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UNIVERSITY OF ALBERTA

LIVING WITH A LIVER TRANSPLANT

by

GLENDA ANNE MEEBERG ©

A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of
MASTER OF NURSING

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FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **LIVING WITH A LIVER TRANSPLANT**, submitted by **GLENDA ANNE MEEBERG**, in partial fulfillment of the requirements for the degree of **MASTER OF NURSING**.

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Vince G. Bain

Date: April 28, 1992

DEDICATION

This thesis is dedicated to two very special people in my life:

- To Gord, my wonderful husband, for giving me the confidence to undertake this thesis, for sharing his computer expertise, and particularly for his continuous love and support.
- To my father, for always providing me with helpful advice and encouragement, and for his assistance in editing this thesis and many other papers over the years.

ABSTRACT

The purpose of this study was to describe what life for liver transplant recipients is like. An inductive, exploratory-descriptive approach was employed. Unstructured interviews were used to gain the necessary information from seven adult liver transplant recipients. After a content analysis of these interviews, ten categories which provided a description of recipients' lives after their transplants were formulated. These categories are as follows: (1) thinking about the transplant, (2) mental activity, (3) physical activity, (4) health/normalcy, (5) caring for health, (6) implications of medications and medical procedures, (7) appreciating life, (8) evolving relationships, (9) awareness of donors, and (10) moving ahead. The findings indicated that life after liver transplantation is much more positive than has generally been reported in the literature to date.

The recipients were happy with their lives, and never regretted having their transplants. They were pleased with their mental and physical function and felt healthy and normal. They tried to maintain a healthy lifestyle, which included taking prescribed medications and having ongoing follow-up care. Therapeutic regimes, or the side effects from them, did not distress recipients. Nor did recipients have trouble adapting to their new body image. They had a great appreciation for life and for the donor who had given them life, and most had closer relationships with friends and family because of going through the transplant experience. Recipients were more conscientious

than they had been before their transplant about helping other people in need. As well, they were enthusiastic about signing their own organ donor cards and about encouraging others to do the same. In general, they viewed the future with optimism.

The conclusions from this research can assist nurses, and other health care professionals, particularly those who rarely see recipients after discharge, to improve the quality of care they provide to them. As nurses learn what liver transplant recipients think regarding transplantation, how patients feel about themselves and their circumstances after discharge, and how they view the follow-up care given them, nurses will be able to more effectively meet patients' concerns and needs, and better prepare them for the future.

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My thesis supervisor, Dr. Anita Molzahn, gave me continuous support and guidance throughout the course of this study. The speed with which she read and returned the drafts of this thesis was much appreciated. Dr. Peggy-Anne Field provided helpful advice and insights into qualitative methods and stimulated my interest in nursing. Dr. Vince Bain supported this research throughout its development.

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Chapter 1: INTRODUCTION

Statement of the Problem

Liver transplantation has become a viable treatment option for individuals with end stage liver disease or fulminant hepatic failure. Although the first orthotopic liver transplant was performed on a human in the 1960s, it has not been until the last ten years that survival rates and other outcomes have warranted taking the risks associated with this procedure. The advent of more effective immunosuppressive agents, cyclosporine in particular, can be credited for this development (Starzl & Demetris, 1990).

Surgically, liver transplantation is a complex procedure. There are a number of anastamoses sites, which are all potential areas for complications. Moreover, the transplant recipient has multiple tubes and catheters exiting from various sites and each of these is a potential location for development of infection. Besides these factors, some recipients are critically ill even before they go into surgery.

Even after the initial stages of the procedure are over, liver transplant recipients are not guaranteed a positive outcome. There is always a threat of rejection of the graft. Thus, individuals who have received a transplant must remain on immunosuppressive medications for the rest of their lives. These drugs suppress the entire immune system so the person is more susceptible to infection.

