospital stay?

b) Can you explain these relationships to me?

c) How do you view these relationships?
Are you satisfied with these relationships?
Are there any changes you would like to see made?

4. Views on abortion and religion.

a) Do your religious views influence how you feel about doing this type of work?

b) Do your views on abortion influence how you feel about doing this type of work?

c) Do you think people perceive ending a pregnancy for fetal anomaly differently than abortion for other reasons?

d) Does the gestation of a pregnancy change how you view the procedure?

5. Nurses' assessment and beliefs of the technology and the patients.

a) What is your assessment of this technology from your professional position as a nurse?

b) Why do you feel this way?

c) What is your assessment of this technology from your patient's perspectives?

d) Why do you think they feel the way they do?

e) Do you have any concerns about this procedure?

THANK YOU LETTER
SENT TO RESPONDENTS

304 Daphne Avenue
Mississauga, Ontario
L5A 1M6

Dear

Please accept my sincerest thanks for your participation in my research on nurses and genetic termination for fetal anomaly. The information and thoughts you so openly and honestly shared with me were invaluable to the writing of the final study.

I am sending you a copy of the final study results. Please do not hesitate to contact me at the address above if you have any questions or comments. Once again, thank you for your efforts in this work. With much respect and admiration, good luck to you now and in the future.

Sincerely,

Catherine A. Swanson
M.A. Ph.D. Candidate

PERINATAL BEREAVEMENT CHECKLIST

A checklist for assisting families experiencing newborn death, stillbirth and miscarriage.

DATE	TIME	BEREAVEMENT ISSUES	SIGNATURE
		Baby Named: _____ No ___	
		Saw baby at birth and/or after death? Mother Yes ___ No ___ Father Yes ___ No ___ Others Yes ___ No ___	
		Touched and/or held baby before/after death? (please circle) Mother Yes ___ No ___ Father Yes ___ No ___ Others Yes ___ No ___	
		Baby Baptised? Yes ___ No ___	
		Autopsy Consent Signed? Yes ___ No ___	
		Remembrances: Pictures taken: Yes ___ No ___ N/A Given to Parents: Yes ___ No ___ N/A Baby Beads: Yes ___ No ___ N/A Crib Card: Yes ___ No ___ N/A Baby Blanket: Yes ___ No ___ N/A Infant Clothing: Yes ___ No ___ N/A Footprints: Yes ___ No ___ N/A Hair: Yes ___ No ___ N/A Other:	
		Family aware of responsibility for burial. Yes ___ No ___ N/A If baby less than 20 weeks family aware of option for burial. Yes ___ No ___ N/A	
		Funeral/Burial Arrangements discussed. Yes ___ No ___ N/A Referred to _____ for further information.	
		Perinatal Bereavement Yes ___ No ___ Package Given Yes ___ No ___	

NAME _____ TELEPHONE NUMBER _____

PREGNANCY HISTORY

Gravida _____ Para _____ Premature _____ Multiple _____

Miscarriage _____ TA _____ SB _____ Neonatal Death _____

Other pertinent information: _____

PRESENT PREGNANCY

EDC _____ Actual Date of Delivery _____

Obstetrical Problems: _____

Delivery: Spontaneous _____ Assisted _____ C/S _____

BABY DEATH

Baby's Name _____

Gestational age _____ Weight _____

Ectopic _____ Miscarriage _____ TA _____ SA _____

Admitted NICU _____ Transferred from: _____

Cause of death: _____

Date of infant death: _____

BEREAVED FAMILY PROFILE

Father's name (if known) _____ Other children: _____

Families' response to the loss: _____

Identified Support Systems: _____

Specific issues for family: _____

Other pertinent information: _____

DATE OF DISCHARGE OF MOTHER: _____

FOLLOW-UP

Name of physician who will provide follow-up: _____

Other Health Care Professional to provide follow-up: _____

Public Health Referral Yes ___ No ___ Reason if no Referral Made _____

~~When patient is discharged please remove from chart and place into the second drawer in the bereavement filing cabinet.~~

PERINATAL LOSS CHECKLIST (Multidisciplinary)

C2

Loss Now:

- Miscarriage
- Stillborn
- Newborn

Weeks Gestation _____

Previous Loss:

- Miscarriage
- Stillborn
- Newborn

Weeks Gestation _____

Reason for Admission/Circumstances surrounding loss:

*Note: Progress notes should reflect assessment, actions taken, patient/family responses and evaluation

