Wound Care: Patients' Perceptions of Self-Care Learning Needs

by

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ABSTRACT

Today, patients are being discharged from hospital, as soon as they are able to manage their activities of daily living, and wound care if applicable. They are taught the particulars of wound care by nursing staff, but it is not known how they actually manage once they get home.

The purpose of this exploratory research was to begin to understand the patients' experience in caring for their wound at home and to understand their perceived learning needs to accomplish that specific task.

Four patients who required self-care of their wound (including incision care, dressing changes and managing a drainage tube) were individually interviewed to determine their experiences with wound care once they were home. One participant was interviewed with his wife who was the caregiver. Interviews took place one to two weeks after the patients' discharge from hospital. Two patients were interviewed once, one was interviewed twice in person, and once on the telephone, and one was interviewed once in person, and once on the telephone. Each face-to-face interview was tape-recorded and transcribed for thematic analysis. Additional contextual data was obtained by interviewing nurses who were responsible for preparing the patient for discharge, and by the researcher's observations regarding the patient participant's actual wound management in the home. Of the four patient participants, three had Jackson-Pratt drains as well as their incisional dressings. One participant had a gastrostomy tube and incision.

Principles of adult learning and the concept of psychoeducative care were incorporated into the analysis of the data. Psychoeducative care is that educative nursing function that meets the skill, informational and support needs the patient requires to perform self-care.

Five themes emerged from the study. “Normalcy” was their need to return to regular life, a return to feeling normal and well. “Decision and control” was the patients need for the ability to make decisions and have some control over events and circumstances. “Learning to do wound care” was their learning needs around managing their wound at home. “Help after discharge” was the need for some kind of resource to be accessed after discharge. “Pain management” was a need for information and resources related to managing their pain at home.

Patients experienced varying degrees of preparation for self-care of their wound and drain. One patient participant was proactive and sought out information and experience, felt well prepared, and managed well at home. The other three received varying amounts and types of instructions and had difficulty managing their wound care.

Recommendations are made for the improved preparation of patients for the self-care of their wound at home.

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CHAPTER 1

INTRODUCTION

The purpose of this exploratory research was to understand patients' experience in caring for their post-surgical wound at home and to determine their perceived learning needs. Four patients were individually interviewed, using open-ended questioning. Additional data was obtained through staff nurse interviews and observations. Thematic analysis, using phenomenologic and hermeneutic methodology resulted in a description and interpretation of the experience of these patients. This is not an evaluation study, rather, its intent is to heighten our awareness of the experience of patients in these circumstances.

Background

In 1990, the Royal Commission on Health Care and Costs examined the delivery of health care in British Columbia (Seaton, 1990). The report of the commission strongly supported the concept of health care "closer to home". It was recommended that health care practitioners develop creative alternatives to the provision of health care in acute care settings. The report clearly indicated a consumer preference for health care in the home (p. C-154).

Patients are currently sent home from hospital as soon as they are able to manage their routine activities of daily living (often with the help of a family member or other caregiver). Occasionally, treatments prevent discharge because they are complex or patients are otherwise incapable of carrying out the procedures themselves. A preliminary study done on the general surgical nursing units at the Greater Victoria Hospital Society (GVHS) demonstrated that 36% of 101 patients required complex wound care as their only intervention in the last two days of hospitalization. Complex wound care, such as care of incisions that are separated or have a drain in place, was identified as the most significant single barrier to discharge (Fulton, Ross, Jones & Service, 1995). According to the GVHS Utilization Management Program (Greater Victoria Hospital Society, 1994), a patient may be sent home, in the absence of other medical or nursing needs, when there has been

> evidence of no bleeding [from a surgical site] for last 24 hours; [when there has been] documented effort to teach patient and/ or [significant other] to clean and care for stoma, appliance. . . and/ or drainage tube(s); when patient or [significant other] able to manage established regime. (p. 25)

There remains the issue of whether the education of patients regarding their wound care is meeting their needs. This research examined the educative component of discharge planning and elicited the views of patients, to determine how and what they needed to learn in order to care for their wounds at home.

This is not an evaluation of patient education in hospital. Rather, the point under examination concerns patient perceptions of learning needs. Acknowledging the importance of the patient's perceptions is the first step to providing learning experiences that will prepare patients for self-care at home. To perceive, is to "apprehend with the mind" or "apprehend through the senses" (Hoad, 1986, p. 345). Perception is also defined as "intuitive recognition of a truth, aesthetic quality, etc.; way of seeing, understanding" (Thompson, 1992, p. 661). When considering perception in qualitative research, it is understood that individual experience is unique and is a product of many and complex factors that make up a person's world. Munhall and Boyd (1993) explain that "perception is the original awareness of the appearances of phenomena in experience" (p. 103). The experience of individuals is unique and their awareness of that experience is dependent on their "take" of the elements of that experience. In the analogy of the five blind men examining the elephant, each has his own version of what an elephant is like. Like the blind men, we all experience similar circumstances in vastly different ways.

Patients' perceptions of learning needs include what they apprehended through their senses and what they understood about the experience.

ADULT LEARNING THEORY

This research was about adults preparing to care for themselves, especially the care of their surgical wound (incision, drains and dressings). Although participants did not express the need for education to be based on adult learning theory, their statements contained themes that relate to what we know about adult learners and adult learning. The following section, therefore, describes the learner, the process of learning, scheme theory, and the dimensions, domains and typologies of adult learning. These theories will be used in the analysis of the patients' experiences in learning and performing self-care of their wound.

Cranton (1994) describes learning as both a process and outcome: the steps taken and the change that is achieved. In particular, the process of acquiring specific sets of knowledge and skills, engaging in learning to solve problems, and questioning assumptions and values, are inherently part of adult learning (Cranton, 1994).

The Learner

An integral part of adult learning is the learner. Each adult comes to the learning episode with a unique set of characteristics involving age, intelligence, memory, cognitive abilities (Merriam & Caffarella, 1991), personality type, culture, philosophy, experience and life phase, learning styles, autonomy, values and self-directedness (Cranton, 1992, p. 21). As well, learners possess attitudes, assumptions and beliefs about health, health care, the role of the learner, the role of the teacher or nurse, and their abilities as a learner and care provider. It is clear that adult learning is complex and unpredictable.

What is Learning?

Learning is a process that seems to have multiple issues and factors affecting when, how, why and where it takes place. Learning has been viewed as a cycle that includes concrete experiences, reflective observations, abstract conceptualization and active experimentation (Kolb, in Cranton, 1992, p. 40). Phases of learning can be broken down into (a) selective perception, (b) storage in short-term memory, (c) encoding, (d) storage in meaningful pieces such as concepts, schema, (e) retrieval, (f) response generation, (g) performance, and (h) feedback (Redman, 1993, p. 81). Learner characteristics mentioned above figure prominently in the process as do societal and cultural factors - especially at adulthood.

Scheme Theory

A useful way of approaching learning is to think of it in a broader, contextual way. Merriam and Caffarella (1991) describe *scheme theory* as proposed by a number of theorists. This cognitive theory views prior knowledge as interacting with new knowledge in producing new frames of reference called scheme. In an interactive way, scheme are active processes, not simply static boxes of information stored away. The scheme are an individualized accumulation of our experiences and our world view (Merriam & Caffarella, 1991, p. 170). Rumelhart and Norman (in Merriam & Caffarella, 1991, p. 171) describe three modes of learning that fit the scheme framework: *Accretion* refers to the daily accumulation of information, *tuning* to the slow, gradual changes in scheme, and *restructuring* to the creation of new scheme and reorganizing of previously stored information. Crucial in scheme theory is the role of life experience in learning, a key feature of Knowles' (1980) influential assumptions of adult learners. Adult learning is achieved by using prior knowledge and experience and is guided by the learners goals.

Androgogy, a term first introduced by Knowles, is the "art and science of helping adults learn" (Knowles, 1980, p. 43). He advocated that helping adults learn is different from helping children learn because adults possess characteristics such as self-directedness and prior experience, and because their orientation to learning is life- or problem-centred. Teaching adults, in this view, includes consideration of what they bring to the learning experience and what they expect to get out of it.

Dimensions, Domains and Typologies of Adult Learning

Cranton (1994) discusses four *dimensions* of adult learning that have been cited in the literature. She categorizes adult learning as designed to free people from the oppressive state they are in (literacy, equal access), gaining knowledge and skills (normative, professional development, skills training), satisfying personal needs (consumerism, recreation, felt needs), and engaging in critical reflection (questioning the political and economic system) (p. 3).

Based on Habermas' domains of knowledge and Mezirow's *domains* of learning, Cranton (1994) identifies three *typologies* of learning: subject centred, consumer oriented and emancipatory. *Subject oriented* learning is the acquisition of facts, concepts, problem-solving strategies or technical or practical skills. Traditional patient education involves this kind of learning: how to care for your diabetes, what steps to take in deciding what to include in your daily intake of food, et cetera. Often considered the "meat and potatoes" of learning, it is based on expectations of the learner and is comfortable because it answers practical questions.

Consumer oriented learning (Cranton, 1994) occurs when a person expresses a need to learn. Much of the self-care movement in the health care industry uses this kind of learning. People read books and attend lectures on how to be healthy, what foods to eat, how to stay physically fit, how to raise a well-adjusted child and a myriad of similar topics. Consumer oriented learning fits well within a self-directed learning framework, where the teachers are facilitators or mentors for the learners. In health care, we are often pleased when people take the initiative to seek out sources of information and learn about their illness and health, assuming that it will promote greater self-awareness and produce better health in the long run.

Emancipatory adult learning, Cranton's (1994) third typology, deals with those programs and materials that promote "a process of freeing ourselves from forces that limit our options and our control over our lives, forces that have been taken for granted or seen as beyond our control" (p.16). We (both the health care consumer and the health care professional) make assumptions about the role of the health care professional and the role of the patient/consumer in the teaching and learning process. Emancipatory learning implies that our repertoire of teaching approaches include the examination of underlying assumptions regarding learning, health, and roles in health care. Emancipatory learning requires us to assess the effect assumptions have on our lives, explore alternatives and options in meeting our health care needs, plan for changes in our lives to achieve newly formed goals and beliefs, and make the necessary role changes and then reintegrate into our social circle with the new perspective.

Cranton (1994) makes it clear that not all learning requires a transformative element. Perhaps not many learning episodes do, but I assume that, in achieving health for people, we need to examine healthy practices in such a way as to transform our current lives to include new behaviours, roles, perspectives, or, in short, new scheme. Transformative learning means more than simply adopting specific behaviours such as a particular diet. It means a shift at a deeper level and could produce some significant lifestyle and attitudinal changes.

In the foregoing description, I have deliberately used terms that include the health care professional in the process of transformation. We cannot hope to achieve a perspective transformation in our patients without fully understanding our own position. The process is a societal change that includes providers and consumers.

Adult Education Theory Into Practice

A brief review of some of the definitions of *patient learning* will clarify the current stance of health care professionals regarding patient education. Oberst (1989) claims that any definition of patient education must include a clear definition of self-care. In her view, self-care is "any action or psychological process undertaken to promote, assess, maintain, or restore one's own health, comfort, or perceived well-being" (p. 621). She defines patient education as programs intended to directly influence coping and self-care behaviours. Luker and Caress (1989) define patient education as "imparting information, skills or knowledge by the nurse, with the aim of bringing about demonstrable behavioural or attitudinal change in patients" (p. 712). Although attitudinal changes are seen as a part of the learning process, the focus of these definitions is demonstrable behavioural changes.

Advised by the above review of adult education theory, patient learning may be viewed as the process of acquiring sets of knowledge, skills, attitudes and beliefs resulting in the ability to problem-solve real life situations related to health and self-care. It includes a process of questioning assumptions and values that in part make up the internal scheme that we rely on to direct our lives. The learner is a unique individual with characteristics such as experience, a developmental life phase, inherent potential for growth and a degree of motivation and self-directedness, which affect the amount, pace and content of learning. Learning occurs in a social milieu where interactions with others and the environment are primary factors.

Two of the above theoretical perspectives will be used in the analysis of the patient data in this research. Cranton's (1994) typologies of learning will clarify different perspectives in viewing adult learning, and scheme theory (Merriam & Caffarella, 1991) helps us understand the process of learning in adulthood.

PROBLEMS WITH PATIENT EDUCATION

With the trend toward shorter hospital stay, patients are discharged when no active treatment is in progress, and as soon as they are reasonably able to manage their own care at home. They are discharged with the support of a home care nurse or, if they are able, the patients or their caregivers are taught to do their own wound care. This trend provokes questions that are the basis of this research. How do people best learn to provide this care? How do they manage in their home environment doing this sometimes complex, wound care? What practical problems arise for the patients who do their own wound care at home?

A review of the literature on patient education shows a predominant focus on the instrumentality of nurses' role in educating patients regarding the *right way* of caring for themselves. In general the research has shown a distinct lack of success in the teaching of patients in hospital (although conflicting evidence exists). There are reports of patients learning from sources that nurses would find unacceptable. Hopps (1983) found patients gained considerable information from sources other than the health care team. Engström (1984) found that 44% of patients considered it important to speak to fellow patients to find out what they knew about illnesses, operations, examinations, investigations and medications. The authors attribute this finding to a deficiency in education provided by nurses.

Although health care professionals voice concerns that patients should become "partners in their medical care regimens" (Smith, 1989, p. 584), this is belied by the terms health care workers in hospital use such as "compliant", which implies conforming to the way *we think they should behave*. Disagreement exists between patients and nurses over what information they should receive and there is a discrepancy between what the patient wants to know and what the nurse thinks they want to know (Close, 1988). Arthur (1995) cites a study where patients were asked about sources of information and information needs. Eighty-two percent of patients obtained information related to their disease from television and 54% stated they had not received information from health care professionals. These are examples of the research that indicates a gap between what the patient perceives he or she needs and wants and what health professionals think the patient needs or wants, and also differences of opinion as to what are appropriate sources of information.

In preparation for this research, numerous studies of patient education were reviewed. Almost none dealt with self-care of surgical wounds, and they nearly all used quantitative methods to determine the efficacy of patient education (Engström, 1984; Bostrom, Crawford-Swent, Lazar & Helmer, 1994; Poroch, 1995; Derdiarian, 1989). These studies show varying degrees of success in actually achieving a response (such as coping, lower anxiety, acquisition of knowledge, and satisfaction) to education.

When considering the patient's voice in studying patient education, very different issues arise. In a partially qualitative study, Wikblad (1991) found that diabetic patients experienced a kind of censorship from the health care team. Patients with poorly controlled diabetes were treated with only cursory care, felt threatened and unequal. This was in contrast to patients with good control, who received positive feed-back, although they sometimes felt mistrust, despair, humiliation and aggression. The measurement scales mentioned in the studies above did not include items on censorship, mistrust, despair and humiliation; they focus for example on "very satisfied" or "not satisfied". There is a huge difference in understanding between being "very dissatisfied" and terms like "despair" and "humiliation". The former seem somehow sanitized and in comparison to the latter, lack real meaning.

PROBLEM STATEMENT

Patients are being discharged with wound care requirements and we do not know how they manage when they get home. Health care professionals think they know what the patient needs to learn prior to discharge to manage their wound, but no research has identified what these patients experience when they go home or what they perceive their learning needs to be in that circumstance. Health science research indicates an inadequacy on the part of acute care hospitals in meeting the perceived needs of patients, despite deliberate efforts to do so. Finally, most of the research in this area of patient education is of a quantitative nature: the patient's voice is seldom seen as data or considered in a phenomenological way.

PURPOSE OF THE RESEARCH

The purpose of this exploratory research is to begin to understand the patients' experience in caring for a wound at home and to understand their perceived learning needs to accomplish that specific task. By inquiring into the patient's lived experience, we deepen our understanding and open a meaningful dialogue between professionals and patients that may be fruitful in producing appropriate educative care. This study is not intended to evaluate current programs nor will it propose new programs. Rather, it will identify themes and patterns that have been reported in this inquiry by a small number of patients with wound care.

RESEARCH QUESTIONS

1. How do adults experience their wound care after discharge from hospital?
    a. What are their issues related to self-care of wounds?
    b. What are their perceived learning needs at the time of discharge?
    c. What resources do they use to learn their wound care?
    d. How do they evaluate sources of information?

CHAPTER 2

LITERATURE REVIEW

Self-Care

In response to the trends of decreased hospital stay and increase in chronicity of illness, health care practitioners feel it is important for patients to be educated in self-care. Giloth (1990) notes that, in US hospitals between 1975 and 1978, there was an increase of 62% in the number of patient education programs with written goals and objectives. Patient involvement in care in hospital is seen as a key component of the education program. Giloth has reviewed the range of educational, organizational and environmental strategies currently being tried in hospitals and other health care institutions to increase patient involvement and she has explored the effectiveness of patient education. She cites four roles that patients should play in the curing process:

> becoming aware of activities that will enhance or retard healing; adopting an active role in their own rehabilitation; providing health providers with critical information about symptoms; and coping with a disease or condition after they leave the hospital. (p. 30)

Giloth (1990) also identified significant barriers that reduce the effectiveness of patient education by preventing or decreasing the patient's active involvement. The barriers include: (a) a hospital environment that creates loss of personal control, lack of privacy and social isolation; (b) changes in health care utilization that means patients are in hospital for shorter periods, are sicker while they are in hospital and, therefore, are less receptive to education; (c) the situation that care is often implemented as a series of tasks rather than as an interactive process that would support the development of new skills; (d) health professional training that has not prepared students to integrate teaching into their demanding work schedule: physical care is rewarded more than teaching; and (e) educational programs that focus more on cognitive rather than behavioural or psychosocial factors. Didactic information is stressed while critical strategies such as skills training, family involvement and practice opportunities in real situations are overshadowed (Giloth, 1990).

