

LEARNING NEEDS OF LIVER RECIPIENTS DURING CONVALESCENCE

by

ELAINE MILLIE BEYER

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Department of Nursing

The University of British Columbia
Vancouver, Canada

Date August 31, 1998

ABSTRACT

Client education is an important aspect in the provision of holistic care for those clients who have undergone liver transplantation. Yet there remains a paucity of research that identifies the learning needs of liver recipients. Research pertaining to transplantation addresses such issues as functional and psychosocial outcomes, stressors, information needs of the family, and quality of life following transplantation. The majority of the studies are quantitative in method and employ questionnaires to obtain data. As a result, liver recipients' perceptions of their learning needs during convalescence have not been explored. Grounded theory provides the research design for this qualitative study which explores the learning needs of clients who have undergone liver transplantation during convalescence. In utilizing this research design, common circumstances, experiences, meanings and behaviours were taken into consideration. Symbolic interactionism was the conceptual framework for this study which enabled common circumstances, experiences, meanings, and behaviours to be understood from the perspective of those who have actually experienced liver transplantation. There were 6 study participants who had undergone liver transplantation of whom 5 were interviewed twice and the other participant only once. Data analysis was simultaneously carried out with data collection utilizing the constant comparison methods as outlined by Corbin and Strauss (1990). The participants' learning needs were identified to entail "Crucial Learning Needs" and "Knowing What to Expect". Three main categories emerged from the latter area which include: mastering recovery, transition, and reflection. Each category had within it several subcategories. As a result of this study, health care professionals may anticipate and assess liver recipients' learning needs and have insight into the experience of convalescence following liver transplantation. Implications for nursing practice and research have emerged which are addressed.

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DEDICATION

I dedicate this thesis to my parents.

For every dream you made come true, for all the times you stood by me,
for all the truth that you made me see, for all the love I found in you, I'll be
forever thankful.

You were my strength when I was weak, you were my voice when I
couldn't speak, you saw the best there was in me, I'm everything I am because
you love me.

You are my inspiration.

Diane Warren (1996) Because you loved me.

CHAPTER ONE

Introduction

Despite the emphasis placed on client education, many clients feel that they are not adequately prepared for hospital discharge (Vaughan & Taylor, 1988). Discharge teaching is a pivotal component of client education and is important in the provision of holistic nursing care. Carter (1981) suggests that "for some patients the day when they can return home will be awaited eagerly, but for others, it will be clouded by doubts about how they will cope during their convalescence" (p. 826). Although clients' doubts and learning needs should be addressed during discharge teaching, that teaching may be at times incomplete.

Clients' basic care is the priority most of the time; discharge teaching is too often the nurse's last priority. The lack of priority given to discharge teaching may be due to a shortage of nurses and the perceived indifference of middle management toward discharge teaching (Robinson, 1991; Runions, 1988). Shortened hospital stays may also be a reason for the scarcity of discharge teaching especially when post operative recovery is uncomplicated. When clients are discharged early, the time allotted for nurses to spend on discharge teaching is minimal (Boyd, 1987; Giloth, 1990; Noble, 1991). One cause of incomplete discharge teaching is nurses' lack of knowledge regarding the recovery process at home during convalescence (Arenth & Mamon, 1985; Baker, 1989; Lindeman, 1989; Runions). Some authors suggest that a second cause is that curricula within nursing education programs do not effectively prepare students for the task of client education and for application of principles of teaching (Close, 1988; Giloth; Kruger, 1991; Tilley, Gregor & Thiessen, 1987).

Breemhaar and van den Borne (1990) found that prior to surgery, clients are

given a substantial amount of information for the immediate post operative period. After the operation, the quantity of information is greatly decreased. In a review of the literature pertaining to clients and information given to them, numerous studies have shown that pre operative information given to clients promoted the direct physical recovery and psychological coping in relation to the surgical operation. As a result of the pre operative teaching, health care costs were cut and the length of hospital stay was decreased (Leino-Kilpi, Iire, Suominen, Vuorenheimo, & Valimaki, 1993). Literature pertaining to the effects of education on the client's wellbeing after discharge was not located; however, researchers in a study which examined the effects of client education on those with arthritis found that the participants who had received health education experienced less pain, less disability, and visited their physicians less frequently (Lorig, Lauren, & Holman, 1984).

It is important to discover the learning needs of clients who undergo surgical procedures so that discharge teaching can be effective. A surgical procedure which poses unique challenges to health care professionals is that of liver transplantation. The unique challenges arise from the acute and chronic nature which liver transplantation places on each recipient. Acuity stems from the surgical procedure and the recovery process related to the surgery. The chronic aspect stems from the life-long commitment of taking immunosuppressive medication as well as the complications that result from this treatment. It is therefore imperative that liver transplant recipients' learning needs be identified. Once these learning needs are known, nurses may incorporate this knowledge into the discharge teaching process, thereby facilitating a less stressful convalescence.

Statement of Purpose

The purpose of this study was to identify the learning needs of liver transplant clients during convalescence and also to determine how these learning needs change during convalescence. The research question which guided this study was:

What are the learning needs during convalescence of clients who have undergone liver transplants and how do these learning needs change during convalescence?

Definition of Terms

For the purposes of this research study the terms "liver transplantation", "learning needs", and "convalescence" were defined as follows:

Liver Transplantation: "the grafting of liver tissue from one person to another" (Taber, 1997, p. 1126).

Learning Needs: "the gap between [the client's] present level of competencies and a higher level required for effective performance as defined by [him/herself], [his/her] organization, or [his/her] society" (Knowles, 1970, p. 85)

Convalescence: "the science of coping with physical irregularity caused by illness or surgery allied to the art of creating a structured regime of rehabilitation of the mind and body suited to the patient's condition, character and normal life style, probably over a predictable time span" (Acland, 1984, p. iii); "the recovery process after an acute assault, such as surgery, which takes place over time, and has duration which varies individually. Convalescence is characterized by numerous physical and psychological factors. It also involves the transition of roles and responsibilities" (Beyer, 1991).

Significance of the Study

Between 1989 and 1992, 778 adults received liver transplants in Canada

(Kidney Foundation of Canada, 1994). Nurses' lack of knowledge regarding the recovery process, lack of preparation in teaching skills, and the low priority given to discharge teaching affected these 778 Canadians. Between 1989 and 1994 the Vancouver Hospital Site of the Vancouver Hospital and Health Science Centre report that 85 liver transplants had been done (British Columbia Transplant Society, 1995). The average length of hospital stay following liver transplantation has been gradually decreasing. From 1989 to 1991 the average hospital stay was 28.64 days, from 1992 to 1993 the average stay was decreased by almost 2 weeks to 14.92 days (J.A. Ford, personal communication, January 5, 1994). Decreased hospital stays affect the amount of time for client education, which in turn may lead to clients being discharged without the information they need during convalescence.

The first human liver transplant was performed in Colorado in 1963 (Omery & Caswell, 1988). There has been a steady increase in the annual number of liver transplants in Canada, ranging from five transplants in 1983 to 218 in 1992 (Kidney Foundation of Canada, 1994). Within the last 17 years, liver transplantation has changed from an experimental procedure to a therapeutic intervention (Kuhn, 1986). The increased success of liver transplantation is due to several clinical developments: "organ preservation, organ compatibility, immunosuppression therapy and treatment protocols for rejection episodes" (Omery & Caswell, p. 626).

Literature pertaining to liver transplantation primarily discusses the ethical issues associated with the surgery as well as the client's experience during pre operative, intra operative, and post operative periods (Hall, 1984; Omery & Caswell, 1988; Ryan, Lewis & Jenkins, 1989; Smith, 1985; Traiger & Bohachick, 1983; Weichler, 1990).

Transplantation is acknowledged to be a major event in the life of a person, as it not

only affects the individual, but also his/her family (LoBiondo-Wood, Bernier-Henn, & Williams, 1992; McGary Buse & Pieper, 1990; Voepel-Lewis, Starr, Ketefian, & White, 1990; Weichler, 1990; 1993). It has also been acknowledged in the literature that convalescence is a period of stress for clients and their families (Davis, 1987; 1990; Surman, Dienstag, Cosimi, Chauncey & Russell, 1987). Clients' learning needs during convalescence following a liver transplant have not been widely investigated. One study that explored the information needs of mothers of children who were hospitalized for liver transplants found that the majority of information needs were related to the care of their child after discharge from the hospital (Weichler, 1990).

Identifying clients' learning needs during convalescence following a liver transplant will assist hospital and community based nurses to conduct individual needs assessments when planning client education. Discharge teaching tools may be developed, incorporating the research findings. Manuals could be developed to assist nurses with the task of discharge teaching. Clients and health care providers may benefit from knowing about the experience of those who have undergone liver transplantation. If the narrative reports of this study are shared with clients and health care providers, they may be better able to judge what is "normal" and to predict a recovery trajectory in the post transplant surgery experience.

Assumptions

The assumptions for this study were as follows:

1. Clients who are convalescing from a liver transplant will experience surprising and unpredictable events/situations for which they feel unprepared.
2. People are generally able to articulate their learning needs during convalescence.

3. If information about convalescence is provided to clients, the period of convalescence will be less stressful.

4. All people are unique and each will have different learning needs, depending upon the meaning convalescence holds for them.

Conceptual Framework

Symbolic interaction (S.I.) provides the theoretical framework for the study of the learning needs of clients who have undergone liver transplantation. According to this theory, the world we live in is subjective -- one in which each person has unique interactions among other people and with him/herself (Blumer, 1969). Symbolic interaction contains five concepts: the self, the act, social interaction, objects and joint action. Each of these concepts, as well as the three premises of the theory of symbolic interaction, will be discussed.

A concept pivotal to symbolic interaction is that of the "self". The "self" ascends from interaction and is the result of a social process (Blumer, 1969). The concept "self" is unique only to humans. By possessing a self, human beings are provided with "a mechanism of self interaction with which to meet the world" (Blumer, p. 62). Therefore, a human being is able to perceive oneself, communicate with oneself and act toward oneself. Mead describes the self as a process (Blumer). It is through a reflective process that the person makes indications to oneself, "noting things and determining their significance for his line of action" (Blumer, p. 63). It is also through interpretation that the person acts toward his/her world and organizes his/her action. It is the self which experiences the convalescence following a liver transplant. It is the self which assigns meaning to this experience. It is in interaction with a client's self that the researcher is able to assist him/her to articulate this experience.

The second concept is the act. It is through a process of self interaction that human action is formed. An individual must first identify what he/she wants before he/she can act. One must "establish an objective or goal, map out perspective lines of behaviour, note and interpret the actions of others" (Blumer, 1969, p. 64). The construction of the act is dependent on the individual's ability to observe, interpret and judge (Blumer, p. 69). In this study, it is anticipated that each participant will have observed, judged, and interpreted his/her experience of convalescence uniquely.

A third concept of S.I. is that of "social interaction". There are two types of social interaction, "non symbolic interaction" and "symbolic interaction". Non symbolic interaction is a response to a gesture or action made without interpreting the gesture or act. In symbolic interaction, the gesture or action is interpreted and the response is based upon the meaning produced by the interpretation (Blumer, 1969). Symbolic interaction is a developmental process. There is constant interpretation between the participants involved with social interaction. "The participants in it have to build up their respective lines of conduct by constant interpretation of each other's ongoing lines of action" (Blumer, p. 66). It is the definition and interpretation of the client's experience which is the focus of this study.

The fourth concept is that of "object". An object is defined as "anything that can be designated or referred to" (Blumer, 1969, p. 68). The character of the object is dependent upon the meaning given to it by the person involved with the object. The person's action toward the object is dependent upon the meaning the object has for him/her (Blumer). The same object may have a different meaning for different individuals. After a liver transplant, the period of convalescence may be considered an object for the person or persons who underwent the operation. Even though a number of

people undergo liver transplantation, convalescence will be a unique experience and have different meanings for each of them.

The last concept of S.I. is "joint action". Joint action is the "interaction in which people are fitting together their acts" (Charon, 1985, p. 155). The interaction may be between two people such as a nurse client interaction or among individuals in a group setting such as a support group. The individuals in the joint action occupy different interpretations and act from their individual perspective in a unique and separate way. It is not the mutual interpretations but rather the fitting together of the acts that define this as a joint action (Blumer, 1969). "Without actions, any structure of relations between people is meaningless" (Blumer, p. 71). The client who has undergone a liver transplant participates in joint action with health care providers, significant others, and, at times, other clients. It is anticipated that the participants in this study will identify some common understandings and experiences related to the convalescence period. They will also reveal their unique interpretations of the experiences.

The premises of S. I. theory are:

1. "Human beings act toward things on the basis of the meanings that the things have for them" (Blumer, 1969, p. 2).
2. "The meaning of such things is derived from or arises out of, the social interaction that one has with one's fellows" (Blumer, 1969, p. 2).
3. "These meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters" (Blumer, 1969, p. 2).

The first premise states that the meaning a person attaches to things will influence how a person acts toward it (Blumer, 1969). An illustration of this would be if a

person has had a liver transplant and perceives discharge from the hospital as a positive event, then he/she will desire discharge teaching. In contrast, if a person does not feel they are ready to be discharged home and views discharge as a negative event, he/she will be unwilling to engage in discharge teaching.

The second premise is that it is through social interaction in which meaning of things is derived (Blumer, 1969). If a client has a liver transplant due to cirrhosis of the liver, secondary to alcoholism, the meaning of the transplant may be one of shame or guilt. If a liver transplant was necessary due a possible autoimmune disease, the event may not elicit shame or guilt but rather relief or happiness.

The third and final premise of symbolic interaction is that the meaning placed on the object by an individual has been derived through interaction which the individual has had with him/her self. It is this meaning which guides and forms the individual's action (Blumer, 1969). For example, if a client has a liver transplant and perceives it as a "new lease on life", this individual will be more likely to discard unhealthy pre operative practices (e.g. drinking alcohol). If a client interprets the liver transplant as an enforced surgical intervention, he/she may not be as motivated to exchange his/her unhealthy habits for healthy ones.

Interaction is a process which takes place between one person, two people, a group of people or a society. Through interaction, meaning is placed on actions and in turn the actions affect interaction. In studying the learning needs of clients, it is important to be aware of the various interactions and meanings which affect their actions.

Organization of the Thesis

The thesis is organized in the following manner: chapter one introduces the study and its significance to nursing, as well as the conceptual framework. In chapter

two, the relevant literature is reviewed and presented. Chapter three explicates the research design, which includes a description of the setting, the participant population in the study, the data collection method, ethical considerations, and limitations. Chapter four describes the research findings. It is within chapter five that the research findings are discussed including the implications for nursing practice and research; this chapter also consists of the summary and conclusion of this research study.

CHAPTER TWO

Literature Review

While there exists a plethora of nursing literature pertaining to client education, discharge planning (Arenth & Mamon, 1985; Boyd, 1987; Cook & Alley, 1992), and concerns following discharge, (Boyle, Nance, & Passau Buck, 1992; Bull & Lawrence, 1985; Leyder & Pieper, 1986; Nicklin, 1986; White & Holloway, 1990), there is a paucity of literature pertaining to clients' learning needs during post transplant convalescence. Consequently, health care personnel are not fully aware of clients' learning needs during convalescence following liver transplantation and thus cannot provide holistic nursing care beyond hospitalization in terms of client education. The review of the literature in this chapter will occur in two parts. The first part will focus on literature pertaining to transplantation; specifically, the psychosocial and physiological functioning, the stressors, the lived experience, and the informational needs of caregivers, as well as clients' quality of life post transplant. The second part of the literature review will focus on learning needs; specifically, clients' perceptions of information needs, clients' concerns during convalescence, and clients' learning needs as perceived by clients and nurses. The review will be organized according to the three main premises of symbolic interaction theory.

Transplantation

There exists a dearth of post liver transplant articles; because of this, the literature review will include research in the areas of renal, heart, lung, and liver transplantation. This literature provides insight into clients' learning needs during convalescence following organ transplantation.

The criteria used in the selection of the literature were as follows:

1. The substantive research described in the article/paper must have been either qualitative or quantitative, as well as systematic, structured, and purposeful. The author(s) must have also provided information regarding conceptual framework, research design, method of data collection, and characteristics of the sample.
2. The literature had to pertain to the experience of post transplantation and the learning needs of clients who have undergone organ transplantation.

First Premise of Symbolic Interactionism

The first premise of symbolic interactionism states that the meaning a person attaches to something will influence how he/she acts toward it (Blumer, 1969). Literature reviewed relevant to this premise includes topics such as psychosocial and physiological functioning, stressors, and the lived experience associated with organ transplantation. .

Functional and psychosocial outcomes (Bohachick, Anton, Wooldridge, Kormos, Armitage, Hardesty, & Griffith, 1992; Fletcher, Novick, Braun, Popowniak, & Steinmuller, 1983; Gallager-Lepak, 1991; Robinson, Switala, Tarter, & Nicholas, 1990; Samuelsson, Hunt, & Schroeder, 1984; Tarter, VanThiel, Hegedus, Schade, Gavalier, & Starzl, 1984), stressors, (Frey, 1990; Sutton & Pelletier Murphy, 1989; White, Starr, Ketefian, & Vopel Lewis, 1990) and the lived experience of transplantation (Thomas, 1993) have been studied by various researchers. Most researchers in this area have not reported reliability or validity measures of data collection tools, this being one of the major limitations of the studies. Table 1 (Appendix A) presents a detailed summary of the nature of the research for each of these studies, including the research question, the sample, the research design, and the major findings.

Functional and Psychosocial Outcomes

The research literature pertaining to functional and psychosocial outcomes is

presented in a discussion of research designs and research findings.

Research design. Six research studies were located that measured the functional and psychosocial outcomes post transplant. Of these, two (Robinson et al., 1990; Tarter et al., 1984) investigated outcomes associated with liver transplantation, two (Bohachick et al., 1992; Samuelsson et al., 1984) with heart transplantation, and two (Fletcher et al., 1983; Gallager-Lepak, 1991) with renal transplantation. Two research studies (Bohachick et al., 1992; Gallager-Lepak, 1991) included pre and post transplant measures in the investigation of functional and psychosocial outcomes. All studies were quantitative in design, utilizing survey methods and measures of physiological (e.g., treadmill performance) and psychological functioning to determine post transplant outcomes. A major limitation in five of the studies was that reliability and validity measures for the tools used in the studies were not reported. A limitation in two of the research studies (Gallager-Lepak; Tarter et al.) was related to the sample size in that the researchers' investigation involved less than a dozen clients.

Research findings. The researchers in five studies reported that functional capacity improved following transplantation (Bohachick et al., 1992; Fletcher et al., 1983; Gallager-Lepak, 1991; Robinson et al., 1990; Samuelsson et al., 1984). These studies focused on one or more of the vocational, domestic, sexual, and social elements of functional capacity. Functional capacity and outcomes were measured in the research studies and improvements were noted in each study, but each study had a different interpretation of what functional capacity was and how it was to be measured.

In terms of vocational functioning, it was reported that the amount of time taken off work due to illness decreased following transplantation and convalescence (Bohachick et al., 1992). In addition, more clients either gained employment, attended

school, or did housework after their transplantation (Fletcher et al., 1983; Robinson et al., 1990; Samuelsson et al., 1984). Clients who had undergone transplantation had fewer physical limitations than they had before the transplantation (Bohachick et al.; Fletcher et al.; Gallagher-Lepak, 1991; Robinson et al.). Forty-five percent of clients prior to transplantation were unable to go outside of their homes; however, 3 years after liver transplantation, 94% of clients were able to walk at least three blocks (Robinson et al.). Gallagher-Lepak found that the greatest improvement in functional capacity took place during the first 6 weeks after transplantation.

Functional capacity is dependent on a number of factors, one of which is the side effects of medications. A number of researchers have identified side effects associated with the use of immunosuppressive drugs. Samuelsson and colleagues (1984) list the side effects as changes in physical appearance, muscle weakness, and skin problems such as tenderness and bruising. These researchers found that some clients on immunosuppressants were required to restrict their activities because of decreased muscle strength, skin tenderness, and activities which cause bruising and skin abrasions (Samuelsson et al.). Robinson and his colleagues (1990) corroborated Samuelsson and colleagues' results by reporting that 12 out of 14 clients had weakness, lack of coordination, pain, or restricted movement with the use of their extremities. Forty three percent of clients studied complained of joint pain, 10% had joint swelling, 13% developed gout, and 6% developed arthritis. Fletcher and colleagues (1983) found that 10% of the clients studied developed cancer after transplantation. In another study, 4 out of 43 clients who had undergone liver transplantation developed malignancies (Samuelsson et al.).

Sexual functioning is another measure that researchers have used as an

indicator of functional capacity. Bohachick and her colleagues (1992) found that four out of six domains in sexual functioning improved significantly after transplantation. These four included sexual performance, frequency of sexual activity, sexual interest, and sexual satisfaction. Fletcher and colleagues (1983) reported that, prior to transplantation, 40% of male clients were impotent and 89% of female clients had decreased libido. Decreased libido resulted in female clients having sexual intercourse less frequently than once a month. After transplantation, all male clients were potent and all female clients had sexual intercourse at least monthly. Married participants in the Samuelsson and colleagues (1984) study were asked to rate their sex life on a scale of 1 to 10. Post transplantation, 13 participants rated their sex life at 5 or above, and 3 rated it below 5. The participants did not rate their sex life prior to transplantation; thus one cannot assess whether perceived improvements and greater satisfaction with sexual function are direct outcomes of transplantation.

Tarter and his colleagues (1984) compared clients who had undergone liver transplantation to those in a control group with a chronic illness. They found that those who had undergone transplantation were not impaired on measures of social functioning and psychiatric status. However, in comparison to the normative population, participants who had undergone liver transplantation presented with higher levels of anxiety, somatic distress, concern, frustration, depression, worry, and social withdrawal. The researchers also identified that routines of daily living were disrupted, including sleep and rest, eating and appetite, work capacity, and recreational pastimes. Research participants who had undergone liver transplantation were found to have impairment of greater than or equal to 20% in the aforementioned activities (a score near to or equal to zero is normal).

The research pertaining to functional and psychosocial outcomes of organ

transplantation has indicated that most clients experience positive changes in their functional capacity and psychosocial functioning post transplant. Researchers (Tarter et al., 1984) in one study that specifically investigated outcomes associated with liver transplantation have suggested that liver recipients experience more anxiety and disruptions in their daily lives than the normative population. No research was located that specifically compared or contrasted the functional and psychosocial outcomes of various organ transplants.

Stressors

The research literature pertaining to stressors associated with transplantation is presented in a discussion of the research designs and findings.

Research design. Three quantitative research studies (Frey, 1990; Sutton & Pelletier Murphy, 1989; White et al., 1990) were located that investigated the stressors associated with renal transplantation. Each of these studies investigated stressors in relation to the psychosocial outcomes of organ transplantation. Data collection occurred at a variety of time periods post transplant in these studies. For example, Sutton and Pelletier Murphy investigated the stressors associated at 0-23 months and 24-48 months post transplant. Frey, however, studied renal recipients 6 weeks after their transplant. White and her colleagues studied clients 3 weeks to 6 months after transplantation.

Research findings. Frey (1990) and Sutton and Pelletier Murphy (1989) studied stressors of clients who had undergone renal transplantation. The primary stressor reported by participants was that of repeated hospitalizations. Other stressors included the possibility of rejection, cost of medication, uncertainty about the future, and side effects of the medications (Frey). In comparing results from this study to one conducted

by Hayward, Kish, Frey, Kirchner, Carr and Wolf (1989), Frey found the stressors were similar; however, there were differences in rank order. While repeated hospitalizations were identified as creating the most stress for participants in the Frey study, the possibility of rejection was the primary stressor in the study by Hayward and colleagues (as cited in Frey). While cost factors were identified as the highest stress factor in Sutton and Pelletier Murphy's first study group (0-23 months post transplant), fear of kidney rejection was identified as the highest ranked stressor in the second study group (24-48 months post transplant). White and her colleagues (1990), on the other hand, found that clients who had undergone renal transplantation identified their specific stressors as the uncertainty of whether the transplant would be successful, as well as the risk of infection, the long term side effects of anti-rejection medication, and whether the change in physical appearance would affect their social life. The researchers also identified stressors for clients such as uncertainty concerning transplant success, fear of injury to the kidney, and the lack of normalization of their lives.

The stressors associated with liver transplantation have not been investigated to date. Research in this area pertains to renal transplantation. The findings of this research indicate that the post transplant period is characterized by stress related to financial and personal costs as well as concerns associated with the medication and uncertainty pertaining to the viability of the transplanted organ.

The Lived Experience of Liver Transplantation

The lived experience of liver transplantation is presented in a discussion of the research design and the research findings.

Research design. Only one research study was located that specifically investigated the lived experience of organ transplantation. Thomas (1993) studied the

lived experience of 13 people who underwent liver transplantations in a phenomenological research study. Seven themes emerged from the data: conflict, financial aspects, control, self perception, support network, spirituality, and gratitude.

Research findings. The participants in Thomas' (1993) study described two types of conflict - "inner conflict and conflict with the social-political economics of the health care system" (p. 175). Inner conflict was identified as tension and stress, and outer conflict was associated with the social-political economics of the health care system emerged as frustration, anger and fear. Internal struggle was also expressed by participants in the study because someone had died in order for them to live. Another source of internal struggle was "the dichotomy of feeling normal and not normal at the same time. They felt normal but when they analysed the concept of transplantation on another level, the awesomeness of the experience made them feel 'not normal' " (Thomas, p. 176). Uncertainty about the future and complications such as rejection, infection, and hospital readmissions were expressed as additional concerns. Conflicts with the social-political-economics of the health care system were identified as the loss of disability benefits once the liver recipient would return to work, the possibility that the recipient would not be hired because they had a liver transplant, and the possibility of losing health insurance if the liver recipient was to change jobs.

The financial aspects of transplantation, noted by Thomas (1993), may not be totally relevant to the Canadian experience as Thomas' study was conducted in the United States which requires individuals to pay for medical services. Some aspects of the research findings appear to have some applicability to the Canadian situation. For example, returning to work was described as a multidimensional experience. Some recipients wanted to return to work but when they did, they found it difficult to "keep up

the pace" (Thomas, p. 180). Flexibility and scheduling in the workplace were identified as crucial.

Control was an aspect of the lived experience of transplantation, specifically, the loss of control (Thomas, 1993). A frequently cited example of loss of control was having to choose between transplant or death. Strategies used by the participants to assume control included assuming an active role in self care decision-making, refusing to participate in self care decision-making, and deliberately contravening the post transplant directives from health care professionals (by not taking vital signs; not being careful with a cut; going into crowds; or taking medication when it was convenient rather than when it was prescribed).

Support networks were perceived to be very important by the liver recipients (Thomas, 1993). When they perceived a lack of support, the participants stated they were frustrated and angry. Support was demonstrated in various forms, including cards and letters and interactions with family members, friends, other liver recipients, or members of the participants' church.

Spirituality was another theme arising from the Thomas (1993) study. Some participants viewed the transplant as a miracle. These participants struggled with the question of why God had saved them and not others. Many of the participants maintained a philosophic view of living life to its fullest each and every day. They stated they took pleasure in what others see as the small things.

Gratitude to the donor and the donor's family was felt by the recipient whether their attitude toward the experience was positive or negative (Thomas, 1993). Most recipients wrote letters to the donor's family thanking them for their gift. For some, writing this letter was one of the hardest things they had to do. The recipients felt as

though they had a responsibility to take good care of the donor's organ which was now theirs. Also, many felt that they had to somehow repay the gift; this was done by helping out at the Red Cross, or becoming a volunteer in various organizations such as the organ transplant society.

Thomas' (1993) research findings are congruent with other research in the areas of functional and psychosocial outcomes and stressors associated with organ transplantation. Thomas, as other researchers in this area has identified several sources of anxiety (eg. loss of control) in the transplantation experience. Her contribution to our understanding is more than the mere identification of concerns and stressors. She has assisted health care professionals in understanding the complex and often ambivalent experience of transplantation.

Summary. It is evident from the research that clients' functional capacities may improve following transplantation; however, this improvement is associated with added stress. Each client's experience of transplantation is unique but some aspects of recovery are shared by all. The meaning clients attach to the transplantation process, functional capacities and outcomes, as well as stressors, will affect the way in which clients act toward the transplantation process. This meaning will either positively or negatively influence their convalescence.

Second Premise of Symbolic Interactionism

The second premise states that it is through social interaction that the meaning of things is derived (Blumer, 1969). The literature relevant to this premise includes the impact of a child's transplant on the family; caretakers' information needs; stress, coping, and quality of life in family members of transplant recipients. The impact of transplantation on family members (LoBiondo-Wood et al., 1992; McGary Buse &

Pieper, 1990), stress and coping of family members (Voepel-Lewis et al., 1990), and information needs of parents after their child's transplantation (Weichler, 1990; 1993) have been the focus of various research studies. Table 2 (Appendix B) provides a summary of the research studies in terms of the research question, the sample, the design, and the major findings.

Impact of Transplantation on Family Members

The research literature pertaining to the impact of transplantation on family members is presented in a discussion of the research designs and findings.

Research design. Two research studies (LoBiondo-Wood et al., 1992; McGary Buse & Pieper, 1990) were located that investigated the impact of organ transplantation on family members. One study (Voepel-Lewis et al., 1990) investigated stress, coping and quality of life in family members of clients who had undergone transplantation. All studies were quantitative in design utilizing questionnaires to elicit data. The questionnaires utilized to collect data in three studies (McGary Buse & Pieper; Voepel-Lewis et al.; Weichler 1990; 1993) were developed by the researchers. Of these, only one questionnaire used in the research study by Voepel-Lewis and her colleagues had been used in a previous study; however, measurements of validity and reliability for the instrument were not reported. The impact of transplantation on spouses whose partner was undergoing cardiac transplantation was investigated in one study (McGary Buse & Pieper)

Research findings. The impact of transplantation on the lives of spouses (McGary Buse & Pieper, 1990) and family members (LoBiondo-Wood et al., 1992) has been investigated in two studies. Spouses of clients who have undergone cardiac transplantation perceived the period after transplantation to be more positive than the

pre transplant period although there were no significant differences in stress scores from the pre to post transplant period (McGary Buse & Pieper). In a study conducted by LoBiondo-Wood and her colleagues the participants were divided into two groups, the first group involved children who had undergone transplantation less than a year and the other group included those children transplanted for more than a year. The researchers reported that predictions of family adaptation were found to be different depending on the length of time after transplantation. In the first group, the maternal perspective regarding the impact of a child's liver transplantation on the family indicated that "60% of family adaptation could be predicted by family stress, parental coping patterns and the amount of social support" (p. 464). This finding was demonstrated by 12 families; however, the researchers recommended that the result be interpreted with caution as the sample size was small. In the second group, no significant correlations were found for the prediction of family adaptation based on family stress, parental coping patterns, and amount of social support. Several themes arose that were identified as being the most stressful since transplantation for all family members. These included fear, uncertainty, finances, and separation issues. Voepel-Lewis and colleagues discovered that one of the most stressful and difficult concerns verbalized by family members of renal recipients pertained to medication, and more specifically, to the long term side effects of the immunosuppressive drugs.

The research that has investigated the impact of transplantation on family members indicates that transplantation is a stressful event, plagued by concerns related to medication side effects, and complications associated with transplantation. To date, the impact of liver transplantation on family members in terms of adult liver recipients has not been investigated.

Information Needs of the Family

The research literature pertaining to the information needs of the family is presented in a discussion of the research designs and research findings.

Research design. The information needs of parents of children who have undergone transplantation have been studied by one researcher in two separate studies (Weichler, 1990; 1993). The first study (Weichler, 1990) was qualitative in design, utilizing an interview guide consisting of 13 open ended questions. All interviews occurred within the first month after the child's transplantation. The second study (Weichler, 1993) utilized a quantitative design in which questionnaires were given the day of discharge to parents of children who had either undergone a liver or renal transplant. The questionnaire on average was returned 2 to 3 months post transplant.

Research findings. In analysing the results of the two studies (Weichler, 1990; 1993) many similar information needs were identified pertaining to the different phases of the transplant process. For example, in the discharge phase, parents had information needs regarding medication and the signs and symptoms of rejection/infection. In the earlier study (Weichler, 1990), mothers expressed concern whether or not their child would be able to lead a normal life.

Information needs of family members of adult liver recipients or even the recipients themselves have not been investigated to date. The information needs identified by parents are congruent with the literature pertaining to stressors. The stressors identified in the literature (Frey, 1990; Sutton & Pelletier Murphy, 1989; White et al., 1990) such as rejection, infection, and medication are essentially the information needs identified by parents of children who have undergone either liver or renal transplantation. Data gathered in the two studies (Weichler, 1990; 1993) occurred within

a 3 month period. It has not been investigated whether information needs change over a longer period of time.

Summary. It is evident from the research that the transplantation process not only affects organ recipients but their families as well. Family members of organ recipients face numerous stressors and are able to identify specific information needs. These stressors and information needs are often different from the person who has undergone organ transplantation. As well, the family members' perceptions of transplantation are often different from those of organ recipients.

During the transplantation process, social interaction is taking place between clients and their family members. It is through this interaction that the meaning of the transplantation experience is derived. This interaction may have a negative or positive effect on a client's convalescence.

Third Premise of Symbolic Interactionism

The third premise of symbolic interactionism states that the meaning placed on the object by an individual has been derived through interaction which the individual has had with him/her self. It is meaning that guides and forms the individual's action (Blumer, 1969). The literature pertaining to this premise refers to the quality of life (QOL) after organ transplantation.