Check to indicate completion

Chart

Signature/Date

1. Informed that baby is dying/has died by: _____
(name)

- Mother
- Father
- Others _____

2. Discussed anticipated course of pregnancy, labour and delivery including pain control with:

- Mother
- Father
- Others _____

3. Discussed possible appearance of baby at delivery with:

- Mother
- Father
- Others _____

4. (Neonatal) Prognosis of infant discussed by:

(name)

5. (Neonatal) Withdrawl of treatment discussed (if applicable) by:

(name)

6. Saw baby when born or at time of death

- Mother
- Father
- Others _____
- declined
- declined
- declined

7. Touched or held baby

- Mother
- Father
- Others _____
- declined
- declined
- declined

PERINATAL LOSS CHECKLIST (Multidisciplinary)

Check <input checked="" type="checkbox"/> to indicate completion	Chart	Signature/Date															
8. Baptism <input type="checkbox"/> To be done <input type="checkbox"/> Done <input type="checkbox"/> Not applicable																	
9. Baby Named: _____ Weight: _____ Sex: _____																	
10. Memory Packet <table border="0"><tr><td></td><td>Given</td><td>On File</td></tr><tr><td>Polaroid Picture</td><td><input type="checkbox"/></td><td><input type="checkbox"/></td></tr><tr><td>I.D. Bracelet</td><td><input type="checkbox"/></td><td><input type="checkbox"/></td></tr><tr><td>Crib Card</td><td><input type="checkbox"/></td><td><input type="checkbox"/></td></tr><tr><td>Other Keepsakes</td><td><input type="checkbox"/></td><td><input type="checkbox"/></td></tr></table> Specify: _____		Given	On File	Polaroid Picture	<input type="checkbox"/>	<input type="checkbox"/>	I.D. Bracelet	<input type="checkbox"/>	<input type="checkbox"/>	Crib Card	<input type="checkbox"/>	<input type="checkbox"/>	Other Keepsakes	<input type="checkbox"/>	<input type="checkbox"/>		
	Given	On File															
Polaroid Picture	<input type="checkbox"/>	<input type="checkbox"/>															
I.D. Bracelet	<input type="checkbox"/>	<input type="checkbox"/>															
Crib Card	<input type="checkbox"/>	<input type="checkbox"/>															
Other Keepsakes	<input type="checkbox"/>	<input type="checkbox"/>															
11. Autopsy consent <input type="checkbox"/> Signed <input type="checkbox"/> Declined <input type="checkbox"/> Further discussion requested Report to be sent to: _____																	
12. Burial Arrangements 1) Parents informed of need for burial by _____ (name) <input type="checkbox"/> Not applicable 2) Arrangements discussed <input type="checkbox"/> Yes <input type="checkbox"/> Further discussion required																	
13. Accomodation planned after delivery <input type="checkbox"/> Antepartum <input type="checkbox"/> Postpartum <input type="checkbox"/> Discharge home																	
14. Perinatal Loss Resource Package <input type="checkbox"/> Given																	
15. Social work notified <input type="checkbox"/> Yes																	
16. Clergy notified <input type="checkbox"/> Yes <input type="checkbox"/> Declined <input type="checkbox"/> Deferred Name of Clergy _____ Phone # _____																	
17. Public Health Nurse <input type="checkbox"/> Yes <input type="checkbox"/> Notified																	
18. Who will be providing follow-up care? (Family Doctor, Neonatologist, Obstetrician) Name and Address: _____ _____																	

CHECK LIST FOR GT PATIENTS

C3

1. Patient Information Sheet received from Genetics.
2. Tent and gauze inserted by M.D. in Amnio Suite.
3. Tent and gauze removed Time: _____
4. Fetus delivered Time: _____
5. Placenta delivered Time: _____
6. Fetus and Placenta examined by Doctor: _____
Genetics: _____
7. Fetus and Placenta sent to Pathology.
8. Patient requires Rhogam. Time given: _____
9. Documentation completed to reflect above.

ADMISSION

You will be telephoned regarding the exact day and time of admission. Please report to PATIENT RECEPTION in the main lobby of the hospital once you have received this information.

ADMISSION TO THE WARD

The Nursing staff will go over some essential paper work with you.

This includes: -consent for induction of labour (required)

-consent for autopsy (if applicable)

The nurse will also ask your decision regarding arrangements for the baby after the delivery. You can arrange for a private burial or cremation in which case the nurse can put you in touch with the appropriate people who can help you make these arrangements, or you can choose to have the hospital take care of the remains. The nurse will also ask you if you prefer the term "baby" or "fetus". You will also be given the option to see the baby after the delivery.