Wound Care

Literature on patient self-care of wounds is limited. Some work has been published regarding teaching patients care of gastrostomy tubes (Alltop, 1988) and t-tubes (Quinless, 1984), but these are prescriptive rather than research-based. Hospitals sometimes have "discharge instruction" sheets that include a section on wound care or treatments. Lewis & Collier (1992) illustrate one such sheet that has two blank lines for the health care professional to write instructions regarding wound care. Watterworth & Podrasky (1989) have developed a wound care discharge sheet that was found helpful to remind patients of the step-by-step procedures to follow when caring for their wound. They found the demonstration-practice method of instruction was enhanced by supplementing it with written information, received in advance of discharge. Patients and their care-givers were gradually prepared for 3-4 days prior to discharge, and they were coached through the process of the dressing change several times.

Jaffe (1993) provides a teaching checklist for home care nurses to use when teaching patients their wound care. The document is not a handout but, rather, a checklist for the staff to indicate the progress of teaching for their own records. The checklist includes such items as theory of wound healing, aseptic methods, the actual treatment, care of drainage systems, disposal of supplies and appropriate reporting to health care professionals. There are spaces to indicate when the patient was "taught/demonstrated" and when they "stated/performed" the required knowledge or skill. The procedures identified in the checklist are similar to the ones nurses follow in hospital or the home.

Perry and Potter (1994) list six points for nurses to consider when instructing patients regarding self-care of closed wound drainage systems. Nurses should teach clients (a) the nature of anticipated drainage, (b) the expected progress of wound healing and drainage volume, (c) the estimated date of drain removal, (d) that unexplained dark red drainage is a major concern, (e) how to change dressings located around the drain site (primary caregiver and client), (f) to wear loose-fitting clothes, (g) to keep the drain lower than waist level at all times, and (h) not to pull or tug on the tubing and to secure it to clothes with a safety pin (Perry & Potter, 1994, p. 1050).

Patients' Perceptions of Self-Care Learning Needs

Trends of shortened hospital stay and increased focus on patient services provided in the community have spurred some research into the perceived learning needs of patients at the time of discharge. Icenhour (1988) interviewed

150 ambulatory surgery patients to determine their perspectives regarding the quality of interpersonal care they received, including, in part, the quality of teaching. She found that patients perceived better quality of teaching when it was done deliberately with adequate time allotted, and when teaching was considered a critical part of patient care.

Engström (1984) interviewed 120 patients and measured their subjective need for information during their hospital stay and their subjective experience of the adequacy of the information. She found general dissatisfaction with information about prognosis, diagnosis, and medications. With regards to the post-hospitalization period, she concludes that in order to meet the goal of having the patient understand the treatment program and its consequences and also be able to distinguish and localize symptoms in him or herself, there needs to be a well though-out and planned education program. She also concludes that the personnel must understand the patients' need for, and reactions to the information given and there must be a functioning communication network between the different personnel categories to ensure the appropriate person does the teaching.

In Canada, Bubela et al. (1990a) have developed an instrument, the Patient Learning Needs Scale (PLNS), by which they assess factors that influence patients' information needs at the time of discharge (1990b). The researchers identify the greater informational needs of females, of those with low and middle levels of education, of those diagnosed with cancer, and of those with extensive medication regimens. They point out that educational strategies should include early referral to material resources or personnel such as pharmacists or clinical nurse specialists. Material resources should include pamphlets, videotapes and other material for discharge education. These researchers recommend that further research be done to identify specific populations' desire for information, and that the family should be used as an important additional source of information about patient learning needs when preparing for discharge.

Bostrom, Crawford-Swent, Lazar & Helmer (1994) have used a condensed version of the PLNS in the United States to study the learning needs of hospitalized and recently discharged patients. Their findings were similar to those of Bubela et al. (1990a) and they found that recently discharged patients put a greater emphasis on the importance of most health information provided in the hospital than did those who are still in hospital. The authors stress that patients need information resources they can access quickly during their transition from hospital to home. Strategies to meet this need are suggested: a 24 hour hotline, telephone follow-up of discharged patients, and computerized, standardized patient instruction materials for the topics that are most frequently important to patients.

In a qualitative study, of patients discharged home with visiting nurse support, Stricklin (1993) found that patients felt themselves to be inadequately prepared by hospital personnel to cope at home. Many did not know what to expect of the visiting nurse and, therefore, experienced much anxiety. In contrast to the anxiety and uncertainty caused by lack of preparation, patients and caregivers who felt thoroughly prepared, were appreciative of the visiting nurse's (home care nurse) skill in repeating demonstrations and helping the caregiver not to feel "stupid". The visiting nurse allowed them to repeat the skill over and over until they had mastered the technique. Some patients also felt it was important to learn about care once they were in their home in the real situation. Here they felt comfortable with supportive staff.

FRAMEWORK CONCEPTS

Among nursing theorists, Dorothy Orem (1985) is considered a humanist (Marriner-Tomey, 1989). She has proposed a theory of self-care that views nurse's role as compensating for the self-care deficit of her patients. Nurses provide a supportive-educative role in helping patients learn to do for themselves. The word *care* is used frequently in this paper. Care, according to Orem (1985, p. 9), refers to the attention, service and protection provided by persons who are in a position that requires them to "be in charge of" or "take care of" others. *Taking care* of another, Orem says, implies an interpersonal situation wherein one person helps the other with their needs: a relationship of interpersonal helping. Care also means the particular state of mind one has for another: *To care* means to be concerned or have an interest in another. According to Orem (1985), there are commonalities among care situations that include interpersonal, helping and regulatory or adjusting features:

The care giver *makes up for* what the person under care cannot do

> wholly or in part and at the same time respects and fosters the developing or developed action capabilities of the person under care; and the help provided ensures that existent needs are met by regulatory or adjusting type of activities. (p. 9)

Care is often burdensome for both parties; it requires both knowledge and developed skills, as well as information about the patient's condition and circumstances, including the opinions, interests and concerns of the patient and their caregiver. People may be so burdened they prefer not to receive care, may have untoward side effects from care and may refuse care (Orem, 1985).

Psychoeducational Care in Discharge Planning

Devine (1992) defines *psychoeducational care* as providing patient education and psychosocial support. Psychoeducational care includes *health-care-relevant information* such as the timing of activities, descriptions of procedures to be performed and the roles of health care professionals. *Skills teaching* includes such behaviours as deep breathing and coughing exercises, crutch walking, and wound care. *Psychosocial support* involves identifying concerns of individuals and attempting to alleviate those concerns, providing appropriate reassurance, fostering problem-solving skills, encouraging the patient to ask questions, and providing supportive treatment (Devine, 1992). Considerable overlap exists in the provision of the above three elements of psychoeducational care.

Preparation for discharge should be an ongoing process, wherein the informed client is prepared as events unfold and gradually assumes greater responsibility for self-care during the entire post-operative period (Lewis and

Collier, 1992). Post-operative patients need information about: (a) care of the wound site and dressings; (b) action and possible side effects of medication, when and how to take them; (c) activities allowed and prohibited; (d) dietary modifications; (e) symptoms to be reported; (f) when and where to return for follow-up care; and (g) they need answers to any individual questions or concerns (Lewis & Collier, 1992).

Patient and family education is seen as critical to successful discharge planning and is seen as a continuous activity (Menke, 1988). Patients are informed of many things before admission to hospital and they will not receive all the required knowledge and skill while in hospital. Shorter hospital stays, and factors such as anxiety, pain, or the influence of medications, means that patients are often sent home before they are able to comprehend new information. For this reason, some hospitals have instituted programs that afford a link with the hospital such as telephone follow-up, hotlines, outpatient classes, and inpatient programs where a person is admitted *with a caregiver* for the express purpose of teaching the patient and the caregiver while the caregiver actually contributes to the care (p. 241).

For the purposes of this research, psychoeducative care will be defined as a caring role that begins before the time of admission. It includes imparting information, teaching skills and providing psychosocial support in such a way to prepare the patient and their caregiver for self-care and discharge.

Self-Care

Orem (1985) uses the term *self* in self-care, as the *whole being*. Self-care means "for oneself" and "given by oneself". It is "the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" (p. 84). Adults normally care for themselves but ill, disabled and elderly people at times require others to assist in all or part of their self-care behaviours, in these circumstances self-care refers to their continuous contribution to their own continued existence, health and well-being.

Redman (1993) claims self-care has developed in two ways: as a philosophic position giving individuals more tools to manage their own health and as the reservation of responsibility to patients and families for kinds of care formerly provided by health professionals. The self-care philosophy aims to correct the imbalance of the provider-patient relationship, moving patients from dependence to more contractual arrangements. She addresses the inequity that exists in health care between provider and patient:

> Available evidence indicates that a great deal of self-care is given but that it is often ignored by health practitioners or that it is considered "not real medicine," that patients' skills in self-care are not supported, and that their definition of the problem is believed to be unimportant. (Redman, 1993, p. 283)

It was assumed in this study, that health care practitioners had much to offer patients toward their greater well-being and independent self-care. It was also assumed that, because a patient had contact with health care providers, they were searching for information, care and support toward their greater well-being. Self-care refers to a continuous substrate of behaviour: customs, life-style, and actions such as self-diagnosis and self-treatment. But medical care is synonymous with health professions and the medical practice acts define and limit practice to licensed individuals. In so doing, they overlook the option of self-care (Redman, 1993).

In this study, self-care is as defined by Orem (1985): those activities a person initiates and performs on their own behalf, to ensure health and well-being. This broad definition, intends to capture a range of endeavours, not simply the taking of prescribed medication or the following of medical regimens.

Wound Care

There are a number of factors that affect how a person recuperates and copes with a wound in a home setting. These factors are ability to cope with illness, changes in body image, mobility restrictions, pain, decreased energy levels, side effect of medications, appetite and dietary changes and role changes. Additional factors such as visual deficits, restricted range of motion, cognitive abilities, wound location, general debility and amount of support in the home must also be considered (Davidson, Landega & White, 1992).

There are three types of wound healing: primary, secondary and tertiary intention (Hess & Miller, 1990; Hollinworth, 1994; Wysocki, 1989). Healing by primary intention occurs when a wound is sutured and heals with the wound edges well approximated. A drain may or may not be present. Healing by secondary intention occurs when a wound could not be approximated due to size, infection, haematoma (local collection of blood in the tissues) or dehiscence (separation and disruption of the previously joined wound edges, Lewis & Collier, 1992) and heals from the base of the open wound through a process of granulation, contraction and epithelialization. This usually results in a large scar. These wounds require special care and cleansing, usually some sort of moist environment (dressing) to heal quickly. Tertiary (or delayed primary) healing occurs when a wound is left open for three to five days to allow edema or exudate to resolve. It is dressed with appropriate packing/dressings and the skin edges are approximated at a later date. The wound then may heal by primary intention as above.

Drains that are left in place when the patient goes home are most frequently Jackson-Pratt®[1] drainage systems (see Appendix A). In some instances other tubes or makes of drain are insitue. Wound care is defined as the technique of changing dressings on the wound (incision and/or drain site), cleansing the wound, irrigating or packing the wound and emptying drains, measuring contents and sometimes milking the drainage tube to remove clots. It includes the ability to solve problems regarding the wound and understanding when and who to notify about adverse symptoms.

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[1] Registered trade mark of Allegiance Healthcare Corporation.

CHAPTER 3

RESEARCH DESIGN

This exploratory study is descriptive and interpretive in design and utilizes triangulation (more than one method of data collection) to gain a fuller understanding of the life-world of the participants who have been discharged home with a complex wound. George Willis (1991), in his work on phenomenological (descriptive) inquiry, describes how *experiencing* involves three interrelated processes of *perceiving, thinking* and *acting*. How these three processes are, or are not connected, determines the kind of experience the person has. Willis explains that humans have highly developed inner life-worlds where they self-consciously think through the meanings of their perceptions and weigh alternate courses of action. The life-world where people live are deeply personal and autonomously derived. These inner life-worlds are the places where action flows from and it is here that descriptive inquiry wishes to focus.

The process of inquiry from this perspective includes a scanning of one's own (the researcher's) life-world to expand and refine one's perceptions and to empirically scan evidence of the life-world of others. These scannings are rendered into descriptions of life-world perceptions. Sometimes they can be compared to determine what different ones have in common and to determine how they are influenced by the context where they occur.

Interpretation, or assigning meaning to the naturalistic stories of the participants in this study is done to inform our practice. Munhall & Boyd (1993) state that all description of experience is inescapably interpretive. The degree of interpretation or the depth of analysis involved in the interpretation can be minimal or extensive, according to the intentions of the research. According to Benner (1985) the task of interpretation is to uncover the meaning in everyday life in such a way that does not destroy, distort, decontextualize, trivialize or sentimentalize.

David Smith (1991) explains how hermeneutic (interpretive) inquiry is interpreting the life-worlds through the study of words and their historical and etymological roots. Interpretive inquiry challenges the assumption that life in general should, or could, be brought under control though a one "correct", logical procedure. It contributes to our understanding that meaning is "arrived at referentially and relationally rather than absolutely" (Smith, 1991, p.197). Because the process of interpretation involves dialogue and consensually derived meanings, the researcher must be prepared to deepen his or her self-understandings and the reports of such studies should include a report of the researcher's own transformation while involved in the process.

Smith (1991) claims this method of inquiry is derived from what is being investigated, it cannot be fully prescribed beforehand. Although he calls the method a "dialogical messing about" (p.198), he does mention four requirements. The researcher must: (a) develop a deep attentiveness to language, how it is used by self and others and thereby gain a sense of where the words point historically; (b) develop a deepening sense of the basic interpretability of life (deconstructing the world rather than "receiving the delivered goods"); (c) realize that interpretive inquiry is about the question of human meaning and how we can make sense of our lives so that life can go on, using imagination to make everyday experiences meaningful in the "grander scheme of things";

(d) understand that interpretation is about creating meaning, not simply reporting it. The self is intimately involved in the making of the meaning, and takes responsibility for making proposals about the world (Smith, 1991, 198).

Researcher Assumptions and Biases

Assumptions are convictions; they are fundamental non-debatable truths held (by the researcher) in order for the research to proceed. In descriptive and interpretive research, assumptions, biases, intuitions and perceptions function to link the researcher to the world (Lauterbach, 1993). By explicating researcher bias and convictions, the researcher attempts to hold them in abeyance. The process is called bracketing or setting aside those assumptions and biases and experiencing the phenomenon as if for the first time (Lauterbach, 1993). Lauterbach (1993) claims "astonishment before the world" (p.106), is necessary to lay aside our natural reaction to phenomena. If I accepted the stories of the participants though my nurse's eyes, as simply *the way it is*, I would miss the meanings inherent in the experience. Astonishment, then, allows me to be more attuned, more receptive to meaning.

I have had a long history as a surgical nurse and educator and am entrenched in the medical world with its formal knowledge (science), and beliefs about the role of the patient and that of the health care professional. I spent three and a half months as a patient in an acute care hospital that engendered an attitude of advocacy for patient concerns. As well, over the years, I have had occasion to be involved with family and friends who have attempted to take control of their health care behaviours and have met with resistance from health care professionals. These experiences have created a more critical, or analytical, view of the role of a nurse. In more recent times, in a professional role of identifying and promoting quality patient care, I have taken on a new perspective in that I am more proactively seeking alternative methods to provide health care in our changing health care system. With health care regionalization occurring as I write this paper, it is forefront in my mind that we need to seek out alternative solutions, such as providing a "seamless" service to clients and patients who use primary, secondary and tertiary care in our region. Seamless implies a health care system that patients and clients can move through, from service to service or department to department, with continuity of care, without difficulty, without experiencing untoward events, without "falling through the gaps".

Some of the assumptions at the outset of this research were: (a) patients and/ or caregivers want to learn self-care in order to go home at the earliest opportunity; (b) independence from health care practitioners, with available support, is desirable; (c) early discharge from hospital is appropriate if the patient and/ or caregivers are adequately prepared for self-care; (d) it is the responsibility of health care professionals in general and nurses in particular, to educationally and psychologically prepare a patient for discharge (this includes providing access to knowledge and information); and (e) patient perceptions of needs are important in planning education programs.

Self-As-Instrument

Qualitative research differs from the more common (in health care) quantitative approaches. Eisner (1991, pp. 33,34) describes how, in qualitative research, one uses "the self as an instrument". He explains that in the absence of survey tools, data do not jump out and present themselves. I use my own frame of reference and set of intentions to engage the situation and make sense of it. In this research, I have used participant voice, data from nurses related to the training/ teaching of patients, observations of actual patient wound care behaviours, my own sense (as a person) and my expertise (as a nurse), to determine what is reasonable, to describe the experience and perceptions. The researcher-as-instrument, according to Eisner, uses sensibility and schema to make sense of complex situations

> Sensibility alerts us to nuanced qualities and the schema relevant to a domain, the significance of what to seek and see. Without sensibility the subtleties of the social world go unexperienced. Without a schema no sorting into significance is possible. (Eisner, 1991, p. 34)

In this study, there are several sources of data and different methods of data collection. By examining and comparing the different data collected, one is not determining which source is "true" or "correct" but rather, one attempts to provide a fuller understanding of the situation (Hunt, 1991).

Context

The study was done within four nursing units of the Greater Victoria Hospital Society. Permission was obtained from the GVHS Research and Ethics Review Committee (Appendix B) and the University of Victoria Human Research Ethics Committee (Appendix C). The patient participants were recruited by asking staff nurses to identify potential participants while they were still in hospital (see letter Appendix D). Although this system produced four participants, the researcher was not notified in a time to allow an interview prior to the patient's discharge. The interviews, with one exception, therefore, took place in private homes after full consent had been given by the patient and/or significant caregiver(s).