Even minor infections are potentially lethal to the individual. In addition, the immunosuppressant agents have a number of unpleasant side effects. For example, steroids are associated with Cushingoid symptoms, mood swings, and depression. Cyclosporine therapy predisposes one to renal dysfunction, arterial hypertension, hirsutism, cataracts and fine resting tremor, among other problems. However, liver transplant recipients are living longer, and in better health, than before cyclosporine became available (Smith & Ciferni, 1990; Starzl & Demetris, 1990; Staschuk & Zamberlan, 1990).

Because liver transplantation is a relatively new procedure, there has been little research that evaluates what transplant recipients' lives are like. Most studies that have been carried out in this subject area have focused on easily quantifiable outcomes, such as survival rates or employment status. Very few researchers have considered psychosocial aspects of liver transplantation, and even fewer have looked at what recipients themselves think and feel about their lives posttransplant. Little is known about what the lives of transplant recipients are like after they are discharged.

It would be helpful for nurses to be aware of what it has been like for previous transplant recipients once they are at home. If descriptive data about the lives of individuals after liver transplantation were available, it would enable nurses to direct their care toward clients' perceived needs more effectively, to prepare clients emotionally for discharge, and to know how best to provide follow-up care. When one is trying to understand something as personal and individualized as peoples' thoughts and feelings about their lives, quantitative scales with standardized response choices may not provide the depth of data required for adequate assessment. The researcher was interested in how clients describe their thoughts and feelings about their lives in their own words. Therefore, inductively driven, qualitative data were necessary.

Purpose of the Study

The aim of this qualitative study was to gain an understanding of the thoughts and feelings of liver transplant recipients about their current lives.

Research Question

The research question that guided this study was "What is it like to live with a liver transplant?" as evidenced by recipients' descriptions of their thoughts and feelings about their lives at the times they were interviewed.

Significance of the Study for Nursing

A major reason given for doing organ transplants is to improve the quality of life of the recipients. A goal of nursing is to improve quality of life of individuals also. It is hoped that the findings of this study will provide some necessary groundwork for future research into the role of nurses in improving liver transplant recipients' lives. If nurses have a better understanding of what liver transplant recipients lives are like, from recipients' perspectives, they could use this data in several ways. Nurses could pass on such information to future liver transplant recipients to help them prepare for their transplant and to know what they may expect afterward. Also, it could enable nurses to provide more effective and client-focused follow-up care.

Overview of the Thesis

A literature review is presented in the next chapter to provide a profile of the literature published to date on the topic of life after liver transplantation. Chapter 3 describes the methods employed in this study. The findings are highlighted in Chapter 4. In Chapter 5, a discussion of the findings is provided in view of the literature. Chapter 6 includes implications for nursing practice, limitations of the present research, suggestions for future research and a brief summary of the thesis.

Chapter 2: OVERVIEW OF THE LITERATURE

Very little research has been done to describe the lives of people after they have had a liver transplant. However, when one examines the available literature on transplantation, three relevant types of data emerge. First, there are studies in which attempts have been made to describe patients' lives after liver transplant by looking at indicators such as independent functioning or return to work. Secondly, various researchers have made attempts at determining liver transplant recipients' quality of life. Finally, there is literature in which psychosocial aspects of transplantation are considered. These three bodies of literature will be discussed in this chapter.

Life after Liver Transplantation

Of the small number of published research studies that pertain to the lives of liver transplant recipients, none have really focused on letting patients express, in their own words, how they think and feel about their lives posttransplant. Instead, the studies derived their conclusions about recipients' lives from a variety of objective criteria regarding performance.

In one study (Robinson, Switala, Tarter & Nicholas, 1990), patients' functional outcomes after liver transplantation were examined. The researchers found that almost half of the 31 patients who responded to their questionnaire had some limitations in the functioning of their extremities, although very few needed assistance with activities of daily living, or with mobility. About two-thirds of these individuals were able to work after their transplant, whereas only a small number were working prior to transplantation because of problems such as lack of endurance, lack of concentration, or bone fractures. Based on these data, the authors concluded that liver transplantation enables patients to have "an active, successful, and satisfactory existence" (p.427). But, this does not indicate that the patients themselves thought this way about their lives.