The QOL of transplant recipients has been researched in five studies (Brennan, Davis, Buchholz, Kuhn, & Gray, 1987; Colonna et al., 1988; Hauser, Williams, Strong, Ganza, & Hathaway, 1991; Kober, Kuchler, Broelsch, Kremer, & Henne-Bruns, 1990; Tarter, Switala, Arria, Plail, & Von Thiel, 1991; Wolcott, Norquist, & Busuttil, 1989). Once again, research in this area has been plagued by the limitation of no reported reliability or validity measures of data collection tools. Table 3 (Appendix C) presents a detailed

summary of the nature of the research question, the sample, the research design and the major finding for each of these studies. The following discussion presents the research design and findings pertaining to the QOL following transplantation.

Research design. Six research studies were located that investigated the QOL in organ recipients. Of these, four (Colonna et al., 1988; Kober et al., 1990; Tarter et al., 1991; Wolcott et al., 1989) investigated QOL associated with liver transplantation, one (Brennan et al., 1987) with heart transplantation, and one (Hauser et al., 1991) with kidney transplantation. One research study (Kober et al.) was longitudinal in that data collection occurred pre operatively, 2, 6, 12, 24, and 36 months post liver transplantation. Two studies (Colonna et al.; Tarter et al.) incorporated control groups into their research design which allowed them to compare liver recipients QOL with other groups. All but one study (Hauser et al.) were quantitative in design utilizing survey methods to determine QOL post transplant. Colonna and his colleagues studied both adult and pediatric liver recipients. Once again, a major limitation of four out the five quantitative studies was that reliability and validity measures of the tools used in the studies were not reported.

Research findings. All studies which have investigated QOL found improvements in various aspects of the participants' lives. Brennan and colleagues (1987) found that general and personal QOL, as well as a positive perception of change in health status, increased after transplantation. Three clients with a personality disorder, however, reported a decreased general QOL. Colonna and colleagues (1988) reported a highly significant ($p < .001$) improvement in QOL. Kober and colleagues (1990) noted that clients who have successfully survived a liver transplant have a distinct increase in their overall QOL. Clients who have been transplanted for 3 months or more rated their QOL

higher than clients in a control group diagnosed with chronic liver disease. Tarter and his colleagues (1991) identified significant decrease in disturbed behaviour and burden and an increase in social performance following liver transplantation.

In terms of employment status after transplantation, researchers have determined that clients with personality disorders experience a negative change in job satisfaction/performance, whereas clients without a personality disorder experience positive changes (Brennan et al., 1987). Prior to transplantation, only 32% of clients worked either full or part time. After transplantation, 75% of the same clients worked (Colonna et al., 1988). In contrast, Tarter and his colleagues (1991) found the work capacity of clients was the only improvement that was not significant from pre to post transplantation. The Tarter study had 53 clients; there were only 28 participants in the study by Colonna and colleagues. The smaller sample size may account for the discrepancy in the results.

Colonna and colleagues (1988) determined that, prior to transplantation, 61% of their liver recipient participants experienced activity intolerance. After transplantation, only 7% of the participants experienced activity intolerance. The improvement post operatively was significant ($p < .05$). Only pediatric clients had a less striking improvement, attributable to their good pre operative activity tolerance. Significant improvement in ambulation, mobility, body care, and movement were noted in the study by Tarter and colleagues (1991). In another study, (Wolcott et al., 1989) the researchers identified that, after transplantation, 53% of the participants could do household tasks, 80% had restrictions in vigorous activity, and 48% had some restrictions in moderate activity. It is difficult to assess whether these results are significant as pre operative functioning of the participants were not reported.

Hospital admissions after liver transplantation were studied in two research studies. Colonna and colleagues (1988) determined that the number of hospital admissions decreased from 3.07 to 0.87 for adult clients in the study. Admissions for the pediatric participants in the study were not significant. Brennan and colleagues (1987) found that few hospital readmissions were associated with a positive general QOL score.

Tarter and his colleagues (1991) found that there was less improvement in psychological adjustment pre to post liver transplantation (70.2%), whereas physical adjustment was 89.5%. The researchers reported that sleep, rest, eating and appetite, home management, recreation, and pastime improved after transplantation. Kober and colleagues (1990) found that although some anxiety existed for those who were transplant survivors, it was slightly lower than for those with chronic liver disease.

Summary. There has been a general consensus among researchers that transplantation improves the recipient's quality of life. It is uncertain whether such a conclusion can be deemed to be representative of the experience of the entire population of organ recipients as the small samples and limitations of research design have hampered the generalizability of this research. Also, in studies that have researched QOL, the researchers have maintained various interpretations of what QOL is and have used various instruments to measure the phenomenon. Quality of life was measured according to the researchers' perceptions of what they interpreted QOL to be, not the clients' interpretation of it. For example, persons who have undergone transplantation may recover full ability to take care of themselves but still be unable to work. If the perception of QOL is based upon ability to work, a client may rate their quality of life as poor. The meaning of transplantation has to be articulated by the client;

it will guide and form a client's action as it pertains to QOL post transplant.

Learning Needs

The second part of the literature review focuses on learning needs. The areas of literature reviewed include the perceptions of clients regarding to their information needs, concerns clients have during convalescence, and the information needs of clients as perceived by clients and nurses. The review of the literature is organized according to two of the three premises of symbolic interaction theory. The third premise is not included as research studies supporting it were not located.

First Premise of Symbolic Interactionism

As stated previously in this report, the meaning a person attaches to something will influence how he/she will act toward it (Blumer, 1969). Relevant literature pertaining to this premise includes clients' perceptions regarding their information needs and clients' concerns following discharge. In analyzing the findings, it is important to recognize that the study participants had medical conditions other than liver transplantation. These findings, therefore, may not be entirely generalizable to clients who have undergone liver transplantation.

Clients' perceptions regarding information needs (Chan, 1990; Grady, Buckley, Cisar, Fink, & Ryan, 1988; Hanisch, 1993; Wingate, 1990), clients' concerns following discharge (Boyle, Nance, & Passau Buck, 1992; Leyder & Pieper, 1986; Vaughan & Taylor, 1988; White & Holloway, 1990), and a comparison of clients' and spouses' needs (Moser, Dracup, & Marsden, 1993; Orzeck & Staniloff, 1987) have been investigated by various researchers. In most of the research studies, measures of validity and reliability were not reported for the instruments utilized. Also, a number of researchers either developed their questionnaires from a review of the literature or modified existing tools.

Table 4 (Appendix D) provides a detailed summary of the research studies including the research question, the sample, the research design, and the major findings.

Information Needs

The research literature pertaining to the clients' perceptions of their information needs presented in a discussion of the research designs and the research findings.

Research design. Two research studies (Chan, 1990; Wingate, 1990) were located that investigate clients' information needs following a myocardial infarction. One study (Grady et al., 1988) determined what information clients perceived important following cardiac surgery. The study by Hanisch (1993) investigated the importance of information needs during hospitalization at 6 weeks to 6 months following discharge of clients who either had a myocardial infarct or cardiac surgery. All studies were quantitative in design utilizing survey methods to collect data.

Research findings. Researchers have investigated clients' information needs during hospitalization and after discharge. Wingate (1990) and Chan (1990) utilized the Cardiac Patients Learning Needs Inventory (CPLNI) to identify clients' perceptions of their information needs. Chan identified that clients' perceptions changed from pre to post discharge. Wingate also noted that clients' perceptions of what is important to know changed from the time they were in the coronary care unit to the time when they were at home. A comparison of Chan's and Wingate's studies reveals that, prior to discharge, there was a consensus among both study groups that the most important information to learn included risk factors, medications, and anatomy and physiology. It is interesting to note that, prior to discharge, the rank order of these learning needs was different for both studies while, following discharge, the rank order of the learning needs was the same. Both studies listed risk factors as first, followed by medications and then anatomy

and physiology.

Two studies (Grady et al., 1988; Hanisch, 1993) identified common information needs that clients perceived were important to learn. These pertained to medication and activity. In addition, Hanisch found that soon after discharge clients perceived information regarding signs and symptoms of complications and what was normal to be important for them to know. The information that clients felt was least important pertained to sexual activity. The researchers in one study (Grady et al.) discovered that information that was given to clients in preparation for discharge such as limits regarding lifting and driving was not the information they felt was important know.

It appears that clients with cardiac conditions who are discharged from the hospital have a limited scope of perceived information needs. Clients felt they needed information regarding medications, risk factors, and activity/restrictions; some clients asked about anatomy and physiology. Questionnaires were utilized to collect the data; therefore, it is difficult to ascertain whether the research results reflect the perceptions of clients, or if the questionnaires were developed based on what researchers thought clients' perceptions of their information needs would be. The meaning clients place on learning needs will influence how they act toward discharge teaching. For example, if clients perceive the information they receive is important, then they may be open to learning that information. If, however, individuals perceive that the information given is not pertinent, they will not be receptive to learning. It is imperative, therefore, to identify clients' perceptions of learning needs so that health care personnel may offer information which will be of benefit to them during convalescence.

Clients' Concerns

The research literature pertaining to clients' concerns is presented in a

discussion of the research designs and research findings.

Research design. Four research studies were located that measured clients' concerns following hospital discharge. One study (Leyder & Pieper, 1986) investigated surgical clients' concerns prior to discharge and one week following discharge. Two studies (Boyle et al., 1992; Vaughan & Taylor, 1988) identified concerns of both medical and surgical clients following discharge. White and Holloway (1990) studied concerns over a 4 month period following discharge expressed by clients who had back injuries. All studies were quantitative in design and utilized survey methods to determine clients' concerns following discharge. In three studies (Boyle et al.; Leyder & Pieper; Vaughan & Taylor) the researchers developed the questionnaires with only one research study (Boyle et al.) reporting reliability and validity measures of the questionnaires.

Research findings. Concerns of clients during convalescence were identified in four studies. Leyder and Pieper (1986) asked surgical clients to identify their concerns prior to discharge. The three concerns identified as priorities in this study were foods that upset the stomach, activity/restrictions, and what to do for discomfort. One week after discharge, two of the three concerns changed. The three priority concerns became normal and abnormal signs, what to do about incisional discomfort, and which foods upset the stomach. Only the ranking order of concerns, not the concerns themselves, changed from pre to post discharge. Leyder and Pieper's research findings suggest that clients may identify changes in their concerns 1 week post-discharge. It remains unclear whether clients' concerns change during a longer period of convalescence.

Boyle and her colleagues (1992) studied the concerns of 150 medical-surgical clients within 4 months of their discharge. The greatest concerns identified by clients were understanding their progress, amount of activity/restrictions, insurance coverage,

medication, pain control, and when to contact the doctor. In both studies by Leyder and Pieper (1986) and Boyle and her colleagues, the researchers identified that younger people had more post discharge concerns than older people. Leyder and Pieper determined that younger clients were more stressed than older clients and the more education and the higher anxiety scores clients had, the more concerns they expressed. Boyle and her colleagues reported that clients under 45 years of age had more concerns regarding pain control. Also, participants in their study who were under the age of 25 and over 65 wanted to know about their progress more than those who were between the ages 25 and 65.

White and Holloway (1990) found that the majority of calls received by a clinic nurse from clients who had been discharged from hospital between 2 weeks to 3 months and after 6 months pertained to medications. Concerns expressed by clients included the perception that they were taking too many medications and lack of information regarding drug interactions. Some of the questions asked by clients of the clinic nurse pertained to the application of knowledge learned in the hospital to everyday life situations.

Vaughan and Taylor (1988) studied the "little worries" (p. 28) of surgical clients who had been discharged from the hospital for 1 month. The five areas of post discharge concern identified by the researchers included general well being, wound management, specific personal functions and specific general functions, and recovery. The researchers determined that many of the clients' concerns could have been avoided by giving clients the needed information when their concerns were identified.

The research regarding post discharge concerns of hospitalized clients reveals that there is a wide variety of concerns that clients experience during convalescence. It

is apparent from the studies reviewed in this report that clients who have undergone similar procedures generally have similar learning needs. For example, clients who were discharged following cardiac events had similar needs (Chan, 1990; Grady et al., 1988; Wingate, 1990). Although generalizations can be made about learning needs, clients express these needs in different ways and at different times in their convalescence. Unless the client experiences the need for certain information, the information is unlikely to be learned. It is important, therefore, to identify the learning needs of clients who have undergone liver transplantation so that this information can be included in the teaching of future liver recipients. It is also important to continue to be cognizant to the learning needs of individual clients.

Clients' and Spouses' Needs: A Comparison

The research literature pertaining to the comparison of clients' and their spouses' needs is presented in a discussion of the research designs and research findings.

Research design. Two research studies (Moser et al., 1993; Orzeck & Staniloff, 1987) were located that investigated clients' and spouses' needs during recovery and convalescence. Researchers in one study (Orzeck & Staniloff) investigated the needs of clients who had myocardial infarctions and their spouses. The other researchers (Moser et al.) studied both clients who had myocardial infarctions and clients who had undergone coronary artery revascularization along with their spouses. Both studies were quantitative in design and used survey methods to determine the needs of clients and their spouses.

Research findings. Moser and her colleagues (1993), as well as Orzeck and Staniloff (1987), reported the information needs ranked highest by clients pertained to specific facts and general information in relation to their condition. In both studies,

clients and their spouses ranked information regarding what to do in an emergency situation as very important. Moser and her colleagues found more than 70% of clients and spouses who participated in the study reported not receiving information regarding emergency situations. Spouses in both studies felt it was important that caregivers have the client's best interests in mind and provide physical, as well as emotional care. Spouses in both studies ranked information needs higher than did clients. The spouses also ranked the following information as important: talking to the client about concerns the spouse may have; giving the spouse information regarding the expected psychological course of the client; and providing periods of time when the spouse is away from the client. Clients, on the other hand, identified these needs as less important than did their spouses.

For the most part, the information needs of clients and their spouses have been determined to be relatively similar. The needs for information regarding specific facts and general course of the condition and what to do in an emergency situation are consistent findings in both studies (Moser et al., 1993; Orzeck & Staniloff, 1987). While these needs were identified for clients who have had a cardiac event, no research was located that specifically investigated the information needs of clients who have undergone liver transplantation.

Summary. Research indicates clients have a variety of learning needs and concerns following discharge. These learning needs and concerns tend to change from pre to post discharge. It is important to note that spouses tend to rank learning needs pertaining to many aspects of the conditions higher than do clients. The meaning clients place on their learning needs during discharge teaching will affect the way they respond to the teaching. This meaning will either negatively or positively influence their

receptiveness to teaching and ultimately influence their convalescence.

Second Premise of Symbolic Interactionism

As previously stated in this report, the meaning of things is derived through social interaction (Blumer, 1969). The literature that is relevant to this premise includes clients', nurses', and physicians' perceptions regarding clients' learning needs. Table 5 (Appendix E) provides a summary of the research in terms of the research question, the sample, the design, and the major findings. The following discussion presents the research design and findings pertaining to clients' and nurses' perceptions regarding clients' learning needs.

Research design. Seven research studies were located that investigated clients' and nurses' perceptions regarding clients' learning needs. Clients who participated in these studies had a variety of illnesses such as epilepsy (Dilorio, Faherty, & Manleuffel, 1993), cancer (Lauer, Murphy, & Powers, 1992), congestive heart failure (Hagenhoff, Feutz, Conn, Sagehorn, & Morganville-Hunziker, 1994), cardiac events (Gerard & Peterson, 1984; Karlik & Yarcheski, 1987), acute psychiatric problems, general medical problems (Farrell, 1991), and renal failure (Goddard & Powers, 1982). All studies were quantitative in design utilizing questionnaires to elicit data. In all but one study (Karlik & Yarcheski), the researchers developed their own questionnaires based primarily on literature reviews. This study was a partial replication of a study by Gerard and Peterson. The majority of these research studies did not report reliability or validity measures.

Research findings. Clients' learning needs as perceived by clients and nurses have been researched in seven studies. Dilorio and her colleagues (1993) also included the perceptions of physicians. Researchers in four of the seven studies determined that

nurses rated clients' learning needs as being more important than clients did (Dilorio et al.; Farrell, 1991; Goddard & Powers, 1982; Lauer et al., 1982). Yet, Hagenhoff and her colleagues (1994) found that both clients and nurses rated information needs as equally important. Clients in the research study by Dilorio and her colleagues, however, ranked learning needs lower than nurses but higher than physicians. Medication information was ranked as most important by clients and not by nurses in the study by Hagenhoff and colleagues. In the studies by Gerard and Peterson (1984) and Karlik and Yarcheski (1987), medication information was ranked number one by nurses but not by clients. Dilorio and her colleagues revealed that medication information was ranked first by clients, nurses, and physicians. There were, however, differences in the ranking of learning needs within the category of medications. For example, clients' most important learning needs related to medication pertained to medication side effects, what to do if they had a problem, and what to do if they ran out of medication while out of town. Physicians felt that the most important learning need of clients was what they should do if they missed a dose of medication. Nurses identified that the general rules of taking medications as well as the reasons for taking it were the most important learning needs of clients. In the study by Hagenhoff and her colleagues, clients with congestive heart failure rated medication information, anatomy and physiology, and risk factors as most important to learn. The clients identified that these areas were the most realistic to learn while they were in the hospital. Nurses, on the other hand, identified risk factors, medications, and diet as the clients' most important learning needs.

The difference in perceptions between clients and nurses were most apparent in the study by Lauer and her colleagues (1982). Clients with cancer ranked knowing their diagnosis 1st in a ranking of importance, whereas nurses ranked it as 6th. Plan of

treatment was ranked 2nd by clients and 13.5 by nurses. Nurses ranked availability of financial assistance 1st, whereas clients ranked it number 18.5. The discrepancy in what nurses and clients perceive as important could result in clients going home with insufficient information relevant to their situation.

Goddard and Powers (1982) identified that little agreement existed between the nurses and clients as to what was important for clients undergoing haemodialysis to learn. This discrepancy was apparent in the ranking order of the various information need items. The information need ranked 1st by clients pertained to the prevention of injury to their fistula; nurses ranked this item as 8th in importance. Nurses ranked the information need pertaining to the reasons for food and fluid restriction as 3rd; clients ranked it 20th.

Farrell (1991) studied the accuracy of nurses' perceptions of clients' needs. The findings demonstrated that overestimation of clients' physical and emotional needs occurred with all nurses who participated in their study. Nurses who worked on general medical-surgical areas overestimated "environmental issues, client sensation, physical integrity, degree of client worry, sense of dignity, and need for social contact and stimulation" (p.1065). Psychiatric nurses overestimated clients' "needs/concerns in respect of [clients'] worry, need for social contact and privacy" (p. 1065). The researchers concluded that "nurses held opposite views to their patients" (p. 1066).

Summary. The perceptions of clients, nurses, and physicians as to clients' learning needs have been shown to differ considerably. Researchers in this area have clearly revealed that one reason for a perceived lack of discharge teaching may be the different perceptions clients and nurses have as to what is important and pertinent for clients to learn during convalescence. It is imperative that nurses recognize these

differences in perceptions so that teaching may occur that is based on clients' perceived learning needs.

During the information giving process, social interaction is occurring between clients, nurses, and physicians. If during this interaction each person's perceptions are different regarding the client's learning needs, a negative effect on the client's convalescence will surely result.

Summary of the Chapter

By utilizing the theory of symbolic interactionism as an organizing framework for the literature review, it is evident that the meaning clients attach to convalescence will vary depending on their psychological and psychosocial functioning, the types and number of stressors they encounter and the lived experience associated with transplantation. Also, the meaning generated by the client's information needs, concerns and his/her concerns compared with his/her spouse will also influence the meaning associated with convalescence. The transplantation process is not experienced exclusively by the organ recipient, in fact, the literature examines the impact of transplantation on family members. Family members form their own meanings regarding transplantation which influences their information needs, stress, coping and quality of life. Through social interaction between the organ recipient and his/her family members, the meaning of convalescence is derived. This also pertains to the social interactions between the organ recipients and health care professionals. The research indicates that there exists some discrepancies in perceptions regarding the learning needs of clients among clients, nurses and physicians. Therefore, the meaning clients attach to their convalescence and learning needs are influenced and derived through social interaction. The literature associated with quality of life must be interpreted with caution as

researchers' perceptions may differ considerably from that of organ recipients. It is not the clients' meaning of quality of life that is being investigated in the research studies but rather the researchers' perceptions of what quality of life should entail following transplantation. Only the client through interaction with him/herself can derive his/her own meaning of quality of life which will in turn influence his/her meaning of convalescence.

Despite the available research, there still exists a void. Researchers have not identified the learning needs of liver transplant recipients during convalescence. Within the body of research in this area, a paucity exists in the comparison of the similarities and differences between the various types of organ transplantation. For example, are the learning needs during convalescence for liver recipients similar to those clients who have undergone heart, kidney, or lung transplantations? The research literature pertaining to information needs does not address liver transplantation at all (except for the caretakers' information needs); thus, health care professionals do not know for certain whether the information they give to clients pertaining to recovery at home is what the clients need to know. The research literature has demonstrated that nurses' and clients' perceptions of learning needs differ considerably.

The research presented in the literature review is not without its limitations. Research conducted in the areas of transplantation and learning needs have been predominantly quantitative in design. The use of quantitative methods does not allow the depth or meaning of the transplantation experience to emerge from the data. Also, the utilization of these methods does not allow a holistic understanding of the transplantation experience and the learning needs associated with it. Another limitation found in the research was the inconsistent intervals after hospital discharge at which

data collection occurred. Because the data were collected at various time periods during convalescence, patterns of learning needs were difficult to recognize. Additionally, the questionnaires utilized in the research studies were developed for each particular study. Measures of validity and reliability were often not reported. In some of the studies, modified questionnaires were utilized without the researchers reporting the new measures of reliability and validity. An important limitation of the various studies is that the research was based on different interpretations regarding a specific phenomenon. For example, the quality of life after transplantation is conceptualized and measured differently in the various studies thereby limiting the generalizability of these results.

Clients' perceptions of convalescence after transplantation must be identified in order to provide them with the necessary information and support they feel is necessary. Also, clients' experience of convalescence following transplantation must be better understood so that health care professionals may provide holistic care. Most importantly, clients' learning needs must be identified to ensure that clients are taught the necessary information which will decrease the stressfulness of convalescence.

This study is a pivotal first step in terms of identifying clients' learning needs during convalescence following liver transplantation. By identifying the learning needs, health care professionals may integrate them into discharge teaching. Creative teaching strategies can be developed based on the clients' perception of what they need to know during convalescence, not what health care professionals perceive as important for clients to learn. This study is unique in that the learning needs were identified by clients, rather than by health care professionals, as to what they perceived as important to learn.

CHAPTER THREE

Research Method

A grounded theory approach in the tradition of Strauss and Corbin (1990) was chosen to direct the research design of this study. In the grounded theory research method, theory is generated from the ground up, taking into consideration common circumstances, experiences, meanings, and behaviours among a specific group; thus the developed theory will have meaning to those from whom it was derived (Hutchinson, 1993). Grounded theory has been described as a process that is systematic as well as intensive. From the initial interview, the processes of collecting, coding, and analysing the data are done simultaneously (Hutchinson). The analytic procedures outlined by Strauss and Corbin are done for the following reasons: to build theory rather than test it; to provide rigor to the research process; to assist the researcher to bracket biases and assumptions prior to and during the process of research; and to "provide the grounding, build the density, and develop the sensitivity and integration needed to generate a rich, tightly woven explanatory theory that closely approximate the reality it represents" (Strauss & Corbin, p. 57).

Because of its emphasis on process, grounded theory research is particularly appropriate when a researcher seeks to investigate change or experience over time (Morse, 1994). Consequently, the research study was an examination of learning needs over time; therefore, the selection of grounded theory as a research method was most relevant. Grounded theory is a fitting research method when there is a paucity of research within an area (Bowers, 1988). It is evident from the review of literature in the area of liver transplantation that learning needs of clients during convalescence following transplantation have not yet been addressed. Grounded theory provided a

suitable method by which to explore the research question of this study.

The theoretical orientation of this grounded theory study was symbolic interactionism. The direction provided by symbolic interactionism as a conceptual framework of the research enabled the phenomenon being researched to be understood from the perspective of those who have actually experienced it (Chenitz & Swanson, 1986). The process of grounded theory research began with simultaneous data collection and analysis (Strauss & Corbin, 1990). Analysis consisted of a constant comparison of the data using various coding methods. From the data analysis, hypotheses were generated and tested. In order to test the hypotheses, participants were selected based on their ability to provide information pertaining to the hypotheses. This type of participant selection is known as theoretical sampling (Strauss & Corbin). The research process continued until saturation occurred; that is, when the data did not offer any new information (Strauss & Corbin). The research procedures and techniques as outlined by Strauss and Corbin, such as the sampling procedures, data collection, analysis of the data, and scientific canons, will be discussed in the following sections of this chapter. In addition, ethical considerations and limitations of the study will be addressed.

Sample

Once ethical approval was granted for the study, the researcher met with the Clinical Nurse Specialist (CNS) for the transplant program in an urban tertiary care hospital to describe the study and obtained her participation in the recruitment of participants. The CNS sent a letter of invitation (Appendix F) to potential participants who met the inclusion criteria. The inclusion criteria of the potential participants were those who:

1. had undergone liver transplantation within the last 6 years;
2. were able to communicate in and read English;
3. were of legal age (19 years old);
4. lived in the Lower Mainland of British Columbia; and
5. were able to articulate their learning needs (as assessed by the CNS).

The letter of invitation to participants included the researcher's name and telephone number. Participants contacted the researcher by telephone. When the participant contacted the researcher, the researcher explained the purpose of the study, answered any questions, and set up an initial interview. During the first interview, any further questions the participant had about the study were answered before he/she was asked to sign the consent form. A copy of the signed consent was given to each participant.

The sample consisted of 6 liver recipients, 3 men and 3 women. Four of the participants were married, 1 was divorced and 1 was single. Three of the participants had post secondary education. In terms of employment, 1 participant worked full time, 1 was expecting to return to work full time, 2 participants had retired because of their illness, 1 participant was on compensation, and the last participant did not feel able to return to work. Their ages ranged from 64 to 33. The mean age was 52. The length of time from transplantation to the initial interview ranged from 1 month to 3 years. One participant had been transplanted for 3 years; 1, a year and a half; 2 participants, 6 months; another, 4 months; and 1 participant, 1 month.

Sampling Procedures

In grounded theory, sampling procedures are specific and purposive. They are based on theoretical sampling in which participants are chosen to be interviewed

because the concepts in their stories contribute to the understanding of the evolving theory (Strauss & Corbin, 1990). Theoretical sampling was conducted according to the type of coding during analysis of the data (Strauss & Corbin). Strauss and Corbin state "sampling and analysis must occur in tandem with analysis guiding the data collection" (p. 178-9). Three types of coding in data analysis guided sampling procedures: open, axial, and selective.

Coding. During open coding, participants were chosen based on their experience with the phenomenon under study. The participants provided data that the researcher was able to "discover, name, and categorize phenomenon" (Strauss & Corbin, 1990, p. 181). Participants who volunteered to be in the study provided data describing the learning needs they had during convalescence after a liver transplant. During axial coding, participants were selected based on their ability to provide data that validated the relationships between concepts identified in the ongoing data analysis (Strauss & Corbin). In the initial phase of the study, the participant who was interviewed had been at home convalescing for 1 month. During axial coding, participants were chosen specifically because they had been convalescing at home between for longer periods of time; i.e., 4 to 6 months post transplant. During selective coding, discriminate sampling took place in which the participants who could provide verification of the descriptions from other participants were selected (Strauss & Corbin). The data collected from them provided verification of relationships between categories, as well as information that developed previously poorly defined categories (Strauss & Corbin). Discriminate sampling lead to the selection of participants who had been convalescing after their liver transplant for more than a year, 1 participant for a year and a half, and the other, 3 years.

Saturation. The number of participants in the study and the sampling procedure also depended on the saturation of codes. Once the discovered categories in selective coding were "expanded, dimensionalized, and limited" (Stern, 1980, p. 22), saturation of the categories was accomplished. In order to achieve saturation, sampling continued until (1) data obtained from interviews became repetitious; (2) categories were dense with paradigm elements, variation and process; and (3) the relationships among categories were confirmed (Strauss & Corbin, 1990). Once all the above were achieved, saturation had occurred and data collection ended.

Sampling Plan. A provisional sampling plan provided a starting point at which the grounded theory researcher began to sample study participants. This beginning sampling was based on criteria noted in the literature as affecting the learning needs of transplant recipients. Since recipients of organs studied at various times during convalescence have been found to experience a variety of stressors and needs associated with transplantation, it was important to interview organ recipients who had been convalescing at home for various lengths of time (Frey, 1990; Sutton & Pelletier Murphy, 1989; White et al, 1991). Based on the findings of previous studies, the provisional sampling plan included those participants who were convalescing at home for 1 month, 6 months, and more than a year.

Data Collection

The method of data collection for the study was initially formal unstructured interviews. The unstructured interviews served to elicit information regarding the phenomenon under study. May (1991) suggests that interviews during the initial stages of a study can be unstructured in order to allow the informants' perspectives to emerge. As data collection and analysis proceeded, the interviews became semi-structured in

nature, informed by the data that had been analysed in previous interviews and the relevant literature. These interviews were face-to-face encounters, conducted usually in the homes of the participants with two exceptions. One participant was interviewed in the transplant clinic conference room and the other in a conference room at the university. Participants were asked to describe what it was like for them when they came home from the hospital after their liver transplantation. This initial question conveyed to the participants that they were the experts most able to describe the phenomenon which is under study (Bowers, 1988). The participants were asked to clarify or elaborate those aspects of their experience that the researcher did not fully understand. The initial interview lasted between 1 ½ to 2 hours.

Once the first interview was transcribed and analysed, categories of data began to emerge and the subsequent interview was more structured in order to elicit data that would uncover and verify possible relationships among concepts (Strauss & Corbin, 1990). The participants were sent a copy of their transcribed interviews. A second interview with all participants was necessary in order to clarify or validate the collected data in the first interview. One participant made revisions as there were some areas on the tape that were difficult to transcribe because the person's words were unclear.

Data Analysis

The three types of coding in grounded theory -- open, axial, and selective-- provided the means to analyse the data (Strauss & Corbin, 1990). In the process of open coding, data were broken down and closely examined, and phenomena which emerge from the data was named and categorized (Strauss & Corbin). Once categories, properties, and dimensions of the phenomena were identified, axial coding began. In axial coding, a category was scrutinized in detail; relationships among categories were

analysed and subcategories (conditions, context, action/interaction strategies, and consequences of the category) were investigated (Strauss & Corbin). Selective coding was carried out upon selection of a core category. Relationships between this category and other categories were then sought. Finally, verification of the relationships between categories were made and the categories that were not fully developed or refined were explored further (Strauss & Corbin).

Constant Comparative Method. The constant comparative method of analysis formed the basis of the coding process (Strauss & Corbin, 1990). This method of analysis encouraged comparing, as well as questioning, data. It is through the constant comparison of data that concepts were given precision and specificity (Strauss & Corbin). "The main aim of this method is the generation of theoretical constructs that, along with substantive codes and categories and their properties, form a theory that encompasses as much behavioural variation as possible" (Hutchinson, 1993, p. 200).

Memos. Writing memos was an important aspect in the analysis of the data in that memos were a written record of the process which took place (Strauss & Corbin, 1990). Memos provided a step-by-step account of the theory that was being developed. They also provided a record of the researcher's thought process in the past, present, and future. In the review of research memos, data collection was directed to alternative avenues. Memos were also used to write the final theory (Chenitz & Swanson, 1986).

Memos were written in each type of coding and had specific purposes (Strauss & Corbin, 1990). The three types of memos are code notes, theoretical notes, and operational notes (Strauss & Corbin). Code notes were made in the initial analysis of the data. Code notes included conceptual labels, paradigm features, and indications of process. (Strauss & Corbin). Theoretical notes were used in the documentation of the

researcher's decisions regarding direction in which theoretical sampling would follow. They contained inductive and deductive thoughts regarding categories, and the "properties, dimensions, relationships, variations, processes, and conditional matrix" (Strauss & Corbin, p. 197) of these categories. Operational notes were the researcher's thoughts in terms of the directions in which sampling proceeded, the types of questions that were to be asked, and the kinds of observations that were to be made (Strauss & Corbin).

Process. Process is an important aspect of grounded theory that was integrated into the analysis (Strauss & Corbin, 1990). Strauss and Corbin state "by process we mean the linking of sequences of action/interaction as they pertain to management of, control over, or response to, a phenomenon" (p. 143). When analysing the data changes in conditions, their affect on action/interaction were also sought. These changes brought a sense of time and movement into the data analysis (Strauss & Corbin). In order to identify change, one must look at the conditions in which change took place. Strauss and Corbin note the following:

(1) change can occur in a set of conditions that leads to or causes the phenomenon under condition; (2) there may also be change in any of the intervening conditions that influence actions/interactions; and (3) consequences of previous actions/interactions is one sequence of events can feed back either to (a) add new conditions, or (b) alter the interaction among already existing conditions (p. 151-2).

Ethical Considerations

A number of measures were taken in order to ensure the rights of the research participants. Ethical approval was obtained from the University of British Columbia Behavioural Sciences Screening Committee for Research and Other Studies Involving Human Subjects prior to participant recruitment. Because the participants were out-

patients of the hospital, ethical approval for the research was also obtained from the Hospital Research Committee of the Medical Advisory Committee. All potential participants received a letter of invitation (Appendix F). The letter included the purpose of the study, the participant's time involvement, a description of the data collection process, as well as an explanation of how the findings will be utilized. Prior to the first interview, informed written consent was obtained (Appendix G).