Permission was obtained from three managers to use staff time for the professional staff participant interviews. Data obtained from health care professionals was collected within the contexts of three GVHS surgical nursing units and the Enterostomal Therapy department.

Participants

Four general surgery patients participated in the study. In addition, for each patient, data were collected from one health care professional who had been involved in teaching the patient how to care for a wound. All health care professionals interviewed were Registered Nurses. According to Munhall & Boyd (1994), there are no formulas for the sample size in qualitative research. After each patient participant interview (and before the next) I reviewed the data obtained for thematic analysis (see data analysis section). The common rule of thumb is that once a certain redundancy or saturation (Munhall & Boyd, 1994, p. 441) of the data is achieved, the process can stop, i.e., no new data is emerging. Usually two to ten participants are sufficient to achieve this saturation). Although recurring themes emerged within the first two interviews, all were unique in some ways and had special features unlike the rest.

Eisner (1991) makes a clear point that every particular is an example of a larger group. "Themes embedded in the particular situation, extend beyond the situation itself" (p. 103). In this sense, participant numbers can be small (even one case tells us something), because we are not intending to say that the particular *will occur* in the larger group (as in statistical analysis) but rather that it *has occurred* and therefore may occur in the larger group.

It is the life-world of the patient that is the primary focus of study. Patients were chosen according to (a) the presence of a complex wound that required additional education and preparation for self-care (not receiving home-nursing care) (b) their capability and willingness to participate, (c) their discharge home within the Capital Regional District (CRD) and (d) their ability to speak English. Patient interview(s) included the caregiver if that person was participating in any way with the actual wound care. One interview included the spouse as she was the one who managed the wound care. Another's husband was involved with wound care but was not available for participation.

I visited the general surgery units at GVHS frequently to determine suitable participants. Initially staff were approached in small groups and I explained the research and asked for their assistance. As well, a letter of introduction was left in the communication books (see Appendix D). Two to three days before discharge patients who met criteria were to be approached to determine their interest and willingness to participate. In the process of explaining the research, the staff nurses informed me that patients do not often go home with an open wound. In the past year, practice had changed significantly and home care nursing staff visit almost everyone who has an open wound. As my criteria did not include those receiving home nursing care, patient selection took longer and became exclusively those with tubes and drains. These patients did, however, require skilled wound management.

After each patient interview, the chart was reviewed to determine the name of the nurse who had been giving care at the time of discharge. This nurse was then approached to participate in the study. In place of the discharging RN, for one patient, an enterostomal therapy nurse was interviewed as she knew the patient well and had taught him self-care.

Participants[2] included the following:

1. "Star", a middle-aged woman who underwent a cholecystectomy[3] and was discharged home with a Jackson-Pratt drain. She had previously experienced a diagnosis of cancer for which she had received treatment. She lived with her daughter about 40 minute drive from the hospital. Star's self-care included changing an abdominal dressing and emptying and measuring the drainage from the JP drain. She also had significant pain which needed analgesia.

2. "Rosey" - a young left-handed woman who had a left mastectomy and was discharged with a Jackson-Pratt drain. Rosey had three small children and her husband at home, about 10 minute drive from hospital. Her self-care included changing a dressing that covered the breast area and extended up into her armpit. Self-care also included managing the JP drain as above.

3."Char" and "Bill" - a young couple interviewed together. Bill was discharged after bowel surgery with a gastrostomy tube[4] in place. Char was working at the time and they had two small children at home. Self-care for Bill included changing and managing a

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[2] Participants have been deliberately but not substantively disguised.

[3] Gallbladder removal.

[4] Rubber tubing into the stomach.

small abdominal dressing over the site of the gastrostomy tube. They lived about 30 minutes from the hospital.

4. “Grete”, a right-handed middle-aged woman who had undergone a right mastectomy and was discharged with a Jackson-Pratt drain. Grete had a husband at home to help out. They lived about 30 minutes from hospital. Grete’s self-care included changing a breast dressing and managing the JP drain as above.

There are many other elements to the self-care requirements, such as milking the tubing and managing to bath with the drain in place. These will be described later in more detail.

All participants were given an information sheet/ consent form explaining the study (see Appendices E & F). They kept one copy of the form and were given an opportunity to ask questions regarding the study. Few if any questions were asked prior to beginning the interviews. It was also made clear to the participants that they had the right to withdraw from the study at any time and nobody did so.

METHODS: DATA COLLECTION

Although it was intended to interview patients prior to discharge, because of the speed of discharge, the delay in nurses notifying the researcher, and because of participant preference, they were interviewed anywhere from one to two weeks after discharge from hospital. With one participant, interviews took place in hospital when she was admitted a second time for complications. In one instance, the patient was approached in hospital prior to discharge. The other two were phoned after discharge, and asked if they wished to participate. When the patient consented to participate, personal data was collected from the patient's chart, including age and phone number and address (for follow up phone calls and home visits). Appointments were scheduled at a time most suitable to the participant. Most people wanted to feel better, more recuperated, before having the researcher come into their home. Subsequent sessions were scheduled according to the wishes of the participants. In all instances, the researcher invited them to call back if they had anything further to add, once they had time to consider the discussion. Although it may be argued that memory of acute feelings will fade after a number of days, I felt that the wishes of the participants were of paramount importance.

Interviews

Interviews depend on verbal reports about experiences, perceptions, preferences, problems, feelings, attitudes or whatever other phenomena are relevant to the study. Several advantages inhere in open-ended interviews: (a) they allow patients to tell their story in an empathetic, face-to-face encounter; (b) collection is possible from persons who cannot write (as in questionnaires); (c) they are usually more effective in getting at people's complex feelings and perceptions; (d) they allow a dialogue to clarify issues the researcher or participant does not understand and to probe in depth areas that seem significant; and (e) allow the researcher to discover the unexpected (Wilson, 1993, p. 224).

Disadvantages of interviews, according to Wilson (1993, p. 225) include: (a) participant expectations that the researcher will, in some way be instrumental in solving problems for them; (b) data collection and data analysis procedures are time consuming;

(c) comparisons across different interviews are difficult because not all questions will be the same; (d) interviewer must be able to use clear, non-leading language and have the ability to listen well and expand on and clarify participants statements; and (e) tape recording may cause self-consciousness that could influence their statements (avoidable in an anonymous questionnaire).

No comparison across populations or individuals was attempted with the data analysis and therefore, sequencing and wording differences between participants was not an issue.

Patton (1987, p.108) compares three styles of interview. The *informal conversational interview* allows the participant total control of the topic and direction of the discussion. The *interview guide* is a list of questions or issues that are to be explored, providing some structure but not predetermining the order or even the actual wording of the questions. The third type of interview utilizes the *standardized open-ended* format. This includes a predetermined series of questions that all participants are asked in the same sequence. This provides greater consistency between interviews, especially useful when using more than one data collector, when one wants to minimize interviewer effects.

Patient participant interviews in this study followed the *interview guide* (Appendix G), allowing a fair bit of flexibility in the discussion, not restricting the participant and yet returning to the topic at hand. An important part of this interview was to help participants feel comfortable and at ease discussing issues, not censored or made to feel that their views are unimportant or not the "real issue". The researcher remains open to new ideas, becomes involved in exploring the issues with the participant and, in this way, can become personally transformed in that her initial values and beliefs may change.

Munhall & Boyd (1994) explain the process of engagement of the researcher and participant as "one of intersubjective 'being with' the other" (p.118). This means a dialogue that is not fettered with expectations and stances but with empathetic conversation.

In-depth, open-ended, conversationally styled interviews took place in the hospital and the patient's residence and lasted as long as it took for the participant to fully express his or her views on the topic. Interviews, most of which were 45-60 minutes long, began with an introduction to the study. Two patient participants were interviewed once. One was interviewed in person twice and once on the telephone. One was interviewed once in person and twice on the telephone. The researcher attempted to draw out statements indicative of the patient's experiences, feelings, attitudes and beliefs regarding learning and the requirements of wound care. Face-to-face interviews were tape-recorded. All participants agreed to this and the tape-recording did not appear to adversely affect the interviews. Soon after, the researcher made notes regarding facial expression, body movements, and other important points and general impressions gained during the interview (see field observations).

On several occasions, participants would start talking about issues of importance to them and then cut themselves off saying "Oh, that is not about the wound". I had to reassure participants that it was all right to talk of other things if they were very important to them. Experiences peripheral to doing the wound care itself was instructive in helping to understand the context and corollary issues.

Health Care Professional Interviews

Appointments were made with health care professionals for on-duty time, at a time of day most convenient for them and in a quiet, undisturbed location on the nursing unit, allowing approximately 30 minutes for each taped interview. Two health care professionals were interviewed in their homes, at their request.

The health care professional interviews were also done using an *Interview Guide* (Appendix G) that provided some structure to keep on track but allowed flexible probing when I determined it was appropriate to explore subjects in greater depth (Patton, 1987).

Field Observations and Journal

When appropriate, I asked the patient participants what they are currently doing for wound care and probed for the patients' comments and concerns about the procedure. Observations, as well as the participant voice, allowed me to make judgments about the wound care.

I made jot-notes and then soon after, supplemented these with narrative and reflections on the experience, not only the specifics of the treatment but also the context, for example, the home and circumstances under which the treatment was done. In making notes of the experience, the researcher should focus on what is seen, heard, smelt and felt, not analysing and judging immediately. This will produce clear, focused and detailed records (Jeroski, 1992).

The field notes are part of a journal I have maintained for the duration of the study. According to Rodgers and Cowles (1993), it is important for researchers to keep a journal that documents the context of the data sources, the methodological decisions (and rationale) made along the way, their thoughts and analysis of the data (including literature sources), and the researcher's personal response to her experiences with the research including her attempts to maintain neutrality in the data collection and analysis.

METHODS: DATA ANALYSIS

The tape recorded interviews were transcribed on computer diskette. Large margins were used, to make notes of impressions and initial themes. An initial quick review was done to develop an overall sense of the main issues or content areas. These initial themes were not necessarily the ones intended for investigation but provided, rather, a broad perspective. This overview was set aside while a more analytical approach was undertaken (Jeroski, 1992). These initial themes were used later to provide a reliability check.

All the transcripts were reviewed as soon as possible after the interviews to start developing themes and key perceptions to take into subsequent interviews. When conversing with the same individuals a second time (when applicable), themes and perceptions derived from earlier interviews with that person were validated and explored further. After several interviews confirmed the themes, I established categories and coded (assigned a keyword) the themes. Words of the participants, reflecting their voice and their life-world, were used to code the themes. For example, what I would call "wound drainage", was named "leakage" as that was their word. As themes were identified, I wrote notes that captured the essence of meaning more sensitively than single coding labels did (Lauterbach, 1994).

After the initial review and coding, I used the QSR NUD*IST (1995) computer software program to sort through the transcripts and code all the statements of patient participants according to the themes identified. Coding continued until all the perspectives were categorized into the identified themes.

Later, the health care professional's interviews and my journal notes were reviewed with the view to shedding light on the context and consequently my interpretation of meaning.

The researcher is a vital instrument in the process of reporting the experiences of others. This creative process makes for some ambiguity in the data analysis, because one cannot know beforehand what will turn out. Munhall and Boyd (1993) make some suggestions to clarify this ambiguity. An important part of data analysis is repeated review and pondering of the meanings of the parts and the whole. Repeated patterns in the data are used to support the description. Contradictions in the data are useful to point out the "real" contradictions in peoples lives (Munhall & Boyd, 1993, p. 444) and to identify limits of the interpretation. Identifying differences between participants is important in understanding the diversity of individuals' experience.

Validity

According to Sandelowski (1986), validity, or the "truth" of qualitative research, is achieved by the discovery and representation "of human phenomena or experiences as they are lived and perceived by subjects" (p. 30). The truth is defined by the participant rather than by the researcher. The more accurately the researcher portrays the participant's experience, the more valid the research. To that end, I have used several methods to ensure the data and subsequent rendering was faithful to the participant's experience.

To begin, I tape recorded all the interviews and transcribed them verbatim. During the interviews, I tried to confirm my impressions using reflective communication techniques, such as asking for clarification, and re-stating my understandings. With two participants, I was able to interview them a second or third time to further establish the validity of my initial impressions, as well as collect data on their further experiences.

Triangulation improves the validity of research (Patton, 1987, p. 60). For the purposes of this study, triangulation, is defined as obtaining data from three different sources. I interviewed health care professionals, not to prove or disprove the patient participants' experience, rather to provide contextual understanding and place them within the context of the nursing units where they learned their wound care. The views of nurses also allowed me to validate my own perceptions as a nurse. What I think as a nurse is consistent with what my colleagues think. That my views are representative, allows me to make statements about nursing with a greater degree of confidence. Triangulation was also achieved using direct observation of the patient's wound and wound care.

A threat to the validity of experimental research occurs when the researcher becomes too close to the participants, and loses the required objectivity (Sandelowski, 1986). In phenomenological research, it is important for a researcher to become involved with participants in a less objective way, in order to fully understand their experience. When a researcher clearly states her position and relationship to the participant, and identifies how she was influenced by the participant, this allows the reader to make judgments about the validity of the research (Sandelowski, 1986). I have explained my position as a nurse and as a researcher and have tried to achieve a balance between empathy and objectivity in recounting the lived experiences of participants.

Reliability

Qualitative research is rarely repeatable (Sandelowski, 1986). This is due to the uniqueness of participants and to their relationship to time, place, researcher and circumstances. Reliability is defined instead, in terms of auditability or confirmability (Sandelowski, 1986). Confirmability is achieved in this research by a full explanation of the methods used and by description of participant characteristics. A decision or audit trail, kept in a journal, and explained in the report, allows others to follow the logic in describing and justifying what was done and why (Rodgers & Cowles, 1993).

As the selection of themes from the volumes of data is crucial in reporting the experiences, it is important to justify the decisions made. Themes were chosen for several reasons. Frequency of occurrence is one main criteria. If the theme recurred in three or four of the patients' stories, then it was considered important. The other criteria included closeness to the central purpose of the study and relevance to the main research questions.

The selection of themes presented a challenge for me. I wanted to present four case-studies with all the nuances of the individuals' experience, to talk about what the experience meant to them and why. This would involve more biographical information in order to show the context of each person's experience, and I felt confidentiality of information would be jeopardized with such an approach. The results, therefore, are less meaningful than they would be with more biographical and contextual information. I have drawn in bits and pieces of the patient's situation and experience (Participants section, page 34-36 and Findings section, pages 48-66), in a less biographical way to give the reader a better understanding.

Generalizability

Phenomenological research typically proceeds with a small number of participants, and broad generalizations are seldom made. The data helps us develop an understanding of the lived experience of these few persons, rather than to generalize. Features of the study may be transferred by the reader, however, as she finds similarities with her own situation. This study's purpose is to sensitize people to the experience of patients going home with an open wound and to give us some clues about what health care professionals might be missing in the teaching of patients. Applicability beyond the research participants is achieved by enlisting participants who can illuminate the subject of the study (Sandelowski, 1986). Patients who required self-care of their wound at home, were seen to represent that group. The researcher's task is to establish the position of the participant for the reader (Sandelowski, 1986). I enlisted the first four patients who met the research criteria, I did not select out those who may have been more articulate (Sandelowski, 1986) or who in any other way, would skew the representativeness of the experiences and views. "Fittingness" is when findings can fit into contexts outside the study situation and when the reader finds meaning and applicability to their own experiences (Sandelowski 1986). In this research, readers may see some of the patients' experiences parallel their own in similar or different hospital or home circumstances.

Identifying limitations and delimitations is important in confirmability of the research findings. The description of participants and their experience allows the reader to judge if other individuals and age groups may have different experiences. It is limited to those with specific wound care requirements who were performing the wound care on their own. Patients with home nursing care assistance would have different experiences.

A significant limitation in this study was that two participants were not interviewed a second time. Even with the two that were interviewed again, the short relationship did not allow for the development of trust necessary for full disclosure of personal experiences.

CHAPTER 4

FINDINGS

A total of five themes were identified in this study. Two occurred with all four of the patient participants. The first is "normalcy" and the second is "decision and control". In each participant, these two themes became clear. All four wanted information and support to enable them to make decisions and have control over their care. And they wanted, very much, to return to a normal life. As will be seen in the following pages, these two themes are intertwined with the three other themes "learning to do wound care", "help after discharge" and "pain management". Not only did these two themes occur repeatedly but the issues appeared to be of greater importance to the patients than the actual wound care itself. This finding has major implications for how we provide psychoeducative care.

Normalcy

The desire to return to their normal life was expressed by all participants. It consistently appeared to be the most emotional part of their experience. The concept of normal for them included doing things that they would normally do, feeling as they would normally feel, and being whole again, as in the absence of disease. Grete was impatient to get back to her normal routine.

> I guess I knew there would be an end to this. I mean it had a start and it had to have an end. It wasn't getting any less sore I can tell you that. That annoyed me a bit but I blamed it on the drain. It just felt like continuous fire, you just couldn't get a comfortable position in bed. But again, I thought once the drain is out it will get better. And now it's certainly very variable, I am sure I will see progress each day. And also I want to get back to normal living just

> as soon as I can. This being a patient is for the birds.

She claimed that the pain was not the big issue nor was having her breast off "I don't mind losing the breast. I feel, let's just get on with getting back to normal health and activity, be normal, act normal, do normal things." Then, after talking about herself for the duration of the interview, she became frustrated with the focussed attention on her sick role "I am so sick of this 'I' word. I have not been sick for ... like this ... if I can help you, fine, but ... I just want to get back to health."

Perhaps the most poignant of the four patients was Star, who desperately wanted to return to her normal life.

> Yeah ... I cried a little at times ... things like that ... I got myself dressed and went and sat in the back yard. Tried to soak in some sun. It wasn't really hot, the sun was there but it really wasn't hot ... anything, just to feel normal.