HOSPITALIZATION

The duration of your hospital stay can be anywhere from 24hrs to 4 days. We cannot predict how long your particular labour will be. Most people are here for about 2 days. The procedure you will have done is called amniocentesis and involves the insertion of a needle into the womb and withdrawing about 2 tablespoons of fluid. Chromosome analysis will be done on this fluid. A synthetic hormone will be introduced into the womb using the same needle. Occasionally this procedure will have to be repeated if cramping has not started within 24hrs or if labour stops. After delivery the Obstetrician will check to make sure the placenta has been expelled. If not, you may have to go to the operating room to have a procedure called a D & C to remove the remainder of the placenta. Your nurse will be able to answer your specific questions.

DISCHARGE

Women commonly experience swelling and tenderness of the breasts as one would if one had a miscarriage at this stage of pregnancy. It may take as long as six weeks before menstruation resumes normally. Many couples find this experience affects them in different ways. If you feel you are having difficulties that are not resolving themselves, please feel free to contact us as we have a team of professionals available to help you. Our phone number is (416) 820-4104. If you experience health problems or have medical concerns afterwards, contact your family doctor. The genetic counsellor will call you at home a few weeks after you have left the hospital. However, you may call us at any time.

GLOSSARY OF TERMS**PRENATAL DIAGNOSTIC TECHNIQUES**

The prenatal diagnosis of a genetic condition is a two-step process. The first involves gathering information or material from which a diagnosis can be made. This may require an invasive procedure, such as amniocentesis or taking a biopsy in the case of CVS. Ultrasonography is also a first-step technique that can yield substantial information on the status of the fetus and the pregnancy in general. The second step involves the laboratory analysis and interpretation of information to reach a diagnosis. (Royal Commission Report on New Reproductive Technologies. 1993 Volume 12, p.5)

AMNIOCENTESIS

Amniocentesis is the most common invasive prenatal diagnostic procedure in Canada. It is normally carried out between 15-17 weeks gestation. The pregnant woman is given a local anaesthetic and a needle is inserted through her abdominal wall and into the cavity of the uterus. A sample of amniotic fluid which surrounds the fetus is withdrawn. The extracted fluid contains fetal cells which are artificially cultured and analyzed with chemical and microscope tests for chromosome abnormalities such as Down's syndrome, neural tube defect and biochemical (metabolic) abnormalities.

The most common reason for doing amniocentesis is advanced maternal age - 35 years of age or over. Maternal risks are low and considered minor. These include vaginal bleeding, amniotic leakage, abdominal cramping, and nausea. Risks to the fetus include needle puncture, damage to the umbilical cord, placental separation, infection of the amnion and placenta, premature labour, and spontaneous abortion. Studies have reported spontaneous abortion rates of between 0.25 percent to 5 percent.

CHORIONIC VILLUS SAMPLING (CVS)

CVS is the sampling of tissue from the membranes that surround the fetus. The sample is taken by suction through a tube inserted into the uterus through the vagina or through the abdominal wall. This fetal tissue can be biopsied between the eighth and twelfth weeks of gestation. CVS detects the same defects as amniocentesis, except for neural tube defect. By comparison CVS has a number of advantages. Chorionic villi contains cells that are actively dividing, and, therefore can be used immediately for cytogenetic analysis without the need for culture. This permits earlier diagnosis, saving weeks of anxious waiting for results and termination is a much safer procedure and less

stressful when done in the first trimester. The major disadvantage of CVS is *mosaicism* (the presence of two cell lines in the culture), which happens frequently, leading to difficulties of interpretation and the need for clarification by amniocentesis. It also carries the risk of miscarriage.

MATERNAL SERUM ALPHA-FETOPROTEIN TEST (AFP)

This is a blood screening test which is different from a diagnostic test. Screening shows who may have a higher or lower chance of having either Down syndrome or neural tube defect. This test cannot tell if the fetus actually has these, only further testing such as ultrasound or amniocentesis can show that.

A small sample of the pregnant woman's blood is taken at about 16 weeks gestation. The amount of certain substances in the blood; estriol, alpha-fetoprotein and chorionic gonadotropin are measured. An unusual amount of these substances suggests a higher chance that the fetus is affected. Although 8 out of 100 women have a positive test result, most times these are *false positive*, meaning the fetus does not have Down syndrome or neural tube defect. The reason for this is unknown.

SCREENING TESTS

Screening tests are designed to be offered to all pregnant women, not just those at higher risk. If an abnormal test result is revealed in one of these screening tests, the woman is at higher risk of having an affected fetus and would then be offered a diagnostic test to provide a definitive diagnosis of the condition of the fetus.