Participants were informed that they might withdraw from the study at any time without affecting their medical or nursing care. They were also assured that their names would not be associated with the research transcripts or findings, ensuring confidentiality. The researcher assigned a code, known only to her, to each research participant. This code was used to refer to the participant in the transcripts, research reports, and presentations of the research findings. Any information that could identify the participant was deleted from the transcript.

Only the researcher and her thesis committee had access to the data. The audiotapes and transcripts were stored in a locked cabinet for which the researcher has the only key. Ten years after the completion of the study, the audiotapes and transcripts will be erased/shredded. No harmful effects to the participants of this study were anticipated. Indeed, being given a chance to tell their stories may benefit the participants. Future liver transplant recipients may also benefit from the increased knowledge of clients' needs during convalescence following liver transplantation as discharge teaching may be improved as a result of this study.

Scientific Canons in Grounded Theory

Strauss and Corbin (1990) confirm that qualitative studies such as those using the method of grounded theory need to be judged on certain canons or standards, as

are quantitative studies. The canons used to judge quantitative research are inappropriate; therefore, Strauss and Corbin have suggested modifying these to fit qualitative research. These canons include "theory-observation compatibility, generalizability, consistency, reproducibility, precision, and verification" (Ibid, p. 250). The procedures of data collection and analysis in the proposed research took into account these specific canons.

Theory-Observation Compatibility. The first canon is that of theory-observation compatibility (Corbin & Strauss, 1990). Because the process of data collection and analysis in grounded theory are so interrelated, theory-observation compatibility is accounted for (Corbin & Strauss). When conducting a grounded theory study, analysis of the data takes place with the first interview. From this analysis, the proceeding interviews obtain direction. Data analysis permeates the entire data collection process enabling relevant concepts of the phenomenon to be pursued (Corbin & Strauss). A concept is not automatically incorporated into the theory; if it does not consistently emerge in the analysis, then it is discarded (Corbin & Strauss). Corbin and Strauss explain "grounding theory in the reality of data thus gives this method theory-observation congruence or compatibility" (p. 7). Theory-observation compatibility was maintained in this study by ensuring that the concepts which emerged from the data were consistently identified in the ongoing process of data collection and that a concept was identified as a part of the theory when it emerged consistently throughout the analysis.

Consistency. Corbin and Strauss (1990) address the second canon, consistency, in two ways. First, consistency is maintained in data collection by ensuring that when a concept emerges from the data, it is "qualified" (p. 9). Qualifiers are those things that identify "the conditions under which phenomena occur, the action/interaction form they

take, the consequences that result" (p. 9). By noting qualifiers, specificity may be given to concepts. Second, consistency can be achieved through theoretical sampling in which a concept may repeatedly emerge from the data in connection with the phenomenon that is being studied. Once connections were established, the concept indicators were examined in the proceeding data collection methods.

Precision. Precision, the third canon of grounded theory research, was maintained in this study by the constant comparison of data (Corbin & Strauss, 1990). The comparisons of incidents for similarities and differences throughout data analysis allowed only those phenomena which were truly similar to be grouped together. "Precision is increased when comparisons lead to sub-divisions of an original concept, resulting in two different concepts or variations on the first" (Corbin & Strauss, p. 9).

Verification. Verification, the fourth canon, took place during axial coding. During coding, hypotheses were developed regarding relationships between categories. Once a hypothesis was developed, it was observed for in proceeding encounters, and revisions were made to them as they were supported or not supported by the data (Corbin & Strauss, 1990). Before a hypothesis was accepted it must have been identified as applicable in every instance with relation to the phenomenon (Corbin & Strauss).

Reproducibility. The fifth canon of grounded theory, reproducibility, is associated with judging qualitative research. Corbin and Strauss (1990) explain that another investigator who follows the same general rules of data collection and analysis as the original researcher under similar conditions should observe a similar general scheme emerge as that in the original study. In the study, the procedures and techniques outlined by Strauss and Corbin were followed for data collection and analysis. Written memos also provided a paper trail to permit other researchers to follow the inductive, as

well as deductive thinking, that occurred during the building of the theory (Strauss & Corbin, 1990).

Generalizability. The final canon of grounded theory research is generalizability. Corbin and Strauss (1990) state "the generalizability of a grounded theory is partly achieved through a process of abstraction that takes place over the entire course of research" (p. 15). The intent of grounded theory is to identify conditions that contribute to specific sets of action/interaction relating to the phenomenon and what happens as a result. The theory is only generalizable to situations similar to those from which the theory was generated. To achieve generalizability in this study, theoretical sampling was systematic and widespread, allowing broader variations and conditions to emerge which was built into the theory (Strauss & Corbin, 1990).

Limitations

The limitations of this study are associated with experience of the researcher, time constraints, sample selection, and generalizability of findings. As the researcher's first study using the grounded theory method, the data gathered and analysed may have been more in-depth; late interviews explored certain areas more fully than earlier interviews. Thus the process of writing this document led to an effective evaluation of the earlier interviews and provided insight into the learning needs of liver recipients during convalescence.

Time constraints prevented the presentation of the study findings to a focus group. The purpose of the focus group was to share the grounded theory which results from the study with the participants and to seek their validation of the theory (Kruger, 1988; Morgan, 1993; Stewart & Shamdasani, 1990). Instead, the data were clarified and validated during the second interview of the study participants.

Finally this study involved sample selection that was purposive and specific, however, liver recipients other than those who participated in the study may have different learning needs than those who participated in the study. Thus generalizability of the study's findings, can only be applied to situations similar to those from which the theory was generated.

Summary of the Chapter

The grounded theory research method as described by Strauss and Corbin (1990) formed the research design of the study. This method allowed the exploration of the lived experience of liver transplantation and identify what information is needed during convalescence. It is through the developed grounded theory that health care professionals will "understand the contextual reality of behaviour" (Hutchinson, 1993, p. 210). Because the developed theory is based on the experiences of those who have undergone liver transplantation, it will also have relevance and meaning for future liver transplantation recipients.

CHAPTER FOUR

Findings

The learning needs of clients who have undergone liver transplantation were investigated in this research study. It was the individual transplant recipient's perceptions regarding the transplant experience which determined his/her crucial learning needs as defined by each individual. These perceptions were influenced by the liver recipient's previous experiences, interactions with him/herself and others, as well as by the meaning placed on the transplant experience. This chapter includes a discussion of the study participants' crucial learning needs, as well as their learning needs in relation to knowing what to expect after transplantation during convalescence. The common circumstances experiences and meanings pertaining to knowing what to expect during convalescence were placed into three main categories: mastering recovery, transition, and reflection. There were seemingly few crucial learning needs stated by the liver recipients; however, each recipient felt that they needed to know what the post transplant experience would entail. For these recipients, the gap in knowledge regarding knowing what to expect following transplantation created important learning needs.

Crucial Learning Needs

At the end of their second interview, participants were asked what they felt their crucial learning needs were after transplantation. Each participant had unique learning needs; however, there was some consensus on common needs. One participant emphasized, "there is so much to learn and it is all crucial". For most, learning about the medications was crucial. They needed to know about side effects and how the body would react to various medications. One participant's "runny nose" was a worry until she

understood it to be a side effect. Learning about her medications reduced her anxiety. When participants learned about serious side effects they sometimes became worried about more things than they felt they should. One woman related, "I think about the side effects a lot. You get a sore throat and you check for lumps. Am I getting lymphoma?" Understanding that the immune system is suppressed as a result of medication and the implications associated with this were also important learning needs. One participant became very conscious about her immune system and stated,

When I thought of an immune system, I thought of AIDS. I felt like somebody with AIDS that I hadn't got an immune system. You see what those people go through and you think oh my God, am I going to go through the same thing? Because nobody really really tells you.

Understanding the laboratory values for the various blood levels was also an important learning need for some participants. In addition, sharing information among liver recipients regarding various topics associated with transplantation was seen as crucial. Each individual felt different about his or her limits, all felt being able to test and know their own limits was another crucial learning need. One man said about limits, "once you learn them, stick to them". Others claimed it important to be able to shift abilities with shifting limits and learn about their "potentials" as well, "it's a matter of rediscovering yourself ". Finally, 1 participant identified a desire to have known more about the role changes between marital or significant partners especially as these changes contributed to " financial problems, stress problems and commitment problems". Although limits and role changes were identified as crucial learning needs by the study participants both will be discussed in the next section Knowing What to Expect as they are more related to expectations during convalescence.

The interviews contained very little about specific details regarding crucial

learning needs. The liver recipients' actual specific learning needs were few. What was common throughout the interviews was the need to know what they would go through during convalescence and knowing what to expect.

Knowing What to Expect

The common circumstances, experiences, and meanings which emerged from the interview data regarding knowing what to expect during convalescence were placed into three main categories: mastering recovery, transition, and reflection. Within each main category there are several subcategories which describe elements associated with the main category. If liver recipients are able to know what to anticipate during convalescence, their learning needs can be identified and met.

Mastering Recovery

Each of the participants in this study experienced convalescence. During the interviews they identified their individual learning needs. These learning needs encompassed a number of aspects pertaining to knowing what to expect in terms of the recovery process, and are comprised of support and information sharing, comparing self with others, establishing limits, and dealing with the unknown.

Support and Information Sharing

In order to master recovery after transplantation, the liver recipients required support and most found sharing of information an important aspect of the recovery process. Through support and information sharing, the participants were able to learn what to expect during convalescence.

The participants stated that the support and information sharing they received from other liver recipients helped them greatly during their recovery from transplantation. Support group sessions were held in the hospital by liver recipients, once a month in

which formal presentations would usually be given by various health care professionals. Another forum in which information and support were obtained took place in the outpatient clinic. Liver transplant recipients and their significant others would come to the clinic for follow up appointments once they were discharged from the hospital. After discharge, the recipients would go to the clinic twice a week for approximately 2 months and then only once a week for 3 months. Depending on their progress, the frequency of the participants' clinic visits varied. Clients who recovered quickly came less frequently to the clinic.

In the clinic, a large waiting room provided an opportunity for clients to share information and support one another. Indeed, this was where much of the information sharing between liver recipients took place. One participant found that the support she received from other liver transplant recipients at the clinic provided her with encouragement and a new understanding which assisted her to accept what she was going through, especially if the information related to a complication of the transplantation such as rejection. She also found that, by sharing similar situations, she could be more realistic about the future, especially when the person she was talking to had their transplant for a longer period of time. She recalls:

It's like they (other liver transplant recipients) are teachers because they've had the experience. One lady talked about her experience with rejection 3 years ago where you know she had been doing really well. She said, '99% out of 100% well'. She just had the occasional temperature, and she had an episode of rejection that really brought her down. It's good to see that she survived.

Most of the participants found the sharing of information in the clinic and in support group meetings to be a positive experience. One participant said she found out more information at the clinic from other transplant recipients than from the nurses. She stated that what makes this sharing so effective is that people who have had their

transplant for 2 weeks share the same waiting room with those that have been transplanted anywhere from 1 month to 7 years; the number of experiences and amount of information in the room are vast. As the transplant recipients converse among themselves, they discover common experiences. An example offered by one participant was regarding a runny nose she had. In talking to another person who had had a transplant a number of years previous, she realized that this symptom was a side effect of one of the medications and that eventually it would stop. Knowing this helped the participant reduce her anxiety. One participant made the comment that support and information sharing was, "therapeutic because something can happen to you that you are not prepared for. This way you know what is going on".

One participant had both positive and negative experiences with the support and the information sharing which took place in the clinic waiting room and at the support group. She did not like going to the monthly support group meetings because it reminded her of an Alcoholics Anonymous (AA) meeting. Like at an AA meeting, the beginning of every meeting people are asked to introduce themselves and state whether they have had a liver transplant, if they are waiting for one, and for how long they have been waiting. Two participants commented they did not enjoy listening to other transplant recipients' problems while in the clinic waiting room. One participant stated it bothered her to go to the clinic because she overheard other transplant recipients talking about the complications they were experiencing. She found herself going home feeling somewhat depressed and wondering if the same thing would happen to her.

One participant said this about going to the clinic:

I guess it's a repeat of everything, and you hear it over and over and over and you get sick of it. I started to dislike going to the clinic because people talked about the same thing over and over. Forget it. Get on with their life. That's what I say.

The same participant had been experiencing numerous transplant-related complications and was on the waiting list for a second transplant. He did not want to hear other liver recipients' experiences, especially if they were negative. He stated he would rather hear about their positive experiences.

Comparing Self With Others

Through the process of sharing information, participants found themselves comparing their recovery to that of others. Their strong need for the comparison stemmed from a need to gauge how they were progressing physically. These comparisons had both a negative and positive impact on the participants' ability to master recovery. While comparisons helped people understand what they were going through, it also gave them a false gauge, encouraging the "quick " recovers and falsely discouraging the "slower" ones. One participant found that, as she listened to the success stories of other liver recipients, she placed expectations upon herself based on what the other people had accomplished. When her experience did not support her expectations, she was disappointed and ill-prepared. For example, she had heard of people going back to work 3 months post transplant. However, 6 months after her transplant when she had gone to work for 1 day as a trial and was extremely fatigued, the fact that she was not able to work a day without being exhausted was disappointing to her. After listening to others' stories, this participant felt as though she should be doing better than she was. Her expectations caused her to push herself and do things she was not ready to do. A participant who had had his transplant for only 6 months felt somewhat "jealous" of other people who had received a liver transplant, were discharged from the hospital, and would "go like rockets". His progress was slower due to complications of transplantation. Intellectually, he knew he had "been through a lot"

but, when he compared himself to others, what he perceived about his lack of progress was difficult for him. By contrast, one participant said when she listened to stories about people not being able to do the things she was able to do, even though they had their transplant prior to hers, she wondered if she made a quicker recovery than was typical. One participant said that, by comparing herself to others in the support group, she was able to conclude that the puffiness in her face, caused by a medication, would eventually decrease. No one in the support group had a puffy face and so she reasoned it must be temporary.

One participant said he felt "behind, right off the bat" compared to other liver recipients. He wanted to be "up and about like everyone else". No other transplant recipients he met seemed to have as many problems as he was having. It was not until he visited the clinic that he realized that these people did have other less visible complications as a result of transplantation.

Some participants recognized the difficulty with making comparisons and gauging one's recovery on the speed of the recovery of others. One participant, who had his transplant longer than any of the other participants, stated he did not compare himself to other transplant recipients. He stated that too many factors were involved which make each transplant recipient unique. Some of the factors he mentioned were the degree of illness prior to transplantation, the condition and match of the liver, the length of operation, and metabolism of drugs. He felt these factors were not always taken into consideration when comparisons were made and that comparisons could easily lead to feelings of disappointment and jealousy.

Establishing Limits

For all participants in this study, establishing limits was an important aspect in

the mastering of recovery. During the recovery process, limits tend to fluctuate; therefore, it is necessary for the liver recipient to test his/her limits. It is also necessary that he/she is aware of these limits. It is evident from the data that learning needs are associated with the establishment of limits.

Testing for Limits. All the participants experienced a need to test their limits on their own. Testing for limits was described by one participant as "everyday you try like a little baby. Start walking. You are not completely balanced, but you try, you fall down a little, but you try again. You go, you go, you go, and little by little you do more". Many of the participants' experiences are captured by this description. One participant recalls being both curious and apprehensive about what his body would allow him to do after transplantation. He recalled that even in the days of his recovery in the hospital, he began to explore his body by testing out his comfort and strength levels. He states,

I was not very strong. I felt quite fragile and was very tentative in the challenges I was willing to take on in terms of movement and even adjusting for comfort. I did a lot of rolling and tried to find the greatest possible mechanical advantage in dealing with what I felt was a very vulnerable area in my body.

Participants felt that it was important to "listen to their body". When they became tired, it was time to quit whatever they were doing and relax and rest. One participant recalled doing "a little more each day" pushing herself to test her limits but not so much that she would be fatigued. Many participants found testing for limits was a repeated exercise in trial and error:

... so I try little by little. Lets see if I can move faster, see if I can stay up a little longer, and I was finding out how much I could take and ready to pay the price if something was wrong. A few times I paid the price for what I did. It was too much.

One participant noted that, as his condition changed, he had to retest his limits.

Prior to the change in his condition, he was able to walk for a set distance and did not

have to stop and rest. As his condition deteriorated would have to sit and rest frequently during the course of his walk.

Knowing Limits. When liver recipients can be more aware of their limits, they can work within them with some degree of comfort. When asked what their limits were, many participants stated at first they did not feel that transplantation placed any limits on them. One participant stated that, among other things, she was unable to run up the stairs like she used to; however, she would push herself until she was tired. She noted that she was limited in the amount of time she was able to stay out in the sun. Another participant stated she did not feel as though she had limits because she was able to do more than she did 1 month previously. Another participant who had his transplant for a few years, stated he was able to "work handily within them [his limits] now"; his limits were no longer "shifting". The limits he lived within included decreased abdominal strength, which also affected his back strength, and decreased limb dexterity and strength due to nerve damage. Some participants spoke not only of physical limitations placed on their bodies but physical limitations placed on their lives. One participant stated that going to the clinic all the time, remembering to take medication everyday, and being hesitant to travel outside of Canada to developing countries (where he may acquire infections more readily because of immunosuppressive drugs) placed limits on his life. The same participant felt as though he could not neglect his health as he might have had he not had a transplant. One participant not only acknowledged the limits transplantation placed on his life but also stated that these limitations extended to his spouse's life as well. He said, for example, that his wife would love to go on a cruise; however, he feels that he can not travel because of the blood tests associated with transplantation. Also he feels that if he were to become sick while on the cruise, he

would have to "survive on [his] own or die". While he has told her to "go on her own", she will not go without him. The same participant said this about limitations:

You got to cope with some limitations: I cannot go to the mountains. I cannot go fishing for 6 or 7 hours. I take my boat, I take a friend, I take my wife with me. I never want to be alone anymore. I go on the water; after 2 hours I have to be at home.

Two participants felt that immunosuppression (a result of drug therapy) was another aspect of transplantation which could be limiting, depending on the person's perception of it. One stated, for the first month post transplant, she was significantly aware of being immunosuppressed. While pushing a cart at stores, she would wear gloves. While dusting her house, she would wear a mask. She refrained from flying on an plane for 1 year to avoid the recycled air of air planes. Now, over a year since transplantation, she states she must remind herself that she is immunosuppressed, especially when around ill children; most of the time she does not think about immunosuppression. Another participant stated that although one's immune system is suppressed, one does not have to "buy into a contamination anxiety". This fear, he explained, can be very limiting on your life both physically and psychologically. Someone with this anxiety might not want to go to a movie for fear of being infected with pneumonia or, as he put it, "touch the beggar's hand because he might have leprosy".

Dealing With Uncertainty

The entire transplant experience was plagued by uncertainty. All the participants in this study had to deal with uncertainty during convalescence. By acknowledging the uncertainty associated with transplantation learning needs may be identified and interventions may be implemented.

From the anticipation of surgery to years after the transplant, participants

claimed that not knowing what is going to happen, or what they can expect, is a great concern. One stated, "you don't always know what is going to happen next. Nothing they tell you is for sure". When "little aches, pains, twitches and twinges" occurred that were unexpected, the participants did not know whether odd sensations were because of the normal aging process, side effects of medication, or rejection. One participant recalled, "you get this little twitch or something different that you did not feel before. You never think, well, it is age. You think it's my liver. Oh my God. I'm having rejection".

For the participants in this study one of the lingering uncertainties associated with transplantation was rejection. One is "never really sure" if or when rejection will take place. Although it can be detected in the laboratory results before the liver recipient has symptoms, rejection is on their minds constantly, especially in the early stages of recovery. One participant stated,

Nobody can tell you what [rejection] is like. They tell you it's like having the flu. Then nobody knows, not everybody's the same. For the first 3 months, I bet you, I walked around with a thermometer in my mouth.

This participant thought "every little thing" was associated with rejection, but she was also disgusted with herself because of her paranoia. Although this individual had never experienced a serious episode of rejection in the more than 1 year of having a transplant, she still wondered whether she would ever reject, saying, "it is always in the back of the mind". Because no one has ever told her that she will not experience rejection, she stated that the thought "is always right there". She managed to cope with this uncertainty by accepting it. "I just go with the flow. There is nothing that you can do about it". Participants recognized that even the causes of rejection can be hard to establish. One gentleman described the uncertainty associated with his latest episode of rejection,

I thought that it had been caused by being sick like having the flu or something like that. [The physician] said 'you just never know'. He is looking into a cloudy crystal ball himself so there could be any number of causes for this and we don't know.

One participant associated not knowing what would happen with feelings of confusion; another with fear. The first stated "when you are feeling good, you get a call from the clinic saying 'Oh, you better go to the hospital' ". The other participant feared the blood transfusion during surgery would give her AIDS.

Another participant experienced a difficult period of not knowing what was happening to him when his physicians thought he was having an episode of rejection and performed a series of eight liver biopsies. Although the biopsy results mirrored rejection, the blood results did not support their diagnosis. Finally, he was told that his primary disease (leading to the liver transplant) might be returning. This was confirmed with a series of blood tests. Although the gentleman could not know how quickly his new liver would be damaged and to what extent, he felt relief when he finally knew a provisional diagnosis. He stated, "I am not so much affected by the sickness but I know it is coming back and I have to be ready to face it". Knowing, he added, would allow him to prepare for the future. He could do the things that he really wanted to do and not do things that were less important to him.

Summary

The category mastering recovery is made up of four elements which are based on common circumstances and experiences of the 6 participants interviewed for this study. For the most part, participants found the support and information sharing helpful in discovering commonalities and alleviating stress. As a result of information sharing, comparisons were made and used to gauge recovery. While comparisons had either a

negative or positive impact on recovery, all participants engaged in it to some extent revealing a natural tendency in all participants. Part of mastering recovery involved testing limits and knowing their limits. As limits changed during the early part of recovery, limits had to be retested. Dealing with the unknown was the element that all the participants shared. Participants each had their unique ways of coping with the many stressors associated with transplantation.

Transition

Each of the participants in this study experienced a transition from pre transplant to post transplant and from hospital to home that required them to not only experience physical changes but also psychological ones. These experiences comprise many aspects of dealing with change. One aspect of these transitions is not knowing what to expect. The uncertainty associated with this creates "the need for new knowledge and skill development" (Schumacker & Meleis, 1994, p. 122). Therefore, transitions associated with discharge, losing/regaining control, priority shift, body changes, antisocial/social behaviours, and normalcy produce unique learning needs for liver recipients.

Discharge

Hospital discharge is one of the first and most obvious transitions of convalescence. Going home and being at home evoke feelings that often surround any stressful time. The feelings experienced by participants included confusion, anxiety, abandonment, and happiness. One participant describes the confusion she felt when she was discharged from the hospital:

The brain is really not functioning clearly when you are leaving the hospital. You are confused because your mind is going 50,000 different ways ... you are thinking, "Am I going to be in trouble when I get home? Is the operation going to work?"

Although some participants looked forward to going home, some spoke of feelings of anxiety and abandonment associated with leaving the safe environment of the hospital. In the hospital, recipients were observed and monitored continuously. Help was just a call light away. At home, they feared needing help quickly and not getting it. Their anxiety was coupled with a sense of abandonment. Also, the participants were not quite sure of what it was going to be like when they got home. They wondered what would happen if they ran into a crisis situation and how they would react.

Once at home, feelings of confusion, anxiety, abandonment, and happiness continued. One participant, although very happy to be home, recalls being exhausted, in pain, and unable to sleep well. This participant found that it took a lot of effort to do the things she did prior to her illness, such as getting herself ready in the morning. Referring to the first month after hospital discharge, she said, "basically you're just struggling to sort of keep your head above water". Another participant described returning home as being "in limbo"; not knowing what to do and what not to do. It took the participant a few days to be reoriented and start doing things for herself. One participant had been feeling ill for a number of days. When he was finally notified that his cyclosporin level had been low, he understood why he had been feeling ill. This particular incident confirmed his fears that, once he left the hospital, things would go wrong.

Losing/Regaining Control

Losing/regaining control was for participants one of the most important transitional experiences. For them, regaining control, or failing to regain it, was measured by their feelings pertaining to work, their ability to make role changes as necessary, and the stability of their mental processes.

Feelings pertaining to work. It was evident to some participants that they were losing or regaining control in their lives based on their feelings pertaining to work. One participant felt ready to go to work but also nervous about whether her abilities had changed as a result of transplantation. Another participant wanted to work; however, she was leery about having symptoms of rejection and having to take time off work to recuperate. Returning to work for one participant was a way of not identifying himself as an invalid. "I don't want to be a handicapped person. I want to be a normal person with a manageable condition and, not only that, but a growing person too, not just sort of a postponed death". As with others, this man's return to work represented recovery from transplantation.

For those unable to return to work, the transition to home was difficult. One individual felt very lonely and lost when she was no longer able to work. After the transplant she missed going to work and envied her husband when he left for work. Another participant offered, "I miss work. I miss the power. The power is like morphine. You take a little and you want more". Stopping work meant a loss of control in their situations. They perceived a return to work as a measure of regained health and control. Only 1 informant, who had not worked due to a previous illness, stated that he did not miss work. Nor did he express any desire to return to work after the transplant.

Role changes. The difficulty of changing roles from being independent to being dependent on a significant other was discussed by most participants in this study. This transition was associated with losing and regaining control of their lives. One participant, who was staying with a family member post transplant, left after having been there only 1 week. The reason she gave was that "too much was being done" for her, and she felt as though she was being "pampered". This participant felt frustration when she wanted

to do something and could not because of lack of physical strength or lack of endurance. She felt that she was relying on someone else to do things for her. For another participant, not being able to drive a car was a great source of frustration. To assert his independence, rather than always relying on his wife to drive him everywhere, he took the bus whenever he could. Another participant viewed the change of roles in regard to dependence between himself and his wife negatively:

There is another big thing for me ... to have been the boss. I was the boss, now I am nothing, I feel worthless. I was the one providing...[now] she is ready to go back to work as a necessity, but I am not anymore the provider. I am in another role.

The same participant commented that he understood why many marriages experience strain after transplantation. He felt that it was related to, in part, the family roles that sometimes change. He described when he was ill he and his wife would go boating, and she would steer the boat. Now that he is feeling better he stated, he wants "to steer the boat". His wife's hesitancy to let him do this leads to conflict. He described the role change for him as tougher than the physical discomfort of "steering". Another participant found that, as she began to feel better, she was able to be less dependent on her spouse. He then began to "feel useless" because she was doing more things for herself.

Mental processes. All of the participants experienced to varying degrees an improvement in mental processes from pre transplant to post transplant. Not surprisingly, they felt this was a positive transition resulting from the surgery. Before transplantation, most participants suffered from a degree of encephalopathy. One participant stated that her spouse recalls her saying "funny things that did not make much sense". Another participant stated that he did not realize his mental processes were changing pre transplant. He said his decline was such a gradual change that he

only began to notice it when, in conversations, he would forget words. Later, this deterioration progressed to where he did not know what he was talking about or even where he was. After transplantation, at the time of the interview, he still had to search for certain words; however, he stated that his mental processes had "cleared up some".

One participant stated that the change in her mental processes was very apparent after transplantation. She said, "I was living in a daze but I didn't realize it until I came out of it...it seems like somebody took a cloud off your mind, like all of a sudden the sun came through". Only 1 participant mentioned that his decision making abilities had not returned to what they were prior to his illness. This upset him, but then he acknowledged to himself that he was not the same person he was before the illness began. The loss was great for him because, prior to the transplantation, his occupation had required him to make complete decisions. Now his decision making capabilities had deteriorated and he wondered if they would ever improve.

Priority Shift

Participants' priorities changed as a result of the experience of transplantation. While being forced to shift priorities is often difficult, many found the result of this shift something they could accommodate. For some, this was even a welcome change. One participant stated, that as a result of transplantation, her priorities had shifted towards taking better care of herself and respecting her body more. She also mentioned that she thought about her health at least once a day; whereas, prior to transplantation she had taken her health for granted. Another participant was more appreciative than she had been of the things around her and she felt that her patience increased. One participant mentioned that she could not be bothered getting mad or upset anymore; she no longer saw any point to it. She described an incident pertaining to her pension and stated that,

prior to transplantation, she would have "worked" herself up and become extremely upset. Now, she does not let things such as this bother her. One participant said the transplant experience increased his awareness of how he reacts in certain situations. This awareness allows him to feel more courageous about some aspects in his life but more frightened about others. Another participant stated transplantation:

pushed me to understand that some things that I was doing before was wrong, that what the basic value of life is different from my value. I tried to change a little bit even more now and I think that, because I am getting a little bit better, I have a tendency to go back to my old way of thinking which is to do everything faster, do everything yesterday and when you do that you put a big burden on your shoulders and you impair your possibility of being happy.

Body Changes

All of the participants noticed changes in their bodies from pre transplant to post transplant; changes that were sometimes disturbing but most often welcome. Pre transplant, the participants suffered from muscle wasting, ascites, jaundice, lethargy, weakness, and muscle cramps. One person recalled:

before the operation I had gotten used to the fact that my body shape had become distorted through wasting muscles and ascites and, to a certain extent, edema and the discomforts associated with that. I had gone through this transformation and was significantly reduced physically [prior to transplantation].

Although physical improvements varied between participants, increased energy and endurance occurred for 4 of the 6 participants post transplant. One of 4 stated she felt much better post transplant but she had become restless because of her increased energy,

I am much more restless of course when you watch television for a whole year, but I can hardly sit and watch television anymore. I'm up and down, up and down, and I can't seem to settle down and even enjoy a show, shows that I used to enjoy.

Although the changes she experienced were mostly positive, she did experience some negative changes. For example, her eye sight was deteriorating and she had less

strength in her hands and fingers. One participant stated that she had less muscle tone after the operation; however, she was not following an exercise regime as some of the other participants were. Another participant mentioned that he now had a protruding stomach which he did not have prior to the transplantation. One participant did not feel as though the changes were for the better. He mentioned that the physician thought that he was in better shape following the transplant; however, the participant felt that he was not. In fact, he stated that he felt as though he was "dwindling away".

Some of the body changes post transplant are caused by the side effects of the medications. The side effects of the medications mentioned by the participants were "chubby cheeks", increased hair growth and decreased bone density.

Antisocial/Social Behaviours

The transition from antisocial to social behaviour was identified from pre to post transplant. Most participants went from not wanting to see friends shortly after the operation to becoming more sociable once they started to feel better; their sociability could then be equated with their recovery. One woman stated that, even prior to transplantation, she had become quite jaundiced and her health had declined significantly, decreasing her desire to socialize with any of her neighbours. She simply did not want to answer their questions.

A lot of it was that I didn't want to talk to people. I was hurting inside and I knew what I looked like and so I just avoided everybody. I wouldn't even go to the laundry, I quit going to bingo. I quit going to the do's. I just went into whatever you call this solitaire for about a year.

After her transplantation and quick recovery, she began to talk to her neighbours and go out more. Another woman, while in the hospital, shunned visitors other than immediate family. When a close friend would visit, she would later compare the visit to a marathon

because she had been so exhausted at the end of it. When she was discharged from the hospital, she still had her family screen her telephone calls and visitors. She said:

I found there were a lot of demands that because you have been sick and you are home and people sort of assume that you are better but you are only 1 day better than you were in the hospital and although it seems like a big progression to get out, and it is, physically, it is not.

Several of the participants claimed that receiving visitors while in the hospital or during early convalescence was very tiring. One gentleman felt that people were coming to visit because they had never seen someone with a liver transplant. He did not feel that the visits were genuine, rather that he was on display. This experience was so negative that, when he was discharged, he had his telephone number changed and unlisted. Another participant said he felt like "Patsy the Wonder Dog" when he had visitors. He felt obligated to entertain them and would end up expending the energy he felt could have been used for his recovery.

Normalcy

The transition to normalcy following liver transplant is a unique individual process which brings with it individual learning needs. Each participant seemed to have a notion of what normalcy meant to them. Participants could gauge how well their recovery was progressing and the transitions associated with it by comparing their status to what was perceived as "normal". One participant felt she had achieved what she called "normalcy" 2 weeks after being discharged from the hospital. One of the indicators of normalcy for her was that she worried more about having a myocardial infarction than about her liver. She commented that she found constantly reminding herself that she must avoid people who have colds or the flu difficult. Her suppressed immune system, a side effect of medications, was something she easily forgot. While normalcy was described differently

for every person, this woman defined normalcy as not thinking of herself as a person who has had a liver transplant.

Another participant, who had his transplant for a number of years, shared his insights on normalcy after transplant.

The people in my circle are all just about carrying some burden or another so normalcy doesn't seem to me to be a fixed position. And so I think it is just a comparative state and it depends on what you compare it to. If you have a very fixed idea of what that is, or a group of associates who are all very much the same, then you have a more limited idea of what that is. For me, I see enough of the world to see that normal is very different for everyone and that, within a fairly broad range, I can feel normal too. So, for me, it becomes a matter of whether or not I feel better or worse in relation to whatever sort of steady state I feel as though I have achieved intellectually. I know that I can't be normal except within a community of transplant recipients and even there I see a broad spectrum of relative health and well being ... It really depends on where your point of identification is. If you are strongly identified as a sick person and have difficulty even after you have been cured, let's say, relinquishing your identity as a sick person because it is an umbilical cord through the clinics, through the medications that continues to follow you where ever you go through life and just in some point you have to surrender to that. This is now another part of me and it depends on how and where you identify with it. If you identify with it strong, with being sick and tired, and of course it is different for everyone, some people have a lot more problems with being a normal person somewhat unencumbered by medical problems because that is a definition for a normal person.