She went on to count the days she had "lost" being in and out of hospital. Then she said "I felt a little gypped of this month." Returning to normal involved doing things that were part of her usual life pattern. She had been spending her time in her apartment because of the pain. But to make herself feel better she tried to do some things, such as going out with her daughter and son-in-law for Father's Day dinner. Although she forced herself, she was uncomfortable and had trouble camouflaging the drainage tube under her clothes. The pressure from her clothes on the Jackson-Pratt (JP) drain site prevented her from enjoying herself.

A spouse was involved with the sick role of her husband and also wanted to return to normal life. Char was adamant that Bill be allowed to come home, after a hospital stay of one month. She pleaded with the doctors to speed up the discharge time even though her husband was not taking a solid diet yet.

> You know trying to keep kids lives together and running up to the hospital once or twice a day and you know, working, you just can't do it all. The sooner he gets home the easier it is on all of us cause that time we spend running back and forth to the hospital, it's darn near an hour a day just running. The kids hate it up there, you drag them up there and make them sit quietly in the waiting room, and it's just so much easier to keep up the schedule. [He] does a lot better at home, we do a lot of quiet walking.

The concern to return to normal was affected by the diagnosis. Three of the participants experienced a diagnosis of cancer and many statements alluded to wanting to return to the pre-cancer state. Star referred to cancer as "big naughtiness" when anticipating the results of a repeat diagnostic scan "I am just hoping that the bone scan will come back with no naughtiness anywhere, big naughtinesses. I don't want to go back on chemo..." She dreaded chemotherapy because of the side effects.

> I just can't cope. The chemo was [terrible]. He [physician] said until I got into trouble he wouldn't do it. I haven't had it [chemo] since ... At this point I don't think I could cope with chemo. I just had too much. It really affected me very badly.

Learning the details and nature of the illness is important for some people to return to feeling normal. Rosey was told that, although her disease was genetic and could recur in the opposing side, it would not recur in the side with the mastectomy. This knowledge seemed to be very important for her to begin to feel back to normal, or on familiar ground. She had a biopsy on the non-operative side that came back negative.

> But what the doctor did say today that made me very happy is that I will never have to again worry about cancer in this side. Because he said, the other side - yes, because even though it had a benign

> lump, it will still have to be checked twice a year - whatever - mammograms, exams ... and they will watch because it is very likely the other side could become malignant because you have the gene ... [But] you don't ever have to worry about [the operative] side developing malignancies again.

Sorting through the nature of the illness - cancer - was also important to Grete who had gathered information prior to her surgery. She had spoken to friends and relatives who were in the medical profession and read extensively about her illness. Even so, she appreciated her doctor's advice regarding how she would respond to her change in body image after surgery.

> Oh yeah, but I had been warned about that. GP was kind and he said "initially you are probably not going to like what you see". And you read that too, but to hear it ahead of time ... it was ok, it was good.

The return to normalcy for this woman included a change in body image that she had prepared for and had been advised about but she admitted that there was a huge emotional piece that needed to be worked through. When speaking about learning wound care she differentiates between the physical self-care and the emotional component.

> There is a fair bit of physical stuff in it, but there is a chunk of emotional stuff. I was maybe ok on the physical, I was up and down and performing and going back and forth and doing my washes and that sort of stuff in the hospital but I wasn't doing the dressings and maybe part of the [adjustment] was accepting the new, trying to accept a new profile, image.

Once she had learned the skill involved in doing her own wound care and had a chance to reflect, she had a different perspective "And perhaps I could take some blame, perhaps if I had been ready to try and look at myself, and to do it. But I found that there was enough hurdles initially [at] home". As she began to adjust emotionally, she felt a sense of normalcy returning.

> If I have to dress it, I can do that, its a snap. And I'm further ahead days wise - looking and adjusting, and accepting and going forward. And I've got a really good prognosis, they got it all, and so its just a matter of concentrating on that and getting back to good health.

It was important for all participants to have details, facts and possibilities clarified beforehand, and then receive more information after the surgery. For some this included the details of what to expect, every step along the way of the surgical experience and after. This information was a way for them to exercise their ability to make decisions and partake in some control over their experience. This became, for all, a major theme in the research.

Decision and Control

This theme is very difficult to encapsulate in one term or label. At times I labelled it *independence* because some of the statements were about people wanting to do things for themselves, taking care of themselves:

> I don't want to go through that again, it was very frustrating, very frustrating. Bad enough when you don't feel well enough, and you have to constantly rely on someone's help ... I have been a caregiver all my life. It is very difficult to turn around and be given care to. On a constant basis. Being a mother to my children, I was looking after them, never mind they looking after me. So it was quite a reversal and I wasn't very comfortable. It's not that ... they would [not] do [it] right ... it's just that I didn't want to impose.

Star was fiercely independent and yet she needed assistance. This independence, and insistence on continuing on a course established by her doctor, got her into severe difficulty with pain and wound management. When I asked her about her reluctance to ask for assistance, she said "it could have been my own resistance, that I was trying to deal with the problem on my own. Because I just accepted that that is just the way it was, nothing could be done until a certain time".

For Star, control included feeling clear headed.

> And when it comes to painkillers ... I have had so much difficulty with different kinds of drugs, I suffer, I think I can take physical suffering sometime, except when it is really bad, more that I can take a fuzzy head. When I have no control, emotionally or, you know, consciously, over my situation, it really bothers me.

Decision and control included taking on the responsibility to learn and make plans and decisions. Char was involved with her husband's care from the beginning of his illness three years previously. She made a habit of being present when wound care was being done in order to understand and learn. She was comfortable with learning new things and said, "they brought me in on any decision that was being made". But she did not wait to be included in decisions, she pursued information and action that they felt they needed "[she] had already been enquiring if I could come home with my JP, on TPN[5] and home care. She was already trying to line that up before". And taking on the responsibility produced results "Even this time, I know [the doctor] wouldn't have let him come home if it weren't for the fact that he knew that I was taking on the responsibility - because I begged him".

In relating an experience from a previous hospitalization, Bill and Char described an experience where they felt control was taken away. They felt that the professionals did not believe them and did not value their opinions. They had been previously instructed

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[5] Total Parenteral Nutrition is intravenous fluids containing the essential nutrients.

about the symptoms to watch for and, when they noted these symptoms, they came to hospital, as instructed, only to be treated as if they did not know what they were talking about. Because they took the responsibility to learn, they wanted and expected the ability to make decisions and have control.

Although, at times, patients want to go home, perhaps prematurely, there are others who want to make the decision to stay a bit longer in hospital. They appreciated being given the option of being discharged, or waiting another day or so. Rosey had young children at home and knew that it would be difficult going home with the amount of pain she was having. Waiting another day, until her husband could be there, allowed her the control she required to regulate what she felt was acceptable versus unacceptable.

Decision and control is dependent upon information. Patients cannot make decisions and take control unless they have the facts in advance. Grete found this particularly problematic.

> I came in on the Monday, Tuesday was an in-patient. On that day they said "you can go home" and I said "please I don't feel ready" and they said, "By 7 o'clock tomorrow morning I hope you will be feeling ok". So it was like the decision was made. So it was like a day and a bit. And I had been told 2 to 4 days. I wasn't totally comfortable going out at 7 o'clock in the morning.

When asked what kind of information she needed to feel comfortable, she said

> I have been trying to think of that. I guess ... I would have liked ... a clearer understanding of what was to happen in hospital. And then would get to a certain point and then would be ready for discharge. I didn't know what the criteria [for discharge], pros and cons would be. Expectations of what I could be doing myself and should be doing myself. I would have liked to have had hands-on [wound care] ... but with somebody standing by helping with first impressions and first actions. I'm sure I could have done it.

She talked about feeling "pushed through the system" and "abandoned". The feeling of abandonment was shared by Star in relation to both pain management and wound management. In both cases, although they were taught the simple technique of emptying the JP drain, there was significant information not discussed. Information, skill development and then the ability to make decisions, was important for them.

> I would have liked that choice. Perhaps it is impossible in that short time frame, but I am speaking as if I am not emotionally entwined now and I am saying - if I knew what the job was [wound care], I would like to have the option somewhere in the game to say "I could do that" and take it on or have someone help me though that period [home care]. Maybe that is too ... that isn't able to be put into the system, having that item of choice, but I would like it to be there.

Learning to do Wound Care

Learning to do wound care is the third theme identified in this study. Three of the participants had a Jackson-Pratt (JP) drain in place at discharge. All three had been shown how to *empty and reactivate the drain*. They had all performed this technique while in hospital and had also been taught the *measurement of the fluid* obtained using a small graduated container. They were instructed to do this at home and to *report to the physician* the amount of drainage, as this would determine when the drain could come out. None of the three had any difficulty performing this skill but there were differences in the instructions, and incomplete information. "They showed me how to do it, not necessarily how often". Star explains how she was taught

> She showed me how to empty and to milk it to make sure there was no clogging. In that part, I can see no problem at all. I think they have given me ample instructions in that . And she did tell me that

> if it gets so full in such a way, that I was to empty it. And she showed me how to squeeze to cause the vacuum and she also gave me little sample bottles to measure it with. And she told me to measure it daily because I was to let the doctor know how much when I was to see him".

Upon closer questioning, she was emptying the JP once or twice a day. The amounts obtained varied from 40 to 70 millilitres at a time. The other two patients did not mention criteria for emptying. All three felt they understood the emptying and measuring, but they experienced *leakage from the JP site.* They were not prepared to deal with leakage spilling out onto bedding and clothes. This leakage had either not happened when they were in hospital, or they were not aware of the volume or its origin.

> So, day one I was to measure it, I came home and things were quiet and I didn't really think the dressing would have to be done that day, and everything was fine until about six o'clock that evening and I had a flood and I was in a ... [mess] through the back [soaked her clothing] ...It was probably around the drain. I don't know where it came from.

Star, after experiencing leakage in hospital, had drainage leaking around the tube site for many days at home. At first she did not know where it was leaking from "Perhaps if I knew exactly what I was dealing with I would have been better prepared. Not for one minute did I realize I was leaking from the Jackson-Pratt". The leakage was highly distressing for her.

> It was just the actual site where it was really oozing very badly. I wore my camisole where I had my Jackson-Pratt [and] it was soaked through, my nightgown was soaked through, my sheet was soaked through, so it was annoying and I was really not feeling [well], I was home after the fourth day of my surgery [and] I wasn't feeling all that well."

The leakage from the site was sometimes sporadic and unpredictable. Rosey did not change the dressing for four days and then, suddenly, it leaked

> It only does it sometimes. Like I got up this morning and came downstairs and before I got all the way downstairs it was running down my side and I thought AHHH. When I went upstairs and emptied it, it was only like 15 or 18 cc's in the ball. But it may have been just the way I was lying, it may have twisted the tube a bit and caused it to have a little bit of a hole that it could leak out of. 'Cause you are lying down. The other time I was just sitting up there and it leaked out, so it may have been a clot that was in there.

Some of the patients were taught to "strip" or *"milk" the tubing*, a technique to dislodge any potential clots that may have formed in tubing since the previous reactivation. "The nurses never did strip it in there ... they emptied it ... But the doctor showed me how." Of the two patients that were taught this technique, Rosey found it the most difficult. For her, it required two hands and, with a mastectomy, the hand on the operative side is not strong and manoeuvrable and the process causes some pain.

> Today he [doctor in the office] said again "are you stripping it to get the blood clots out?" I try but that is very awkward when it is in one armpit that is very sore to try to hold it so you don't rip it out and try to strip it with the other one. When there is no one around to help with that ... Because it is bruised from all the other surgery. When I do it, I can't strip it from the tip because I can't reach that high so I have to hold it as high as I can with one arm and then pull down because you can't reach up ... you can reach up but you can't hold on tight enough ... not to pull at the incision. So when my husband does it he can hold it up there, but still when the doctor did it today again, it hurts at the incision site when he's stripping it down. He did get some good clots out today ... So that part I found awkward.

Rosey's husband helped her with the JP when he was home but was away a significant amount of the time. She associated her inability to do the milking with the leakage.

> And it feels just awful because it runs down the inside and runs all

> the way down to your hip. And it feels just weird, but the ball had not been even 25 cc's in it when I took the stopper out. But I'm wondering now if because I hadn't been able to strip it, that maybe clots had gotten in the top of it and didn't allow the fluid to go in and so the fluid runs down the outside.

Star had been milking the tube but she was quite vague as to frequency.

Nurses did not, in these instances, teach the patient how to *change their dressings*. The patients were told that it might need changing but that it probably wouldn't and that the doctor would change it in a week in the office. Rosey perceived no difficulty in doing it at home, "I had seen them do it ... You just took the one off and put a new one on". She felt competent.

> Changing dressings is something I've done all my life. I'm not an LPN or anything but I did do nurses aid and candy striper work and [homemaker work] so they may have known that or they may have just because I didn't seem afraid of dressings or bandages or anything they probably assumed that I would know.

Although Rosey claimed it was easy, she did not actually change the dressing before the appointment with her doctor, even though it had leaked. She and her husband reinforced the existing dressing.

Grete did not find it so straightforward "Basically, I could get my arm up like this. But you can't see around corners, you can't see where the stab wound is coming out". Grete's husband ended up reinforcing the dressing with old dressings she had in the house. She then asked a nurse friend to come and do the dressing change.

Star really struggled to keep the drainage from spilling out everywhere.

> Once I got home it was just oozing out of me, there was just no way for me to keep up with it. I even used Kotex pads to put around the area ... I can't say I resented it ... it wasn't nice ... I

> would use that, and it would get wet and I would have a bath and start all over again. Like I said, at least twice a day, I had to ... In between time I would use so much of my gauze up I would use paper to stash up in the area to soak up the extra moisture.

Although Star had been experiencing a lot of drainage in the hospital, the nurses changed the dressings and did not carry through with instructions to her.

> I remember before I left, the last dressing was really soaked right through. And I remember the nurse was putting on one after the other ... my God ... what were all those 2x4's for! I actually felt guilty, honestly. Because she kept packing it up, one after the other, my goodness, you know. And it was the middle of the day, and before I went [home] they changed another one, so I did have a lot of it, but I didn't realize it was coming from there [the JP site]. I thought it was coming from the other one [incision].

Star had not tried, initially, to learn from the nurse.

> First of all, when I laid down, and they were looking at it, and were working with it, I didn't make a point of sitting up and seeing what was happening. I just left it up to the nursing staff to do their job.

And when questioned further about learning the details of the wound care she claims that

> I don't even think they realized how much draining there was. It was something that was to be done here. She fixed me up to go home with it, she said it might have to be changed but it might not be necessarily so. Well it was very necessary!

Although she did not participate with her current wound care, she had ample experience managing her previous urostomy[6]. She spoke of how the home care nurses had taught her urostomy care "Maybe I should have had home nursing to the home, which I had after I came back - when I had my [urostomy], it was very helpful. I felt a little abandoned [this

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[6] Urinary diversion from the bladder to the abdominal skin, pouched on the skin with a plastic appliance.

time, when I had to care for myself without home care]".

These experiences contrast dramatically with that of Bill, where Char participated actively in the wound care on an ongoing basis.

> The nurse cleaned it for me and showed me how to clean it and change the dressing and she even gave me some supplies to get me started on. It was pretty simple. Straight forward, just use some rubbing alcohol and then change, clean gauze on it. She put a mepore dressing on it ... so that was pretty straight forward.

Once they got home, although he had been shown the wound care, he needed Char's help. He admitted that, had it not been for her care, he would not have been able to manage at home. "You know, I was a bit reluctant to do it. [Groaning] 'Oh, I don't want to do this' ... so [she] did a lot of it." When asked what he would have done without his wife to help, even though he claims it was straight-forward care, he said "Home care. Either I wouldn't have been home, or home care".

In describing how she learned, Char said "Yeah, I just stay and watch and they show me. We would chat a lot. I actually made friends with just about everyone up there. They really included me in all of his care". This couple also was proactive in seeking answers to questions. Having been through nine surgeries in three years, they were more aware of the kinds of things they would need to know once they got home.

> I asked the nurse about my G-tube and what I should do ... would she flush it for me and then change the dressing? Because I was hopefully going home tomorrow ... So the only concern I had when I was leaving [was] to see if the G-tube should be flushed out ... I asked [the doctor] about it ... if I did get nauseated, should I open it?

Bill also adapted prior learning regarding showering with an intravenous, to the situation of the gastrostomy tube:

> I enquired about that, about showering and they said that would be another thing to ask the doctor. So what I did is what they showed me with [intravenous tubes] before, you know, I covered it with saran wrap and I got some of that orange tape to make it waterproof. So that's what I did. So I had a shower, I wouldn't bath with it.

Bill was able to adapt prior learning to the new circumstances, while Star had difficulty transferring what she had previously learned regarding her urostomy to the current dressing changes.

Other experiences indicated learning needs prior to discharge. *Reconnection of a detached drain reservoir* is a potential need. At one point Rosey was astounded to find that the reservoir (bulb or ball) of the JP drain had come off.

> I thought "Oh, it feels big". And I had just drained it. It was inflated. And I thought "Did I forget to squeeze it before I stuck the little thing [stopper] in" So I went back in the bathroom and there was some [drainage] in there and emptied it, squeezed it, cause the cap was in and put the cap back and let go and it went zzzt and filled up again. Well the drainage tube had come off the ball. And it was hanging down my back. It was because the ball was pinned to my nightgown and I realized the ball wasn't connected to the drainage tube.

She reconnected the tube without difficulty, but did not know the correct procedure, or the recommended course of action (cleansing the connection and/or notification of health care professional). This kind of break in the system can lead to contamination of the wound.