ULTRASONOGRAPHY

In medicine, high frequency, low intensity sound waves passed through the body are converted into electronic signals that are displayed on a video screen. Ultrasound for PND has three main purposes: (1) direct examination of the external and internal body structure of the fetus, to estimate size and look for malformations of skeletal and other major organ systems; (2) as an adjunct to other PND techniques to enhance safety and accuracy - for example, to guide the needle for amniocentesis; and (3) to obtain general information about the pregnancy, such as gestational age, location of placenta and presence of multiple fetuses.

The clinical value of ultrasound is widely accepted. All centers employ its use for PND procedures and it is a routine part of obstetric care. Safety has been the subject of debate. Some authors contend that its widespread, indiscriminate, routine use has proliferated without extensive critical assessment. Yet, the literature suggests otherwise. These studies show no deleterious effects, there is no evidence of increased fetal death, abnormality or intrauterine growth retardation.

FETAL ANOMALIES

DOWN'S SYNDROME (Trisomy 21)

Individuals with an extra chromosome no.21 are born with this condition, where there are characteristic physical features and a greater susceptibility to certain medical disorders, such as heart problems. Each person with Down syndrome is different. Many have productive lives, some have very limited physical and mental capabilities. There is no way to predict how serious any of the disabilities may be.

NEURAL TUBE DEFECT (NTD)

The neural tube is formed early in the development of the nervous system, at about five weeks in the human fetus. NTD's are thought to occur when the neural tube fails to form properly, the brain or spine does not develop properly. There are two kinds of NTD's, spina bifida and anencephaly. Little is known about the causes.

Spina bifida - is an opening in the bones around the spinal cord. Usually the opening is not covered by the skin. It can lead to mental and physical disabilities. Each person is different. Persons with spina bifida may not walk and may not be able to control their bladder or bowels. Usually they have hydrocephalus, water on the brain. There is no way to predict how serious the problems will be, some people lead productive lives.

Anencephaly - the fetus is missing much of the skull and brain. A baby with anencephaly will die shortly after birth.

RECESSIVE CONDITIONS

To inherit a recessive condition, people must receive copies of the relevant allele, or form of the gene, from both parents. If they inherit only one copy from one parent, they generally show no symptoms and are considered carriers for the condition. Four familiar recessive conditions include;

phenylketonuria (PKU) - a metabolic problem that can result in mental retardation.

Cystic fibrosis - a glandular disturbance that leads to the accumulation of mucus in the lungs and repeated infections.

Tay Sachs disease - a fatal neurological disease of young children. Prevalent in Ashkenazi or east European Jewish descent.

Sickle-cell anemia - a blood disease that can be extremely painful and disabling. Prevalent in African Americans.

PROCEDURES

CURETTAGE

This is a scraping of the inside of the uterus to remove its contents. Following pregnancy termination by labour induction, it is common for the placenta to not adequately separate. This is particularly so in pregnancies of less than 24 weeks gestation, owing to the premature nature of development. If the placenta does not separate on its own or if excessive bleeding occurs, a curettage is done. Since the cervix is already dilated, a curette is used to scrape the inside of the uterus to remove the remaining placenta. Retained placenta can cause bleeding and infection. Anesthesia such as a spinal, epidural, local or general will be administered.

DILATION & CURETTAGE (D&C)

A pregnancy termination procedure that can be done up to 14 weeks gestation. The cervix is dilated and a curettage is performed.

DILATION & EVACUATION (D&E)

A surgical technique for pregnancy interruption that involves dilation of the cervix and removal of the pregnancy from the uterus. It can be safely done from 15-20 weeks gestation and by an experienced physician, performed up to 24 weeks gestation.

An advantage of D&E is that it is an outpatient procedure that can be done in 30-45 minutes. It is less expensive than an induction procedure done in hospital. A disadvantage is that the fetus is not removed intact and consequently a full autopsy cannot be done.

SOCIAL ABORTION

A term adopted by North American society that refers to an abortion of an unwanted pregnancy, in the first trimester of pregnancy.

APPENDIX D

RECOMMENDATIONS

Notwithstanding the resourcefulness, competence and moral independence exhibited by the GT nurses, the situation in which they are required to work is ethically problematic. First, the issue of professional burnout from stress is high. The nature of the work itself raises this probability: but when the work is unacknowledged, unsupported and silenced, burnout is almost inevitable. Furthermore, given that genetic terminations are on the rise, the frequency with which willing nurses are required to manage them will increase, thus exacerbating the risk of professional burnout. It would be far better to acknowledge, support and reward this work. This may attract other nurses who may positively accept the expansion of responsibility.