Another participant expressed similar views on normalcy.

Normalcy for everyone like us is different. We have to cope with something that we are not ready to cope with. We will not be normal and if we compare to the other people. We will accept a standard of living which we are dependent on the hospital, dependent on drugs, dependent on the family, dependent on the caretaker, and you have to balance all the different help you get from others, all the different dependencies and try to live the best you can ... at this moment I feel sick. I feel nauseated. I feel shaky and I say, for this is normalcy for me. I have to accept it. But basically we are not what we used to be.

While claiming he was experiencing normalcy, he made it clear that his life was far from "normal". A third participant stated, "I feel like I have made the transition between being that person who has an illness that interferes with her life and a person that it doesn't".

Reflection

The category reflection refers to participants' descriptions of giving a lot of thought to certain issues which continued to have an impact on their lives, whether recently transplanted or transplanted years ago. Although not recognized as producing learning needs at the time, it was upon reflection that the learning needs associated with dreams and hallucinations, mortality, enrichment, donor and acceptance of the graft were recognized.

Dreams and Hallucinations

The reflection of dreams and hallucinations is not unique to liver transplantation. The dreams and hallucinations experienced in the hospital remained vivid to liver recipients even after discharge. Because these dreams and hallucinations were so vivid for the participants learning needs emerged as a result. Many described the dreams and hallucinations as scary enough that they still thought about them from time to time. One participant who hallucinated in the intensive care unit thought that a physician who came to see her was the devil. She recalled that she was trying to get away from him by pressing herself into the bed, but he kept coming closer and closer, and she could not get any farther away from him. She was so frightened she could not speak. She also recalled thinking the key ring around the nurse's arm was a snake. A dream which really bothered her was about seeing everyone dressed in white robes and standing in a big light house. It was all glass, and there was a "big, big, big, big, bright, bright, bright light. Everyone was walking; however, no one was talking. It was dead silent, and it was all hazy. I thought what is this? After death?"

Another participant recalled dreaming that the hospital was on fire. He also clearly remembered dreaming about whole societies of vegetable people related by

species. One hallucination included the smell of rubbing alcohol which made the participant think that the medical personnel were going to remove some toxic chemical by setting his arm on fire to remove the chemical. This hallucination made him quite anxious. He stated that he still thought about these dreams and hallucinations: "They're quite vivid and I bring them to mind periodically and look at them again and think about what might have been going on for me at the time". Another participant vaguely recalled one hallucination being about a nurse accusing her of hiding a bottle of liquor in her dress. She remembered becoming so upset that she began screaming for her husband who had to be called into the hospital to calm her down. The participant related "in my own mind I still believe that it happened. That's the silly part about it. I still believe it".

One participant had numerous hallucinations which remained vivid in his memory. He could still recall fine details about them.

I will say that I was seeing my body on the operating room table and I saw when they put the tube in my throat and they opened up and did the bypass. I saw when they cut it. I saw when the doctor was upset with something. I can't remember exactly what it was. I saw my surgery from the side. He opened up. He cut the portal vein. He clamped the stuff. I saw the bleeding. I saw everything I saw when he reperused the organ. It was okay.

When he was on the ward he recalled becoming paranoid and feeling used as a "guinea pig". Hallucinations and dreams seemed to be significant to the meaning of having a transplant. While many did recall the bad dreams and gave them a lot of thought, 1 participant recalls only that his dreams were colourful, but he adds "the bad things you don't remember anyways".

Mortality

In facing transplantation, all participants faced their own mortality. Unlike with kidney transplantation where failure leads to dialysis, failure of a liver transplantation

leads only to retransplantation or death. While reflecting on mortality pre operatively seemed for participants to be associated with fear and anxiety regarding the surgery itself, reflections post operatively were more abstract and finally even enriching. One participant stated that she thinks about mortality a lot more now than before she had before she was ill:

You actually live day to day. I do, cause you never know. You appreciate things better. You look at things different. That's why I say this isn't a dress rehearsal. This is it. You got to appreciate it. It wakens you up.

Whether this positive approach after transplantation is influenced by relief and/or clearer thinking that she experienced after surgery is unknown. Another participant stated that he would rather die than linger and added:

I do feel that the process of transplantation can, if you are open to it, be a blessing in that regard because it is a direct confrontation with your own personal death and not in a morbid way but in an existential way and so I think that is a good thing. We are all going to die sometime and that very fact is one of the things that makes being alive so great.

He could put this into the larger context of his reflections on mortality.

The reason that some traditions advocate contemplation on death is because their main emphasis is on living in the present moment and there is some thought that being aware of your own death helps you to appreciate the present moment....We are quite phobic about death. There is a lot of death denial, lots of sweeping under the carpet. There is a lot of fear, real fear, fear of hell. We have not been very good at creating healthy atmospheres in our society for death and so I think that it can be very difficult for people depending upon what their belief structures are to live with the knowledge that they may achieve a premature demise....I feel profoundly grateful that I didn't get you know ...

Such reflections allowed him to feel not ill but lucky:

I've had friends die of cancer, brain tumours and heart attacks and what not and I've got a second chance. You know, I got to go right to the very very edge of not making it and can be brought back by a medical miracle.

A participant who waited a year for her transplant had time to reflect on her mortality. She had accepted the fact that there are things that cannot be changed,

saying, "it's in God's hands now so if He wants me I'm as ready as I'll ever be, if He gives me another chance. I'll thank Him and be eternally grateful and do the best with my new life". One participant knew that the transplantation was not a cure for his primary disease. His main reason for having the surgery was so that he could be with his wife. He recalled, "I realized that it was too much for her, that she could not cope being alone". This participant stated he had come to terms with his sickness but chose to have the surgery so that she would not be alone.

Enrichment

Many participants felt that their lives had been enriched by transplantation, a change made evident in their appreciation of life. Learning needs may arise from a liver recipient's sense or lack of sense that transplantation is an enriching process. One participant stated:

When you watched your life dabble away with hepatitis or biliary sclerosis or something like that and you know your vitality is just maybe your youth is gone or your middle years, you just want to sleep all the time. It's really difficult to understand what that means and, for me, not being that way anymore is so wonderful but that's something for the positive side of the operation is important to understand too, not just the negative anxieties. I think its also the positive and the sense of rebirth.

Although transplantation caused this gentleman pain and discomfort, as well as a decrease in physical ability it also enriched his life in terms of inner growth. The second chance at life was not taken lightly by the participants.

I think it has been really good shocker. I still see the amount of slumber that I have in myself, the ways in which I limit myself. I don't really grasp life fully but I am more aware of how I don't grasp life fully.

One participant described thinking

of things that never mattered to you for a lot of years because you were too busy making a living and doing all the things you have to do in life and you just sort of forget where it all started from.

She did not want her second chance at life to go by without doing something special. One gentleman spent over 200 days in the hospital prior to transplantation and recalled he could not enjoy anything. Now he found he is doing things that he once loved, like fishing, and paying attention to the "little things"; e.g., looking at animals, insects, and noticing flowers. He added, "I didn't care at all. I had my job. Now, I start paying attention to [my wife]. It's worth it. I didn't want to go for surgery, but, now that I did it, I am happy". Only 1 participant who was still experiencing complications post transplant felt his life had not been enriched by the transplant. He commented "maybe, after things start working, it will".

Donor

Once home again, past the anxiety of waiting and undergoing surgery, participants sometimes found themselves reflecting on who the donor was and what his or her circumstances might have been. One woman stated that the psychological part associated with being a recipient of a donor liver was too overwhelming for her; she had to "put it aside for a while" so she could concentrate on the physical aspects of recovering. Another participant stated that, though she wished she could have had the transplant sooner, it was "[unfortunate] someone [had] to pass away, that's the sad part". Her strong desire to find the family of the donor stemmed from wanting to thank them but also wanting to find out what kind of a lifestyle the donor had "did he or she [take] care of the liver?" Another participant was sorry that the person he received the liver from had died prematurely, but he did not feel guilty. He was extremely grateful for "the whole chain of events" that brought the liver to him. He was thankful that the person had a donor card, that the family recognized the need for the organs, and that the physicians "had the guts" to ask for the organs. In contrast, another participant stated

she talks to her liver and asks her "guardian angel" that if the angel comes across the donor to please thank the donor "because she certainly gave me a new life". Having a donor's liver was for this participant "still right in my mind but gradually I'm hoping that it will become a fact of life as long as, deep down, you don't forget where it [the liver] came from". One participant was thankful that the person donated his/her liver but this participant did not want any details about the donor. He stated "it doesn't seem important; as long as it works, it's mine".

Acceptance of Graft

Accepting the idea of having another person's liver inside of you, keeping you alive, is an overwhelming concept with which the participants had to deal after the surgery. For the most part, the participants accepted the graft. Only 1 participant stated it was too overwhelming to deal with. Most accepted the notion of dependence on another's organ. One woman said she accepted the organ donation as "mine". Her possessive feeling communicates a sense of responsibility:

I take care of it because I don't want to damage it. That's why I would like to meet the people and let them know that it's been taken care of. At the same time, I don't go out and have a drink to damage it.

Another participant stated there was never a time when he did not feel the graft was his. He claimed "this liver is my liver. It's not somebody else's liver that's in there waiting for me to reject it". Another participant stated "I don't even think that it is someone else's. I don't even let it into my mind". She also mentioned that other liver recipients she knows do not ever talk about the graft as though it is not theirs. One participant who was experiencing complications from the transplant stated, "It's mine now. It's in there now. Even if it don't work, it's mine". In contrast, 1 participant had a difficult time accepting the graft:

My main problem was not accepting the graft. I think I felt quite guilty because I felt like I had to kill somebody to get the graft. I was not accepting the idea of a dead body and a live Soul. The body was dead and was kept alive only because they wanted to do the graft. It took a long time and a lot of talking, a lot of reasoning to accept this idea. I felt like I was guilty of murder and finally got accustomed to the idea. The graft is integrated in me but it's not mine. It is only a loan. It doesn't belong to me. It burdens me with a lot of responsibility. I would like to have a little sip of wine but I won't do it.

Evidently, while acceptance of the graft is most often reached, there are various ways in which an acceptance is reached. Some accept it immediately whereas others have to struggle with the notion.

The category reflection encompasses several elements which are derived from the common meanings shared by the participants. With any major life event, reflection will take place, however, the process of transplantation provides several aspects of which may be reflected upon. Participants try to make sense of their dreams and hallucinations during convalescence. Mortality as well as enrichment is reflected on in this process. Reflection about the donor and acceptance of the graft are indeed shared by all participants and an important part of convalescence. Perhaps because of the life and death nature immediately following transplantation, liver recipients do not recognize the elements discussed in the Reflection category as producing learning needs. It is only after time that they are able to reflect upon these important elements and realize that there are gaps in their knowledge which require various kinds of information.

Summary of the Chapter

This chapter, I have described not only the participants' crucial learning needs during the transplant experience but also the common circumstances, experiences, and meanings which emerge from the data regarding knowing what to expect during convalescence following liver transplantation. The learning needs of clients during

convalescence are common, yet highly individualized. This is evident from the categories and subcategories which emerged from the data. Although participant's common experiences gave rise to the categories of mastering recovery, transition, and reflection, the subcategories describe both common and unique experiences associated with transplantation.

In order for liver recipients to master recovery, several things had to occur. First, the sharing of information was a means of support and for many liver recipients listening to others' experiences, whether good or bad provided them with the reassurance that they were not alone in their experience. Support and information sharing for the most part was, where common experiences were shared and discovered among those who have undergone liver transplantation. While support and information sharing was taking place, comparisons were also being made. It is through making comparisons that individuals try to determine whether he/she is recovering faster or slower than others. While this may have a positive impact on the recovery of the person who is recovering faster and without complications, it could discourage the person who is recovering slower from transplantation.

Both testing for limits and knowing one's limits were for the participants in this study important elements in mastering recovery. A significant amount of time was spent testing for limits in the early part of convalescence following discharge in order to establish limits to work within. Since these limits were not always physical and not always personal, they could affect psychological aspects and other people as well. Establishing and recognizing limits was essential in mastering recovery. A common experience all liver recipients shared was dealing with uncertainty associated with transplantation. Not knowing what to expect after transplantation was difficult for all the

participants. Rejection was one such entity that remained in the forefront of all the participants thoughts whether they had recently received a liver transplant or they had been transplanted for a number of years. Mastering recovery was a multidimensional process involving not only physical but psychological and spiritual recuperation as well. It was also associated with complex learning needs.

Throughout the process of convalescence, liver recipients experience a number of transitions in which several learning needs can be identified. Perhaps the first and most significant transition is being discharged from hospital to home. This transition is associated with feelings of confusion, anxiety, abandonment and happiness. Losing and regaining control was another transition that was captured in such events as being able to return to work, the change of roles from being independent prior to the diagnosis of liver disease to becoming dependent on hospital staff, family and friends during and after the transplantation process and trying to regain independence throughout convalescence. Also, the losing and regaining control of mental processes was important for all the participants. The shift in priorities was also seen as a transition. For example, after transplantation liver recipients paid more attention to their health and adopted healthier behaviours. All participants mentioned the changes that took place in their bodies prior to and after transplantation. For the most part these changes were positive in that strength and endurance increased post transplant. The negative changes had to do with side effects of the medications. Several liver recipients experienced a transition from antisocial to social behaviour. This transition was in part due to the recipient not wanting to expend energy dealing with visitors and answering questions regarding the reasons for transplantation. Each participant made the transition to normalcy, at least what their perception of normalcy was. Liver recipients encounter

several transitions during the transplant process, therefore it is important to recognize learning needs associated with the transitions and intervene where possible.

All participants who experienced transplantation underwent reflection. The reflection on the meaning and experiences of dreams and hallucinations continued months and even years after transplantation. They remained vivid in the minds of most liver recipients and therefore must have had meaning for them. All participants had to face their own mortality and emerged from the transplant process with a sense of peace, although the process was difficult for some, others were able to ease into it. Most participants felt that the transplantation process had enriched their lives, by allowing them to see things in a different light and re-examine what was important to them. Reflection regarding the donor was a difficult task. Coming to terms with the fact that someone had to die in order for the liver recipient to live was overwhelming for some. After much reflection many of the participants accepted the graft inside of them and the circumstances which brought the gift of life to them. It is evident that reflection plays an important role in transplantation. There are several issues that liver recipients had to reflect upon. By recognizing these issues, inferences about learning needs can be made and appropriate nursing interventions proposed.

CHAPTER FIVE

Discussion

Two types of learning needs have been identified which may be associated with the acute and chronic aspects of liver transplantation. The first type is crucial learning needs encompassing four areas that participants stated were crucial for them to learn during convalescence. These four areas included medications, more specifically the side effects, the body's reaction to medications and immunosuppression, laboratory values, limits, and role changes. The two latter learning needs will be discussed in detail in the next section 'Knowing What to Expect'. The study participants' crucial learning needs reflected the acute nature of transplantation and constituted the information participants felt was most important to learn early in their convalescence as it had the most impact on their lives at that time. The second type of learning needs were associated with what to expect during convalescence following liver transplantation. Both types of learning needs will be discussed according to the three categories which emerged from the data: mastering recovery, transition, and reflection. Some of the subcategories reflected the chronic nature of transplantation in that the participants had to deal with various aspects associated with transplantation for the rest of their lives.

The findings of this research study were similar to the findings of relevant studies found in the literature. The issues, concerns and learning needs associated with various types of illnesses appear to be analogous. In this chapter, the research findings will be compared and contrasted with other study findings located in the literature, followed by a discussion of how each category relates to practice and future research imperatives. Medications and laboratory values will be discussed in the first section under 'Crucial Learning Needs', whereas limits and role changes will be discussed in the 'Knowing What to Expect' section.

Crucial Learning Needs

Liver recipients identified information pertaining to medications as one of their crucial learning needs. Many wanted to know specific details regarding potential side effects, as well as the ways the body reacts to medication and immunosuppression. Research concerning informational needs of clients who had myocardial infarctions (Chan, 1990; Gerard & Peterson, 1984; Karlik & Yarcheski, 1987; Wingate, 1990), clients who were undergoing haemodialysis (Goddard & Powers, 1982) and chemotherapy (Lauer, Murphy & Powers, 1982) suggest that information pertaining to medications constitutes a significant learning need for these clients as well. For example, in a research study by Dilorio and colleagues (1993), the researchers found the type of information clients required differed from the information nurses and physicians perceived clients needed to know. The reasons for the differences in clients' and nurses' perceptions regarding medication learning needs may be twofold. First, it has been found that nurses provide explanations regarding therapy in order for clients to understand why the treatment is necessary (Dilorio et al.). Clients, on the other hand, may not feel that this information is pertinent to them at that time as they are more interested in knowing practical information such as the side effects of the medications, and what to do if they have a problem taking the medication. The other reason for the discrepancy in the perceptions of learning needs may be that nurses teach what they are comfortable with and/or what their knowledge base is regarding the information being taught (Dodge, 1972); therefore, enough information or the right information about medications is not given to clients. Medication side effects may not be evident in the hospital but may become apparent only after prolonged use; therefore, the nurse working in the hospital may not have experience with specific long term side effects.

Information regarding long term effects is unlikely to be taught to clients by hospital nurses.

Differences in perception and lack of knowledge on the part of health care professionals may explain why liver recipients identified information pertaining to medications as one of their crucial learning needs during convalescence. Medication is the most influential element inhibiting the body from rejecting the transplanted organ. Learning about medications is significant to the liver recipient. For him or her, the feeling of having sufficient or pertinent information regarding medication will undoubtedly be stressful. For the participants in this study, anxiety resulted from not knowing whether the sensations that they were felt in their bodies was the result of rejection, medication side effects or aging. Some of this anxiety could have been alleviated if the necessary information had been provided. Because the medication used for immunosuppression has a number of side effects, providing liver recipients with information that pertains to medication is crucial in reducing their anxiety and fear.

Laboratory values were also identified by the liver recipients as a crucial learning need during convalescence. This is congruent with research involving information needs of caretakers after childrens' renal or liver transplants (Weichler, 1990; 1993). Although caretakers identified learning about laboratory values as important early on in the transplant experience, most often the liver recipient is too ill right after surgery to make sense of the laboratory results. It is not until they are feeling better and can attend to new information that this learning need is recognized as a crucial one.

Laboratory values are indeed an important aspect in the experience of transplantation as they will often be the first indicator to the physician that rejection is taking place. Also, the dosage of the immunosuppressive medication is ordered

depending on the levels in the blood. These levels are closely monitored to ensure that a therapeutic level is maintained. If these levels fluctuate, serious complications may occur. Since rejection is a persistent threat to an organ recipient (Craven, Bright & Dear, 1990), it is no wonder that learning about laboratory values and understanding them was identified as crucial. Knowing the significance of the laboratory values provides the liver recipient with some sense of control in what is often perceived as an uncertain convalescence.

Implications for Nursing Practice and Research

One implication for practice which emerged pertaining to the crucial learning needs of liver recipients' is that what the client perceives is important must be taught, not only what the health care professional perceives to be important. Both the literature and the study participants support this practice. Listed as crucial learning needs by liver recipients were medications and the associated side effects, the body's reactions to medications, immunosuppression, and laboratory values. Health care professionals should develop teaching programs which address these issues. Research will illuminate when the best time is to teach liver recipients, prior to discharge or after discharge and what the best teaching methods are for liver recipients who may have some cognitive impairment because of changes in their mental processes due to encephalopathy, medication side effects, rejection, infection, metabolic factors, or hemodynamic events.

Knowing What to Expect

The second type of learning needs identified from the analysis of the research data pertained to knowing what to expect during convalescence post transplant. These learning needs will be discussed according to the subcategories which compose the three main categories: mastering recovery, transition and reflection. The first category,

mastering recovery, encompassed learning needs associated with support and information sharing, comparing self with others, establishing limits and dealing with uncertainty.

Mastering Recovery

Support and Information Sharing

Support and information sharing was indicated by the participants as a valued resource by which they could obtain information associated about what to expect during convalescence. Researchers postulate that support and information sharing is a significant way in which uncertainty associated with illness is decreased (Cope, 1995; Hanisch, 1993; Mishel & Braden, 1988).

Participants in this study indicated that they often found out more information from other transplant recipients than from the nurses. People who have similar diagnoses may share similar experiences. Because of this, if they know others with similar problems, they are able to provide or obtain advice from these persons (Cope, 1995). Perhaps rather than wanting to understand the physiological basis of their symptoms (Mishel & Braden, 1988), the most likely information a health care professional would provide, clients are instead seeking "resources that would support their personal explanation for the stimuli" (Mishel & Braden, p. 103). This is facilitated through support and information sharing among people who share similar experiences.

Some participants found information sharing therapeutic as it prepared them for events that may happen during convalescence. There may be two reasons for this: first, insufficient information may cause an elevation in emotional distress. Acquiring information pertaining to an illness may assist the person to have a "sense of personal control" (Hanisch 1993, p. 83). Criddle (1993) found that if a person is given the wrong

information, or no information, about their illness and treatment they feel "less than able to actively participate in their healing" (p. 210), thereby decreasing their sense of personal control. For example, if liver recipients share information regarding their experiences in the treatment of rejection, then listeners who have not yet experienced it will be more prepared than someone who has not been told what the experience is like. The informed people may feel that they have more control because they are more aware of not only the treatment and all it entails, but also that people who have had episodes of rejection live to tell about it. Another explanation for the therapeutic nature of information sharing and its ability to prepare liver recipients for things that may happen is that it enhances "event familiarity" (Wortman as cited in Mishel & Braden, 1988 p. 99). When people with similar experiences share information, the person who has not yet had the experience is able to recognize the event when it happens. This may decrease the uncertainty associated with the event. For example, in the treatment of rejection, the medication used causes chills and fever. For many liver recipients, rejection is imminent; however, many are aware of the side effects of this medication and, therefore, go into the treatment knowing that they may experience chills and fever and that it is the medication which is the cause and not some complication of the transplant.

Some participants in this study, noted the greater the amount of information they received from other liver recipients especially about complications, the more uncertainty they felt. Johnson and Morse (1990) report that learning about complications can be very overwhelming for some people. When people share information describing possible complications, some found it very stressful. In fact, knowing about the complications made people "overly sensitive to unfamiliar sensations with their bodies" (p. 132).

The support group was another forum in which information was shared and support given. It was usually attended by liver recipients who were living in the community although hospitalized liver recipients also attended. Support and guidance in support groups has been shown to affect adaptive behaviour, physical health, mental well-being as well as successful social functioning, whereas a lack of social support may cause psychological impairment or even illness (White, Richer, & Fry, 1992). There was a distinct difference between the participants who attended the support group and those that did not; the most noticeable difference was that those who did not attend the support group experienced more uncertainty regarding various symptoms and possible complications associated with transplantation. This uncertainty may relate to the fact that by not attending the support group liver recipients were not receiving the type of information which could alleviate some of the uncertainty pertaining to transplantation. One possible explanation for the lack of attendance at a support group may be that participants wanted to limit the amount of information they were receiving (Cohen, 1993). Lazarus (as cited in Burckhardt, 1987) postulated that "preservation of uncertainty" as in the case of the liver recipient involves limiting the amount of information they receive. This "can facilitate hope, morale, and involvement with living and help the person tolerate or relieve pain and emotional distress" (p. 545). The liver recipients in the study did not acknowledge that they were "preserving uncertainty" by limiting the information they received however, they did indicate that some of the information that was shared in a support group, especially with regard to complications associated with transplantation, made them think that they would also experience the same complications. Thus, by not being aware of the complication, they may not have had to worry about it.

Many participants found the support group very beneficial, especially in terms of the information sharing that took place. Mishel (1988) reported that an important function of a support group was as a forum in which networks could be established between members in order to share experiences, thereby decreasing the uncertainty associated with the disease. Many participants wanted to be aware of the possible symptoms or complications associated with transplantation so that when it happened to them, they could be prepared and not worry about something that was not happening. Additionally, in a support group liver recipients are able to share and learn from personal experiences that cannot always be fully understood by family members and health care professionals (Cope, 1996). Participation in a support group provides members with mutual feelings of strength and empathy which may "produce an immense feeling of connectedness among participants" (Cope, p. 476). In addition to sharing information, these people also share common elements of an illness, thus enabling them to better understand what each other is encountering. The support group provides a forum in which experiences unique to liver recipients can be discussed and comparisons can be made.

Comparing Self with Others

Comparing self with others emerged from the data as a way for liver recipients to gauge their recovery. This was used as an indicator as to how well they were mastering their recovery. Research relating specifically to comparisons within a particular client population was not found; however, information was extrapolated regarding the comparisons made by clients from three research articles (Johnson & Morse, 1990; Mishel, 1988; Riether, Smith, Levison, Colsonis, & Epstein, 1992). Several functions related to comparing self with others were identified in the study. Many participants

made comparisons in order to predict how long their recovery should take and what they should be achieving within a certain time frame. Because there are so many factors which determine how well one recovers from transplantation and because each liver recipient's recovery is unique, the liver recipient who compares his or her recovery with someone else's may be setting him/herself up for failure. By placing expectations on oneself during convalescence, one can be disappointed and experience anxiety (Riether et al.). Yet a positive effect may result when a person compares him/herself to those who are not doing well. Johnson and Morse state in their study of people who have experienced myocardial infarctions that the person who is doing better than cohorts may have an increased sense of well-being. Mishel identified this as a method of "neutral[izing] threatening material" (p. 231). On the contrary, when participants who had faced numerous setbacks compared themselves with liver recipients who were doing well, they experienced jealousy.

Another function of comparing self to others, especially in terms of symptoms, is to know whether the experiences and symptoms a person is having are representative of others who have undergone the same procedure (Johnson & Morse, 1990). This is especially important in liver transplantation as there are so many symptoms associated with medication side effects. Being able to distinguish whether a symptom is the result of the medication taken or a complication that has arisen can decrease one's uncertainty (Molleman et al. as cited in Mishel, 1988).

Establishing Limits

Establishing limits, specifically testing and knowing limits, were indicated by the participants as substantial learning needs following liver transplantation. Research focused on testing and knowing limits was not found pertaining to liver transplantation

but was cited in studies relating to the illness recovery process (Criddle, 1993; Fleury, Kimbrell & Kruszewski, 1995; Johnson & Morse, 1990; Selder, 1989). All the liver recipients in this study felt a need to test their limits. Limits post transplantation must be discovered and the ways in which one functions within those limitations must be determined. In fact, "the options chosen will manifest one's personal value system" (Lambert & Lambert, 1987, p. 531). Testing limits or competency testing may be a way of reducing uncertainty and restoring one's integrity. Competency testing entails selecting a skill or behaviour that a person was able to do prior to an event such as transplantation and then undertaking the same skill or behaviour after the event. If the attempt is successful, the person will become more sure of him/herself and his/her skills (Selder). Testing limits is one way to gauge one's progress. By setting and accomplishing goals, one is able to gain a sense of their improvement (Johnson & Morse).

Liver recipients found it important to listen to their bodies when they were testing their limits. Other research has noted that people who had experienced myocardial infarctions found it necessary to "become sensitized to their body's needs and demands and [learn] to trust physical cues" (Johnson & Morse 1990, p. 133). By becoming more in tune with their bodies they can determine whether to stop or continue the activity in progress.

Different people use different methods for testing limits as is evident in the study results. Testing limits may involve "pushing" oneself "a little more each day" as described by 1 study participant. Johnson and Morse (1990) describe "the practice of cautiousness" (p. 132) in some of their study participants. By being cautious and avoiding overexertion, people with myocardial infarctions avoided harming themselves

unknowingly and thus were able to minimize their uncertainty. The level at which people practised cautiousness differed; some were cautious when they were doing something for the first time and others took it to the extreme whereby "they remained inhibited" (p. 132). Another researcher (Criddle, 1993) found that participants had a difficult time knowing if they were doing too much or too little in terms of activity to ensure they were having a positive impact on their healing process. Similarly, in this study, the participants were cautious at times about challenging their limits because they were uncertain and apprehensive about the outcome of doing so.

Testing limits was one way for a person to explore his/her strengths and challenge personal barriers. By testing limits, the person could progress past the event (such as transplantation) and identify new goals (Fleury et al., 1995). As indicated by Johnson and Morse (1990), testing for limits is a continuous process that takes place over the course of convalescence and is based on the person's condition. The participants concurred that a person will continue to test for limits up until the time he/she "regains a sense of mastery" (p. 133). However, Surman (1994) found that clients who were stoic "compensated for their illness by pushing themselves beyond their illness" (p. 298). If the client was not successful in achieving the goals that were set by him/herself, he or she may experience a "depressed mood" and a "diminished self worth" (p. 298). This was not the case with any participants in this study; yet some were frustrated when they set unrealistic goals based on what they saw others doing. Corbin and Strauss (1988) postulate that limit testing is one way of defining and redefining one's identity through refamiliarization of the body; when attempts fail, anger and depression often result. "One must let go, grieve, and achieve closure on lost aspects of the self before one can move on" (p. 80).

Once a person has established his/her limits, it becomes important to accept those limits he/she were not successful in changing. At times, expectations have to be modified in order to include the limitation into one's life. By testing one's limits, a feeling of wholeness and a sense of identity integration can be achieved "through continued validation of each successful performance-however altered, changed or flawed the actual performance" (Corbin & Strauss, 1988, p. 82). Limitations may be eliminated through the modification of expectations. Eventually, with the integration of the limitations into one's life, they may no longer be viewed as limitations but as part of one's abilities. Thus with an acceptance of limitations, one is able to spend more time and energy on other facets of life (Johnson & Morse, 1990). Only 1 of the liver recipients who participated in the study appeared to be at the stage of integrating the limits associated with transplantation. He had had his transplant longer than the other recipients in the study. This may account for the differences in the participants' experience in this regard. Increased duration of convalescence may provide more opportunity to test for limits and to integrate these into one's life.

The types of limits liver recipients identified were not all related to physical activity. The participants listed among the limitations experienced following transplantation as the need to go to the transplant clinic for blood work, taking medications, and travelling. Certain precautions, such as ensuring one's medication is kept cool and avoiding contact with possible sources of infection, may be difficult in some areas of the world. One participant mentioned that not being able to neglect or ignore his health was a limit transplantation had placed on him. Immunosuppression was also noted as a limitation placed on the participants' lives. Even travel by air plane where the air is constantly recycled, perhaps exposing a liver recipient to someone's

pathogens, is a consideration for liver recipients. The family of the recipient are also faced with limitations. For example, restrictions to where the liver recipient can go safely may also restrict his/her social life with a partner.

Dealing with Uncertainty

Research with respect to dealing with uncertainty associated with transplantation (Bohachick et al. cited in Frey, 1990; Hathaway, Strong & Ganza, 1990; Leyendecker et al., 1993; Surman, 1994; Sutton & Pelletier Murphy, 1989; & White et al., 1990), healing (Criddle, 1993) and other illnesses (Mishel 1988; Mishel & Braden, 1988) indicates that uncertainty is stressful. Hilton (1992) describes uncertainty as a:

cognitive state created when an event cannot be adequately defined or categorized due to lack of information. In order to organize information, a person must be able to recognize and classify it. This requires that the stimuli be specific, familiar, consistent, complete, limited in number, and clear in boundaries. They must also correspond to a familiar frame of reference, and be congruent with the person's expectation. Life threatening situations seldom have these characteristics. Symptoms can be ambiguous and or novel, information may be unclear, incomplete or not understood. There may be few elements in the situation that are familiar or recognizable. Uncertainty often continues after hospital discharge. (p. 70)

There is substantial amount of uncertainty which accompanies transplantation. Participants in this study identified areas of uncertainty as rejection, causes of aches and pains, and not knowing what is going to happen next. According to Mishel (1984), it is not the event that is stressful, but rather the "vagueness, lack of clarity, and lack of information about events" (p. 169). For example, when a transplant recipient experiences flu like symptoms, it can either be an indication of the flu or a potentially life threatening episode of rejection. The lack of clarity associated with this can be stressful for many liver recipients.

Uncertainty was present when study participants tried to distinguish the

significance of the aches and pains they experienced during convalescence. Due to the number of potential causes, the significance of these aches and pains was clouded by ambiguity, making it difficult to ascertain whether it is minor or major problem. Hilton (1992) notes, "the greater the ambiguity, the more inference that is required for making judgements about the significance of an event" (p. 70). The result of this uncertainty is often stress (Hilton; Mishel, 1984).

The uncertainty associated with not knowing what will happen next was identified as "living with sustained uncertainty" (Cohen, 1993, p. 84). In Cohen's study, parents of chronically ill children felt that just knowing the status of their child's health could change within a short period with sometimes no warning "robs [them] of any respite from the reality of threat" (p. 84). Those study participants who had their transplanted organ for less than a year experienced more uncertainty than those who had their transplants for more than a year. Upon reflection, the latter group stated that they faced similar uncertainties during early convalescence. A longer duration in convalescence may provide a recipient with the time necessary to organize and obtain information and decrease uncertainty.

A sense of feeling out of control may be the result of uncertainty (Thomas, 1993). Hilton (1992) found that "uncertainty limits the individual's sense of control over the danger and thus increases the sense of helplessness" (p. 70). This may increase stress which can have an effect on the individual's physiological, as well as psychological health (Criddle, 1993). Thomas identified several strategies (both positive and negative) used by liver recipients to regain a sense of control during convalescence, such as learning one's laboratory results, not taking daily vital signs, not paying attention to cuts, going into crowds, and taking medications at times other than those prescribed

by hospital staff. These coping methods reflect emotion-focused strategies (Folkman & Lazarus, as cited in White et al., 1992). The type of coping mechanism used is related to the levels of distress one is experiencing; therefore, the higher the distress associated with uncertainty, the more one uses emotive coping methods (Christman et al., 1988).