Rosey also wondered about *bathing at home* and asked the nurses. She was told not to bathe or to get the dressings or incisions wet. However, when she saw the doctor on the first visit after discharge, not only did he say she should actually soak in the tub to soften the suture line, he told her that he had advised her of this while she was still in hospital. She did not remember this instruction. She noted the contradiction between hospital staff and doctor and she regretted not following his instructions to bath, because, as he said, the staples would not have hurt so much when removed, they would have been soft without hard particles adhering.

Although Grete received instructions about *arm exercises* from a physiotherapist in hospital, Rosey did not. She was given a booklet by the "Reach to Recovery" Volunteer[7] who visited her in hospital. The booklet mentioned arm exercises to help relieve the tightness and lengthen the tendons in her elbow. She asked the doctor about the exercises, and he said they were a good idea.

Help After Discharge

The fourth theme concerned the need for *help or resources after discharge*. One participant wanted the phone number of a professional person to call and ask advice, and one wanted more explicit written material that could be referred to later. Three participants talked of friends and family who were available to help with wound care and activities of daily living.

As mentioned above, Star claimed to want to do everything for herself but she did refer to her daughter helping out "I had some supplies but not all of it. And I didn't exactly want to [get] my daughter into it, she's already doing so much for me". All of the

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[7] Women who have had a mastectomy who visit patients to support and advise them.

other three participants referred to family helping out with making meals, assisting with wound care, shopping, running errands, assisting with bathing, and so on. Two of the participants mentioned friends unexpectedly helping out. This help included arranging whole meals for the family, offering to do housework, offering to mind children and so on.

Resources are required for the person at home. Resources are anything that is offered or sought as a source of support, information, or action after discharge. Learning needs include *what or who, when and under what circumstances, to contact for support, information or action.* The learning needs identified by participants were in part addressed by nurses and doctors in hospital and in one case there was a sheet of home instructions given prior to discharge. Much of the information on the sheet was too general to be helpful or was not applicable. For example, under "dressings" instructions were "you may bath, keep drain site dry" and "dry dressing daily". There were no details about specific procedures, where to get supplies, what to watch for or when to notify the doctor or other health care professional. Nurse participants and some of the patient participants felt there should be a *written resource* that address some of the learning needs following discharge.

When discussing the events after discharge, Rosey wanted to be able to *phone back to the nursing unit to ask questions.* She actually did this, without being told to and found it most helpful. She claimed the issues were nursing ones and that she didn't want to be waiting for the doctor to return the call hours, or days later. She wanted the information now and knew that the nurses would be on the unit and that she could ask them. She also did not want to phone the doctor's office for advice because she did not want to bother him.

Pain Management

The fifth theme that all four participants had much to say about was pain experienced after discharge. In one case it was a problem that disturbed sleep and prevented comfortable rest and relaxation. In the other three interviews, pain became a major dimension of the entire discussion.

Star had extremely troublesome pain at the JP site but she also had uncontrolled abdominal pain for eleven days. She was reluctant to, and did not phone the doctor for the initial seven days prior to the first office appointment. She made do with anti-inflammatory medication that did not take away the pain. Although she tried to explain her pain to the nurse at the time of the office visit, she still did not get adequate pain relief. When asked why she did not pursue getting a different analgesic, she stated

> I had to wait until it was up [the appointment time came around]. But when I once got there I wanted him to know that indeed I had trouble and I expressed that [to the office nurse who was removing the staples]. But because it didn't look visibly, although there was a tiny bit of redness around where the Jackson-Pratt entered into the body, that is probably irritating to the skin, she thought it was a skin irritation and yet to me internal, it was deeper than that. It was not a superficial thing, it was deeper. I was desperate to try to explain that.

After being sent home without seeing the doctor or getting a different analgesic, she went back four days later and saw the doctor "The following Monday I tried to explain it to the doctor and he gave me some [narcotic analgesic], but with [it] I got sick". At that point she was re-admitted to hospital for pain control and investigations. When I enquired about why she did not try to get something more for pain earlier she said "Well, I sort of took it with a grain of salt. I went home with this [analgesic] and I was to see a doctor on a certain date and I sort of had to cope with it ..." After further questioning she stated "In a sense I am independent. I'm used to taking care of myself, so it was something I had to deal with".

Rosey anticipated the pain of the JP removal with extreme dread. She had been in the hospital bed next to a woman who screamed in pain when her JP was removed and she thought that would be her experience when the time came. She mentioned this to me when I saw her in hospital before discharge and she said the nurses had "ripped" the JP out of this other woman. She also said that a nurse told her having the JP removed was the worst part of having surgery. In preparation for the removal she was going to take extra pain killers. She also focussed on the pain of the JP site, the pain of the staples pulling on her skin, the painful experience of having tape removed from her forearm where the intravenous line entered. Pain was a big part of her experience.

Bill had many tales of painful experiences. He had been on narcotics many times and he identified a significant learning need early on.

> I had one really bad experience. This is the second time I had this internal pouch hooked up. The first time I came home I was really sore and I was on [narcotic], it just wasn't going easy for me. I was going to the washroom a lot and had a bad rash, and I stopped taking the [narcotic]. And I really wasn't aware, you are supposed to taper yourself off [the narcotic] so I was hot and sweaty and had the chills and really cold and that went on for a couple of days, and just felt terrible

After going through withdrawal for a couple of days he contacted the doctor and found it takes about three days before symptoms of withdrawal disappear, unless you taper off gradually.

Grete found herself in severe trouble with constipation from taking narcotics, despite taking preventative measures on her own initiative. She claimed that the taking of preventative measures should have been stressed at the time of discharge.

Nurses' Views Regarding Preparing Patients for Discharge

The nurse participants were explicit about the details of what a patient requires and what a nurse and doctor need to consider in preparing patients for discharge. This data is summarized below.

- Patients are often overwhelmed with their illness, diagnosis, prognosis, especially those with a diagnosis of cancer.
- They are under the influence of attention-altering medication or have difficulty listening and assimilating information.
- Patients need time to think and assimilate and think of questions to ask.
- Patients often feel intimidated by health professionals, especially physicians, and therefore do not ask pertinent questions.
- Nurses can play a significant advocate role in prompting patients to ask specific questions of the physicians.
- There is a lack of continuity between nurses and shift to shift for patient teaching (the teaching for discharge is often done by a nurse or nurses who are not on shift the day of discharge, and assumptions can be made about how much the patient understands at the time of discharge).

- There is a lack of time for patient teaching with patients who are short-stay.
- Patient self-assessment is subjective and they need specific criteria for acting and reporting, for example, characteristics of wound drainage to report, a degree of body temperature to report, or criteria regarding pain management problems.
- Nurses do not appreciate the anxiety and fear that some patients experience when faced with doing their own wound care.
- Nurses make assumptions about what will happen when the patient is at home, about how they will cope and what is "simple" and "easy" and they fail at times, to teach from the patient's perspective.
- Patients need practice doing any skill such as dressing changes, emptying drains and measuring contents and stripping or milking the tubing.
- Verbal and hands-on instruction should be supplemented with written instructions. These can be sent home with the patient and caregiver for reference when they actually have to apply the knowledge. They can refer to it when they can absorb the information without the stress of the hospital surroundings and when they feel better.
- Patients with mastectomy need extra emotional support and counselling that some nurses may not feel prepared to offer.
- The patient needs a contact or resource for when they go home.

Nurses had definite views about what details should be taught to patients directly or provided in a handout.

DISCUSSION OF FINDINGS

This discussion draws on the patients perceptions of their learning needs, on the perceptions of nurses, as they see patient learning needs and on my own assessment and perceptions of what I saw, heard, and judged to be their learning needs. Although this study was about patient perceptions, the purpose of the research was to identify what patients experience when they went home. While patients may not identify those experiences as learning needs, a nurse would identify them as such.

I do not intend to make broad generalizations but rather to raise awareness by reflecting on the experiences of these five individuals and stimulating thought on how health care professionals and health care consumers can understand and deal with self-care learning needs.

To begin the discussion, I would like to assert that, from my own understanding of patients' experience and from my discussions with the four nurse participants, none of the above patient participant statements came as a total surprise. The experiences of the patients resonated with my own.

This discussion includes some theoretical understandings that I have used to organize and make sense of the data. I found it a challenge to develop a theoretical framework to organize the information I wish to write about. There is so much in the adult education and nursing literature (Bubela et al., 1990a; Stricklin, 1993; Bostrom, Crawford-Swent, Lazar & Helmer, 1994) that is useful and this thesis supports findings in these studies. But I have chosen to discuss three of the theoretical or conceptual approaches as presented in Chapters 1 and 2. The work cited by Devine (1992) regarding psychoeducational care highlights various patient learning needs including: skills teaching, health care relevant information and psychosocial support. Cranton's (1994) typologies of learning (subject oriented, consumer oriented and emancipatory), is helpful in describing the different kinds of learning that these patients required. Merriam & Caffarella's (1991) review of scheme theory (accretion, tuning and restructuring) is useful in understanding how patients learn over time, how they build on prior knowledge and experience, and how prior learning and experience can hinder learning relevant new knowledge. The three approaches overlap, they are not separate concepts but complementary and interwoven in a complex way.

Psychoeducative Care: Skills Teaching

The first component of psychoeducative care described by Devine (1992), involves teaching skills. Three of the four participants, had significant learning needs around the logistics of wound care. Although the three patients were given some instruction, including practice in emptying and measuring the contents of the JP drain, there was a lack of understanding regarding the frequency of the emptying. Emptying the drain reservoir and reactivating the vacuum of the JP regularly is quite important (see Appendix A). The frequency is dependent upon the amount of drainage because as it fills, the suction is lost and fluid builds up inside the patient. The product manufacturers recommend emptying the drainage system when it has collected a maximum of 100 millilitres. Lack of suction on the wound could cause leakage around the site. This leakage is not necessarily dangerous, but it is inconvenient, messy and distressing. Three women experienced this leakage. Leakage could be attributed to overflow fluid due to the development of increased wound seepage from activities in their home environment, or as one participant stated, from lying in one position with the tubing kinked off. It is however, reasonable to conclude that there is a likelihood of leakage around the JP site if the suction is not maintained. Regular emptying and reactivation of the JP on a more frequent basis, would maintain that suction and prevent the fluid accumulation and eventual leakage. Two of the women did not make the connection between the leakage and the reactivation of the JP drain.

The other learning need related to the JP was milking the drainage tube itself. Milking involves grasping and sliding the tubing between the fingers in such a way to create extra temporary suction to dislodge clots or tissue. Although the manufacturers do not make statements about the necessity or frequency of milking the tube, some doctors stress the importance of this milking or stripping while others do not. If there is a clot blocking the tubing, drainage will not occur and fluid will build up and either accumulate or drain out the JP site or the incision. Instruction to milk the tubing is authorized by the physician. A nurse then instructs and coaches the patient through learning this technique including the frequency it is to be done.

The reservoir of the JP drain is attached with friction-fit tubing and can come apart with excessive pulling. The manufacturers stress that patients should never disconnect the tubing and should notify the doctor immediately if it should become disconnected. This disconnection did occur with Rosey and I know it also occurs in hospital. The stopper can also come out of the reservoir. In both cases the aseptic integrity of the unit is lost and drainage can leak out and soil clothing. Patient teaching includes assurance that this may happen, how to prevent it, and what to do if it occurs.

At the time of this writing, the manufacturers of the JP drainage system have developed a non-copyrighted Patient Instruction Guide (Appendix A) for use by physicians who use their product. It details all the manufacturers recommendations regarding self-care of the system. It includes instructions on when to contact the physician.

The other actual wound care that was identified as a learning task was the dressing change itself. The three women claimed not to have received any specific instructions regarding the dressing changes. This was confirmed by three of the nurse participants who do not expect that patients will need to change the dressing prior to the first doctor's appointment. Obtaining supplies was a problem for two patients. Nurse participants claimed that "simple" dressing changes are often seen by professionals as straight-forward and unproblematic, one patient participant found this to be the case. The other three found the procedure difficult, painful and emotionally challenging. Simply looking at the wound can be a significant hurdle for a woman with a mastectomy, one that she is not ready for, for several days or much longer. The logistics of changing an underarm dressing with one hand, while experiencing discomfort and emotional upheavals, presented a major obstacle to self-care.

Stricklin (1993) found that home care nurses used repeat demonstrations, and allowed the clients to repeat the skill over and over until they mastered the techniques of wound care. She found that patients felt it important to learn the care in their home when they were faced with the real situation. Redman (1993) describes the process of learning as stages. The stages of selective perception, storage in short-term memory, encoding, storage, retrieval, and response generation, explain how individuals absorb and retain information. The patients in my study, for example, were not necessarily in an emotional and physical state of readiness to learn. They were receiving narcotics, not feeling well, or had major emotional hurdles to overcome. One patient had a social or cultural factor that made her reluctant to seek out learning. Another was in hospital for a short time and was not exposed to learning opportunities. These factors made the learning process difficult. The perception of incoming information and learning was impaired. Review and discussion of information allows people to arrange information and learning into meaningful chunks or pieces that facilitates storage for future use. With three participants this may have been the problem. For example, if they were taught about their wound care only briefly, selective perception may occur: they may only remember fragments of what was taught. If the teaching did not include follow-up discussion or review, the patient would probably forget the material. With any skill or learning, the hands-on practice not only allows for learning the psychomotor skill but also facilitates the memory process. The performance solidifies learning and allows the individual to adapt their technique to deal with problems that arise. The teacher can assess these abilities and provide corrections and suggestions.

Individual learner characteristics affect the learning process. In the case of Char and Bill who proactively sought out knowledge and information relevant to the wound care, the nurse may not need to take charge and direct learning as much as he or she would with a person like Star, who simply received care without inquiry into what was required or without taking an active role. Ongoing patient assessment includes the assessment of readiness to learn and readiness to take the initiative in learning.

Psychoeducative Care: Health Care Related Information

All four participants described needing information about the factual aspects of their illness and treatment, the hospital routines and what was to be expected in and out of hospital. This information was seen as crucial to their ability to make decisions and retain some control. There was a need for specific information as well. For example, information about narcotic withdrawal management and narcotic side-effect management (constipation) did not apply to all patients. This information would not only assist in their self-care but in their self-determination and their return to a state of being normal.

The Pre-admission Clinic of the hospital provided some information when the person came in for advance diagnostics. Individualization of information for patients is important. A woman being admitted for mastectomy was told by Pre-admission Clinic staff that she would be in hospital for 2-4 days. She was then most upset when told by the physician, that she could leave in less than 24 hours. She already felt that four days would be a short time frame for this surgery. She felt abandoned and "pushed through the system" when it was suggested she could go home the next day.

Perhaps the most important information a person needs to receive in hospital is where and how to get resources once they are at home. Doctors always give the patient a phone number to call for their follow-up appointment. Some patients are set up with home care and/or home maker services prior to discharge. All of the participants in the study identified a need for after-discharge support. They needed questions answered and assistance with problem-solving. They required help with dressing changes, and needed extra supplies. They voiced a concern that when they needed a resource, the need was urgent. One woman used her friend for this support, and one patient phoned the nursing unit. Three patients used their physicians as resources. The one woman who did not use resources was unhappy about her situation. She had home nursing care after an earlier surgery, and she stated that she would have liked this choice again.

I have mentioned above that written resources (instruction sheets) are considered helpful for patient information after discharge. A written resource serves to reinforce the learning that occurred in hospital such as, the steps to changing the dressing, how often to empty the drain, what symptoms to watch for and when to contact professionals. Printed instructions allow the patient and caregiver to review information at their leisure when learning is not compromised by the stress of hospitalization, feeling generally unwell and the effects of medications.

Obtaining supplies was a problem for two participants. The problem was not due to cost, or because they did not know where to get supplies, rather, they felt too poorly to go out. In both cases the problem occurred in the first few days after discharge, when they were still feeling weak and unable to cope. In one instance, a nurse friend took charge and brought supplies and, in the other case, the person made do with tissue and Kotex pads. Although participants denied that cost was a factor in obtaining supplies, they felt that dressings were expensive. The three participants with cancer were unaware of free dressings that can be obtained from the Canadian Cancer Society.

Nurse participants in this study generally instruct patients to either get in touch with their physician, go to a walk-in medical clinic, or come into Emergency if they were concerned about signs and symptoms of complications, such as bleeding or infection. Some patients I interviewed were comfortable with attending these agencies or offices, but felt they required some other source of help, specifically nursing support at home to assist with dressing changes and problem solving. Although this need can be attributed to a lack of adequate teaching prior to and during the hospital stay, there will always be problems that arise that are not easily solved.

Psychoeducative Care: Support

The third element of Devine's psychoeducational care, is the supportive aspect. Bill's wife performed his wound care for him, and she supported him emotionally. The emotional support was important, as he claims, the wound care itself was "straightforward". He said that without her, he would have been in hospital for another 3-6 weeks or would have required home nursing care for the wound care. This is alluding to the huge support component of her care. There are clearly implications for discharge planning when this kind of caregiver support is not present.

Women who undergo mastectomy find it supportive to have others, such as Reach to Recovery volunteers, who understand their circumstances, spend time with them, listen, and offer support such as advice and empathy as they work through the process of coming to accept a new profile or image. They need reassurance that what they are going through is normal, that it will take time, that they should take each step as an accomplishment, and that things will improve.

Health care professionals understand this support need of patients and it goes beyond education or teaching per se. It includes such elements as empathic communication, understanding and reassurance, answering questions and concerns, providing assistance when required and supporting decisions. All four participants needed this kind of support and it is mentioned here for the sake of completeness. One cannot exclude such support. It is integral to patient teaching. With two participants, the supportive component was identified as deficient. Not surprisingly, the time directly following surgery is the time of greatest need, and when lack of support is felt most keenly. The patient needs -- embedded in the three themes of normalcy, decision and control, and help after discharge -- especially highlight the need for supportive care from health professionals.