In another study, by Esquivel and associates (1988), it was reported that the survival rate for transplant recipients 1 to 6.5 years posttransplant was 68% (although some of these people were retransplanted). The researchers commented favourably on the percentage of transplant recipients who returned to work (33% full time and 8% part time), and on the small number of patients who required assistance with their care at home postoperatively (4% compared with 50% preoperatively). They concluded that 94% of the individuals were "successfully functioning" post-transplantation. Again, however, the study does not indicate that patients were asked how they felt about their lives. In addition, the definition of the phrase "successful functioning" is not provided and could be questioned.

Iwatsuki, Shaw and Starzl (1985) wrote an article reporting the five year survival rates for the 170 recipients of orthotopic liver transplants at a particular hospital between 1963 and the first month of 1980. They stated that, "The actuarial survival rate at five years is 19.4%, and that at ten years is 17.9%" (p.259). It must be noted that cyclosporine was not available for any of these patients at the time of their transplant, although eight of them did receive this medication later on at some point during the course of their treatment. There was only a brief section in the article regarding the rehabilitation of the 33 recipients who were alive at least five years after transplantation. The researchers stated that 31 individuals either continued their education, or worked full-time or part-time within or outside the home. The authors concluded that except for two survivors, all were rehabilitated. However, the assessment of rehabilitation seems rather narrow and objective since return to work or education were the only factors considered. Based on these findings, the authors then stated that the quality of life of these individuals was satisfactory. However, it is questionable whether these results are reliable and valid indicators of what the recipients' lives were like posttransplant.

A book published by two physicians in 1990 was devoted entirely to the subject of liver transplantation, from its origins to the present time. However, only one page was allotted to the nature of patients' lives post-transplant (Starzl & Demetris, 1990).

In the field of nursing, two books have been written by nurses and for nurses. Both were published in 1990 and provide guidelines for post-operative nursing care of transplant recipients. In the chapters on liver transplantation, directives for nursing care centre on clients' medical problems, and are focused on the potential complications (Smith & Ciferni, 1990; Staschuk & Zamberlan, 1990). This is probably because there is so little information available describing the lives of liver transplant recipients. Nurses need more information to prepare such patients for discharge and to help them deal with their lives posttransplant. It is evident that the literature on liver transplant recipients' lives is incomplete and does not accurately reflect the satisfaction the recipients themselves have with their lives.

Quality of Life

In much of the research examining peoples' lives following a liver transplant, researchers have tried to measure quality of life. A major problem with such studies is that the term "quality of life" is infrequently and inconsistently defined.

In one early study, the researchers stated they were assessing liver transplant recipients' quality of life, but used very objective, quantifiable indicators for doing so (Starzl, Koep, Schröter, Hood, Halgrimson, Porter & Weil, 1979). They studied the quality of life of 44 recipients who lived at least one year after transplantation. The following four factors were examined: return to work or school, the dose of steroids, the amount of jaundice, and the percentage of time spent hospitalized. Although these may be good indicators of the subjects' health status, it is questionable whether they actually reflect quality of life. Certainly there is no indication that the subjects had any input into the assessment.

Another group of researchers (Tarter, Erb, Biller, Switala, & Van Thiel, 1988) defined quality of life as "a multidimensional construct that encompasses functional, behavioral and cognitive capacities, health status, emotional well-being and psychosocial adjustment" (p.216). They conducted two studies to determine the overall quality of life of recipients before and after liver transplantation, one with liver transplant recipients, and another with the recipients' significant other. The researchers administered several scales that had graded response choices. In the first study, the 10 recipients who completed the scales were, on average, three years posttransplant. In the second study, an unspecified number of patients and their significant others were assessed before the transplant and then again an average of two years posttransplant. They concluded that liver transplant recipients obtain normal, or close to normal, functioning in terms of cognitive abilities, health and emotional status, and competency relating to social, vocational, and behavioural skills. However, they found that some indicators of hepatic encephalopathy are still present three years after transplantation. These researchers reported that transplant recipients have a significant improvement in quality of life from their pretransplant state, although they never obtain the quality of life they had prior to developing liver disease.