Cohen found that, in the beginning of an illness, parents followed their child's prescribed treatments rigidly; as their confidence in their abilities increased, testing of boundaries began. Two examples of boundary testing are increasing or decreasing the dose of medication and elimination of a treatment. If the changes in the treatments were uneventful, the parents in Cohen's study felt that their dependence on the health care professionals could be decreased. This feeling provided them with a "sense of mastery" (p. 92). Only one of the participants who had the transplant for more than a year stated that she took her medication at different times than prescribed and did not limit contact with sick children even though she knew the risks associated with that behaviour. Yet when she described her experiences during early convalescence, she stated that she followed the prescribed regimes closely. With an increased duration in convalescence, the level of uncertainty may decrease and one's sense of mastery may increase.

Research related to transplantation (Bohachick et al., 1989) reveals that uncertainty concerning the future is also a factor for organ recipients. Cohen (1993) postulates that when a number of uncertainties exist, thinking about the future or even making plans may cause an increase in anxiety. The future is dealt with by the "restructuring of time into shortened units" (p. 85) and by "living one day at a time". Many of the study participants embraced the "one day at a time" philosophy, especially those who had recently undergone transplantation. Being uncertain about what is going to happen next and a perceived lack of control associated with events or the future are

phenomena that liver recipients experience. In addition to this uncertainty, they must also deal with the stress generated by it.

As in other research (Mishel, 1988) it was found that lack of symptom pattern, illness experience and information also cause increased levels of uncertainty. If symptoms form a pattern, uncertainty and ambiguity pertaining to the illness can be decreased (Mishel & Braden, 1988) and "the meaning of the symptoms can be determined" (Mishel, p. 225). In order to form a symptom pattern, the following characteristics must be present: "number, frequency, location, intensity, and duration" (Mishel, p. 226; Mishel & Braden, p. 99). However, if the symptoms are inconsistent in their characteristics, and a pattern is not discernible, uncertainty is created (Mishel). Also, if the symptoms are not distinguishable as to whether they constitute a major or minor problem, uncertainty is generated. If the client is able to distinguish symptom patterns, some sense of control may be felt in that comparisons can be made and treatment can be monitored (Mishel & Braden). Illnesses in which symptom patterns vary produce a higher level of uncertainty than in those illnesses where symptom patterns are consistent (Mishel, 1981). This was illustrated in this research when the study participants expressed uncertainty about the symptoms they experienced as a result of the side effects associated with the medication they were taking.

It is known that some aspects of uncertainty associated with the lack of illness experience can be decreased through event familiarity (Mishel & Braden 1988). Mishel and Braden describe event familiarity as referring to "the degree to which a situation is habitual, repetitive or contains recognizable cues" (p. 99). In this study, the less time participants spent in convalescence, the more uncertainty they experienced. This trend may have occurred because everything they were experiencing was so new and there

was nothing habitual or repetitive in their situation. The participants who had a longer duration of convalescence were able to recognize cues which could then "be associated with events from memory and their meaning [could] be determined" (Mishel, 1988, p. 225). This study supports the notion of other researchers (eg. Mishel & Braden) that it takes time and experience in order to develop event familiarity.

Event congruence or the lack thereof can affect the amount of uncertainty one has. Mishel (1988) describes event congruence as "the consistency between what is expected and what is experienced in illness related events" (p. 227). The more event congruence one has, the less uncertainty one experiences (Mishel). The support group and the information sharing that took place among liver recipients and between the health care professionals provided clients with knowledge and event congruence. For example, liver recipients knew what to expect regarding the treatment of rejection because this was discussed often in the support group and there was consistency between what was expected and what was experienced; therefore, uncertainty regarding this was lessened.

Rejection is cited by several researchers as a major source of anxiety (Leyendecker et al., 1993; Surman, 1994) a major stressor (Frey, 1990; Sutton & Pelletier Murphy, 1989) and a threat (Bohachick et al. 1992; Heyink, Tymstra, Sloof, & Klompaker, 1990) to transplant recipients. The participants stated that the threat of rejection was at the forefront of their minds immediately after transplant but lessens over time. This finding concurred with those of Heyink and colleagues. Leyendecker and colleagues noted that insecurity and anxiety regarding complications lasted for approximately 1 year following transplantation. Only 2 of the study participants had been transplanted longer than 1 year. Both appeared to be not as anxious and insecure

regarding complications than those participants who had been transplanted for less than a year. Their decreased levels of anxiety and insecurity may be due to their increased duration in convalescence which has enabled them to become aware of symptom patterns, event familiarity, event congruency. Perhaps they have developed a sense of mastery during their extended convalescence. Another explanation as to why one's feelings of anxiety and insecurity lessen with an increased duration in convalescence may be as follows:

although the uncertainty that cannot be eliminated from one's life is likely to enhance the sense of disorganization and instability, uncertainty can move a person toward a new state of adaptation. When someone with a chronic illness achieves this new state, he or she has learned to accept uncertainty as a "natural rhythm of life" and begin to view it as an opportunity rather than a danger. (Mishel 1990, as cited in White & Lubkin, 1995 p. 61)

Acceptance of limitations and reduction of uncertainty through support, information sharing and comparing self with others may be the precursors to mastering recovery.

Implications for Nursing Practice and Research

The learning needs associated with the events that occur during the liver recipient's process of mastering recovery are substantial. Evidence from the data reveals "gaps between [the liver recipient's] level of competencies [following transplantation] and a higher level required for effective performance [during convalescence] as defined by the [liver recipient] ..." (Knowles, 1970, p. 85). These gaps are what constitute each liver recipient's learning needs. They are unique to the individual and can emerge at any time during convalescence.

Health care professionals need to be able to identify which individuals are benefitting from taking part in support group activities and which are not. Some study participants felt they did not benefit from attending the support group and, so, stopped

going. Yet these individuals said they experienced more uncertainty than did those who attended the support group. Because of this finding, health care professionals may have to provide extra support to those liver recipients who do not attend the support group to minimize their uncertainty.

The support group is a valuable resource for liver recipients who have just undergone transplantation and those who have had their transplant for a longer period of time. From this study, learning needs of liver recipients are associated with wanting to know what to expect during convalescence. In order to facilitate these learning needs during the support group, health care professionals should generate discussion among liver recipients regarding their experiences during convalescence; in doing so the recently transplanted individuals will learn from the experiences of other recipients. Also, by doing this in such a forum, any misconceptions or misinformation given may be clarified by health care professionals. An implication for research regarding support and information sharing is to identify the information liver recipients share among themselves so that health care professionals are aware of this information and can incorporate it into their teaching material. Research pertaining to support and information sharing has been conducted on various populations; however, research was not located involving liver recipients. Exploring liver recipients' experiences with support groups seems essential. Also, a comparison of learning needs between the liver recipients who attend the support group and those who do not could be investigated. A comparison could be made of the perceptions health care professionals have of liver recipients' information needs and of the perceptions of the liver recipients regarding their information needs. This study could be longitudinal and incorporate the assessment phase prior to the clients being accepted as a transplant candidate, pre operative, post operative, pre

discharge and post discharge. Another study could investigate whether providing liver recipients with information they perceive is important increases their sense of control and decreases their level of uncertainty.

Knowing that comparisons take place among liver recipients provides health care professionals with insight into the recipients' learning needs. For example, comparisons may lead to a liver recipient setting him/her self up for failure, by anticipating this, health care professionals can assist liver recipients to establish more realistic goals and expectations. From the data and the literature, it is evident that feelings of jealousy and diminished self worth can be the result of comparing self with others; health care professionals must recognize this and intervene as necessary. Liver recipients must be told everyone is unique and that several factors determine a liver recipient's experience post transplant. Implications for nursing research include studying what effect comparing self with others has on liver recipients more specifically, the effect of comparing self with someone who is doing better and someone who is doing not as well. In researching these comparisons health care professionals will understand the effects and functions of these comparisons and implement strategies in order to benefit liver recipients.

The process of testing limits is one way of decreasing uncertainty and gauging recovery. With this in mind, health care professionals may assist the recipient with testing his/her limits by providing the information and support needed. Also by assisting the recipient to set and achieve realistic goals, a sense of improvement will follow. It is important to recognize when recipients are over cautious or pushing themselves too hard as this may produce negative consequences. It should be stressed that testing for limits takes place throughout convalescence. The health care professional must be aware when the liver recipient establishes his/her limits so that the recipient can be

assisted with the acceptance of his/her limitations. Health care professionals must also be cognizant that liver recipients' limitations are not only related to physical activity but to lifestyle, such as to time because of multiple visits to the clinic, need for medication, their need to avoid contact with some individuals because of immunosuppression and their social limitations placed on the family. These limitations need to be discussed and addressed. Implications for nursing research stem from understanding the process of testing and establishing limits and from understanding the process of integrating and accepting the limitations transplantation places on recipients' lives.

The uncertainty of an event is related to the vagueness, lack of clarity, and lack of information associated with it (Mishel, 1984). Therefore, implications for nursing practice regarding uncertainty includes meeting the learning needs of liver recipients in order to increase their feelings of control and decrease their sense of helplessness. This may be accomplished through learning new effective ways of coping, identification of symptom patterns, event familiarity, event congruence, and providing the necessary information that the liver recipient perceives he/she is lacking.

Although many researchers acknowledge that uncertainty is present throughout the transplantation process, no studies to date have specifically examined this topic in detail pertaining to liver transplantation. Research could measure the amount of uncertainty at particular time intervals throughout transplantation. Also, rejection is noted as being a major source of uncertainty. Because of this, the experience of rejection both physiological and psychological aspects should be explored.

Transition

Discharge

For the study participants, the transition from the hospital to home was a much

anticipated event; once home, each experienced feelings of uncertainty, anxiety, abandonment and happiness. The uncertainty resulted from not knowing what to expect once discharged from the hospital. Selder (1989) postulates that "it is the absence of knowledge about the recovery process" (p .439) which is the main cause of uncertainty. Convalescence following transplantation is plagued with uncertainty pertaining to rejection, infection, limitations and the future, all of which evokes feelings of anxiety. Other researchers have found that anxiety increases prior to discharge (Surman et al., 1987; Weichler, 1993; Wong & Bramwell, 1992) and peaks at discharge from hospital (Christman et al., 1988; Jones et al., 1988). This finding is similar to what the study participants experienced.

Although the study participants were eager to be discharged from the hospital, many expressed apprehension and anxiety when the time drew near. The apprehension and anxiety stemmed from the sudden lack of being monitored by health care professionals 24 hours a day. This is similar to the finding of other researchers (Allender, Shisslak, Kaszniak, & Copeland, 1993; Heyink et al., 1990; Surman, 1994). In fact, Surman and his colleagues (1987) report that this separation anxiety was so severe that psychotherapy was required for some to address the participants' fears of separation. In one study, a heart recipient who had been readmitted into the hospital with vague somatic complaints three times within 10 days of hospital discharge was allowed to remain admitted to the hospital but was granted day passes to be at home, enabling the person to eventually cope with his separation anxiety (Allender et al.). Although the transition from hospital to home produced feelings of anxiety, none of the study participants were incapacitated by it. In fact, the longer the liver recipients spent at home during convalescence, the less anxiety they had regarding being out of the hospital.

Losing/Regaining Control

The transition between losing control and regaining control was expressed by study participants as it related to work. Allender and colleagues (1983) postulate that the greater sense of control one has, the less one will become frustrated and depressed; therefore, the transitions associated with losing and regaining control may have either a negative or positive impact the experience of convalescence.

Feelings pertaining to work. Many of the studies in the area of transplantation focus on quality of life following transplantation. Most researchers of this information use quantitative measures to establish their findings; therefore, the feelings of transplant recipients regarding work are not documented. What is documented is the employment status of these people. Bohachick and colleagues (1992) reported that of 44 participants, only 2 were working previous to their heart transplant. At 6 months post transplant, 10 returned to work; 19 remained unemployed; 8 had retired and 7 were homemakers. In another study (Jones et al., 1988), 9 of 14 heart recipients returned to jobs they held prior to transplantation within 12 months of the surgery. From these studies it appears as though some but definitely not all transplant recipients return to work following transplantation. Of the liver recipients in this study only 1 had returned to work full time and 1 was planning on returning to work in the near future. Prior to transplantation 4 study participants had full time employment, after transplantation 2 liver recipients retired. The other 2 recipients were not employed prior to transplantation or after transplantation.

Some factors which were found (Nicholas et al., 1994) to be significantly related to whether liver recipients would be employed post transplant include marital status, length of time liver disease was present, and the health or fragility of their

musculoskeletal system. Liver recipients who did not experience musculoskeletal problems were 7.81 times more likely to be employed. Married liver recipients were 3.18 times more often employed than those who were not. If liver disease was present for less than 2 years pre transplant, recipients were 3.22 times more likely to resume employment. The factors that were found not to have significance on employment following transplantation were age at time of transplant, employment before transplant, education and history of alcoholism (Nicholas et al., 1994)

Robinson and colleagues (1990) found that work performance was influenced by fractures and lack of concentration. While many participants revealed they could work after transplant as well as they could before, some stated they performed better prior to transplantation though not as well as prior to the onset of their disease. Others said their reluctance to return to work had more to do with their employers not providing health insurance for them than a change in abilities (Shapiro & Kornfeld, 1989; Trzepacz, Mauve, Coffman, & Van Thiel, 1986-87). This tendency is likely more prevalent in the United States, though some employers in Canada may be equally concerned with sick time in the case of transplantation caused by episodes of rejection or infection. However, these concerns were not expressed by the study participant who had been working for the last two years.

What is apparent from these studies is that employment after transplantation is highly dependent on the recipient's circumstances especially in terms of physical functioning. What is not known is how these people adjust to not regaining control associated with work, however, the role changes they experience because of this may provide some insight.

Role changes. All of the study participants experienced role changes following

transplantation and expressed the difficulties associated with them. Two articles were found pertaining specifically to role changes associated with transplantation (Heyink et al, 1990; Mishel & Murdaugh, 1987). An understanding of role theory allows researchers to highlight new findings in role transitions. Role theory suggests that the family is made up of interrelated individuals bonded by a communications network. Each family member has at least one role in which the behaviours of this role are based upon culture. In addition, "each role in the family is defined with reference to the roles portrayed by other members" (Gillies, 1988, p. 19). When an individual is not able to fulfil the tasks associated with the role, another family member adopts that role (Gillies) and role transition takes place. Meleis (1975) defines role transition as any:

change in role relationships, expectations or abilities. Role transitions require the person to incorporate new knowledge, alter his behaviour, and this change his definition of himself in his social context. (p. 265)

Many of the study participants recognized the change in their role relationships especially from independence to dependence on significant others. Many discussed the alterations in their behaviours as a result of these role transitions. Criddle (1993) acknowledges that the changes which take place during the "independence/dependence balance" (p. 210) in convalescence produces frustrating struggles. Some participants in this study felt frustration when other members of the family assumed the roles they held prior to transplantation. In their study, Johnson and Morse (1990) found that the women who were mothers and who had myocardial infarctions tried to maintain their mothering roles; when their children provided them with comfort, the women felt uncomfortable. Many informants in Johnson and Morse's study felt that their self-worth was associated with the tasks they performed as mothers, fathers, or providers. Similar feelings were

expressed by the study participants following liver transplantation. Study participants stated that as a result of being dependent upon a significant other, stress was placed on their relationship. One explanation for the added stress is that the significant other witnesses and must deal with the clients' depression, frustration, anger and denial. In addition, the significant other may become over-protective (Moser et al., 1993) and may assume a dominant role (Thompson, Ersser, & Webster, 1995). Another explanation for the stress placed on the relationship may be that when the family tries to protect the client from unpleasant information, the client becomes resentful and humiliated (Winshie, Hackett, & Cassem, 1971). Also, stress may be added to the relationship when the client feels ready to resume previously-held roles but the transition to past roles is met by resistance from family members. Heyink and colleagues (1990) found that when liver recipients were ready to resume the tasks and responsibilities held prior to transplantation, arguments in the family ensued. The reason given for the arguments was that the:

other family members had to get used to the new situation. When the closeness of the family had always been based partly on shared sad experience and when the stability of the family had depended on a habitual pattern of emotional reaction of each member to the patient's disease serious problems sometime arose. This often leads to irritation and arguments. (p. 1081)

Another explanation for the stress placed on a relationship may be provided by Mishel and Murdaugh (1987) who studied partners of heart transplant recipients and found that the partners were very reluctant to give up the roles they took on for their partners during the acute phase of their illness. During the convalescent period, the partners were faced with two images: one was of a future with their spouse and their children and the other was of a widow and her children. Because the future was uncertain, the partners felt they had to obtain some security; some sought employment,

others took over the finances and some refused to give up the roles that had assumed prior to transplantation. These were also ways in which the partners could avoid feelings of powerlessness. In an earlier study, wives who had acquired the role of breadwinner and decision-maker following their husbands' strokes did not want to relinquish these roles when their husbands' conditions improved (Malone as cited in Gillies, 1988).

Uncertainty regarding the future is always an element in the lives of both heart and liver transplant recipients. Because of this, once significant others who acquire new roles may be reluctant to give back them back when the recipient is ready to perform the role. Such a struggle was noted among the study participants; however, the exact cause of the struggle was not determined as the significant others were not interviewed. It was apparent, however, that role transition during convalescence has the potential to create confusion, anxiety, resentment, guilt, and frustration (Gillies, 1988).

Mental processes. Most participants mentioned that they experienced disturbing changes in their mental processes following transplantation. A number of studies have been found which discuss these changes (Bohachick et al, 1992; Craven 1991; Craven, Bright, & Dear, 1990; Freeman, Folk, Sokol, & Fahs, 1988; House, Troy, & Thompson, 1988; Moreno et al., 1993; Riether et al., 1992; Shapino & Kornfeld, 1989; Surman, 1994; Tarter et al., 1988; Trzepacz et al., 1986-87; Tymstra, Bucking, Roorda, Van Den Heuvel, & Gips, 1986). Encephalopathy prior to transplantation can be the result of hepatic insufficiency that varies in severity and is either acute or chronic (Moreno et al.). Surman (1994) in his study found an improvement in liver recipients' organic brain syndrome post operatively but he also found that these participants' cognitive functioning was not completely restored. Post operative encephalopathy and neurological complications are a result of "medication side effects, rejection, infection,

metabolic factors, hemodynamic events, or prior alcoholism" (p. 302). Delirium tends to be common post transplantation. It manifests itself through various clinical presentations (House et al.). "Clouding of consciousness" (p. 537) may present itself clinically as withdrawal; however, upon closer examination, one may find agitation with delusions, illusions, or hallucinations. (House et al.). This experience was common for most study participants and will be discussed in the Reflection category. Trzepacz and colleagues (1986-87) note that unless sensitive neuropsychiatric tests are administered to liver recipients, delirium may escape detection.

Many of the medications used following transplantation have a number of side effects which produce organic mental symptoms (Craven, 1991; Craven et al., 1990; House et al., 1988; Surman, 1994). Cyclosporin, an immunosuppressive drug given to transplant recipients, is responsible for a number of these side effects. Within 2 weeks of the initiation of this drug, mental state aberration may occur, lasting a few days to a few weeks (Craven). Acute side effects of this medication include transient confusional states, visual hallucinosis, and organic anxiety syndrome (Craven et al.). Memory deficits may also be present and may last for several weeks; however, when the transplant recipient's recovery is interrupted by complications, symptoms may persist longer (Craven). Neurotoxic complications associated with cyclosporin usually occur within the first weeks of treatment, although cases in which complications were delayed for several months have been reported (de Bruijn et al. as cited in Craven). Corticosteroids, another medication used by transplant recipients, also produce psychological side effects such as "sleep disturbances, irritability, labile mood, and perceptual abnormalities" (Surman, p. 302). Concentration and attention may also been impaired as a result of depression which may occur with corticosteroids (Surman).

Riether and colleagues (1992) compared psychiatric and neurocognitive outcome after heart and liver transplantation and reported several pertinent findings which may have an impact on the retention of information which may influence their convalescence. Both heart and liver candidates prior to transplantation had sequencing confusion and found it difficult to deal with two concepts at the same time. This led to the client's frustration. It improved 3 months post transplant. Liver transplant candidates had impaired abstraction ability, experienced difficulty in sorting and their test scores indicated that they had "global impairment in the retention of verbal information" (p. 449). Significant improvement was made during the 6 and 12 month follow-up tests; however, the liver recipients did show more impairment 12 months post transplant in some areas of testing (processing and retaining information) than did the heart recipients. Riether and colleagues conclude that "cognitive functioning increases approaching normative values by 1 year after transplant" (p. 448). This is in contrast to what Tarter and colleagues (1984) found in their study of liver recipients. They found that disturbances in cognition, emotional well being and functional behavioural competency were still present 3 years after liver transplantation. Only 1 participant in this study had the graft for 3 years and there was no apparent evidence of psychiatric or neurocognitive pathology; however, no testing was done to measure if these disturbances existed.

Priority Shift

Study participants described the various shifts in their priorities as a result of transplantation. A number of research studies were located that address shifting priorities following transplantation (Leyendecker et al., 1993; Tymstra et al., 1986), surgery (Criddle, 1993), cancer (Moch, 1989), and chronic illness (Corbin & Strauss,

1988; Fleury et al., 1995; Lindsey, 1996). One of the priority shifts mentioned by study participants was that they wanted to take better care of themselves. Criddle found that after surgery, her study participants had "a heightened sense of appreciation for their bodies" (p. 211); also, one of Criddle's participants felt that the experience following surgery "brings you into yourself" and one becomes "in tune with yourself" (p. 211). The study participants expressed the same sentiments; they felt more in tune with themselves physically, emotionally, and spiritually. Perhaps because of this, they were able to examine their priorities and redefine them. Fleury and colleagues found that it was during the process of healing that their participants redefined priorities which enabled them to develop a new sense of self and evaluate those things which were of value. One study participant did not state as many changes in priorities as the others had. His main priority at the time of the interview was to conserve energy. He was on the list for another transplant as the first one was proving to be unsuccessful; therefore, because he was not "healing", he was not able to redefine his priorities.

Following liver transplantation, participants in one study (Tymstra et al., 1986) stated that they appreciated life more and developed a heightened consciousness of the things around them. Also, participants found meaning and satisfaction in the things they did post transplant than they did prior to their illness. Another study (Kennedy, Tellegen, Kennedy, & Havernick, as cited in Moch, 1989) found that clients with advanced cancer who were in remission had "a greater appreciation of time, life, people, and interpersonal relationships" (p. 26). Fifty five percent of the people interviewed in another study (Smith, 1979) found that they became more aware of both the beauty in nature and their own appreciation for that beauty. Several study participants expressed the same attitudes towards these things in their lives; because of the transplant

experience, they viewed things in a different light. Because the alternative to liver transplantation is death, surviving a transplantation allows the future to be looked upon with a new perspective (Leyendecker et al., 1993)

Participants in this study stated that they had an increased awareness regarding how to react in a certain situation or being able to look back at life prior to the illness and analysing it in a new light. Lindsey (1996) found that people with chronic illnesses who had an increased self-awareness described themselves as being more "assertive, self-defining, and self-protective, with an ability to express their needs, desires and actions" (p. 469). Many of the study participants who had an increased awareness could be described in the same manner. It seems as though in this study that the longer the duration of convalescence, the greater the shift in priorities.

Body Changes

The duration of time in which changes in the body take place can affect one's body image. When the change is gradual, one has time to recognize and incorporate these changes into a new body image. Prior to transplantation, many of the study participants had slow and steady declines in their health resulting in weakness, fatigue and jaundice. During convalescence, most participants experienced a slow but steady increase in energy and endurance. Along with these positive aspects, study participants noticed some negative body changes which were not present prior to transplantation. These include a deterioration in eyesight, weakness in hands, arms, and fingers, decreased muscle tone, chubby cheeks, decreased bone density, and a protruding stomach. Weakness in hands, arms and fingers, as well as decreased muscle tone and bone density, can contribute to a loss of function which in turn impacts the ability of one's performance. Samuelsson and colleagues (1984) found that the side effects of

immunosuppression therapy such as loss of muscle strength, tender skin, increased tendency to bruise, and skin abrasions resulted in a restriction of activities for heart transplant recipients. Nicholas and colleagues (1994) found that 60.2% of liver recipients in their study reported weakness and loss of full function of an extremity. They also found that the recipients who suffered from weakness and the loss of function had a higher incidence of not resuming employment post transplant. Participation in activities is one factor which an individual bases their identity on; when this ability is lost, an individual's body image may be threatened (Baird as cited in Bramble, 1995). Also associated with a loss of function are "feelings of dependence and loss of control over the environment and one's self all of which can disrupt one's image of self" (Bramble, p. 290).

Body changes associated with transplantation also include changes in appearance such as "chubby cheeks" which are caused by prednisone. Heyink and colleagues (1990) report that participants in their study found this "difficult to accept". Hicks, Larson, and Ferran (1992) also noted that their study participants experienced some psychosocial problems which they attributed in part to their change in personal appearance. With a visible appearance change such as puffy cheeks, a revision of one's body image may be necessary. Bramble (1995) states it is "the meaning or impact of the change [that] determines necessity for such a revision "(p. 290). Even if the change is considered minor when compared to something as severe as a burn or some other disfigurement, it is the symbolic meaning to the individual which is important (Thompson as cited in Bramble). Learning needs may arise from the acceptance of these changes, if an individual cannot adjust to the changes in his or her body image, physical as well as psychological symptoms may ensue. These symptoms include vague subjective

complaints, pain and chronic fatigue (Bramble). Also, those that are not coping with their altered body image may have an increased risk of infection, may become noncompliant with their prescribed regime, may become socially isolated, and/or may become obsessed with or deny the changes which have taken place (Drench, 1994).

Antisocial/Social Behaviours

Study participants made the transition from antisocial to social behaviours during convalescence. Participants who had been convalescing for a longer period of time displayed more social behaviours than those with a shorter duration in convalescence. The antisocial behaviours study participants described were limiting the number of people they were in contact with, feeling as though they were on display, and not wanting to deal with people's questions. Literature pertaining to antisocial/social behaviours was extrapolated from research in the areas of social isolation (Biordi, 1995), stigma (Saylor, 1995), healing (Criddle, 1993) and transplantation (Bohachick et al., 1992; Packa, 1989; Tarter et al., 1984; Tymstra et al., 1986).

When compared to the normative population, transplant recipients had higher levels of social withdrawal (Tarter et al., 1984). Packa (1988) found that transplant recipient's social functioning prior to transplantation was greatly diminished as a result of limited physical functioning. Also, due to their emotional state, they only wanted to interact with this immediate family members. Tymstra and colleagues (1986) add that prior to transplantation, as the person becomes progressively sicker, contact with people other than their significant others is greatly decreased. The relationships that do endure become closer. It is evident from these studies that social withdrawal begins prior to transplantation and can be the result of decreased physical functioning. In this study, it is clear that this social isolation continues after transplantation. Study participants

indirectly identified several causes as to why they may isolate themselves from others during convalescence. These include increased levels of fatigue, prevention of infection, (Packa, 1988), stigma associated with transplantation (eg. cirrhosis of liver due to alcoholism), and not wanting to expend energy on entertaining visitors but rather using that energy to heal. Criddle (1993) suggests:

they push other people away for a time in order to heal in their own ways. They wanted to know and understand what to expect and were anxious to get started on whatever they were allowed to do. (p. 209)

The participants in Criddle's study felt that "healing was a private, personal experience" (p. 209). One of Criddle's participants distanced herself from people who spoke about their operations because she found listening to them too difficult. Later on, once she herself had healed, she listened to others stories and enjoyed them. This too was the case for one liver recipient in this study: he did not want to listen to other liver recipient's problems because he had enough of his own. He unfortunately had not "healed" and was on the list for another transplant.

A follow-up of heart recipients 6 months after their transplant revealed that they had increased their participation in leisure activities both family and social (Bohachick et al., 1992). Yet for the 2 study participants, who had their transplants slightly longer than 6 months, social isolation continued, perhaps because both of these had numerous setbacks during convalescence. One was on the list for another transplant and the other discovered that his primary disease resulting in transplantation had returned. Biordi (1995) postulates that social isolation "can develop as an individual loses hope of sustaining unrealistic aspirations for a normal or a supernormal self" (p. 179). Another study participant, 3 months post transplant, did not experience setbacks and was

resuming pre transplant activities. It appears that it is not the duration of time spent in convalescence that will dictate when the transition from antisocial to social behaviours takes place but rather the nature of the experiences (negative or positive) during convalescence that play an important role in the transition.

The stigma associated with transplantation may also be a cause of liver recipients' antisocial/social behaviours. Only 1 study participant remained socially isolated until she felt and looked as she had prior to transplantation because of her perception of the social stigma of transplantation. Perhaps other liver recipients who did not participate in this study did the same thing. Goffman (1963) described two types of stigma. The first is called a discredited condition whereby the cues are visibly apparent such as a limp or shortness of breath, or in the case of liver disease, jaundice and ascites. These clues can distinguish someone from the "norm". When these clues are noticed, the person may feel discredited. The second type of condition, known as discreditable, involves non visible cues. Examples include, having diabetes, or being HIV positive or, in the case of transplantation, possessing a donor liver. It is not so much the actual liver but rather the reason for the transplant which most people believe is a result of cirrhosis due to alcoholism. The person is not discredited provided that the condition remains hidden but, once it is discovered, stigmatization may occur. When a stigma is placed on a person, contact is usually avoided as their illness reminds the "normal" people of their vulnerability and mortality (Katz as cited in Saylor). At times, "negative value judgements about persons who are ill or disabled" (Saylor, p. 101) are made by "normal" people. Not only does the stigma placed on a person by others potentially affect social isolation but also one's personal meaning of the illness (Biordi, 1995). In fact, "the degree of isolation is not directly proportional to the extent of

disability" (Creed, Fitzpatrick et al., Maddox, Newman et al. as cited in Biordi, p. 177).

A source of potential stress for liver recipients that may influence the degree of antisocial/social behaviours may be disclosing to people that one has undergone liver transplantation. One study participant did not want to disclose that she had a transplant, and, to ensure she did not have to, she went into what she called "seclusion". In order to avoid or decrease stressful encounters with others, parents of children with chronic illnesses withhold, limit or disguise information pertaining to their children (Cohen, 1993). Packa (1989) postulates that perhaps the transplant recipients do not want to tell people, at least casual acquaintances, about their transplant as it may make others uncomfortable when they are around the recipient. Many study participants did not tell casual acquaintances of their transplants unless directly asked.

Normalcy

The study participants provided a brief glimpse of what normalcy was for them. The literature also provides glimpses into what normalcy is. Some researchers describe the achievement of normalcy in physical terms. For example, Tack and Gillis (1990) described the resumption of activities such as visiting friends, doing household tasks, resuming hobbies or returning to paid employment as activities people did which made them feel "back to normal" (p. 497). Other researchers (Thompson et al., 1995) found that their study participants felt getting back to normal included walking with confidence, driving a car, digging a garden, bowling or being able to do things they did prior to the illness. Keller (1991) described the process that her study participants who had undergone coronary artery bypass surgery portrayed in their achievement of normalcy. This process included surviving which was made up of four categories, fear of dying, fear of mistakes/lack of information and worthwhile suffering. The next stage was

restoring which included the categories of doing what is right and valuing/needing support. The final stage is being fixed, which included feeling lucky and being fixed. Johnson and Morse (1990) found that their study participants who "perceived themselves as having little support and few needs considered themselves' nearly normal" (p. 132); their process of adjustment lead to what the researchers termed a "sense of mastery" (p. 134). With a sense of mastery, tasks were done without worry, confidence in abilities returned, less supports were required, predictability was reestablished, "limits broaden out" (p. 134) and one "feels more comfortable with [oneself]"(p. 134).

Creating a new reality through the acknowledgement that one's previous reality has been altered or changed "supports engagement in the life transition" (Selder, 1989, p.449). In this study, it is apparent that this is one of the ways the transition into normalcy is made. The study participant who had been transplanted 3 years felt he had made the transition into normalcy: he felt in touch with the mainstream of his life, and although he was still conscious of the limitations imposed upon him by transplantation (a sore back and weak arm) he functioned well within those limits. This participant did not dwell on control as other study participants had, perhaps because he had lived for 3 years as an organ recipient and had many experiences associated with transplantation which resulted in a decreased level of uncertainty thereby decreasing his need for control. Corbin and Strauss (1988) catch the essence of this participant's normalcy in their comment "though some chronically ill people make the illness the main focus of their lives, others are able to eventually integrate the illness to varying degrees into the fabric of their being" (p. 151).

Implications for Nursing Practice and Research

Health care professionals need to be cognizant of and acknowledge the feelings liver recipients have associated with being discharged from the hospital. Addressing these feelings and implementing strategies which will help the recipient make a smooth transition from hospital to home are essential. Within the literature is agreement that the transition from hospital to home is stressful; yet, research does not explore ways to make this transition less stressful or to find what strategies work and why. Therefore, an implication for nursing research is to explore liver recipients feelings pertaining to discharge. Also, outcome measures on strategies implemented to make the transition from hospital to home less stressful, less confusing, and less uncertain should be explored.