With these three kinds of psychoeducational care, each individual in this study had needs in common with others and each had needs that were unique. A health care professional may offer information, skill development and support and be ready to tailor the education and support to the individuals needs. The key to helping the patient achieve self-care is in being attuned to the patient's subtle indications for extra support. An example is Star, who did not participate in care and did not even look at the incision. A nurse can be aware of this and encourage the patient to take a more active role early on in the hospital stay.

Typologies of Learning

The second relevant theoretical perspective, is embedded in Cranton's (1994) three typologies of learning. This perspective highlights the different perspectives one can take when viewing patient teaching and learning. *Subject-oriented* learning provides the "meat-and-potatoes" of learning self-care. Traditionally a patient is the receiver of information and skills training. Although the person may choose to engage in the process, subject-oriented learning is really directed by the teacher, the professional. Health care professionals focus on this type of learning. The subject matter, or content is all-important. The professional, as teacher, is the conveyor of that information.

In the case of the participants in my study, logistics of wound care, solving problems related to the drain, bathing, dressing changes, how to manage pain, where to get supplies and who to go to for assistance are all examples of subject-oriented learning. Health care professionals provide this information in the form of hands-on instruction, didactic information or printed and video material. This reflects the pedagogical model of health care education. Androgogical models of education focus on the adult as the self-directed learner who determines much of the content, process and evaluation of learning.

The second typology, *consumer-oriented* learning (Cranton, 1994), is something that we, as health care professionals, have not promoted as much as we could here in Canada. Consumer-oriented learning potential is great. Bill and Char are a good example of consumers who seek information and skill to manage their affairs. They were not satisfied to stand back and receive instructions when initiated by health care professionals. Char was proactive, participated in her husband's care and was constantly learning the details of his condition, treatment and procedures. Although she used experts as teachers, she took control of her learning. Grete is another example of someone who proactively seeks information. Prior to hospitalization, she consulted friends who were health care professionals and extensively researched her condition. In both of these cases they experienced frustration with a system that did not allow independent decision-making and personal control.

As health care professionals we possess information about the hospital, disease, treatments, options and resources. To promote the type of learning Cranton (1994) is referring to, we would develop self-instructional materials that would enable people to prepare themselves for a hospital encounter and take an active role in preparing for their self-care upon discharge. The data in this research do indicate that people are self-directed in attempting self-care. In some instances they are self-directed in learning. However, some patients are passive recipients of health care and do not see it as their role to question or learn about health-related care.

The third typology that Cranton (1994) describes is *emancipatory* learning. Emancipation is a process of freeing oneself from the forces that restrict for example, decision and control. Star was an example of a case where patients think health care professionals are in charge and a patient is powerless to change plans once established. She did not pursue alternative analgesics for her pain, or pursue help with her wound care. She was the first participant I interviewed, and I was so struck by this finding that I made a point of asking all the rest of the participants, including the nurses, what they thought of this situation. All participants identified a reluctance on the part of the health care consumer (themselves or people they know), to *bother* the doctor with what they might consider small or insignificant problems. Nurse participants claimed that nurses have an advocate role, ensuring the patient gets the physician's attention to answer questions while in hospital.

Emancipatory learning involves a transformation of perspective (Cranton, 1994). In the case of Bill and Char, after nine surgeries they likely realized that if they did not take charge of learning, they suffered or did not cope as well. Bill mentioned that, at first he was reluctant to call the doctor with problems but after he had been sick for a while, he no longer felt that reluctance. They both talked about the excellent working relationship they had with the doctors and nurses and felt comfortable speaking their mind. Char talked about having been in the system enough to know what she needed to do to get what she wanted. In reflecting on her statements, this included watching, helping, asking, phoning, reminding, begging.

Star passively received care and did not actively pursue learning or action. Cranton (1994) writes about emancipation as "freeing ourselves from forces that limit our options and control over our lives, forces that have been taken for granted or seen as beyond our control" (Cranton, 1994, p. 16). Star felt that once a certain course was set (a certain analgesic prescribed, a certain appointment made) it could not be changed until the appointed time. Even when she went for the office visit, she was not effective in achieving what she set out to do. The complex individual, cultural and societal influences that would lead her to behave in this manner can only be speculated upon.

To promote a transformation in perspective, the teacher must encourage examination of the forces that limit individual control. Without an external force to stimulate a change in world view, it is often difficult to challenge basic assumptions about roles and processes. A life-changing event (Cranton, 1994, p. 17) (eg. a life-threatening diagnosis or illness), such as that experienced by Bill and Char, is perhaps one of those instances where one is challenged to re-examine basic assumptions and beliefs. As Bill explained, they were reluctant to phone the doctor at first, but after he became more recurrently ill, their feelings changed. This may have prompted their proactive stance on learning self-care.

Scheme Theory

Scheme theory (Merriam & Caffarella, 1991) provides a theoretical perspective that is helpful in analysing these cases. When teaching adults, it is important to consider the great store of previous information they bring to the learning experience. The five participants in this study brought different life experiences to bear on learning self-care of their wounds. Char and Bill brought rich and helpful experiences with previous hospitalizations and subsequent self-care at home which they used to learn new material and which they used to adapt previous learning to the new situation. Rosey had been a homemaker and a care aide. She had little problem figuring out how to change her dressing. This kind of previous learning is stored in scheme or packages of understanding that provides the basis for learning new information and skills.

Scheme theory includes three modes of learning (Merriam & Caffarella, 1991). *Accretion* or the daily gathering of pieces of information such as first learning what the dressing and drain looks like and then how to manipulate the drainage plug and empty it, how to measure the drainage and how to change the dressing. *Tuning* is the gradual change that occurs to our scheme. This might include changes in how we understand our roles in life, or how we value certain things. It is not factual information but rather those changes that happen as a result of accumulated life experiences. Finally, the *creation of* *new, or restructuring or reorganization of existing scheme* occurs in those life-changing events that force us beyond our past experience and understanding. A divorce, a diagnosis of cancer or other significant event can create new scheme or significantly restructure our understanding of certain things. Applying this theory to the cases above, learning factual material, and developing skills and abilities to problem-solve, involves all three processes in scheme theory. On a daily basis the patient can learn new information and over time gradual changes take place to their understanding and abilities. The creation of new scheme corresponds more closely to the above description of a transformative process. New learning and significant life events can challenge our world view, and whole new scheme are formed or existing ones are dramatically changed.

Nurses and other health care professionals who consider scheme theory in planning for teaching patients, deliberately build on previous learning. They recognize that new information that does not have pre-existing scheme must be structured and facilitated in such a way to create new scheme. The accretion process or adding on, is perhaps easier for the adult. For example, a person with previous surgery, like Bill, or previous experience with dressings, like Rosey, may understand about dressings. That previous learning can be identified at the outset, acknowledged and built upon.

Scheme theory can not be applied at the expense of other factors. Star did not participate in learning her wound care, yet she had a pre-existing urostomy. She had learned the care of the stoma and appliances with this earlier surgery and had few problems with the required self-care. It is difficult to understand why she had so much difficulty with the current JP drainage. As mentioned above, the factors are complex and may defy understanding. It could be attributed to some emotional, social or cultural factors.

An older person, with much more life experience, have scheme that can be used to build knowledge and skills upon. It can also be a hindrance to learning new knowledge and skills. On the other hand, as with many of our patients, a surgical experience (mastectomy) may be entirely new and may require a significant effort (with the attending emotional or psychological implications of their illness) to create whole new scheme to begin to perform self-care effectively.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

The five people in this study had some common and some unique experiences in learning about and caring for their wounds at home. When describing the "self-as-instrument", Eisner (1991) indicates how the researcher uses a frame of reference (nursing and teaching) and a set of intentions (thoughts and questions) to engage a situation and make sense of it. My own sense as a person and as a nurse tells me that the feelings and experiences of these people are valid and it has directed me in identifying the significant elements of their experience. The nurses I interviewed also confirmed my impressions. None expressed ideas or opinions that differed from my own. I feel confident that the results are reliable and valid. These individuals can reasonably be seen to represent various experiences that patients have in general. I feel comfortable making some general statements intended to guide nurses to be thoughtful about their practice and take patient's perceptions and experiences into consideration. I will frame these statements around the study research questions.

Research Questions

Below is a brief summary of the findings under the headings of the five research questions.

1. How do adults experience their wound care after discharge from hospital? and 1. a. What are their issues related to self-care of wounds?

The participants in this study experienced various levels of comfort with self-care of their wounds. Bill and Char took a proactive stance and sought out learning from a variety of sources. They experienced no real difficulty in performing the wound care, although Char took over and did the care. Bill did not participate as actively in the actual wound care. They have a supportive relationship with their physicians and nurses. They did identify issues related to their self-care. These included the need to return to normal life, the need for decision making and control in their recovery and issues regarding management of Bill's pain.

Rosey, although she claimed to be familiar with dressings, had difficulty with excessive leakage from the JP site. She experienced uncertainty with problem-solving and she had a great deal of difficulty performing some of the self-care requirements due to pain and the position of her wound. Her husband helped her when he could but was away for most of the day at work. She wanted to be able to telephone a nurse to help her with certain problems.

Grete experienced difficulty with wound care. She could not see the site, and her wound drained excessively once she got home. She felt incapable of doing the wound care because she had not been shown or prepared for changing the dressings. She identified a large emotional component of her recovery and felt she needed a lot of extra support and time to get back to normal. She had a friend come to change the dressings. Prior to hospitalization, she would have liked more information regarding the expected length of stay and expectations regarding self-care. She would have liked some say in whether she could adequately perform self-care or have the option of home nursing care see her. She would also like an instruction sheet to take home to review at her leisure and remind her of what to expect and do at home.

Star experienced excessive pain at home. She also felt ill-prepared to deal with the uncontrolled wound drainage. She did not seek out learning or assistance with her problems in a timely way. She therefore experienced these problems for seven days before the first physician's office visit and then for four days more. She would have liked the option of having home nursing care see her for the dressing changes and other support.

1. b. What are their perceived learning needs at the time of discharge?

Psychoeducative Care

From these four cases, specific learning needs included the three components of psychoeducative care: skills, knowledge and support in learning and self-care.

Skills

- emptying, reactivation, measurement of drainage from a JP drain and reporting of same to the nurse and doctor,
- reattachment of a disconnected JP drain reservoir,
- technique and frequency of milking the JP drainage tube,
- dressing changes,
- arm exercises post-mastectomy.

Knowledge

- type and amount of dressings, solutions, and where to get them, for wound care after discharge,
- available resources to assist with self-care post discharge,
- expectations of the patient and caregiver prior to, during and following

hospitalization,

- action and side-effect of medications, for example: how to gradually come off narcotics to prevent symptoms of withdrawal, and using preventive measures for constipating analgesics,

Support

- empathic listening and reassurance, answering questions and concerns, and action related to learning resources and wound care.

Scheme Theory

The above components of psychoeducative care are helpful in the details of teaching and learning. Another way of examining patient learning is through the three components of scheme theory. Accretion would include the details and logistics of doing wound care, learning the resources available at home, and so on. Evidence of accretion would be the actual performance or stated understanding of particulars. This accretion includes learning the elements of wound care in hospital and then the daily experiences at home that build on that knowledge and understanding.

Tuning would include the gradual changes that a person goes through when trying to accept an altered body image such as in a woman dealing with breast cancer and surgery. This would include learning how to return to the "normal" state of health, of carrying on with life. Tuning would also be evidenced by changes in specific practice over time. All participants had some previous experience with dressings, and this new learning experience added to her understanding and feelings of competence regarding wound care.

Creation of new scheme or restructuring of previous ones, may be illustrated by Star, who, in her attempts to satisfy her need for pain control, may have been forced (through pain and suffering) to assert herself with health care professionals - a behaviour totally new to her. Char and Bill demonstrated this change when they spoke of being reluctant to call the physician. After experiencing a worsening condition, they overcame that reluctance and now access health care professionals whenever there is a need.

1. c. What resources do they use to learn their wound care?

The participants used a variety of professional and non-professional people and materials as resources:

- Reach to Recovery volunteers,
- friends who are nurses,
- physicians,
- nurses in the hospital unit where they had their surgery,
- information sheets,
- textbooks and like material,
- prior learning, from previous surgical or life experiences.

1. d. How do they evaluate sources of information?

Evaluation of sources was not evident in their accounts. They were most concerned with getting support, information and action. For the most part they sought information from professionals. They also went to professional sources such as nurses and doctors to verify information they got from other sources.

Themes and Issues

Five themes emerged from the data. They are normalcy, decision and control, learning wound care, help after discharge and pain management. These themes illustrate that learning to perform wound care is more complex than it appears at first. Only one theme is the actual wound care, and the rest illustrate corollary experiences that impinged significantly on the patients' needs.

Normalcy, was the feeling of wanting to regain a normal state of being, of leaving the sick role. Although getting back to their pre-illness state is not possible, they longed for a return to a "normal" way of living. Any care given by health professionals should be guided by this need. A speedy recovery with timely teaching and support would seem to facilitate the process. Understanding the principles of adult learning such as scheme theory (Merriam & Caffarella, 1991) encouraging self-direction in learning, while offering comprehensive psychoeducative care (Devine, 1992), can promote early independence while assisting the transition to the new "normal" life.

The ability to have *decision and control*, the second theme identified in the experience of patients, is dependent on timely, accurate and complete information. Although I have described the need for patients to take control of their learning and care, this does not mean they can do it without help. A teacher must always start where the learner is, and work from there. In the case of Star she needed a lot of support and information before she would be ready, like Char, to take control of learning. Emancipatory learning (Cranton, 1994) involves shaking off the forces that prevent us from taking control of our lives. Char and Bill illustrate how one can take this control.

Health care professionals must learn not to feel threatened by patients attempting to take control of their own learning. This is not a reflection on the competency of the professional but rather a positive sign that patients are addressing their own learning needs and satisfying their need for decision making and control in circumstances where much of their control is taken away.

Learning wound care, including the technique and appropriate responses, is the third theme. Without reiterating here what is outlined elsewhere, it can be recommended that nurses consider these points in teaching their patients:

1. The patient is a unique individual. Such issues as individual tolerance for discomfort, individual engagement in learning, previous experience with wound care, availability of help at home, the anatomical position of the wound and the logistics of wound care, all require assessment and then learning opportunities modified accordingly. Hands-on experience in doing even simple wound care is exceedingly important, the person learns the skill and the nurse has an opportunity to guide the patient and correct misconceptions and practice.
2. The patient will often need support with the wound care when at home. If they are on their own, measures such as referral to home nursing care would be appropriate. Instead of asking the spouse or significant other to leave the room while the dressing is changed, the nurse can gradually have them observe and then participate in the wound care. In this way, they can become accustomed to taking on the task and will feel more competent and independent in assisting their spouse with care.
3. Even with wound care that is fairly straightforward or simple where there is a

significant emotional component, alternate care-givers should be taught. If there is no one at home to help, home nursing care should be offered. Patients with mastectomy should always be considered as candidates for home nursing care.

4. Health care professionals need to be clear about the recommended care elements. Discrepancies in instructions between different disciplines confuses the patient.

5. Patients do not always have appropriate dressings available in their homes and it is often inconvenient to go out for these when a patient returns from hospital. Pre-admission information could include advice to purchase the necessary supplies in preparation for after-discharge care. This information could include quantity and sources. For example, dressings are available free of charge, with a doctors prescription, to cancer patients through a volunteer organization. This information would also be useful to a significant other if they are purchasing supplies once the person is home.

6. Nurses should not make assumptions about the patients ability to care for a wound or make assumptions that wound care will not be required. Non-leakage in hospital does not mean the wound will be dry at home. The reverse is sometimes true. A patient should be either prepared for the potential problems or given resources to help deal with them if they arise.

Other learning needs included the logistics of bathing and appropriate exercises to perform. As stated above, consistency between professionals in the instructions provided is important.

The fourth theme is *help after discharge*. Bostrom, Crawford-Swent, Lazar & Helmer (1994) found that patients recognize more informational learning needs after discharge. While in hospital a variety of factors (illness, sedation, anxiety and pain) prevent a person from recognizing their own learning needs. Also, they have, in many cases, not had to actually do much of their self-care. It is only when they get home that they realize what they do not know. A common practice is to give patients printed material or instruction sheets for review at home. This practice is based on the understanding that patients are often not ready to learn in hospital and they may not remember important information. Printed material that includes detailed instructions, criteria or parameters for contacting professionals and appropriate individualization of the instructions to address individual concerns would assist patients in performing self-care. Patients should consistently receive printed material and it should be reviewed with them in ample time before discharge to ensure they understand the points made and ask for clarification if they do not.

Help after discharge also includes a resource person to contact should problems arise that the person can not solve or understand. Rosey's suggestion for having access to hospital nursing staff where they were a patient is something to consider. Calling back to the nursing unit for advice is like the suggestion for a 24 hour hotline (Menke, 1988). Walk-in Medical Clinics are often cited by our staff nurses as a source of post-discharge assistance. These agencies should assemble information for the public for a variety of health-related problems and function like a consulting service, especially for the off-hours, when the client cannot contact their personal physician or when the information or assistance desired is more appropriately answered by a nurse or other health care professional. The key is quick, accessible help. Certainly the general practitioner and surgeon should provide written instructions regarding who and when to call for medical help.

Another resource for post-discharge support is volunteer organizations such as "Reach to Recovery" for patients who have had a mastectomy. Information regarding resources (dressings, support) offered by the Canadian Cancer Society or other support groups could be provided. Nursing units, 24 hour hotlines or walk-in clinics, physician's offices and home care offices should have inventories of all the available resources for patient or client education and support.