Second, the absence of cultural and ethical training results in this work being more stressful on the nurses than it needs to be. Adequate preparation would mean that nurses would not be required to process information and make judgements on the spot, without a framework to guide them. When their judgements are good, they would have the confidence in themselves that technical training brings. Conversely, when a judgement is less than optimal, this shortcoming would not be unfairly privatized.

Third, assimilating genetic termination work with general nursing care denies nurses the recognition they deserve for managing a clinical procedure which, in the context of a viable birth, is recognized as requiring the expertise of a physician. Ambiguity about who is really 'handling the procedure' contributes to the downgrading

of nursing responsibility for GTs. Clarity and the negotiated assignment of roles would be preferable to the current blurring of roles.

Fourth, traditional bioethics does not acknowledge the important role played by nurses in ethical decision-making. These are decisions that are constrained by the social structure, cultural settings, social interaction, gendered conceptions, professional relationships and arrangement of power and prestige. The inclusion of the sociological perspective in the ethical debate would situate ethical decision-making in the larger socio-historical context. The sociological perspective would support the argument that there is a place in ethical decision-making for the emotionally invested, attentive worker. This study has shown that GT nurses are capable of using their relationship with their patients to guide them in ethical decision-making. As a result, each patient remains a unique individual and routine patient care may assume a new form.

Furthermore, as Leininger (1990) has argued, there is a need to develop ethical guidelines and practices for nurses to be better able to care for their patients. A beginning ethical knowledge base should be established for GT nurses and for nurses who need and want to explore new ethical care perspectives. This is of particular importance in gaining knowledge of diverse cultures in Canada. This may well prevent many intercultural problems nurses now face such as imprudent actions and inappropriate cultural imposition practices.

Fifth, whether others acknowledge it or not, patients are experiencing reproductive loss and grief. Appropriate facilities should be provided to support the emotion work for nurses. Extra staff should be provided so that the mutual support system that the nurses

have developed can be strengthened. Furthermore, both the emotion work involved in handling genetic terminations and the support sought by nurses as they manage this complex procedure, could be facilitated by expanding the involvement of other care providers. Geneticists, social workers, chaplains and even ethicists could help nurses 'debrief' in productive ways by sorting out conflicting emotions and identifying moral conflicts.

Nursing stress over cross-cultural care could also be eased by consulting social workers, who often receive specialized training in cross-cultural interactions. The emotion work of nurses could be furthered by social workers as well, as they are in a good position to enact follow-up with clients after they leave hospital. Such follow-up could benefit nurses as well as clients, as nurses often express a desire to know how the patient is doing after discharge. Networking among nurses, social workers and clients that crosses the boundaries between hospital and society, could perform the important function of demystifying the termination experience, thus reducing the secrecy which is so damaging for all.

Sixth, an adequate language for expressing the experiences of the care providers and the patients needs to be developed. The appropriate language should come from the patients and the nurses who share the experience and can dialogue about it. Perhaps better training in cultural, ethical and professional aspects of the procedure would permit an appropriate language to develop.

Seventh, there is a need for a national, standardized procedure to develop for genetic termination. This standard should include all health care workers involved in the

GT procedure. For instance, beginning with prenatal testing which would include the presentation of patient information and procedure, clinical practice and continue through to follow-up patient care after discharge from hospital. This would lead to more clarity over role responsibility.

Eighth, there is a need to distinguish between privacy and secrecy around genetic termination. There are two aspects of privacy which are important to preserve. First, is the patient's right not to have information about herself and the procedure disclosed; and second is the privacy of the nurses. Their identity and the fact that they manage this procedure, for reasons of personal security should be respected. With regard to secrecy, it is institutional, social and systemic secrecy that prevents necessary notice, recognition, training, support and remuneration for nurses from taking place. Secrecy actually serves to put nurses more at risk, since no acknowledgement of what is ensuing is offered.

Finally, the experiences of nurses providing this specialized care; their frustrations, innovations and successes in preserving integrity while providing good nursing care, should form part of the developing ethics of nursing. In articulating their professional and ethical experiences, nurses will aid other nurses in the development of their professional and ethical skills. They may also play an important role in building up an alternative discourse, neither medical or political, in which patients may begin to express their grief. Thus the facilitation of nursing integrity will converge nurses' emotion work around this currently hidden, caring activity.