An exploration of liver recipients' feelings pertaining to work as well as issues surrounding losing and regaining control in relation to whether he/she is able or chooses to return to work must be made. If one's identity and self worth prior to transplantation are based upon his/her occupation and if circumstances arise in which he/she is not able to return to work, then strategies must be implemented to assist the liver recipient through this time. Implications for research include the investigation of losing/regaining control in one's life following transplantation as it pertains to work.

Assessment of the various roles within the family unit and any changes that have taken place since the onset of illness should be carried out by nurses. Also prior to transplantation the liver candidate and his/her family should be prepared for the various role transitions that they may experience as a result of transplantation. Strategies should be implemented which would make these transitions less stressful. The needs of the caretaker must also be addressed and researched as he/she may assume many of the

liver recipient's previously held roles. The caretaker may become overwhelmed or may not want to relinquish the liver recipient's role once they have recovered. In either case, continuous assessment and intervention must take place. The difficulties produced as a result of role transitions should be researched.

Within the literature is consensus that changes in mental processes are associated with transplantation. What is not addressed are the effects these changes have on the liver recipient's retention of information. The main implication for nursing practice regarding the liver recipients' mental processes is to rethink the way in which information is presented to clients who may have mental clouding as a result of encephalopathy or of the various side effects of the medications. Assessments of the liver recipients' mental processes should be done prior to the initiation of teaching. Creative ways to teach these clients must be developed taking into consideration their state of cognition throughout the process of convalescence. Research should explore the effects these changes in mental processes have on the recipient and his/her family. Also nursing research should evaluate the strategies and methods of client education to ensure they are meeting the learning needs of those who experience changes in their cognitive abilities.

Needs associated with priority shifts may pertain to the liver recipient's desire to take better care of him/herself, the redefinition of his/her priorities and the increase in self awareness. Implications to nursing practice resulting of priority shifts for liver recipients include taking advantage his/her heightened sense of appreciation for life in order to promote an exercise regime that would counteract some of the weakness, decreased muscle tone, and decreased bone density associated with transplantation. Also the health care professional should acknowledge and discuss the recipients' shift in

priorities to increase his/herself awareness which may result in the recipient being more assertive, self-defining, self-protection and able to express his/her needs. Implications for nursing research include an exploration of the priority shifts associated with transplantation and the changes which occur during convalescence which may reveal differences in liver recipients' priority shifts.

Health care professionals need to explore with the liver recipient his/her perceptions of self image and his/her thoughts and feelings regarding the changes his/her body is or has gone through and plan strategies which will assist him/her in a positive way through these body transitions. Future nursing research could include exploring the liver recipient's perception of the psychological and psychosocial impact associated with body changes and what effect these changes have on their self image.

The transition from antisocial to social behaviors require that health care professionals be cognizant of antisocial behaviors and the reasons for them. Explore with the liver recipient his/her reasons for remaining socially isolated and implement strategies which assist liver recipients to deal with the possible underlying causes of social isolation. Research should be conducted in order to explore the transition of antisocial to social behaviors and the effects stigmatization has on this process.

Implications for nursing practice regarding normalcy include exploring with liver recipient their perception of normalcy and then assisting them with either achieving that goal or modifying their expectations. Health care professionals must be cognizant of the concept of normalcy so that they can assist liver recipients with the integration and adaptation of the various transitions associated with transplantation. Research should continue to explore the concept of normalcy, the process of the transition into it, and the standards by which liver recipients believe themselves normal or not.

Reflection

Dreams and Hallucinations

Many study participants described hallucinations that took place post operatively as very real and very frightening. Dreams and hallucinations are not unique to these liver recipients; in fact, recipients of other organ recipients such as lungs, (Craven 1991, Craven et al., 1990) and hearts (House et al., 1988) also experience dreams and hallucinations. Hallucinations are a side effect of immunosuppressive medications (Craven, Craven et al; Freeman et al., 1988). In fact, with the intravenous administration of cyclosporin, hallucinations often develop shortly after the initial dose (Craven). The kinds of visual hallucinations experienced have been described as involving "complex visual phenomenon" similar to "a movie or cartoon playing in front of [your] eyes" (Craven, p. 98). These were the types of hallucinations also described by the study participants. The hallucinations usually occur within the first 2 to 3 weeks following surgery. All of the study participants' hallucinations occurred while they were in the hospital and left some pondering the significance of them which left them with unanswered questions.

Study participants also described various dreams they had; some described out of body experiences of floating in the air either watching the operation or being surrounded by bright lights. Surman and colleagues (1987) found that their study participants experienced dreams pre operatively which reflected their anxiety about the decision to undergo transplantation. While Allender and colleagues (1983) postulate that the process of acceptance of an organ is not a conscious decision, they state that this acceptance is disclosed through dreams. One heart recipient in the Allender and colleagues' study had the same dream over and over following transplantation: he saw

"a decaying person in a coffin, a woman, a child, and a mysterious person to whom he felt indebted" (p. 230). By discussing his feeling of indebtedness to the donor and by consciously acknowledging that he was not indebted to the donor, the heart recipient's dream did not reoccur (Allender et al.). The dreams of the study participants portrayed the recipients as alone yet among people; in the dreams they tried to communicate with others but no one paid attention to them. One might interpret the dreams as evidence of a sense of isolation or lack of control associated with the transplantation, however, this would require further validation with the participants.

Mortality and Enrichment

This study's findings demonstrate that only after surviving transplantation is one able to reflect on one's mortality and the ways in which one's life has been enriched. Surviving a life threatening illness has been described as "a profound experience because it forces one to contemplate the possibility of [one's] own death" (Johnson & Morse, 1990, p. 129). The study participants who underwent liver transplantation were faced with death but were given a second chance at life: "regardless of the ultimate outcome [transplantation] carries the implication that life has been extended beyond the normal or 'allotted' time and that the person has in fact been granted new life" (Castelnuovo-Tedesco, 1973, p. 359). Liver recipients in other studies also share in this sense of rebirth (Leyendecker et al., 1993).

Faced with death, life becomes more precious. This idea was expressed by the study participants in a variety of ways, including extreme gratefulness or thankfulness for a second chance at life. Researchers have concluded that surviving a life threatening illness gives people a new appreciation for life (Johnson & Morse, 1990) with which they can develop a new purpose (Criddle, 1993) and "re-evaluate what is important in life"

(Mishel, 1990, p .260). All of the study participants expressed gratitude and appreciation for their new life.

Donor

Several study participants expressed curiosity, sadness and gratitude toward the organ donor, while others found the donor difficult to talk about. Two participants who did not share in any curiosity about their donors during the interview were both experiencing complications related to transplantation; they were focusing on becoming well rather than on the circumstances associated with the organ donor. Although study participants expressed sadness that someone had to die in order for them to live, only 1 expressed guilt and stated he actually felt like a murderer. Researchers (Craven, et al., 1990; Heyink et al., 1990; Surman, 1994) have found that many transplant candidates and recipients experience such feelings of guilt. Transplant candidates can feel guilty as they anticipate the death of a suitable donor (Surman) while others fantasize about the occurrence of an accidental death that would provide an organ for their transplant (Craven et al.). Some deal with this situation through the use morbid humour while others deal with it through simply suppressing the idea (Craven et al.). The term "survivor's guilt" (Heyink et al., p. 1019), referring to the transplant recipient living on while another organ recipient from the same donor does not survive, reveals the sources of guilt are as varied as the ways in which recipients deal with the guilt.

Half of the study participants were curious as to whether the organ they had received was from a male or female donor. These recipients made sure they found out the sex of the donor. Other than curiosity, none of the liver recipients expressed consternation about whether their organ was from a male or female donor. This finding is similar to that of Commander and colleagues (1992). Only 18% of their sample

thought about the sex of the donor and, of these, none expressed real concerns. Some studies have shown, however, that the sex of the donor has had an impact on the recipients' acceptance of the organ.

Many organ recipients feel indebted to their donors and the donors' families and often want to meet with the donor's family (Commander et al., 1992; House et al., 1988; Leyendecker et al., 1993). The study participants wanted to meet the donor's family so that they could thank them and let them know that they were going to take care of the donated organ. One study participant wanted to ask the family whether the donor had taken care of the organ.

Acceptance of Graft

The majority of the study participants appeared to accept their transplanted liver without difficulty. Only 1 study participant spoke of his anguish during the process of accepting the donated organ. Another felt it all quite overwhelming to think about; she had to concentrate on getting better physically before she could start dealing with the idea of having received the liver of another. Basch (1973) in his work with kidney recipients found that the attitudes recipients have toward the transplanted organ influences the new body image they must integrate and accept. Also, the way in which the recipient sees him/herself in terms of "being dependent or as 'a vulture' having damaged, robbed or otherwise harmed the donor" (p. 378) can influence the acceptance of the transplanted organ.

Several examples are given in the literature of those organ recipients who have problems with the integration of their new organ. One liver recipient in a study felt as though he had been "pieced together" (p. 1091); he did not feel human. His reaction is understood as the Frankenstein syndrome (Dubovsky, Metzner, & Warner, 1979). Some

researchers (Heyink et al., 1990) found their participants viewed the transplanted organ as "strange or an enemy" (p. 1018). Researchers have also found instances where men who have received organs from female donors feel as though they have a woman inside of them and that they are "becoming feminized" (Castelnuovo-Tedesco, 1973, p. 358). Researchers have reported that some recipients felt as though once they had the transplant they began assuming the traits of the donor, among them criminality, special virtues and artistic talent (Castelnuovo-Tedesco). Dubovsky and colleagues present a case study in which a man who received a woman's liver felt as though he was becoming a woman; he began to wear an earring. This same recipient had a difficult time with the acceptance of the organ and referred to it as an "alien piece of meat" (p. 1090.). Later, he "began to feel that he was married to it" (p. 1090.) The integration of the organ into one's body image may occur over time; however, the process may be "accompanied by difficulties or distortions before a transformed body image can be reconciled" (Basch, 1973, p. 381). Basch provides an explanation for these difficulties or distortions:

prior to transplantation the recipient has individual expectations of himself and his body with regard to his own development and maturity, and this preconceived notions of the type of body alteration which will transpire. These expectations are radically altered by the transplant situation. As in other major surgery there is a jolting disruption of the existing body image which demands sudden adjustment. The new object brought into the body image, superimposed upon the vicissitudes of the interjection and identification mechanisms provides fertile ground for disequilibrium and disruption. This may result not only in a lag in the patient's adaptation but in denial which, in turn, is difficult to maintain because of all the medical reminders of his condition. His expectation that the medicine will help is impaired by the disfigurement of steroidism. His expectation that surgery will be quick or magical complete cure is betrayed by the post transplant complications. In his quest to shed his helplessness and gain autonomy, he paradoxically finds himself more dependent and helpless. (p. 381)

The inability to integrate the transplanted organ into one's body image may have a

profound effect on one's convalescence. With a negative body image, one has a decreased sense of control and may remain in dependent roles. Any transition into normalcy may be difficult to accomplish. Not only does one need to achieve a positive body image which incorporates the transplanted organ but one must achieve a new self image or identity all of which can be complex (Basch). House and colleagues (1988) speculate that "psychosocial factors sometimes trigger rejection of the transplanted organ" (p. 538) and "emotions and fantasies [sometimes] affect the physiologic acceptance or rejection of a transplanted organ" (p. 538). The liver recipients in this study did not express any of the above concerns. It cannot be stated with certainty that none of the participants had any concerns or that these concerns would not develop however, at the time of the interview they were not disclosed. Also, perhaps the liver recipients who do have these concerns did not want to participate in this study.

Implications for Nursing Practice and Research

The practice of nursing needs to acknowledge and explore the liver recipients' dreams and hallucinations in order to address learning needs associated with them. Research can help us to further explore their dreams and hallucinations and as well to discover how convalescence is affected by them.

Mortality and enrichment need to be assessed by health care professionals to explore liver recipients' feelings and perceptions and to assist them through the process of defining how transplantation has affected their lives, whether positive or negative. Research on the subject will increase the knowledge and understanding of health care professionals regarding how these concepts relate to transplantation and interventions that affect recovery during convalescence.

Health care professionals must assess whether or not a liver recipient has

accepted his/her graft and what part of that process he/she is in. Research should explore the liver recipient's experience of graft acceptance and the factors associated with acceptance.

Summary of Learning Needs

Support and information sharing -- one way liver recipients obtain the information they require during convalescence -- is unique in that information shared is lived experience. While some find information that is not immediately needed overwhelming, which may contribute only to further uncertainty, others gain a sense of control from the knowledge that liver recipients share. While most recipients want to share and hear about rejection and its treatment, medication side effects and lifestyle changes, sharing this information provides a gauge in the measurement of their recovery (however positive or negative), minimizes uncertainty and re-establishes hope. Nursing practice must meet the needs of liver recipients related to uncertainty, and increasing their feelings of control. Recipients can learn new effective ways of coping, identify symptom patterns become familiar with events associated with transplantation, and find the necessary information as patterns change.

Making the transition between hospital and home -- clearly a time of confusion, anxiety, even abandonment -- can be made easier only through changes in nursing practice toward assessing learning needs of each individual well before discharge. Later, as each becomes "sensitized to one's body" and trusts "physical cues" (Johnson & Morse, 1990, p. 133), the process of establishing and integrating limits reveals specific learning needs for liver recipients. Many have to modify expectations and while shifting toward recovery, accept their limitations. Many even use their heightened awareness of how to care for themselves to live and enjoy loved ones better. But

because many experience a loss of control or a negative shift in abilities related to work or daily living, changes in lifestyle often affect family members, friends and significant others. Since a liver recipient's new dependence may lead to frustration and a diminished sense of self worth, nursing practice needs to anticipate the reactions to changes in lifestyle that may or may not be temporary.

Changes of mental processes -- often the most challenging of the effects of transplantation and resulting of visual hallucinations, confused states, and organic anxiety syndrome all, side effects of medications -- greatly diminish one's ability to learn. Still, recipients require continual input from health care professionals, even if they may not be able to retain it. Professionals must understand that while liver recipients on medications like corticosteroids will be experiencing irritable moods and perceptual abnormalities that decrease their abilities to concentrate, they must guide recipients through decisions that they want to make and concepts they want to understand.

Achieving normalcy, different for everyone, generates individual learning needs that require listening and understanding. Since attaining the same function they had prior to the onset of their illness is questionable, learning needs will centre around the integration of physiological, psychological social and spiritual transitions that are a result of transplantation. When real changes occur, like deterioration of eye sight, muscle weakness, chubby cheeks, and decreased bone density, nurses must thoroughly assess each liver recipient's perception of his/her body changes and find how these changes relate to body image. Some may require special devices, such as large print books or a telephone with modified numbers. If changes contribute to antisocial behaviour, with fear of infection, of stigmatization, or of having to talk about transplantation, then nurses can address these learning needs.

Those who suffer setbacks and face disappointment that the transplantation has not restored their lives as they expected it would likely face the threat and the fear of mortality. Those who tell of recurring dreams or who recall hallucinations and dreams from the time of hospitalization vividly may be experiencing continued anxiety regarding accepting the transplantation. And those experiencing sadness, curiosity, and/or gratitude, knowing someone had to die for them to live, may be experiencing a measure of guilt. Most make decisions and changes in their lives they are happy with and would not change again. Health care professionals who are aware of the possibilities for learning needs of liver recipients will be able to anticipate problems and guide them toward the best recovery possible.

Summary and Conclusions of the Study

The learning needs of 6 clients during convalescence who had undergone liver transplantation was the focus of this qualitative study. Grounded theory was chosen as the research design which enabled identification of learning needs through common circumstances, experiences, meanings, and behaviours of liver transplant recipients during convalescence, thereby ensuring that the theory has meaning to those from whom it was derived (Hutchinson, 1993). Through the process of simultaneously collecting, coding and analysing the data three main categories emerged: mastering recovery, transition, and reflection. Within these main categories several subcategories are identified providing density, sensitivity and integration thus generating a theory which is a close approximation of the reality it is meant to represent (Strauss & Corbin, 1990). Also by interpreting the data within the context of symbolic interactionism, the perceptions of the liver recipients' learning needs are captured rather than the perceptions of health care professionals', traditionally the focus. This study not only contributes to our understanding of learning needs during convalescence but also provides insight into the

experience of transplantation from the liver recipients' perspective.

The findings of this study are that liver recipients present health care professionals with unique challenges in terms of client education. The acute and chronic nature of transplantation presents clients with unique learning needs. For example, the learning needs associated with the acute nature of transplantation may stem from the surgical procedure in terms of activity limitations. Learning needs pertaining to the chronic aspect may result from uncertainty associated with transplantation. It is evident from the results of this study that the lack of knowledge pertaining to liver recipients' experience of convalescence has impeded health care professionals' ability to provide pertinent information and effective teaching to these liver recipients. Some participants in this study stated they learned more from fellow liver recipients than from health care professionals. Upon analysis, this makes sense as those liver recipients who were providing the information had experienced convalescence and therefore had insight into what might be important information to share.

Two types of learning needs were identified by the liver recipients: these are crucial learning needs and knowing what to expect post transplant. Crucial learning needs entailed learning about medications, side effects, how the body reacts to the medications, laboratory values, limitations, and role changes. These areas were deemed crucial by liver transplant recipients, perhaps because they are related to the uncertainty and loss of control associated with them. There were relatively few crucial learning needs identified by liver transplant recipients the learning needs that did emerge were associated with knowing what to expect during convalescence. This need to know what to expect may be attributed to the myriad of uncertainty associated with transplantation. By knowing what to expect during convalescence liver recipients are attempting to decrease the uncertainty and increase their sense of control.

Issues related to client education have been identified as a result of this study.

One major issue which may hamper the liver recipient's ability to learn is his/her physiological and psychological well being at the time of teaching. Physiologic elements which affect one's ability to process information include "medication side effects, rejection, infection, metabolic factors, hemodynamic events or prior alcoholism" (Surman, 1994, p. 302). A psychological element which may also influence information processing includes increased anxiety, which is often most severe at the time of discharge and is a result of uncertainty associated with transplantation. Perhaps because of these elements, the study participants identified crucial learning needs; the only information they were able to process at any time was information related to these needs. Therefore discharge teaching should focus on information which has been identified as crucial to know as well as individual concerns. Other learning needs pertaining to knowing what to expect can be assessed and addressed during clinic visits. Because liver recipients must attend the clinic, these visits can provide an excellent opportunity to address their learning needs throughout convalescence. The theory generated by this study enables health care professionals to assess liver recipients' learning needs by providing insight into convalescence following transplantation. For example, in the category of reflection, acceptance of the graft is one aspect of transplantation that liver recipients reflect upon. This reflection may be immediate as in the case of 1 participant who felt that he was a murderer and whose learning needs related mostly to acceptance of the graft; his needs had to be addressed during hospitalization. In contrast, another study participant found she was not able to identify her learning needs regarding acceptance of the graft as she was needing time to physically heal before she could think of addressing her psychological needs. What this study has done is provided a framework in which learning needs can be assessed during convalescence. In the above examples, the health care professional who understands learning needs may be associated with psychological acceptance of the graft or with physical recovery will be able to intervene when and how

appropriate.

The results of this study indicate that learning needs change during convalescence. All participants identified information they felt was crucial for them to know at the onset of convalescence, in fact, prior to discharge. After discharge, the focus of their learning needs changed to wanting to know what to expect. These learning needs, associated with mastering recovery, transition, and reflection, evolve throughout convalescence. For example, in terms of establishing limits, liver recipients may have learning needs associated with testing of their limits, and, once these limits are established, learning needs may arise pertaining to the integration and acceptance of these limits into their lives. It is important to note that learning needs are not stagnant but are continuously changing during convalescence and that they are highly individualized. A framework is provided to guide the health care professional in exploring learning needs that may not have been explored had this study not been done. Many health care professionals may provide information regarding activity restrictions following transplantation; however, this study has shown that liver recipients' learning needs go beyond that, their learning needs also include the integration and acceptance of those limits.

This study has made contributions to the existing literature in that it supports many of the research finding pertaining to transplantation. Three studies (Frey, 1990; Sutton & Pelletier Murphy, 1989; Tarter et al., 1984) as well as this study have found that there are several common stressors associated with renal and liver transplantation which are related to immunosuppression, medication side effects, and uncertainty. The question then becomes, are these stressors similar for other types of transplants? If so, perhaps the learning needs of liver recipients are similar to those who are recipients of other organs. In identifying learning needs during convalescence, several categories emerged which were very similar to categories found in the phenomenological study by

Thomas (1993) investigating the lived experiences of liver transplantation. The issues of control, support, spirituality, and gratitude were the same for this and Thomas' groups of study participants.

Because this study looks beyond transplant recipients' information needs and examines recipients' needs to understand medications, side effects, and signs of infection and rejection, it provides health care professionals with insight into liver recipients learning needs related to the social, psychological, physical, and spiritual aspects associated with transplantation. It brings to the forefront the various issues liver recipients must deal with each day such as the ever present uncertainty associated with transplantation. This study identifies liver recipients' learning needs based on their perceptions, not the perceptions of health care professionals or researchers. Still, more research needs to be done in the area of transplantation. As well, this study provides health care professionals with a framework outlining the process of convalescence and allowing them both to assess where liver recipients are in the process and to utilize the interventions based on theory to assist liver recipients through the process. This study also forces health care professionals to rethink the ways clients are presently being taught. Liver recipients are dealing with so much physiologically and psychologically, they can only absorb what is most pertinent to the moment. Health care professionals must then assess what the client feels he/she needs to know.

An interesting finding of this study is one participant's comment that she could not deal with the psychological aspect of transplantation as her energy was being directed towards healing physically. In her case, psychological learning needs were not addressed until her physical needs were met. If she had experienced physical setbacks after surgery, then she might have left any psychological learning needs unaddressed. Such imbalances require further study in health care professionals' emphasis on physical health to provide insight into the recovery process. Health care professionals must learn

when and how to meet the very present psychological learning needs of the client.

The emergent theory of this qualitative study may be used to guide health care professionals in their assessments of liver recipients learning needs during convalescence. By using this theory as a framework, assessments can be made to ensure learning needs are being addressed which affects the liver recipients physiological, psychological, social and spiritual well being thereby making the process of convalescence less stressful.

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APPENDIX A

TABLE I

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|---|---|--|
| Psychosocial Outcome Six Months after Heart Transplant Surgery: A Preliminary Report Bohachick, P Anton, B.B. Wooldridge, P.I.J. Kormos, R.L. Armitage, J.M. Hardesty, R.L. Griffith, B.P. 1992 | Purpose: To quantitatively evaluate the effect of heart transplantation on psychosocial functioning by comparing post transplant against pre transplant functioning | quantitative Psychosocial Adjustment to Illness Scale (PAIS) Profile of Mood States (POMS) n=44 34 men 10 women | <ul style="list-style-type: none"> -clients improved in adjustment after transplantation -overall improvements due to improvements in vocational, domestic, sexual, and social functioning -vocational-less time lost at work due to illness <ul style="list-style-type: none"> -less work impairment in physical performance of job -domestic-less physical disabilities and domestic impairment i.e. difficulties with duties around house -no significant improvements were found in dependency, posture, family communication, family adaptability, financial resources, clients' relationships with their partners -sexual relations significant in 4/6 aspects, sexual performance, frequency of sexual activity, sexual interest, and sexual satisfaction -at 6 month follow up clients reported significantly less impairment with their social life in terms of participation in family, individual and social leisure activities. -significant decrease in POMS mean total score from pre to 6 months post transplant. -significant positive changes in 5/6 subscales. -mean scores for anxiety, depression and confusion decreased significantly. -fatigue scores declined markedly, degree of vigour dramatically increased. -clients were more likely to return to work post transplant if they had been recently employed -25% of the clients reported more psychological adjustment problems at 6 months after transplantation, 11% also reported more mood disturbance than they had before transplantation |
| <u>Research in Nursing and Health,</u> <u>15(3), 165-173</u> | | | |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|---|---|---|
| <p>Functional Capacity and Rehabilitation of Recipients with a Functioning Renal Allograft for Ten Years or More.</p> <p>Fletcher, S.M. Novick, A.C. Braun, W.E. Popowniak, K.L. Steinmuller, D.</p> <p>1983</p> <p><u>Transplantation</u> 35(6), 572-576</p> | <p>Purpose: To survey a well followed group of renal transplant recipients whose excellent long term graft function permitted maximal rehabilitation from end stage renal disease</p> | <p>Karnofsky Activity Scale Psychosocial and Sexual History</p> <p>n = 45 mean age 27</p> | <p>-5 recipients (10%) developed 9 cancers post transplant -while on dialysis 13/45 (29%) described normal activity "part of the time". No patient had an "almost normal" level of activity -21/45 (47%) regarded their level of activity as limited to "self care" -1 year post transplant 42/45 (93%) felt their activity level was "almost normal" -3 patients cited some limitations but normal activity level was present "part of the time" -above activity levels were maintained for most recipients at 10 or more years post transplant -6 (13%) admitted a marked decline in activity after 10 years to levels of "self care". This was due to various reasons (1) return to dialysis (3) cardiovascular disease (1) lymphoma requiring chemotherapy. (1) motor vehicle accident -before transplantation 37/45 (78%) were unable to work or attend school. 2/45 were employed full time, 3/45 attended school -after transplantation 44/45 (98%) attained either full time employment, studies or housework -sexual evaluation comprises 41/45 recipients (23 men and 18 women) who were post pubertal at time of transplantation -pre transplant 14/23 men (60%) stated they were potent. None fathered children while on dialysis -post transplant, all male recipients described a renewed and heightened interest in sexual activity, all were potent. 9 fathered children -while on dialysis none of the 18 women had regular menstrual periods -16/18 (89%) did not have sexual intercourse at least once a month with their spouse or sexual partner -5 recipients delivered 9 children successfully</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|---|--|--|
| <p>Functional Capacity and Activity Level Before and After Renal Transplantation</p> <p>Gallagher-Lepak, S.</p> <p>1991</p> <p>ANNA Journal, 18(4), 378-82, 406</p> | <p>What are the changes in functional capacity and activity level among renal transplant recipients before and at 6 and 16 weeks following transplant</p> | <p>descriptive</p> <p>Symptom-Limited Treadmill Testing</p> <p>Perceived Exertion Rating</p> <p>Human Activity Profile (HAP) 95 item</p> <p>T₁=2 days prior T₂=6-8 weeks after T₃=15-20 weeks after</p> <p>n= 9 6 females 3 males age range 23-60</p> | <p>-functional capacity was lower prior to transplantation than after transplantation</p> <p>-a 24% increase in mean peak oxygen consumption (VO₂) and metabolic equivalent level (MET) was found between T₁ and T₂ while only a 5% increase in main peak VO₂ and MET level was found from T₂ and T₃</p> <p>-mean total treadmill time (minutes) increased from 11+/- 6 at T₁, 15 +/- 6 at T₂, and 16 +/- 6 at T₃ (p< .001)</p> <p>-the change in mean treadmill time from T₁ to T₃ of 4 minutes and 57 seconds represents a 47% increase in treadmill work</p> <p>-mean perceived exertion scores obtained during treadmill testing were not significantly different between tests indicating a consistently high effort level during all testing sessions</p> <p>-overall, cardiorespiratory fitness scores improved among seven subjects from T₁ to T₃. 2 subjects did not improve in their cardiovascular fitness category, both subjects improved within their fitness category</p> <p>-although improvement occurred in most subjects by T₃, compared to age/gender adjusted normative data from healthy subjects, 5 subjects remained in the lowest tenth percentile according to Maximum Current Activity (MCA) scores at T₃</p> <p>-the Normative Impairment Index (NII) is regarded as a more accurate indicator of overall activity level. Scores range from 1 to 94, with higher scores indicating less impairment. Mean scores decreased from T₁ to T₂ and increased from T₂ to T₃, overall the NII scores showed less impairment at T₃ than T₁ (p<.01)</p> <p>-greatest improvement in functional capacity occurred within the first 6 weeks after transplantation. Activity level in contrast improved more slowly after transplant</p> <p>-improvement in functional capacity was greater during the first 6 weeks (24%) than during the 6 to 16 week period (5%)</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|--|--|---|--|
| <p>Functional Outcome After Liver Transplantation: A Preliminary Report</p> <p>Robinson, L.R. Switala J. Tarter, R.E. Nicholas, J.J.</p> <p>1990</p> <p><u>Archives of Physical Medical Rehabilitation</u>, 71, 426-27</p> | <p>What are the functional and vocational aspects of patients surviving liver transplantation at our University Hospital</p> | <p>Questionnaire designed to obtain information on extremity function, ADLs, mobility, endurance, vocation ADL</p> <p>Questions taken from Institution for Rehabilitation Rest Care - Long Range Evaluation System</p> <p>31 clients who had undergone liver transplantation in 1985 who were not decreased by 1988 response rate 31/45 (68.8%)</p> | <p>-14/31 (45%) function was not completely normal in at least 1 extremity -12/14 reported ordinary use of their extremities was accompanied by weakness, incoordination, pain or restricted movement -13/31 (43%) reported joint pain and 3/31 (10%) reported joint swelling -4/31 (13%) reported developing gout since the liver transplant -2/31 (6%) developed arthritis -4/31 (13%) used a handrail or cane for stairs and one required an assistive device on level surfaces -1 client had difficulties with hand skills, 1 used assistive devices for grooming and bathing, one reported needing occasional help for bowel movements -pre transplant 19/31 reported endurance was severely impaired, 9/31 were moderately impaired -3 years post transplant 2/31 had severe impairment and 8/31 moderate impairment in endurance, remainder were normal or had mild impairment -pre transplant 15/31 (45%) unable to go outside the house. 3 years later, 29/31 (94%) were able to walk at least 3 blocks -most common limiting symptoms during ambulation, shortness of breath 13/31, leg pain 7/31, back pain 6/31, heart palpitations 4/31 -post transplant many clients engaged in exercise programs: (25) walking, (10) stationary cycling, (5) swimming, (5) aerobic exercise, (2) weight lifting, (2) jogging -3 years after transplantation 12/31 were employed full time, 3/31 part time, 8/31 home makers, 13/31 work performance was adversely affected by fractures, 7/31 reported a lack of concentration, 8/31 ability to work was just as good as prior to transplant, 14/31 working ability was better than before transplant</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|--|---|--|---|
| <p>Functional and Social Rehabilitation of Heart Transplant Recipients under the Age of Thirty</p> <p>Samuelsson, R.G. Hunt, S.A. Schroeder, J.S.</p> <p>1984</p> <p>Scand J Thor Cardiovascular, 18, 97-103</p> | <p>Purpose: To evaluate the functional and social rehabilitation of all patients still alive who had while below the age of thirty received a heart transplant and survived the first critical 3 months</p> | <p>Health Survey Questionnaire (mailed) 40 questions re: general health, physical fitness, daily living, limitations on activity and transportation, work/school situation and marital and life satisfaction</p> <p>n = 23</p> | <p>-side effects of the immunosuppressive treatment include changes in physical appearance, muscle weakness, and skin problems (tenderness and bruising)</p> <p>-11/23 answered considered their health excellent, 9/23 good, 3/23 fair, 3/23 consider their health better, 12/23 about the same, 6/23 slightly worse, and 2 much worse than people their age</p> <p>-none needed help from another person or special equipment to eat, dress, personal grooming, bathing, or walking across a room</p> <p>-2/23 said they were able to lift 30 lbs, 10/23 60 lbs, 11/23 120 lbs</p> <p>-7/23 able to walk at least 1 mile (30 min), 16/23 3 miles (90 min)</p> <p>-22/23 able to climb 4 or more flights of stairs, 1 only able to climb 2</p> <p>-20/23 able to do domestic chores unaided, ie. shovelling snow, cleaning windows, washing floors, 2 needed help, 1 had not yet tried</p> <p>-14/23 were very concerned with their general physical fitness, 8/23 moderately concerned, 1 slightly concerned</p> <p>-16/23 more concerned with physical fitness than before the transplant, 7/23 thought themselves to be unchanged</p> <p>-6/23 did some form of exercise 1-5 hrs per week, 11/23 6-10 hrs, 1/23 11-15 hrs, 3/23 > 15 hrs, 2 did not exercise at all</p> <p>-11/23 did not have any activity restrictions, 12/23 did have restrictions. Most of restricted activities were related to the person's loss of muscular strength, ie. lifting heavy objects or other vigorous physical activities</p> <p>-6/23 decreased their exercise and active recreations ie. running, skiing, tennis, and contact sports. 13/23 felt they could undertake any kind of activities, 4/23 did not answer the question</p> <p>-22/23 stated they had no difficulty with transportation, 1 had considerable difficulty</p> <p>-none considered themselves completely unable to work, 3/23 were able to work but were limited in the amount or kind of activities, 5/23 considered themselves able to work but limited in the amount or kind of other activities, 14/23 considered themselves not limited in any of the above ways, 1 did not answer the question</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|--|--|--|---|
| <p>Neuropsychiatric Status after Liver Transplantation</p> <p>Tarter, R.E. Van Thiel, D.H. Hegedus, A.M. Schade, R.R. Gavaler, J.S. Starzl, T.E.</p> <p>1984</p> <p>Journal of Laboratory Clinical Medicine, 103(5), 776-782</p> | <p>1) To determine whether liver transplantation, in addition to being a life saving procedure, also can restore the individual to a normal quality of life in terms of social and behavioural functioning, emotional well being and cognitive capacity.</p> <p>2) To determine whether hepatic encephalopathy is fully reversible after successful liver transplantation.</p> | <p>quantitative neuropsychiatric examination MMPI 66 item true/false questionnaire</p> <p>16 PF- 226 items to evaluate personality</p> <p>Sickness Impact Profile</p> <p>n=10 average age=27.80 Control group n=10 average age=39.30</p> | <p>-the 2 groups did not differ from each other on measures of verbal or nonverbal intelligence</p> <p>-transplant patients were significantly better at learning the associations on a 10 item list of word pairs</p> <p>-transplant patients performed significantly better than did the control group on two of the perceptual motor tests</p> <p>-transplant recipients exhibited faster finger tapping speed than did the control patients</p> <p>-transplant patients also performed better than the medical controls in the perceptual motor speed</p> <p>-there were no differences in a number of tests between the transplant group and the control group</p> <p>-a significance difference only on the hypochondriasis scale; patients with Crohns disease scored in the more pathological direction</p> <p>-results indicate that patients who survived liver transplantation are not impaired on measures of neuropsychological capacity when compared with a control group with a chronic disease or with population norms</p> <p>-when contrasted with normative population values, the transplant patients presented a profile of moderate anxiety, somatic distress, and concern</p> <p>-frustration, depression, worry and social withdrawal</p> <p>-routines of everyday living are also somewhat disrupted as indicated by the findings that their conditions negatively affects sleep and rest, eating and appetite, and recreation pastimes. Impairments of > or = to 20% were observed in each of these scales when a score at or near 0 would be normal.</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|--|--|---|
| <p>Stressors in Renal Transplant Recipients at Six Weeks After Transplant</p> <p>Frey, G.M.</p> <p>1990</p> <p>ANNA Journal, 17(6), 443-6,450</p> | <p>Purpose: To identify the type and degree of stressors that renal transplant recipients report 6 weeks after transplantation</p> <p>Theoretical Framework Orem's Self Care Deficit Theory of Nursing</p> | <p>Surveys mailed out Kidney Transplant Recipient Stress Scale (KTRSS)</p> <p>n=48 58% male 42% female return rate 75%</p> | <ul style="list-style-type: none"> -stressor with the highest mean was the possibility of repeated hospitalizations -possibility of rejection, cost of medication, uncertainty about the future, and the side effects of medications are also some of the highest stressors for the Hayward Study and for Sutton and Murphy (1989). -even with the increased graft survival rate with cyclosporin, there continues to be concern about whether or not the kidney will be rejected. -concerns about the future, ranked 2.5. This could be a reflection of recipients believing they have control over what happens regarding their body's acceptance or rejection of the kidney -medications play an important role in the life of all chronic renal failure clients, regardless of treatment modality. Those who choose to have a renal transplant must deal with the high cost of immunosuppressive drugs. Thus it is not surprising that transplant recipients express some degree of stress -side effects of medications was another continuing concern. Specific stressors related to side effects included changes in body appearance. Changes in body appearance could be the result of diet changes, increased appetite, and the effects of steroids. -the possibility of infection had a lower ranking than found by Hayward. This was curious since at the hospital, preventative precautions (hand washing and masks) are enforced immediately after surgery until discharge. One explanation may be that the patients become more knowledgeable about the risks of infection as time goes on. Also they may have more personal experiences with actual infection. |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|--|---|---|--|
| Stressors and Patterns of Coping in Renal Patients Sutton, R.D. Pelletier Murphy, S. 1989 | Patients' perception of stressors associated with transplantation and strategies used by transplant patients to cope with stress | questionnaires End Stage Renal Disease (ESRD) Stressor Scale Jalowiec* Coping Scale n=40 28 males 12 females 2 sub groups of 20 1 group transplants 0-23 months n=20 24-48 months n=20 | <p>- five highest stressors were (0-23 months)</p> <ol style="list-style-type: none"> 1. cost factors 2. fear of kidney rejections 3. weight gain 4. uncertainty concerning future 5. limitations of physical activities <p>- five lowest stressors</p> <ol style="list-style-type: none"> 35. fear of not being accepted by friends and family 34. feeling organ not part of one's own body 33. reversal in family roles with the children 32. limitation of fluid 31. nausea and vomiting <p>- five most used coping methods</p> <ol style="list-style-type: none"> 1. praying 2. objectively look at problem 3. try to maintain control over situation 4. seek information 5. draw on past experience to help with situation <p>- five least used coping methods</p> <ol style="list-style-type: none"> 1. withdraw from situation 2. meditate 3. blame someone else for your problems 4. drink alcoholic beverages 5. take drugs |
| Nursing Research, 38(1), 46-9 | | | |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|--|--|---|
| <p>Stress, Coping, and Quality of Life in Adult Kidney Transplant Recipients</p> <p>White, M.J. Starr, A.J. Ketefian, S. Voepel Lewis, T.</p> <p>1990</p> <p>ANNA, Journal, 17(6), 421-424, 431</p> | <p>1. What specific stressors were identified in the transplant experience?</p> <p>2. What coping strategies did these patients use throughout their transplant experience?</p> <p>3. What relationships exist among study variables including QOL measures?</p> | <p>quantitative</p> <p>Kidney Transplant Questionnaire - used to measure stress and coping</p> <p>25 items in stress section</p> <p>87 items in coping section</p> <p>55 kidney transplant recipients</p> <p>31 males</p> <p>24 females</p> <p>age range 19-67 years</p> | <p>-specific stressors that received the highest scores for concerns (somewhat to a great deal) were:</p> <ul style="list-style-type: none"> - being uncertain about whether the transplant will be a success (74.6%) - concerns about risk of infections and/or viruses (70.9%) - concern about what the long term side effects of antirejection medication might be (63.7%) - worry that changes in my physical appearance will affect my social life (61.9%) <p>- items reported to be of little or no concerns were:</p> <ul style="list-style-type: none"> - losing the affection of someone close to me (81.9%) - keeping my job after the transplant (79.6%) - discomfort or suffering (76.4%) - changes or breakdown in how I will get along with spouse or other family members (76.3%) <p>- the most difficult stressors reported were:</p> <ul style="list-style-type: none"> - uncertainty about the transplant's success (32.7%) - fear of injury to the kidney (25.5%) - trying to get life back to normal (23.6%) <p>- coping strategies that received the highest scores were:</p> <ul style="list-style-type: none"> - I stay cheerful and maintain a positive attitude (98.2%) - I remain realistic (96.1%) - I make the best of it; pull myself up and get moving (92.7%) <p>- coping strategies reported least used were:</p> <ul style="list-style-type: none"> - use of drugs (98.1%) - smoking (92.7%) - drinking alcohol (92.7%) - arrange for someone to give physical care (92.2%) - isolation (83.6%) |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|--|-------------------|------------------|--|
| Stress, Coping, and Quality of Life in Adult Kidney Transplant Recipients White, M.J. Starr, A.J. Ketefian, S. Voepel Lewis, T. 1990 ANNA, Journal. 17(6), 421-424, 431 | | | - QOL scores were significantly higher after the transplant than before ($p < .01$) - statistically significant positive correlation were obtained between the following variables: - total stress scores and total coping scores ($p < .01$) - total stress scores and total number of coping strategies used ($p < .01$) - statistically significant negative correlations between QOL scores before the transplant and total number of stressors reported ($p < .01$) - QOL scores before transplants were predicted from total stress and coping scores ($r^2 = .15$ $p < .05$) - there were no statistically significant gender differences for total stress or total coping score means. |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|---|---|--|
| <p>The Lived Experience: Liver Transplantation</p> <p>Thomas, D.J.</p> <p>1993</p> <p>PhD Dissertation State University of New York</p> | <p>What is the lived experience of persons with liver transplants?</p> <p>Theoretical Framework Martha Rogers Science of Unitary Human Beings</p> | <p>Hermeneutic phenomenology</p> <p>purposive sample of 13 liver recipients</p> | <p>Emerging Themes</p> <p>- Dimension of the Lived Experience of People with Transplants</p> <ol style="list-style-type: none"> 1. Conflict - inner conflict and social political conflict sources: political economy of health care system issues re: donors death, unfulfilled expectations of the transplant, uncertainty ie: future 2. Financial Aspects of Transplantation - cost of transplant, economic independence, insurance coverage, and return to work (males) 3. Control - loss of control caused by illness and transplantation - dealt with by taking calculated risks with their health after transplant 4. Self Perception - participants perception of self as well or ill affected the adjustment to life changes after transplantation 5. Support Network - recipients viewed family and friends and community as important in the health care system, information regarding procedures and their disease and their relationship to higher power were important and provided a sense of support. 6. Spirituality - recipients experienced the transplant in a spiritual context 7. Gratitude - recipients felt a profound sense of gratitude to donors and God for a second chance at life |