The final theme is *pain management*. Unresolved pain that impaired activities of daily living and self-care, narcotic withdrawal and narcotic side-effects were part of the participants' experiences. These experiences are ones that health care professionals deal with in hospital regularly. They need to be followed up with the person going home. The problems are not always resolved on discharge. If pain is not resolved, and if patients are going home on narcotics, appropriate information should be supplied regarding management of pain, modifying the side effects of narcotics and managing the eventual withdrawal from them.

Personal Reflections: My Own Voice Unfettered

The use of phenomenologic and hermeneutic methods, has led me to be reflective about my practice as a surgical nurse. In the following paragraphs I will describe some of the personal learnings that have occurred and point out how patients could benefit from the realizations.

In examining these stories with a sense of astonishment rather than receiving them unquestioningly, I can see that in my practice, I have made assumptions regarding patients' comfort level and capability in performing self-care. One often goes about the routine tasks of nursing without truly considering the patient's situation. I sensed in Rosey, Star and Grete, a certain horror at dealing with the leakage from their wound. The nurse participants also spoke about the unacknowledged reaction of patients. As nurses we do not always appreciate the lay person's reaction to things that are foreign to them, such as uncontrolled wound leakage. We take for granted that they will logically proceed to deal with whatever happens, unperturbed. Bubela et al. (1990b) found greater informational needs of those diagnosed with cancer. In circumstances where a woman has cancer, such as Rosey, Star and Grete, learning is complicated by feelings of fear and anxiety regarding their diagnosis, fear of death, and with mastectomy - grief about the loss of their body image. Three of the nurses in my study were not entirely comfortable with a counselling or emotionally supportive role, rather they expect a social worker or "Reach to Recovery" volonteer to supply the necessary emotional support. But nurses are trained in basic empathic communication techniques. We need to acknowledge this formally in nursing orientation and continuing education programs. Although a social worker or volunteer may be helpful when they are visiting, it is the nurse who is the main support care-giver and should be comfortable with providing empathic, supportive counselling.

The hospital environment is far removed from the reality of the patient's experience in the home. Nurses' education or consciousness-raising regarding the experience of patients after discharge should include a first-hand experience of visiting patients in their homes. In providing a "seamless" service to patients, nurses could actually follow through with a home visit to provide care and assist with whatever issues the patient encounters. In this way, nurses would see what issues and problems arise in the home when patients attempt self-care.

There are barriers to engaging patients in learning, but as I see from talking with Char and Bill, patient and caregiver learning need not require some formal program to teach certain behaviours but rather a way of doing everyday patient care. Icenhour (1988) found that patients perceived better quality of teaching when it was done deliberately, with adequate time allotted, and when it was considered critical to patient care. Understanding how Char and Bill learned, I see that teaching works well when integrated into everyday activities, when recognized as an integral and essential part of doing everyday care.

My reflections have lead me to propose that teaching patients about wound care should start before they are admitted and continue throughout the hospital stay. I can envision a process where a person has a small booklet in which they record their health information prior to admission, and then document learnings and wonderings. The journal could be a place to write down their questions so they do not forget them when the physician briefly appears. It could also be a place for health care professionals to write down instructions that should not be forgotten, and a place where a person can track their road from wellness back to wellness.

I understand that there are significant constraints on time and resources related to patient teaching. My practice of teaching has often been done in a rush and on a "must know" basis, as in the emptying of a specific drain, rather than addressing potential problems that could arise. The supportive element of patient education requires extra time and effort. To help the bedside health care professional address the real and potential learning and support needs, standardized materials can be prepared that address common elements of specific procedures or self-care requirements. With standardized patient education materials available, the professional's time can be spent addressing those individual concerns and needs that cannot be taught through these methods.

Instead of just telling patients things, as I have done in my practice, a variety of methods should be used to provide instructions. These might include hands-on work with dressings and learning principles of caring for a specific piece of equipment like a JP drain by watching a videotape of the procedures. These would be especially helpful as pre-hospitalization teaching methods for short-stay patients when there is precious little time in their post-operative period for learning. Two patient participants were curious about what the tube looked like inside their body. They had not actually seen the whole apparatus. The hospital could have a few spare JP drains on hand that could be used for demonstration purposes.

In thinking about Star and her inability to take the initiative to make demands to address her needs, and reflecting on my own experience with health care professionals, I realize that there is a societal learning need. A need for people to take a more proactive approach to health care and learn about health care needs and treatment options, and the nature of illness, in order to make informed choices and to be prepared for eventualities that occur. In proposing this proactive approach, I do not intend to mean they should be independent of health care professionals, rather, they should know enough to know what to ask, when and who to ask, and how to get what they want.

I have reflected much on the research methods and methodology. Despite the difficulty encountered getting approval for the research, because it did not use positivist scientific methods, I feel the naturalistic methods used were appropriate and revealing. Methodologically, there are different ways of knowing. One can know the probability of something because of statistical significance but there are other ways. I would not have achieved the level of understanding of these participants' experience with a scientific approach. Only by engaging them in discussion in an empathic way, did I learn about the meaningful details of their experience. Then, only on reflecting on that discussion and their experience, did the significance of their experience become evident.

Further Research

This research is not an evaluation study. It is exploratory and descriptive. It has brought many questions to mind that are left unanswered. In this section I will attempt to point out some of the areas that need further elucidation.

Research is required to clarify the needs of surgical patients with different surgical procedures, different treatment regimens or different care requirements. Research is needed to define more particularly the needs of patients related to their needs for normalcy, decision and control during their hospital stay. It is clear that there are significant needs in these areas, which this research did not examine in detail.

There is also a need for research to determine the extent of the problem. A survey of a larger number of individuals, using the themes identified above would assist our understanding of what percentage of people fall into the different categories, self-learners and passive recipients of care. As well, this research has uncovered behaviours that indicate a reluctance to seek out help from professionals. What individual, social or cultural factors lead people to this course and what can be done to overcome these barriers people experience?

Research is required to clearly define the similarities and differences between the general public and patient learners with regards to Cranton's (1994) typology of learning. For example, what kind of learning can nurses assist with when considering consumer-oriented learning? In this paper I have focussed on the nurse or health care professional as the provider of information and instruction after surgery. What kind of self-directed learning do people want to engage in prior to coming into hospital? How can the desire for self-directed learning be stimulated? How can heath care professionals use the potential for self-directed learning to assist their patients and the public in learning about their health-related self-care?

This research has supported findings of previous studies (Bubela et al., 1990b; Bostrom, Crawford-Swent, Lazar & Helmer, 1994; Stricklin, 1993; Close, 1988) and is reflective of what is found in the nursing literature (Devine, 1992; Perry & Potter, 1994; Giloth, 1990; Watterworth & Podrasky, 1989; Jaffe, 1993; Lewis & Collier, 1992; Menke, 1988). Giloth (1990) has identified significant barriers that reduce the effectiveness of patient education. Research is required to uncover the barriers that exist in our health care system that prevents us from implementing what is already known about how patients and clients learn. How can we break down the barriers and provide the psychoeducative care they require?

Finally, societal, economic and political forces are at play in the early discharge of patients from hospital and the subsequent lack of psychoeducative care. Research using critical analysis may give professionals and the public an understanding of those forces and enable them to act, politically and socially, to promote the kind of health care system they require.

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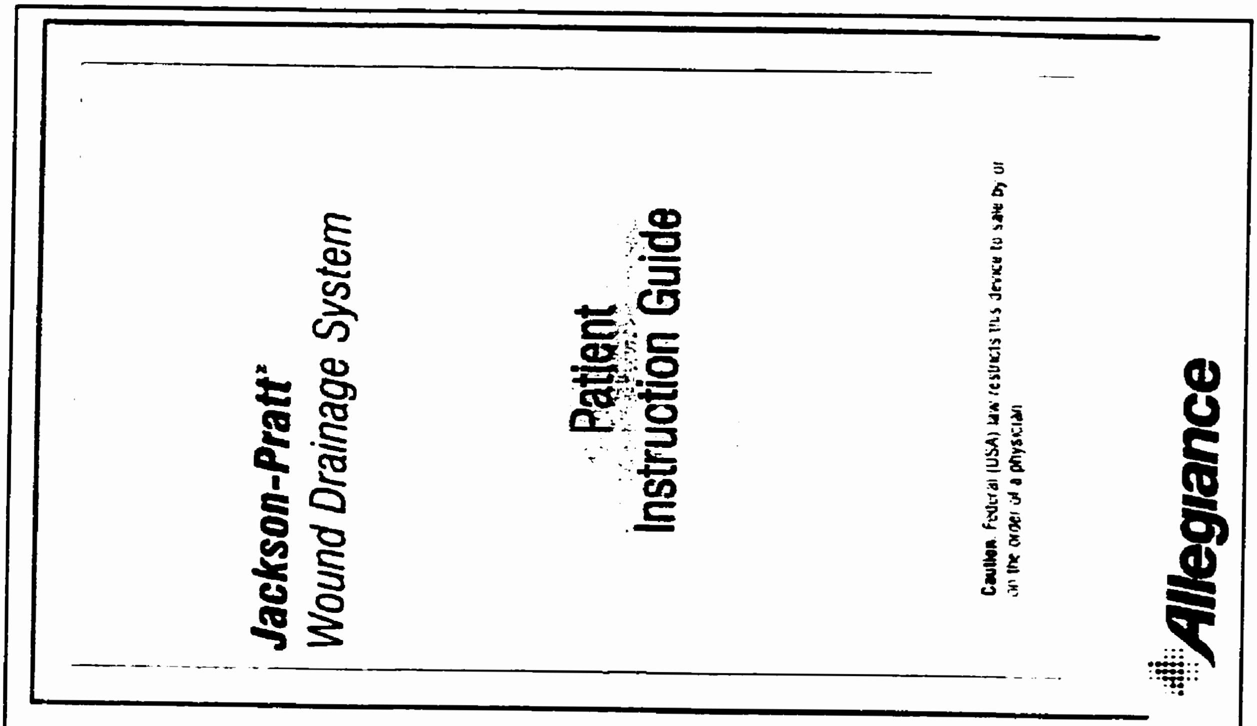
APPENDIX A: JACKSON-PRATT WOUND DRAINAGE SYSTEM



Jackson-Pratt®
Wound Drainage System

Patient Instruction Guide

Caution: Federal (USA) law restricts this device to sale by or on the order of a physician

Allegiance

DRAINAGE VOLUME CHART

	MON.	TUES.	WED.	THURS.	FRI.	SAT.	SUN.
DATE							
TIME							
AMOUNT							
TIME							
AMOUNT							
TIME							
AMOUNT							

Bring this completed chart to your physician on each postoperative visit.

**DO NOT DISCONNECT, KINK OR PUNCTURE THE TUBING THAT IS CONNECTED TO THE RESERVOIR.
IF THIS DOES HAPPEN, PLEASE CONTACT YOUR PHYSICIAN.**

Allegiance

You have had surgery which requires you to continue the use of a Jackson-Pratt® wound drainage system in your home. While in the hospital, your nurse will show you the techniques required to care for your drain site and wound drainage system. General care of the drain site may include changing the dressing daily and cleaning the skin around the drain with mild soap and water. The wound drainage system will require you, or someone caring for you, to empty and reactivate it.

After surgery, you will have a Jackson-Pratt® suction reservoir with a drain (tubing). The Jackson-Pratt system operates by using suction – as the reservoir expands, the suction created pulls out excess fluid. This fluid, if allowed to collect under the skin, could cause infection. The reservoir needs to be emptied at intervals determined by your physician.

Before you empty the reservoir, **be sure to keep a record of the amount of fluid collected.** A chart has been provided on the back of this pamphlet. Record the date, time and amount of fluid which has accumulated. Empty the reservoir as often as directed by your physician, usually two or three times a day. Be certain to follow your physician's instructions carefully.

Activation Instructions for the Jackson-Pratt® 100 cc Wound Drainage System

To Empty (Be in the bathroom or have supplies ready)

Wash your hands before and after handling the reservoir and, if instructed by your physician, wear gloves. Look at the collected fluid and note the amount collected. If emptying directly into the toilet (rather than a measuring container), record the amount of fluid collected on the chart on the back of this pamphlet now.

Caution: Never disconnect the tubing from the reservoir at any time!

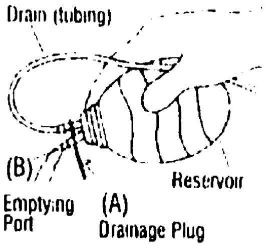


Figure 1

Figure 1: Unplug drainage plug (A) from the emptying port (B), hold the reservoir upside down over a toilet or measuring container (as directed by your physician) and squeeze the reservoir to empty the collected fluid. When the reservoir is emptied of all fluid, you will need to reactivate it.

To Reactivate

Figure 2: Squeeze to compress the reservoir as completely as possible.

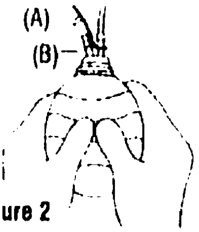


Figure 2

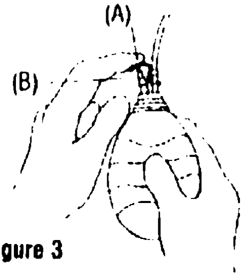


Figure 3

Figure 3: With the reservoir compressed, insert the drainage plug (A) into the emptying port (B) as far as possible and release the reservoir. The reservoir should expand gradually as it fills with fluid. If the reservoir does not expand gradually and collect fluid, contact your physician.

Record the amount of collected fluid on the chart on the back of this pamphlet. Flush the drainage fluid down the toilet and clean the measuring container (if used) with soap and water so it is ready for the next time. Attach the reservoir (using the plastic strap) to your clothing as directed by your physician, usually with a safety pin. The reservoir must be placed below the drain site to maintain adequate drainage. Be certain to empty the reservoir when the fluid collected reaches the 100 cc mark or before.

To Summarize:

1. View and note the amount of fluid collected.
2. Holding reservoir over collection device, unplug the drainage plug and squeeze the reservoir to empty.
3. Reactivate by compressing the reservoir and inserting the drainage plug as far as possible.
4. Record the drainage amount on the chart, including the date and time.
5. Flush the drainage fluid down the toilet.

Call your physician for the following

- **The reservoir cannot be reactivated.**
- **The drain falls out.**
- **The drainage fluid in the reservoir becomes foul smelling.**
- **The patient has a fever.**
- **There is any increased redness, swelling or abnormal drainage from the drain site.**
- **There is an air leak, fluid leak or any other malfunction in the system.**
- **The reservoir is not collecting any fluid.**

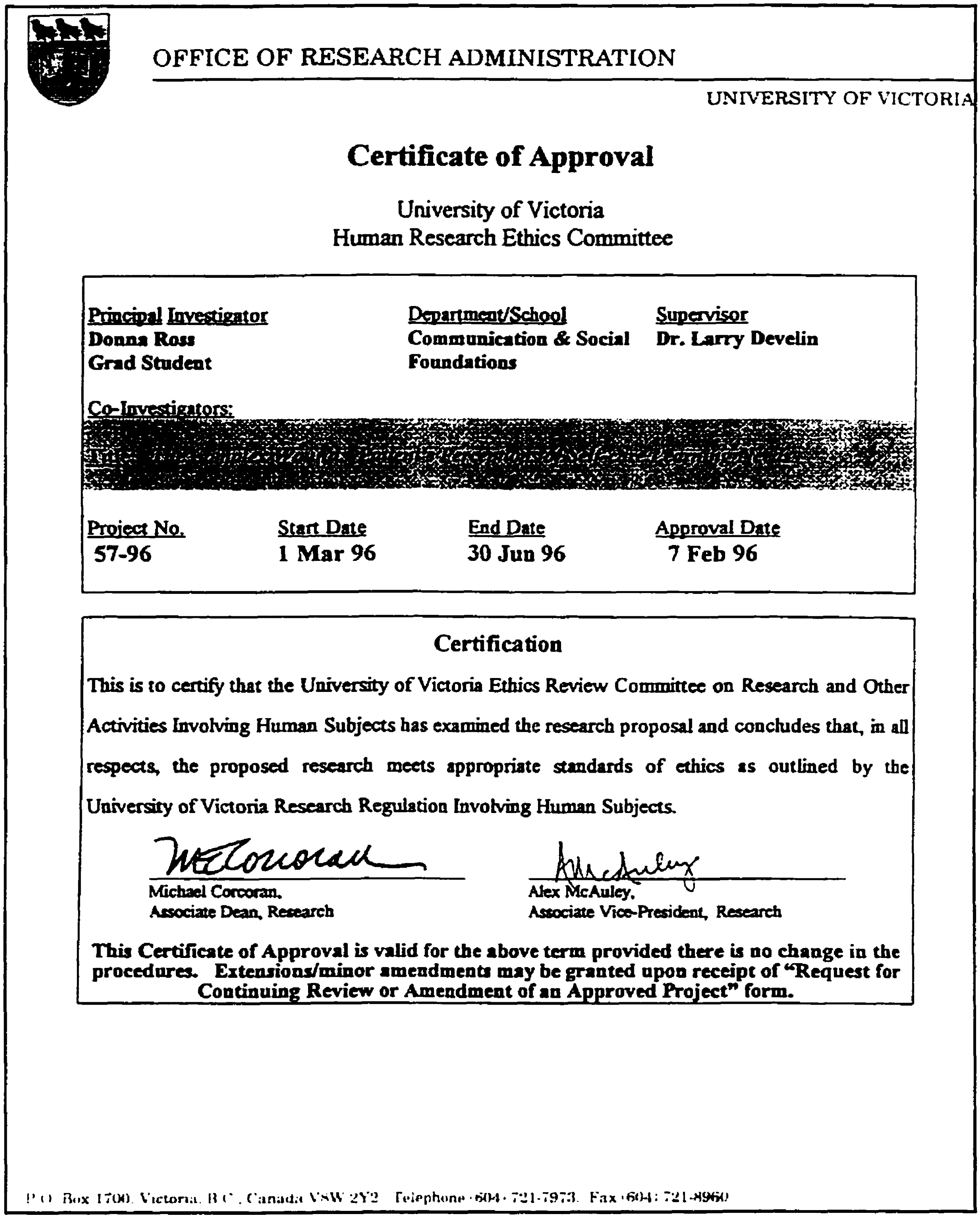
DO NOT DISCONNECT, KINK OR PUNCTURE THE TUBING THAT IS CONNECTED TO THE RESERVOIR. IF THIS HAPPENS, PLEASE CONTACT YOUR PHYSICIAN.