APPENDIX B

TABLE II

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|---|---|---|
| <p>Impact of the Child's Liver Transplant on the Family: Maternal Perspective</p> <p>LoBiondo-Wood, G. Bernier-Henn M. & Williams, L.</p> <p>1992</p> | <p>Specific aims of study were to assess</p> <p>a) whether there was a correlation between family stress, parental coping, social support and family adaptation after the child's successful liver transplant.</p> <p>b) whether the level of family adaptation could be predicted by family stress, parental coping and social support.</p> <p>Conceptual Framework Double ABC-X Model</p> | <p>quantitative questionnaires</p> <p>1) Family Inventory of Life Events (FILE) 71 item index of family stress</p> <p>2) Coping Health Inventory for Parents (CHIP) 45 item self report instrument to assess parent's coping responses</p> <p>3) Norbeck Social Support Questionnaire (NSSQ) measures multiple dimensions of social support</p> <p>4) McMaster Family Assessment Device (FAD)</p> <p>58 mothers 59% return rate</p> | <p>-significant negative correlation was found between social support and family adaptation for total sample ($p < .05$)</p> <p>-sample divided by time, ie. < 1 year post transplant > year - no significant relationships</p> <p>-for families less than 1 year post transplant multiple regression analysis indicated 60% ($p < .04$) of family adaptation could be predicted by the family stress, parental coping patterns, and the amount of social support ($n=12$)</p> <p>-for families > 1 year post transplant, prediction of family adaptation based on the same independent variables was not significant.</p> <p>-most helpful factors since the child's transplant included support, return to daily routine, and seeing the child healthy, happy and growing</p> <p>- themes identified as most stressful since the transplant included uncertainty, fear, finances, and separation issues related to family adaptation.</p> |
| <p>Pediatric Nursing, 18(5), 461-466</p> | | | |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|--|--|---|
| <p>Impact of Cardiac Transplantation of the Spouse's Life</p> <p>McGary Buse, S. Pieper, B.</p> <p>1990</p> <p>Heart & Lung 19(6) 641-647</p> | <p>Purpose: to explore the effect of waiting for heart transplantation and the effect of the transplantation on the spouse's life and perceived stress</p> | <p>non experimental-descriptive</p> <p>Questionnaires</p> <p>1) Perception of Heart Transplantation Questionnaire (PHTQ)</p> <p>38 item with two subscales</p> <p>life (28 items)</p> <p>relationships (10)</p> <p>2) Subjective Stress Scale (SSS)</p> <p>3) Demographic-Illness data form</p> <p>n = 30</p> <p>response rate 70%</p> <p>26 women</p> <p>4 men</p> <p>age range 29-62</p> | <p>-spouses perceived the pre transplant period to have a greater overall effect than the post transplant period</p> <p>-spouses perceived the impact of the post transplant period as significantly more positive than the pre transplant period</p> <p>-the life effect items with the highest scores (perceived to be most influenced by the pre transplant period) were:</p> <p>feelings of fear over loss of spouse</p> <p>need to learn more about transplantation</p> <p>time available for self</p> <p>life in general</p> <p>-the life rating items with the highest scores (perceived effect on life was positive) were:</p> <p>learn more about transplantation</p> <p>availability of support from others</p> <p>relationship with family and friends</p> <p>need to make decisions independently</p> <p>-the relationship items most influenced by the pre transplant period were:</p> <p>need to monitor spouses physical and emotional conditions</p> <p>and sexual activity</p> <p>need to protect spouse from upsetting information</p> <p>-the relationship items with the more positive rating were:</p> <p>feelings of closeness and tenderness with spouse, marriage</p> <p>need to assist spouse with the prescribed medication</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|-------------------|------------------|---|
| <p>Impact of Cardiac Transplantation of the Spouse's Life</p> <p>McGary Buse, S. Pieper, B.</p> <p>1990</p> <p>Heart & Lung 19(6) 641-647</p> | | | <p>-in the post transplant period, the life effect items perceived to be most influenced by the transplantation were: need to learn more about transplantation, life in general feelings of fear over loss of spouse feelings of security</p> <p>-items rated most positive were: need to learn more about transplantation life in general, independent decision making, and relationships with children and grandchildren</p> <p>-the relationship effect items with the highest scores in the post transplant period were: feelings of closeness and tenderness with spouse need to monitor spouse's emotional condition need to monitor spouse's physical condition</p> <p>-items with more positive ratings were: need to assist spouse with the prescribed medical regimen feelings of closeness and tenderness and marriage</p> <p>-no significant difference between pre transplant and post transplant stress scores was found despite the diminished impact and increased positivity of the post transplant period</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|--|---|--|
| Stress, Coping, and Quality of Life in Family Members of Kidney Transplant Recipients | Purpose: To explore specific stressors and coping of family members of patients who have undergone kidney transplantation | descriptive - exploratory Kidney Transplant Questionnaire | <p>-greatest concerns to family members were: long term side effects of antirejection medicine (76%) other medical conditions or complications that might arise (74%) discomfort or suffering of the recipient (72%)</p> <p>-most difficult stressors to deal with were: concern about long term side effects of medications (38%) other medical conditions or complications that might arise (32%)</p> <p>-specific items reported to be of great use to family members were: remain realistic (98%) try to look on the bright side (94%) carry on as I normally would (92%) try to analyse the problem in order to understand it better (90%) draw on past experiences (88%) concentrate on what I have to do next (70%)</p> |
| Voepel-Lewis, T. Starr, A. Ketefian, S. White, M.J. | | 50 family members age range 23-74 74% female 80% married 3 weeks - 6 months | <p>-QOL scores were significantly higher after the family members transplant than before the transplant</p> <p>the total number of coping strategies used correlated positively with the total number of stressors reported</p> <p>there were significant correlations between QOL change (the change in QOL from before to after transplant) and total coping, and between QOL and number of coping items</p> |
| ANNA, 17(6), 427-430 | | | <p>-QOL scores before transplant were predicted from total coping scores.</p> <p>a significant predictive value was found for change in QOL scores when regressed on total scores for stress and coping</p> <p>no statistically significant gender differences for either total stress or total coping scores were found. However, women used significantly more, seeking social support, coping, and positive reappraisal coping than men.</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|--|---|---|
| Information Needs of Mothers of Children Who Have Had Liver Transplants | What are the information needs of mothers of children who have undergone liver transplantation | Descriptive exploratory interview guide with 13 open ended questions 4/13 mother's perception of child's illness 9/13 mother's information needs | Evaluation/waiting phase - 4 major themes evolved a) prior preparation b) feeling of ambivalence c) specific details about surgical procedure d) knowledge of all possible post operative complications |
| Nancy K. Weichler | | convenience sample 8 mothers | Intra operative phase - the need to be kept informed about child's condition 5/8 mothers individual responses: a) fear child was suffering b) inability to ask questions c) feelings of helplessness |
| April 1990 | Conceptual Framework Lazarus - coping modes | ages range 25-26 2 black mothers 6 white mothers | ICU phase 3/8 too stressed to seek information during ICU phase - information needs a) purpose of tubes b) liver enzyme lab values c) blood pressure d) child's overall physical well-being |
| Journal of Pediatric Nursing, 5(2), 88- 96 | | content analysis | Post surgical recovery phase - information needs very concrete and varied a) knowledge of lab values b) signs and symptoms of rejection and infection c) test results d) child's physical activity capabilities e) child's expected emotional behaviour |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|--|-------------------|------------------|--|
| <p>Information Needs of Mothers of Children Who Have Had Liver Transplants</p> <p>Nancy K. Weichler</p> <p>April 1990</p> <p><u>Journal of Pediatric Nursing</u>, 5(2), 88- 96</p> | | | <p>Discharge phase - Questions asked: "what essential information is important for you to possess in order to care for your child after discharge from the hospital?"</p> <p>Medical needs</p> <ul style="list-style-type: none"> - medication, signs and symptoms of infections rejection blood pressure parameters, childhood immunizations and diseases, child's future reproductive concerns <p>Nonmedical needs</p> <ul style="list-style-type: none"> - physical activity limitations, discharge teaching book, follow up procedures, obtaining lab values, diet, return to school - whether the child would lead a "normal life" |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|---|--|--|
| Caretakers Informational Needs after their Children's Renal or Liver Transplant | What are the information needs of primary caretakers of children following organ transplantation? | Descriptive exploratory mailed semi- structured questionnaire over a 2 year period return rate 42% | data presented in relation to the 6 phases of the transplantation process: pre evaluation/waiting phase: #1 need - information on rejection 76% - #1 need to know about rejection 70% - 2nd most important need - to know about the possible complications the child could have 61% - 3rd need - to know details of surgical procedure |
| Nancy K. Weichler | | Convenience sample of 21 caretakers of children who received either a kidney or liver transplant | Major themes expressed: a) child's poor physical growth and appetite b) decreased activity level c) increase in illness |
| April 1993 | | 18 Caucasian, 2 black, 1 Hispanic 20/21 were mothers of the child | intra operative phase: 71% - child's progress during surgery 65% - length of surgery 60% - need to know if the child was suffering |
| | | 1/21 was the father age range 24-43 4/21 single 17/21 married | ICU phase 90% - to know if the new organ was functioning 75% - to know and understand the lab values 72% - to know about the child's pain and suffering and ways to comfort the child |
| ANNA, 20(2), 135-146 | | | post surgical recovery phase 80% - to know and recognize signs and symptoms of rejection 60% - to know how to read the wall chart - lab values, test results, and medicine dosages - availability of physicians, lab values, emotional and physical behaviours of the child, test results and medicine |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|-------------------|------------------|--|
| Caretakers Informational Needs after their Children's Renal or Liver Transplant | | | <p>discharge phase: 64% - to know signs and symptoms of rejection and infection (liver recipient caretakers) 54% - to know medications and their administration (liver recipient caretakers) 80% - medications (kidney recipient caretakers) 60% - signs and symptoms of rejection and infection (kidney recipient caretakers)</p> |
| Nancy K. Weichler | | | <p>reintegration phase 30% - resumed "normal family life" almost immediately 20% - liver recipient caretakers - still hadn't resumed normal life 70% - family unit did well reestablishing it 2 major problems - marital conflict, acting out and disciplinary problems</p> |
| April 1993 | | | <p>2 other questions asked "If you were going to help other parents whose child was going to have a transplant what would you tell them?" 58% - stressed for parents to come prepared, read about transplantation and ask a lot of questions throughout the entire process</p> |
| ANNA, 20(2), 135-146 | | | <p>"As you reflect over the past several months, what kinds of things would have been helpful to prepare you for the transplantation process and care for your child and family?" - to be adequately prepared prior to coming for the transplant</p> |

APPENDIX C

TABLE III

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|--|---|---|---|
| <p>Predictions of Quality of Life Following Cardiac Transplantation</p> <p>Brennan, A.F. Davis, M.E. Buchholz, D.J. Kuhn, W.F. Gray, L.A.</p> <p>1987</p> <p><u>Psychosomatics</u> 28(11), 566-571</p> | <p>Purpose: To examine the quality of life of 11 heart transplant patients at least nine post transplantation in an attempt to determine factors related to outcome</p> | <p>quantitative Quality of Life Questionnaire subdivided into General Current QOL (GQL) which has 4 subscales Personal QOL Change (PQLC) Social QOL Change (SQLC) Job QOL Change (JQOL) Health QOL Change (HQLC)</p> <p>n = 11 10 male 1 female age range 28-56 mean age 45</p> | <p>-the GQL indicated that the patients rated their general QOL as "almost 5" on a 6 point scale</p> <p>-the PQLC indicated their personal QOL had changed for the better from prior to transplantation (+1.8) by almost 2 points on a scale where 0 indicated no change and 6 indicates a great deal of change</p> <p>-the average score of + 0.9 on the SQLC and -.3 on the JQLC reflected changes of less than one point in the areas of social functioning and job status-the average score of + 4.6 on the HQLC indicated substantial positive changes in perceived health status</p> <p>-a diagnosis of personality disorder was associated with a less positive GQL than that reported by those without personality disorders ($p < .01$)</p> <p>-personality disorder was related to more negative or less positive changes on three of the four QOL change scales.</p> <p>-for change in job satisfaction/performance the difference was significant.</p> <p>Patients with personality disorder reported a negative change, while those without reported a positive change ($p < .05$).</p> <p>-diagnoses of depression/anxiety or dementia/delirium during the pre transplant period were not significantly associated with differences</p> <p>in the GQL 9 to 15 months later. These diagnoses less consistently related to the measures of QOL change and none of these comparisons showed significant differences.</p> <p>-in general, a positive GQL and positive changes in 3 of the 4 measures of QOL were associated with fewer readmissions and fewer days in the hospital</p> <p>-the JQLC was significantly more positive in those patients with one or no readmissions during the first 6 months. ($P < .01$)</p> <p>-patients also reported that their personal and health QOL were much improved compared with prior to transplantation, but their social and job QOL were not much improved</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|-------------------|------------------|---|
| <p>Predictions of Quality of Life Following Cardiac Transplantation</p> <p>Brennan, A.F. Davis, M.E. Buchholz, D.J. Kuhn, W.F. Gray, L.A.</p> <p>1987</p> <p><u>Psychosomatics</u> 28(11) 566-571</p> | | | <p>-5 of 11 patients returned to pre morbid levels of vocational functioning within 12 months of the transplant</p> <p>-the findings of this pilot study suggests that, within the sample, the typical patient with more positive QOL following cardiac transplant tended to be married, did not carry a diagnosis of personality disorder, and had a shorter post transplant hospital stay, fewer days of readmission, and fewer biopsies in the year following transplant</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|---|--|--|
| <p>The Quality of Survival after Liver Transplant</p> <p>Colonna, J.O. Brems, J.J. Hiatt, J.R. Millis, J.M. Ament, M.E. Baldrich-Quinones, W.J. Berquist, W.E. Besbris, D. Brill, J.E.p Goldstein, L.I. Nuesse, B.J. Romming, K.P. Saleh, S. Vargas, J.H. Busuttil, R.W.</p> <p>1988</p> <p><u>Transplantation Proceedings</u>, 20(1), Supplemental 594-597</p> | <p>To determine the quality of survival after liver transplantation of adult patients and the parents of pediatric patients who were surviving more than 6 months after liver transplant.</p> | <p>Survey design - a questionnaire containing a variety of questions on objective and subjective indicators of the QOL before and liver transplantation</p> <p>n=58 with 97% return rate</p> | <p>-32% of adults worked full or part time prior to liver transplantation. After transplantation 75% of adults worked either full or part time ($p<.01$)</p> <p>-93% of adults reported only normal to mildly restricted activity tolerance after liver transplantation compared to 39% prior to transplantation ($p<.05$)</p> <p>-improvement in children was less striking due to a better preoperative activity tolerance, but they did improve significantly after liver transplant ($p<.05$)</p> <p>-6 months prior to liver transplantation adults averaged 3.07 admissions to hospital. During first 6 months post transplant hospitalization averaged .87 ($p<.05$)</p> <p>-pediatrics differences in frequency and duration of hospital before and after liver transplant was found not significant</p> <p>-47% of adults felt QOL was intolerable before liver transplant. 27% felt it was poor, 13% satisfactory, 13% felt QOL was good or excellent</p> <p>-after transplantation 67% rated QOL excellent, 27% as good, and 7% as satisfactory. "Improvement in QOL highly significant" ($p<.001$)</p> <p>-1/3 of patients noted the following side effects, hirsutism, hypertension, and edema</p> <p>-75% of patients were completely satisfied, 25% were very satisfied</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|---|---|--|
| <p>Predicted and Actual Quality of Life Changes Following Renal Transplantation</p> <p>Hauser, M.L. Williams, L. Strong, M. Ganza, M. Hathaway, D.</p> <p>1991</p> <p>ANNA 18(3), 295-305</p> | <p>To determine what QOL changes occurred in the lives of the patient since the Hathaway sample following renal transplant, and to determine if staff or patients more accurately anticipate these changes.</p> <p>1. Did patients or staff more correctly anticipate the number of post transplant QOL changes?</p> <p>2. In what categories of the conceptual framework did patients and staff most accurately anticipate outcomes.</p> <p>Conceptual Framework Strauss & Glaser's Chronic Illness and QOL Framework.</p> | <p>exploratory-descriptive design</p> <p>structured interviews</p> <p>convenience sample n=39</p> | <p>-the transplant staff more accurately anticipated the number of QOL changes that would occur than did the patients.</p> <p>-patients greatly underestimated the number of both positive and negative changes would occur.</p> <p>-staff did anticipate more positive changes than actually occurred, but they were much closer to reality than were the patients.</p> <p>- there was no significant difference between the negative changes the staff anticipated and number of negative changes that occurred, the patients again under anticipated negative changes.</p> <p>-staff more accurately anticipated the occurrence of positive QOL changes while patients were more accurate in not anticipating changes which did not subsequently occur.</p> <p>-staff more accurately projected the occurrence of those negative changes while patients more accurately projected the lack of occurrence</p> <p>-patients grossly under anticipated positive changes.</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|-------------------|---|--|
| <p>A Psychological Support Concept and Quality of Life Research in a Liver Transplantation Program: An Interdisciplinary Multicenter Study</p> <p>Kober, B. Kuchler, Th. Broelsch, Ch. Kremer, B. Henne-Bruns, D.</p> <p>1990</p> | | <p>quantitative longitudinal instruments</p> <p>1) EORTC-quality of life questionnaire with 56 items</p> <p>2) STAI-X Anxiety questionnaire-20 items each regarding situational anxiety (state) and tendency to be anxious (trait)</p> <p>-standardized psycho diagnostic interviews pre transplant and 1 year post transplant</p> <p>n=38 Chicago n=29 Hamburg evaluated preoperative, 2, 6, 12, 24, 36 months post transplant</p> <p>Control group Chicago n=12 with chronic liver disease and n=15 healthy</p> | <p>Overall Quality of Life</p> <ul style="list-style-type: none"> -all successful transplant patients have a distinct increase in their overall quality of life -sample of long time survivors almost reaches the levels of healthy controls -compared to patients with chronic liver disease, all liver recipients 3 months after transplantation rate their overall quality of life significantly higher <p>Overall Physical Condition</p> <ul style="list-style-type: none"> -the patients self evaluation of their overall physical condition also shows an increasing tendency, but the levels of healthy controls is not reached -long term survivors rate themselves significantly better than do patients with chronic liver disease <p>General Symptoms</p> <ul style="list-style-type: none"> -included 14 items, the mean values decreased distinctly during the post transplantation period -the change of the preoperative status compared to 24 months after transplantation is significant at a level of $p < .01$ <p>Psychological Parameters</p> <ul style="list-style-type: none"> -Anxiety- Chicago sample-the mean values of the anxiety indices of long term survivors (after 36 months) were slightly lower than patients with chronic liver disease but higher than those of the healthy controls. -during the postoperative period, there were no significant changes of the anxiety index of the transplant patients -Hamburg sample-the mean values of anxiety indices also varied pre operatively and after 24 months without any distinct increase or decrease <p>Psychological Parameters</p> <ul style="list-style-type: none"> -Depression- Chicago Sample-the mean values of the depression index clearly decrease with time after transplantation -Hamburg Sample-the mean values of the indexes dropped also |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|--|-------------------|------------------|---|
| <p>A Psychological Support Concept and Quality of Life Research in a Liver Transplantation Program: An Interdisciplinary Multicenter Study</p> <p>Kober, B. Kuchler, The. Broelsch, Ch. Kremer, B. Henne-Bruns, D.</p> <p>1990</p> <p><u>Psychotherapy & Psychosomatics</u> 54(2-3), 117-131</p> | | | <p>Sex Related Differences</p> <ul style="list-style-type: none"> -Chicago sample-in the groups with periods of transplant function of 2 years and more, female patients predominated even though the sex distribution was balanced at time of transplantation -the mean period of transplantation function for men was 6.5 months and significantly lower than that for women 17.5 months -the mean values of the following dimensions general symptoms, depression, and functional status were significantly better for women than for men -Hamburg sample-the same tendency concerning the dimensions depression, general symptoms, and functional status can be shown in this sample <p>Social Support</p> <ul style="list-style-type: none"> -all patients reported that family support was one of the most important issues during the direct post operative period after transplantation-family support might even effect survival time |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
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| <p>Quality of Life Before and After Orthotropic Hepatic Transplantation</p> <p>Tarter, P.E. Switala, J. Arria, A. Plail, J. Von Thiel, D.</p> <p>1991</p> <p><u>Archives of Internal Medicine</u>, 151, 1521-1526</p> | <p>The study evaluated the extent to which transplantation surgery restored the individual with advanced liver disease to a normal level of psychosocial adjustment.</p> | <p>quantitative Social Behaviour Adjustment Schedule (BSAS) assessment of emotional and social adjustment</p> <p>Sickness Impact Profile (SIP) Self report instrument quantifies the impact of disease on everyday functioning</p> <p>N=53 liver recipients N=35 control group normal control individuals</p> | <p>-pre transplant there was significant maladjustment in the candidates on the scales measuring disturbed behaviour, social performance, and burden on the family</p> <p>-informants of transplant recipients reported experiencing more distress and more behavioural disturbance than did the informants of the normal control group. Social role performance in the informant was impaired also.</p> <p>-prior to surgery the transplant recipients exhibited significant psychosocial and behavioural maladjustments and significant emotional distress and disruption with social adjustment caused by the patients' illness was also present in the informant</p> <p>-based on informant reporting, post transplant patients, as a group, are indistinguishable from control subjects with respect to disturbed behaviour, social performance, and burden they place on other family members</p> <p>-control subjects were rated similarly by the informant on the two assessment occasions</p> <p>-the transplant recipients obtained significantly improved ratings after transplantation compared with the assessment obtained before surgery.</p> <p>Significant improvements were found for disturbed behaviour, social performance and burden</p> <p>-the informants' adjustments also improved as indicated by statistically significant changes on the measures of stress, associated with the patients behaviour, and social performance</p> <p>-no changes in the informants' distress from the burden caused by the patient was found since this factor did not discriminate between the two groups at the time of the pre transplant testing</p> <p>-at the time of the pre transplantation assessment, the liver recipients were still impaired significantly compared with the normal control subjects on eight scales, these being ambulation, social interaction, communication, alertness, sleep and rest, eating and appetite, work, and recreation and pastimes.</p> <p>-residual impairment was manifested on only one of three scales comprising physical well-being, whereas three of four scales encompassing psychological well-being, were significantly impaired indicating that transplantation effected a better recovery of daily routine in the physical than in the psychosocial spheres of functioning</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
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| <p>Quality of Life Before and After Orthotropic Hepatic Transplantation</p> <p>Tarter, P.E. Switalla, J. Arria, A. Plail, J. Von Thiel, D.</p> <p>1991</p> <p>Archives of Internal Medicine, 151, 1521-1526</p> | | | <ul style="list-style-type: none"> -significant improvement from pre to post transplantation was found on all of the scales with the exception of the scale measuring work capacity -the magnitude of improvement across all of the SIP scales (73.9%) -mean improvement in physical adjustment was 89.5% -statistically significant improvement was found for ambulation, mobility, body care and movement -less improvement was reported for psychological adjustment was 70.2% from pre to post transplantation -significant changes were found for social integration, communication, alertness, and emotional behaviour -sleep and rest, eating and appetite, home management, and recreation and pastimes improved -at post transplantation assessment, the mean level of social adjustment measured by the SISAS was indistinguishable from that of normal control subjects. In contrast, the SIP revealed persisting impairments in the transplantation recipients on eight scales. The absolute magnitude of these impairments is very small and not substantially different from 0% impairment -47% of the post transplantation patients could still be classified as being impaired with respect to social integration and home management, while 45% and 43% were still in the lowest quartile for recreation and pastimes and sleep and rest. |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|---|--|---|
| Cognitive Function and Quality of Life in Adult Liver Transplant Recipients | To assess medical, psychologic and social status 4-36 months post liver transplant | questionnaires mailed to clients health status assessed by global health ratings activity restrictions Physical symptoms Psychosocial POMS self esteem (Simons) Index of Well-Being. | Health Status -75% rated physical health as good or better -53% could do their usual household tasks -80% had restriction in vigorous activity, -48% had some restrictions in moderate activity -95% were compliant with medications -17% reported use of some alcohol |
| Wolcott, D. Norquist, G. Busuttil, R. | | n=41 56% female mean age 43.6 years response rate 68% | Psychosocial -minimal mood disturbance, high self esteem and positive life satisfaction except with work, career, and sexual activities -stress was reported high with financial matters and medical treatment -25% were working more than 30 hours per week -48% could only work part time -most reported a large social support network but little current social interaction -men reported higher job/financial stress and tended to have better current cognitive function -women reported better global health and psychologic well-being but also greater family stress -liver recipients who were greater than 12 months post transplant had better health and psychological status but poorer cognitive function than those less than 12 months post transplant -recipients who were 46 years or older generally had poorer health and limited current vocational function abilities than younger recipients -employed recipients had better current health status but did not differ on other measures of QOL |
| <u>Transplantation</u> <u>Proceedings, 21(3)</u> 3563 | | | |

APPENDIX D

TABLE IV

| Title Author Date/Journal | Research Question | Design Sample | Findings |
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| <p>Content Areas for Cardiac Teaching: Patients' Perceptions of the Importance of Teaching Content after Myocardial Infarction</p> <p>Chan, V.</p> <p>1990</p> <p>Journal of Advanced Nursing, 15, 1139-1145</p> | <p>Purpose: to gain insight into MI patients' perceptions of the seven content areas commonly included in cardiac teaching, in terms of how important and how realistic they were for learning before discharge and during early convalescence</p> <p>Study Framework Lazarus's Stress-Coping Theory</p> | <p>Questionnaire - modified Cardiac Patient Learning Need Inventory (CPLNI)</p> <p>Categories- cardiovascular anatomy and physiology (A&P), psychological concerns, risk factors, medications, diet, physical activity, miscellaneous information</p> <p>n=30 18 males 12 females</p> <p>age range 32-85 years mean age 61.4 years</p> | <ul style="list-style-type: none"> -prior to hospital discharge, patients viewed 6/7 content areas as important for learning. Such important information was not rated by subjects as equally realistic to learn. -following discharge, under 'important to learn' there was a slight drop in mean score for 6/7 content areas. -although arranged in a different order, the areas medication, A&P, and risk factors remained in the top three ranks -under 'realistic to learn', from pre discharge to early convalescence, a common rise in mean scores for all 7 areas was noted -information concerning the effects of each medication received the highest mean score. -Other items dealt with general rules about taking medications, why each medication is to be taken, what to do if there are problems with medications. -information regarding A&P-most concerned about knowing the cause of a MI -other items included the cause of chest pain what happens when someone has an MI and how the heart heals -risk factors-chance of having another MI -diet least concerned regarding knowing general rules of eating, and meanings of the terms triglycerides and cholesterol -talking about feelings was not rated as important . - miscellaneous information regarding taking a pulse, reasons for further testing, and where to learn CPR were of lesser importance |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
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| <p>Patient Perception of Cardiovascular Surgical Patient Education</p> <p>Grady, K.L. Buckley, D.J. Cisar, N.S. Fink, N.M. Ryan, S.D.</p> <p>1988</p> <p><u>Heart & Lung</u>, 17(4),349-355</p> | <p>Purpose: To determine from patients undergoing coronary artery bypass their perceptions of the importance and adequacy of preparation regarding preoperative and postoperative information</p> | <p>quantitative -2 questionnaires- pre discharge and post discharge</p> <p>n= 100 for pre discharge questionnaires 81 men 19 women</p> <p>n= 54 post discharge questionnaires 46 men 8 women</p> | <p>Pre discharge Questionnaire</p> <ul style="list-style-type: none"> -following items were above the median for both importance and preparedness- explanation of the type of surgery, intensive care environment, deep breathing and coughing exercises (DB&C) <p>Post discharge Questionnaire</p> <ul style="list-style-type: none"> -patients ranked exercising at home in top third of all items for both importance and preparedness -patients also indicated that medication side effects, whom to contact with medication questions, diet planning, were highly important but feel is the lowest 1/3 in terms of the patients preparedness -limitations re sexual activity and potential emotional changes were ranked in the lowest 1/3 for both importance and preparedness -patients stated they were well prepared re limitations for lifting, driving, resting, purpose of medications, and formal exercise, but these items were not highly important for patients -patients who perceived pre discharge and post discharge teaching to be highly important also tended to feel well prepared -patients felt more prepared than necessary for events and activities before surgery, types of catheters/tubes, DB&C -after discharge patients felt more prepared than was necessary regarding exercise, incisional care, purpose and schedule of medications, activity limitations, the only item for which patients felt significantly less prepared than they wished was medication side effects -after discharge 30-40 year age group (n= 3)identified limitations re: driving, lifting and sex as less important than other age groups. They also felt less prepared in regards to limitations re: stair climbing driving, and exercising compared to other age groups. They also felt less prepared than older age groups re: whom to contact, incisional problems and medical concerns |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|-------------------|------------------|--|
| <p>Patient Perception of Cardiovascular Surgical Patient Education</p> <p>Grady, K.L. Buckley, D.J. Cisar, N.S. Fink, N.M. Ryan, S.D.</p> <p>1988</p> <p>Heart & Lung. 17(4), 349-355</p> | | | <p>-high school educated (n= 58) and college educated (n= 32) participants ranked importance and adequacy of information higher than did grade school level educated participants (n= 2)</p> <p>-men (n= 8) felt more prepared than women(n= 19) regarding type of surgery</p> <p>-after discharge, women (n=8) felt it was more important than men (n= 42) did to know whom to contact for questions regarding medications</p> <p>-men (n= 37) felt more prepared than women (n= 8) regarding emotional changes after surgery</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
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| Informational Needs and Preferred Time to Receive Information for Phase II Cardiac Rehabilitation Patient: What CE Instructors Need to Know | Purpose: 1) To describe the perceived importance of selected informational needs of cardiac patients during hospitalization & recovery 2) To determine at which time interval in the recovery phase patients wish to receive this information | Descriptive in Design modified tool derived from . ostomy teaching tool. non-probability sample n= 41 Myocardial Infarction or Coronary Artery Bypass Graft in the past 6 weeks- 6 months | -32/41 identified four informational items as very important: specific instructions on type and amount of activity/restrictions, what is normal and to be expected after cardiac event, medications, signs and symptoms of complications that need medical attention -most items were rated as either very important or important -informational needs that were most cited related to experience before, during, and after surgery/heart attack, for example dietary modifications self care after return to home and involvement with partner or family in teaching program -20/31 respondents perceived the following as very important pre and post operative care items in addition to health promotion topics regarding cardiac risk factors, diet, Coronary Artery Disease, and involvement of the partner/family -least important was sexual function - any additional information-more specific information regarding discharge, diet and exercise - majority of information items should be taught after the cardiac event but prior to discharge |
| Hanisch, P. 1993 | | | |
| <u>The Journal of Continuing Education in Nursing</u> , 24(2), 82-89. | Combination of Maslow's Hierarchy of Needs and Lazarus' Theory of Coping | | |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
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| Post MI Patients' Perceptions of Their Learning Needs Wingate, S. 1990 Dimensions of Critical Care Nursing, 9(2), 112-119 | Purpose: To compare the post MI patients perception of their learning needs at different time frames during recovery Knowles' Theory of Andragogy | quantitative Questionnaire- Cardiac Patient Learning Needs Inventory(CPLNI) Convenience sample n=32 22 males 10 females age range 37-84 mean age=57.7 years | -patients' perceptions of learning needs varied in different stages from Coronary Care Unit(CCU) to Post Coronary Care Unit (PCCU) to home. -in hospital scores were significantly higher than the home scores. -learning needs were perceived to be greater in hospital than at home -at home, patient selected risk factors, mediation and anatomy and physiology as most important -anatomy and physiology scores were significantly higher during the hospital phase than during the home phase but still ranked third. -medication information scored significantly higher for PCCU, and home than for CCU -risk factors were first priority of CCU and home-items in this category included what factors contribute to the onset of heart disease, how to reduce recurrence of heart attack, and how risk factors affect the heart |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
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| <p>Post Hospitalization Concerns of Medical-Surgical Patients</p> <p>Boyle, K. Nance, J. Passau Buck, S.</p> <p>1992</p> <p><u>Applied Nursing Research</u>, 5(3), 122-126</p> | <p>Purpose: To identify the concerns of medical- surgical patients within the first 4 months after hospitalization</p> | <p>Descriptive Study Survey Design Questionnaire 12 items</p> <p>convenience sample n=150 approximately half male and half female</p> <p>100 surgical patients 50 medical patients</p> | <p>-67% concerned about understanding the progress they are making -66% deciding how much activity is good -61% knowing that their insurance pays -52% knowing what to expect from the medications -51% knowing how to control pain -49% knowing when to consult the doctor -23% all items on the questionnaire were of concern to them</p> <p>Gender and Age -statistically significant differences in two items - women were concerned with insurance and getting help with cooking or housekeeping -under age 45 more concerned with pain control -under 25 and over 65 concerned with understanding the progress they were making</p> <p>Length of Hospital Stay and Type of Treatment -<3 days and >2 weeks-knowing how to control pain -> 1 week having a nurse visit to give them care -surgical patients-more concerned with pain control and activity resumption</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
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| <p>Identifying Discharge Concerns</p> <p>Leyder, B.L. Pieper, B.</p> <p>1986</p> <p>AORN, 43(6), 1298-1304</p> | <p>Purpose: To explore post operative patients' concerns about their discharge to their homes</p> | <p>quantitative- 25 item Discharge Concerns Questionnaire (DCQ) anxiety measured by Profile of Mood States administered one week prior to and one week after discharge</p> <p>n=30 13 men 17 women</p> <p>age range 19-79 mean age 51.8 years</p> <p>93% Caucasian 77% married 84% high school education or higher 79% earned \$15,000 or more per year</p> | <p>-items with the highest score before discharge and one week home were similar. These include: which foods might upset the stomach, how active to be after returning home, what to do for discomfort, and differentiating between normal and abnormal changes associated with surgery</p> <p>-areas of highest concern were related to physical activity post operatively</p> <p>-comparison between total DCQ scores before discharge and at home showed a high congruency existed-patients were able to identify their concerns before going home</p> <p>-age and discharge concerns were related</p> <p>-older patients identified less concern that younger patients</p> <p>-educational level was related to discharge concern-as the number of years of education increased, greater concern was identified-anxiety scores correlated highly with DCQ scores-the greater the anxiety score, the greater the expressed discharge concerns</p> <p>-men and women did not significantly differ in their expression of discharge concern</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
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| Homeward Bound Vaughan, B. Taylor, K. 1988 <u>Nursing Times</u> , 84(15), 28-31 | Do patients get the information they require regarding everyday concerns to get them through the convalescent period | questionnaire-using both open and closed ended questions five main sections were general wellbeing, wound management, specific personal functions, specific general functions, and recovery sent to patients one month post discharge n=64 age range 18-70 years | General Issues of Feeling of Wellbeing -28% felt tired -17% felt anxious and insecure -21% in some degree of pain -70% felt they needed help in the first few days following discharge Wound Healing -59% knew when their wound could safely get wet, 13% did not know and 28% were not sure -67% knew if their wound was healing properly, 13% did not, 20% were not sure Activities of Daily Living -bathing-29% either unsure or did not know when they could safely bath, 30% had difficulty getting in and out of the bath tub -dressing-18% had difficulty getting dressed, 30% had some problems getting comfortable clothing -eating-64% returned to their normal eating patterns, 26% were not sure if their diets were appropriate to aid in their recovery -25% had indigestion, 24% bloated, 22% poor appetite, 18% nausea-bowels-27% had difficulties with their bowel function -sleeping-23% had difficulty in returning to their normal sleep pattern -sexual activity-only one person was given advice and that was to 'take it easy' -a final question was asked to seek the patients recommendations they had in light of their experience. Advice was sought on the rate and pattern of recovery, the do's and don'ts which would aid recovery, the tiredness and potential loneliness |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
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| <p>Patient Concerns After Discharge from Rehabilitation</p> <p>White, M.J. Halloway, M.</p> <p>1990</p> <p><u>Rehabilitation Nursing</u>, 15(6), 316-318</p> | <p>Purpose: to assess the patients' post discharge concerns, as measured by phone calls.</p> | <p>A check list was developed for categorization of problems reported in phone calls from patients or significant others</p> <p>n=79 29% within 2 weeks of discharge 56% discharged 2 weeks-3 months 6% discharged 3-6 months 9% discharged 9 or more months</p> | <p>-medications were questioned most by patients two weeks to three months post discharge as well as by patient six months or more after discharge</p> <p>-major concern-felt like they were taking too many meds, questions regarding drug interactions, rationale for taking drugs</p> <p>-patients discharged within two weeks-asked regarding urinary care and management, change in catheterization times and what to do in special instances-how to integrate information from hospital to home</p> <p>-within two weeks since discharge-respiratory questions and concerns about caretakers</p> <p>-2 weeks to 3 months-medications then skin management and bowel programs</p> <p>-3-6 months-skin management-prevention</p> <p>-6 months or greater 4/6 callers had medication questions</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
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| <p>Needs of Recovering Cardiac Patients and their Spouse's Compared Views</p> <p>Moser, D.K. Dracup, K.A. Marsden, C.</p> <p>1993</p> <p><u>International Journal of Nursing Studies</u>, 30(2), 105-114</p> | <p>Purpose: 1) To describe the importance of selected need to recovering cardiac patients and their spouses 2) To compare the importance ascribed to these needs by the cardiac patients and their spouses 3) To determine whether these needs were met</p> | <p>questionnaires- mailed 28 items listed as need statements</p> <p>Convenience sample of 49 patients and spousal pairs</p> <p>82% male mean age 62+/-13 mean years of education 14.5 +/-3 56% post myocardial infarction 56% post coronary artery bypass graft surgery 28% post angioplasty 82% of spouses- female mean age 59 +/-12 years mean years of education 14.6 +/- 3</p> | <p>Patient Ranked Needs</p> <ul style="list-style-type: none"> -highest-were informational regarding: specific facts about their condition, care, expected physical course after cardiac event, and general course of the disease process, lifestyle changes, and how to make them. -information needed to be given in understandable terms, having their family member receive information on what to do in an emergency. -speaking to a physician or nurse about problems was also ranked very highly.-needs ranked that were not informational included hope for a high QOL and feeling valued by family -intermediate-recovery information about the return to sexual activity -lowest-spending time away from family members, and talking to others going through the same experiences <p>Spouses Ranked Needs</p> <ul style="list-style-type: none"> -highest-included many of the same informational needs ranked highest by patients. Highest was what to do in case of an emergency, receive information about feelings or emotions they may have during the patients recovery, and to have time away from the patient without worrying. -intermediate-included need to feel as if others have the spouses welfare in mind, and to talk to someone about fears and feelings during the recovery period. -lowest-included recovery information about the return to sexual activity and receiving help with household errands and financial concerns <p>Discrepancies</p> <ul style="list-style-type: none"> -although many discrepantly rated needs were ranked highly by both patients and spouses, such as need for information regarding emergencies and the expected physical course, and the need to feel appreciated by the other family member, spouses attached significantly more importance to them. |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|--|-------------------|------------------|---|
| <p>Needs of Recovering Cardiac Patients and their Spouse's Compared Views</p> <p>Moser, D.K. Dracup, K.A. Marsden, C.</p> <p>1993</p> <p><u>International Journal of Nursing Studies,</u> <u>30(2),</u> <u>105-114</u></p> | | | <p>Discrepancies</p> <ul style="list-style-type: none"> -needs that were rated highly by spouses, but that patients found less important, included receiving information about feelings the spouses may have had during the patients' recovery period, having time alone or time away from family members, talking with the patient about concerns, and receiving information about the patients' expected psychological course. <p>Unmet Needs</p> <ul style="list-style-type: none"> -greater than 70% of both patients and spouses reported not receiving need information about dealing with an emergency -other information needs about lifestyle changes, knowing specific facts about care, expected physical and psychological course and sexual activity were unmet with 40-70% of both patients and spouses -spouses reported a high incidence of unmet emotional support needs, such as having time away from the patient and talking to someone about their fears and feelings. |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
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| Comparison of Patients' and Spouses' Needs During the Post Hospital Convalescence Phase of a Myocardial Infarction | Purpose: To determine the importance of cognitive and affective needs and their sub categories of needs in patients and spouses and to compare those needs between spouses and patients | Needs Assessment Questionnaire (NAQ) 40 item self administered 20 questions pertained to cognitive needs 20 questions referred to affective needs | Affective Needs Patients -two highest scoring needs-"It is important for me to be able to depend on my spouse" and "it is important for someone to be concerned about my wellbeing." Spouses -two highest scoring needs centered around the patients' wellbeing -"It is important for medical personnel to attend to the physical and emotional needs of my spouse" and "I need to be able to be helpful to my spouse" -two lowest scoring needs were ones that the patients also had -"I need to be encouraged to cry" and "I need to keep my feelings to myself." |
| Orzeck, S.A. Staniloff H.M. 1987 | | n= 40 men mean age of patients =61 age range 32-80 years mean age of spouses =56 age range 35-86 years average years of marriage 29 | Cognitive Needs Patients -the following were rated as high-information related to receiving factual information regarding heart disease in general and one's own heart disease, having questions answered honestly and knowing what exercises are helpful and what can be harmful to the heart. Spouses -highest scoring means-related to understanding factual information on heart disease, questions answered honestly, knowing what to do in an emergency, effects of exercise or the heart and preventing another MI. -each cognitive need was considered important except for "It is important to discuss financial problems with someone." -the second lowest scoring need related to receiving information on open heart surgery. |
| <u>Journal of</u> <u>Cardiopulmonary</u> <u>Rehabilitation,</u> <u>Z(2), 59-67</u> | | | |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|--|-------------------|------------------|--|
| <p>Comparison of Patients' and Spouses' Needs During the Post Hospital Convalescence Phase of a Myocardial Infarction</p> <p>Orzeck, S.A. Staniloff H.M.</p> <p>1987</p> <p><u>Journal of Cardiopulmonary Rehabilitation</u> 7(2), 59-67</p> | | | <p>Prognostic Needs</p> <p>-all program needs were considered important by both patient and spouse.</p> <p>Patients</p> <p>-highest-"I need to know if I will ever be back to my previous lifestyle again" and "I need to hear my prognosis."</p> <p>-lowest scoring-"I need to feel there is hope and the need to maintain one's role within the family."</p> <p>Spouse</p> <p>-all in this category considered important but knowing one's own role in the family was rated lower by spouse than by patients.</p> <p>Preventive Needs</p> <p>-all were important by both patients and spouses.</p> <p>Patients</p> <p>-3 questions with highest score-"I need to know what to do in an emergency situation." "It is important to know which exercises are helpful and which are harmful to the heart." "I need to know what can be done to prevent another MI."</p> <p>Spouses</p> <p>-two highest scoring "What to do in an emergency situation, and prevention of another MI."</p> |

APPENDIX E

TABLE IV

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|-------------------|------------------|--|
| <p>Learning Needs of Persons with Epilepsy: A Comparison of Perceptions of Persons with Epilepsy, Nurses & Physicians</p> <p>Dilorio, C. Faherty, B. Manleuffel, B.</p> <p>1993</p> <p>Journal of Neuroscience Nursing, 25(1), 22- 29</p> | | | <p>Anatomy and Physiology</p> <ul style="list-style-type: none"> -patients believed "what causes seizures" was the most important learning need. -nurses and physicians rated "what happens when one has a seizure as the most important. -patient ranked "why I have a seizure" higher than did physicians and nurses. <p>General Lifestyle Information</p> <ul style="list-style-type: none"> -nurses and physicians agreed that "when to call a doctor" was the most important learning need. -patients felt knowing the results of medical tests was the most important learning need. -patients rated "ways to make a home a safer place" much lower than physicians or nurses. <p>Four Items Ranked Higher by Patients than by Nurses and Physicians</p> <ul style="list-style-type: none"> - "lowering chances of having a seizure" - "side effects of medications" - "results of medical tests" - "causes of seizures" <p>Items Ranked Higher by Nurses and Physicians</p> <ul style="list-style-type: none"> - "general rules about taking medication" - "name of seizure medication" |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|---|---|---|---|
| <p>Learning Needs of Cancer Patients: A Comparison of Nurse and Patient Perceptions</p> <p>Lauer, P. Murphy, S.P. Powers, M.J.</p> <p>1982</p> <p><u>Nursing Research</u>, 31(1), 11-16</p> | <p>Purpose: To discover and compare patients' and nurses' perceptions of the learning needs of cancer patients.</p> | <p>Questionnaire made up of three sections</p> <p>1) Interview Guide- collected data on nurse and patient characteristics</p> <p>2) Questionnaire- topics of nutrition, chemotherapy, radiation side effects, financial concern, and diagnostic testing</p> <p>3) Three questions concerning cancer patients' learning needs</p> <p>n=27 pts. 15 female, 12 male 9 married, 18 single age range 30-81</p> <p>n= 33 nurses</p> | <p>General Information Items</p> <p>Nurses- highest mean ratings assigned to:</p> <ul style="list-style-type: none"> -availability of financial assistance, caring for self at home, and discussing concerns with family and friends <p>Patients- highest mean ratings assigned to:</p> <ul style="list-style-type: none"> -knowing the diagnosis, plans of care, caring for themselves at home and work, and what would they experience during the diagnostic procedures <p>Treatment Information Items</p> <ul style="list-style-type: none"> -nurses rated a significantly higher mean importance for the radiation items than did the patients -nurses ranked the importance of learning the purpose of chemotherapy relatively low - patients ranked it high -nurses considered knowledge of the effects of chemotherapy a high priority - patients ranked it low -nurses ranked learning about skin care following radiation therapy high - patients did not find this important -nurses did not perceive the same priorities for patient learning |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
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| <p>Patient Education Needs As Reported by Congestive Heart Failure Patients and Their Nurses</p> <p>Hagenhoff, B.D. Feutz, C. Conn, V.S. Sagehorn, K.K. Moranville- Hunziker, M.</p> <p>1994</p> <p><u>Journal of Advanced Nursing</u>, 19(4), 685-690</p> | <p>Purpose: To examine patients' and nurses' perceptions of the importance of educational content for patients with CHF in a hospital setting</p> | <p>Survey Congestive Heart Failure Patient Learning Needs Inventory (CHFPLNI), an adaptation of CPLNI 44 content items addressing cardiovascular anatomy and physiology, psychological concerns, stress control, risk factors, information regarding medications, dietary, physical activity, and miscellaneous information</p> <p>n=30 patients n=26 nurses</p> <p>mean age of patients 68 years male 67%</p> | <p>-patients rated medication information as the most important category of knowledge, followed by anatomy and physiology and then risk factors. These areas were also rated as the most realistic to learn while hospitalized</p> <p>-nurses rated risk factors and medication as most important categories followed by diet also rated as most realistic to learn while in hospital</p> <p>-patients rated activity information as least important to learn-nurses rated A&P significantly lower than patients did with both important and realistic to learn</p> <p>-patients rated medication significantly higher than nurses with importance but no difference in realistic rating was found</p> <p>-patients rated the category of other as significantly more important than the nurses. This category included taking pulse, future testing, out patient testing, signs of other heart problems, where to learn CPR, why oxygen is needed for congestive heart failure, and when to call a physician</p> <p>-one content item "to learn what I can do to reduce stress in the hospital" was reported as important but unrealistic to learn by at least 10% of sample</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
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| <p>Learning Needs of Cardiac Patients</p> <p>Gerard, P.S. Peterson, L.M.</p> <p>1984</p> <p>Cardiovascular Nursing, 20(4), 7-11</p> | <p>Purpose: To examine patients and nurses perceptions of the importance of learning needs in an effort to learn how congruent these perceptions were.</p> | <p>Cardiac Patient Learning Need Inventory (CPLNI) 43 items-8 categories introduction to the CCU, cardiovascular anatomy and physiology, psychological concerns, risk factors, information about medications dietary information, physical activity, and miscellaneous information</p> <p>Educator Preference Tool(EPT)</p> <p>n=31 patients age range 35-84 years n= 36 nurses 20 from CCU, 16 from post CCU</p> | <p>-CCU nurses rated A&P significantly higher than did post CCU nurses -CCU nurses rated medications significantly higher than CCU patients -patients ranked risk factors as most important-nurses ranked this category behind most other categories -A&P was less important to CCU patients than to post discharge patients -activity was far more important to CCU patients than to post discharge patients -both patients and nurses ranked diet as least important -both patients and nurses ranked items dealing with what to do with chest pain and signs and symptoms of angina or M.I. as most important. "When to call a M.D. and what to do with medication problems were ranked similarly as very important Differences with Ranks Nurses and Patients -patients considered how to decrease chances of another M.I. and how to tell when to increase activity, effects of stress on the heart and what activity restrictions applied to [them] as more important topics. Nurses considered these less important than other contact areas -nurses considered of highest importance: signs and symptoms of CHF, general rules regarding medications, why each medication was taken, why patients had chest pain, why activity was limited and how to take a pulse. Patients ranked these items as relatively less important. -these ratings indicate that the nurses believed reasons were more important. -CCU related information of lesser importance included explanations about the usual procedures and policies of the CCU and reasons for having an IV line -within the A&P category, patients believed that what the heart looked like and how it functions were of lesser importance -the only item considered of lesser importance in the psychological information category was talking to someone about fears, feelings and thoughts -diet-patients and nurses believed that 3/5 items were of lesser importance, general rules about eating, diet restrictions, how to adapt the diet to one's lifestyle -activity scale 1/6 rated of lower importance - when to engage in sexual activity</p> |

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| <p>Learning Needs of Cardiac Patients</p> <p>Gerard, P.S. Peterson, L.M.</p> <p>1984</p> <p>Cardiovascular Nursing, 20(4), 7-11</p> | | | <p>-within the A&P category, patients believed that what the heart looked like and how it functions were of lesser importance</p> <p>-the only item considered of lesser importance in the psychological information category was talking to someone about fears, feelings and thoughts</p> <p>-diet-patients and nurses believed that 3/5 items were of lesser importance, general rules about eating, diet restrictions, how to adapt the diet to one's lifestyle</p> <p>-activity scale 1/6 rated of lower importance - when to engage in sexual activity</p> <p>-miscellaneous-how to take a pulse and post discharge testing were considered of lower relative importance.</p> |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|--|--|---|---|
| <p>Learning Needs of Cardiac Patients: A Partial Replication Study</p> <p>Karlik, B.A. Yarcheski, A.</p> <p>1987</p> <p>Heart & Lung, 16(5), 544-551</p> | <p>Purposes:</p> <p>1) to replicate in part the study concerning learning needs of patients with cardiac disease</p> <p>2) to identify a possible source of practising nurses' beliefs regarding the learning needs of these patients by studying nurse educators rather than post CCU nurses.</p> | <p>Instruments</p> <p>CPLNI</p> <p>Education Preference Tool (EPT)</p> <p>n= 30 patients age range 38-78 24 males, 6 females 15 patients from CCU 15 post discharge patients</p> <p>n=30 nurses 15 nurses from CCU 15 nurse educators</p> | <p>CPLNI</p> <ul style="list-style-type: none"> -the category of medication was rated significantly higher by the CCU nurses than the CCU patients -both CCU and post discharge patients ranked the category of risk factors as most important to learn and the psychological category as least important -CCU nurses and nurse educators ranked the category of medication as most important to learn and the A&P category as the least important <p>Both Studies:</p> <ul style="list-style-type: none"> -mean for A&P for CCU patients were almost identical -means for diet for post discharge patients identical -means obtained on the informational categories of psychological, risk factors, and medications were identical or almost identical for CCU nurses -across patient groups risk factors were ranked as highest in importance to learn -CCU patients ranked miscellaneous category as fifth in importance and post discharge ranked A&P third in importance -across nurse groups, medications were ranked as highest in importance for patients to learn -across all groups "what to do for chest pain" was ranked as the most important need item and "When to call a M.D." was also ranked high in importance by all groups in both studies -patients considered "What to do to decrease chances of another MI as very important, nurses considered this as less important -both studies patients also ranked how risk factors affect the heart as much more important than did nurses -nurses considered "why each medication is being taken" as more important than did patients. |

| Title Author Date/Journal | Research Question | Design Sample | Findings |
|--|--|---|---|
| <p>Educational Needs of Patients Undergoing Hemodialysis: A Comparison of Patient and Nurse Perceptions</p> <p>Goddard, H.A. Powers, M.J.</p> <p>1982</p> <p><u>Dialysis and Transplantation</u>, 11(7), 578-583</p> | <p>Purposes:</p> <p>1) to explore the chronic renal failure patient's perception of the importance of specific informational items related to kidney disease and treatment</p> <p>2) to explore the nurse's perception of the importance of these same educational items</p> <p>3) to identify areas of agreement and disagreement between nurses and educational needs of hemodialysis patients</p> | <p>Educational Scale</p> <p>31 items grouped into 9 categories:</p> <p>medications, blood pressure, diet and fluids, prevention of infection, care of fistula, mechanism of dialysis, adherence of medical orders, disease process, and activities.</p> <p>Communication Scale</p> <p>14 items-administered only to patients</p> <p>n=24 patients, 16 men, 8 women age range 40-65 years n=9 nurses</p> | <p>-nurses rated the informational needs of hemodialysis patients significantly higher overall than did the patients themselves</p> <p>-nurses rated the categories of blood pressure, diet and fluid, prevention of infection, and care of fistulas as significantly more important than did patients</p> <p>-items related to diet and fluid restrictions were ranked highest with patient teaching importance with the nurses</p> <p>-preventing injury to the fistula, avoiding constriction of the fistula arm and avoiding infection were highest educational priorities for patients</p> <p>-information concerning the disease process was ranked lowest in importance by nurses and was of little concern to patients</p> <p>-patients were least interested in teaching related to machine operation and meal planning</p> <p>-nurses and patients differed significantly in overall perceptions of educational needs</p> <p>-the greatest area of difference between nurses and patients pertained to diet and fluid restriction</p> <p>-nurses ranked the highest priority to four of the five diet and fluid restriction items-none of these areas were granted the highest educational priority by the patients</p> <p>-patients ranked the item "have to avoid infection" as second in importance-</p> <p>nurses rated prevention of infection significantly higher-patients found it more important than nurses to know about medications and the side effects of them.</p> <p>-information related to disease process and activities was rated least important by both patients and nurses</p> |

APPENDIX F
LETTER OF INVITATION



School of Nursing
T206-2211 Wesbrook Mall
Vancouver, B.C. Canada V6T 2B5

Tel: (604) 822-7417
Fax: (604) 822-7466

LETTER OF INVITATION

Learning Needs of Liver Recipients During Convalescence

Dear Sir/Madam,

My name is Elaine Beyer, I am a Registered Nurse and a student in the Master of Science in Nursing program at the University of British Columbia. I am conducting a research study as part of my education program. I am inviting you to participate in my research study which will identify what learning needs you had while you were recovering at home from your operation. It does not matter whether you have had your operation two weeks ago or six years ago. Your experience is a valuable part of the study.

The study will require you to be interviewed for approximately one to two hours by me either in your home or in a conference room at the Transplant Clinic. Another interview of the same length will be needed in order to clarify some aspects from the first interview. Upon completing the study, you will be invited to attend a group meeting with those who have participated in my study so that I may share with you my findings and you will be able to respond to them. The maximum total number of hours required of your participation will be approximately five.

All interviews will be tape recorded and typed. You will receive a copy of your interviews so that you may review it and elaborate or change any aspects of them.

At the end of the first interview, a few questions regarding background information will be asked, such as date of your surgery.

At any time you may decide to have the tape recorder turned off or portions of your interview erased. You may withdraw from the study at any time and if you do so, it will not affect your medical or nursing care.

Your name will not be used nor will it be associated with the study at any time. Your transcripts will only be identified by a code number assigned to you known only by the researcher. Your participation in this study will remain confidential.

You may refuse to participate in this study. Your refusal will in no way affect your present or future medical or nursing care.

If you wish to participate please call Elaine Beyer at XXX-XXXX

Thank you for your time.

Elaine Beyer R.N., B.N.
XXX-XXXX (H)

Dr. Barbara Paterson R.N., PhD.
Assistant Professor
School of Nursing
University of British Columbia

APPENDIX G
CONSENT FORM



School of Nursing
T206-2211 Wesbrook Mall
Vancouver, B.C. Canada V6T 2B5



Tel: (604) 822-7417

Fax: (604) 822-7466

CONSENT FORM

Title: Learning needs of liver recipients during convalescence.

| | | | |
|--------------------------------|---|------------------------|--|
| Principal Investigator: | Elaine Beyer R.N., B.N. Graduate Student School of Nursing University of British Columbia Telephone (H) XXX-XXXX (S) XXX-XXXX | Thesis Advisor: | Dr. B. Paterson R.N., Ph.D. Assistant Professor School of Nursing University of British Columbia (W) XXX-XXXX |
|--------------------------------|---|------------------------|--|

You are invited to participate in a research study which will identify what learning needs you had while you were recovering at home from your operation. The research study will involve two interviews and one group session. The estimated time commitment required will be approximately five hours. Your participation in this study is totally voluntary.

The study consists of an initial interview lasting one to two hours. You will then receive a copy of the interview and you may revise or elaborate on anything you feel is necessary. A second interview will be necessary to clarify topics discussed in the first interview. Once the study is completed, you will be invited to attend a group meeting lasting approximately one hour with those who have participated in the study so that the findings may be shared and discussed. All interviews will be tape recorded.

Your name will not be used on any transcripts or tapes. Your transcript will only be identified by a code number assigned to you and known only to the researcher. Only the researcher will have access to both the transcripts and tapes and her advisor will have access to the transcripts. The transcripts and tapes will be kept in a locked filing cabinet, accessible only by a key held by the researcher. The tapes and transcripts will be erased/shredded within 10 years following completion of the study. The findings of this study will be published; however, your name will in no way be associated with the study.

You may withdraw from the study at any time and if you do so, it will not affect your medical or nursing care.



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Fax: (604) 822-7466

There are no known risks if you participate in the study. If you do agree to participate, you will contribute information that may benefit other patients who are recovering from liver transplantation.

If you have any questions prior to signing the consent you may contact my thesis advisor Dr. Barbara Paterson regarding any aspects of the study that are unclear. Myself, Elaine Beyer or Dr. Paterson are available prior to, during, and following the study to answer any questions you have about the study.

Authorization

I _____, have read and decided to participate in the research study described above. My signature indicates that I give permission for information I provide in interviews to be used for publication in research journals/articles/books as well as for presentation at research symposia as well as secondary analysis of the data.

Additionally, my signature indicates that I have received a copy of the consent form.

Signature _____

Date _____

Witness _____

Date _____