IF CLOTS FORM IN THE TUBING AND BLOCK DRAINAGE, CONTACT YOUR PHYSICIAN.

Bring this pamphlet
to your physician
on each postoperative visit.

Do not let the reservoir completely fill because the drainage will stop. If that happens, contact your physician.

APPENDIX B: RESEARCH APPROVAL - UVIC



OFFICE OF RESEARCH ADMINISTRATION

UNIVERSITY OF VICTORIA

Certificate of Approval

University of Victoria
Human Research Ethics Committee

Principal Investigator	Department/School	Supervisor
Donna Ross **Grad Student**	**Communication & Social Foundations**	**Dr. Larry Develin**

Co-Investigators:

[redacted]

Project No.	Start Date	End Date	Approval Date
57-96	**1 Mar 96**	**30 Jun 96**	**7 Feb 96**

Certification

This is to certify that the University of Victoria Ethics Review Committee on Research and Other Activities Involving Human Subjects has examined the research proposal and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the University of Victoria Research Regulation Involving Human Subjects.

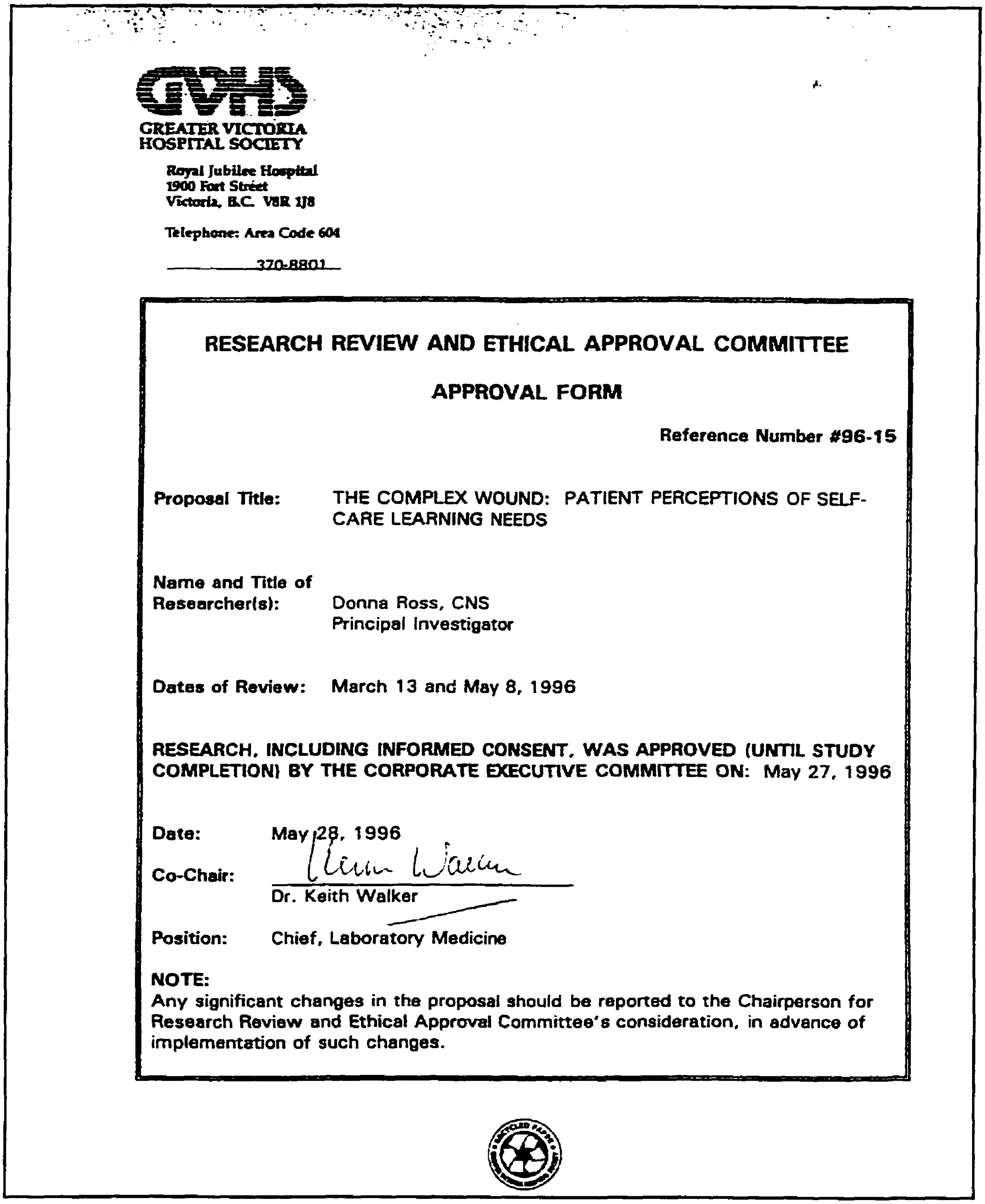
Michael Corcoran,
Associate Dean, Research

Alex McAuley,
Associate Vice-President, Research

This Certificate of Approval is valid for the above term provided there is no change in the procedures. Extensions/minor amendments may be granted upon receipt of "Request for Continuing Review or Amendment of an Approved Project" form.

P O Box 1700, Victoria, B C , Canada V8W 2Y2 Telephone (604) 721-7973, Fax (604) 721-8960

APPENDIX C: RESEARCH APPROVAL - GVHS



GREATER VICTORIA
HOSPITAL SOCIETY

Royal Jubilee Hospital
1900 Fort Street
Victoria, B.C. V8R 1J8

Telephone: Area Code 604

370-8801

RESEARCH REVIEW AND ETHICAL APPROVAL COMMITTEE

APPROVAL FORM

Reference Number #96-15

Proposal Title: THE COMPLEX WOUND: PATIENT PERCEPTIONS OF SELF-CARE LEARNING NEEDS

Name and Title of Researcher(s): Donna Ross, CNS
Principal Investigator

Dates of Review: March 13 and May 8, 1996

RESEARCH, INCLUDING INFORMED CONSENT, WAS APPROVED (UNTIL STUDY COMPLETION) BY THE CORPORATE EXECUTIVE COMMITTEE ON: May 27, 1996

Date: May 28, 1996

Co-Chair: Keith Walker
Dr. Keith Walker

Position: Chief, Laboratory Medicine

NOTE:
Any significant changes in the proposal should be reported to the Chairperson for Research Review and Ethical Approval Committee's consideration, in advance of implementation of such changes.

APPENDIX D: LETTER TO STAFF

TO THE NURSES ON GENERAL SURGERY.
From: Donna Ross. Clinical Resource Nurse.
June 10. 1996

As you may have heard. I am in the process of completing my Master's degree at the University of Victoria. Part of the requirements of my degree completion is a research project and thesis. I have chosen. for my research. to interview four patients about how they manage their wound care once they are discharged. I have obtained approval for the research from the University of Victoria Human Research Ethics Committee and from the GVHS Research Review and Ethical Approval Committee.

BUT I NEED YOUR HELP.

There are two things I am asking you to help me with. First. it would help me a great deal if you would keep me in mind when you are planning discharge for your patients and notify me when you have a potential participant for my study. Patient selection criteria will be:

-any patient being discharged home within the CRD.
-who has an open. separated wound.
-who is not receiving home nursing care (homemakers is ok).
-who can converse with me (lucid. speaks English).

Age does not matter. And they do not need to have had any formal or specific training for their wound care. Just the fact that they have an open wound that needs some sort of dressings or treatment.

I will be coming around once or twice a week to check for potential participants. Once a potential participant is identified. I will speak with them. explain my study and ask their consent to participate. I will be especially careful to sense the patient's and their families wishes in this regard. If I get the feeling they are uneasy about the study. I will not try to persuade them (see consent form). Once they have agreed. I will make arrangements to meet with them the day before discharge and subsequently in their homes.

The other favour I would ask a few of you. is that you agree to be interviewed yourself if you have been the primary nurse or mentor for the patient participant's wound care. Your Nurse Manager has given permission for me to use 30 minutes of your work time and I will make every effort to talk with you at a time when you are not too busy. The purpose of the staff interview is to provide some context. from a health professional viewpoint. for understanding the patients experience (please refer to the consent form).

If you have any questions or concerns about the study. do not hesitate to contact me at my office on 6DN [phone number]. I am looking forward to the data collection phase of my research with great excitement and sincerely thank you for your help.

Donna Ross.
GVHS Clinical Resource Nurse. 6DN.

APPENDIX E: PATIENT CONSENT FORM

The Complex Wound: Patients' Perceptions of Self-Care Learning Needs

Consent Form
PATIENT PARTICIPANT

You are invited to participate in a research project. The aim of the research is to understand your point of view regarding your experience of caring for the wound or incision, when you go home. You opinions are valuable to us because you have an incision that is not yet healed and we want to know, in addition to what we already teach, what kinds of things people like you should be taught before going home.

Should you agree to participate, I will talk to you three times: on the day of your discharge, in your home (or here at the hospital if you prefer), within 48 hours after discharge and about one to two weeks after discharge. Over this time period you will be able to discuss issues that arise as a result of doing your wound care. I will also ask you to show me how you do the dressing change, if applicable. The length of each talk will vary from person to person. I expect it to take between one and two hours.

The conversation will be tape recorded, if you agree, so I won't miss any of your views and the tapes will be typed for me to review. You will have a code name assigned to you so that strict confidentiality will be maintained. No one will be able to associate your comments with you personally. You will be asked not to name any individual when you are speaking but rather to refer to them as their role ie."the doctor" or "the nurse" etc. This is to protect the confidentiality of information about others.

The tape recordings, typed pages and diskettes will be kept in a locked drawer when not being used and I will be the only one allowed access to them. They will be destroyed one year after the report is complete. You are under no obligation to participate and you may withdraw from the study at any time. Whether you participate or not, it will not influence the care you receive now or in the future. You can refuse to answer any questions. At anytime you withdraw from the study part way through, your data will be destroyed if you so request.

If you have any questions please call me at [phone number]. If I am not in the office, I will return your call as soon as possible.

Donna Ross, GVHS Clinical Resource Nurse and Graduate Student at the University of Victoria.
Larry Devlin, Faculty Advisor, University of Victoria. [phone number].

I give my consent to participate in this study and have received a copy of this consent form.

Signature________________________________Date__________________

APPENDIX F: STAFF CONSENT FORM

The Complex Wound: Patients' Perceptions of Self-Care Learning Needs

Consent Form

HOSPITAL STAFF

You are invited to participate in a research project. The aim of the research is to understand patients' perceptions of their learning needs in caring for their wound, in their homes after discharge. You have been chosen by virtue of your involvement in teaching the patient self-care of their wound. Your views are being sought regarding the training you provided eg. how you think the training went and any insights you might have regarding how the patient received the training. This information will be used in attempting to interpret and analyse the patients' perspective.

If you agree to participate in this study you will be interviewed by the researcher for up to 30 minutes on work time. It is understood that patient care issues may intervene in keeping appointments and every effort will be made to accommodate those contingencies. Cancellation of appointments and rescheduling will be acceptable.

The interview will be tape recorded, if you agree, to ensure all your views will be accurately recorded; the recording will be transcribed by myself. Code names will be assigned to all participants to ensure confidentiality and all identifying names will be erased from the transcripts. I ask that you not identify anyone by name in the interview but rather by their role ie. "the doctor", "the nurse" or "the patient". This is to protect the confidentiality of information of others.

The research report, presentations or publications will not include names or any identifying information that would link you to the data. The data (tape recordings and transcripts) will be kept in a locked drawer and will be accessible only to the researcher. They will be destroyed one year after the report is complete. You are under no obligation to participate and may withdraw from the study any time. Neither your participation or non-participation will affect your employment or advancement. If you chose to withdraw from the study midstream, your data will be destroyed if you so wish.

If you have any questions, you may contact me at [phone number] and if I am not in the office, I will respond as soon as possible.

Donna Ross, GVHS Clinical Resource Nurse and Graduate Student at the University of Victoria.
Larry Devlin, Faculty Advisor, University of Victoria. [Phone number].

I give my consent to participate in this study and have received a copy of this consent form.

Signature________________________Date ____________________________

APPENDIX G: INTERVIEW GUIDES

Wound Care: Patients' Perceptions of Self-Care Learning Needs

Patient Interview Guide

Samples of typical questions to be asked *patient participants*:

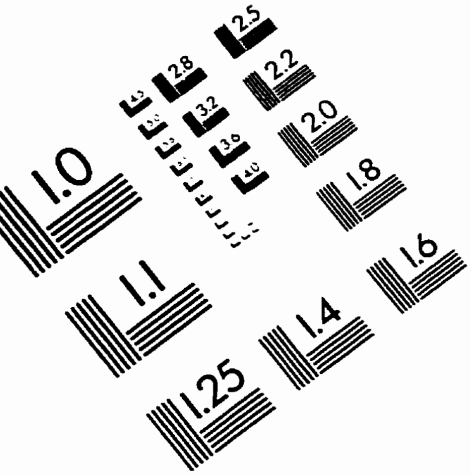
1. How did it go with your wound care when you got home?
2. How did you manage with the dressings?
3. What did you really need to know about?
4. What do you think patients like you should be taught before leaving hospital?
5. Tell me about how you learn?
6. Where or who did you go to for help?

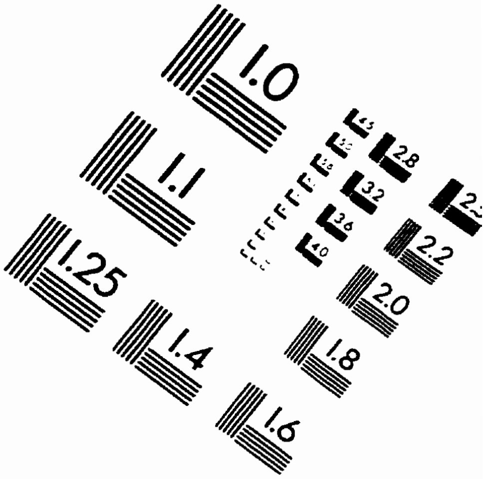
Staff Interview Guide

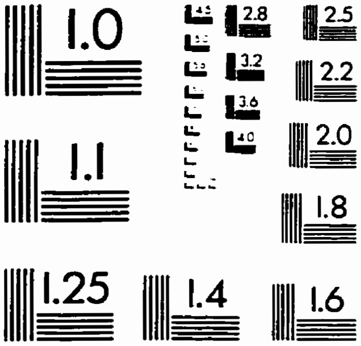
Samples of typical questions to be asked *hospital staff participants:*

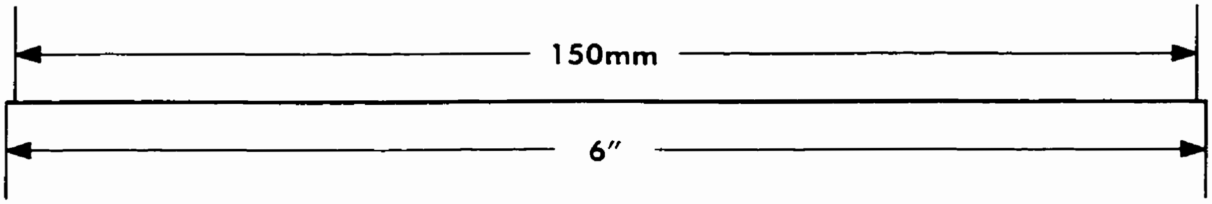
1. How did the training go?
2. What did you think you were preparing the patient to do?
3. What do you think patients should *know* when they are being discharged with an open wound?
4. What do you think patients should *be able to do* when they are discharged in this way?

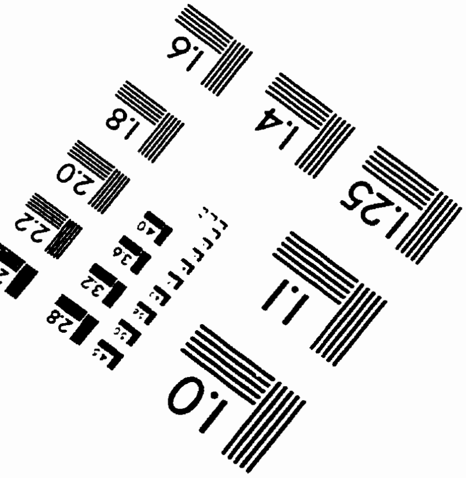
IMAGE EVALUATION
TEST TARGET (QA-3)

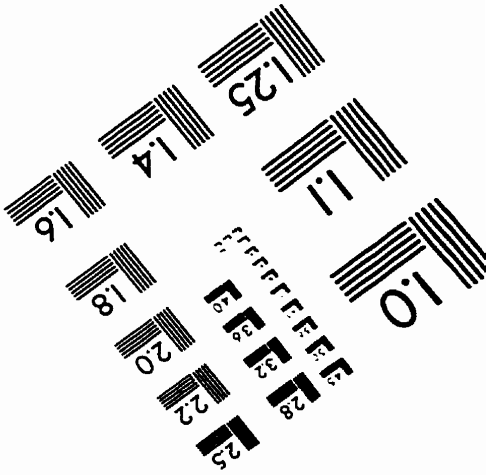












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