In this study, respondents were able to choose only from the set of responses listed on the questionnaires. Thus, one wonders whether they might have had other thoughts and feelings than the responses available to them. The data suggested that recipients' quality of life improved after having a liver transplant. Still, they did not indicate whether those individuals were truly happy with their lives. The subjects were also not able to indicate whether their lives were better posttransplant than prior to the development of liver disease. The reliability and validity of the tools used were not discussed in the study either.

In a somewhat similar study, 26 liver transplant recipients responded to a questionnaire using a Likert scale to quantify symptom frequency, symptom distress, and quality of life (Foley, Davis & Conway, 1989). Among other questions, respondents rated their current quality of life, change in quality of life since their transplant, and expectations for future quality of life. An average quality of life and product of quality of life were then computed using an equation developed by the authors. The authors of the article stated that recipients obtained high scores on these scales, and thus concluded that the subjects had a good quality of life.

However, the reliability and validity of the scales, and the quality of life equation, were not discussed or demonstrated.

Another group of researchers studied liver transplant recipients' cognitive function and quality of life (Wolcott, Norquist, & Busuttil, 1989). Forty-one out of sixty possible participants engaged in the study. Data suggested that liver transplant recipients have a high current quality of life. Yet, it was also found that for most recipients, certain cognitive functions are abnormal post-transplant, and may not improve over time. A problem with this study is that the researchers did not even attempt to define quality of life. Quality of life was measured indirectly by asking respondents questions about their personal health status and psychosocial status. This leaves one with some concerns about the validity of their conclusion that quality of life improved.

Küchler, Kober, Broelsch, Kremer, and Henn-Bruns (1991) attempted to assess the quality of life after liver transplantation in a comprehensive, multidimensional manner. They stated that, "quality of life research must focus not only on the physical condition but also on psychological and social conditions of patients under treatment" (p. 94). Liver transplant recipients from two different transplant centres in different countries were the subjects. In one centre, a cross-sectional design with 38 patients was used, along with two control groups: patients with chronic liver disease, and healthy individuals. In the other centre, a longitudinal design was used to study 29 patients. Subjects completed a questionnaire and also were interviewed. The researchers reported that their instrument had face validity and stated that, as there were no significant differences between the two differing research designs used, they could compare the studies.

In the study as a whole, transplant recipients demonstrated a marked increase in their quality of life posttransplant, as well as in the self-evaluation of their physical condition. Overall, recipients had fewer general symptoms, and their anxiety scores were lower than were the scores of the patients with chronic liver disease. But these ratings were still significantly higher than those for healthy individuals. Family support was reported to be an important factor in the early posttransplant period by all patients. Certainly the study provides valuable information about what the lives of liver transplant recipients are like. However, data that provide insight into what liver transplant recipients _feel_ about their lives would also have been beneficial.

There is only one published study (Tymstra, Bucking, Roorda, & Van Den Heuvel, 1986) in which a qualitative approach was used to study the lives of liver transplant recipients, particularly the quality of their lives. Eighteen patients (or their families if the patient had died) were interviewed either before or after transplantation to determine the psychosocial effects of liver transplantation. The researchers concluded that depression was common in the transplant recipients, and many recipients were bothered by changes in their physical appearance caused by the medications, and by the inability to find work. However, this study focussed more on the reactions of individuals to the liver transplant program than on what they thought and felt about their lives.

From the preceding literature, it is evident that quality of life of liver transplant recipients is better than quality of life in the pretransplant state. Nevertheless, although overall quality of life may be better, an accurate description of what the lives of liver transplant recipients are like is still lacking.

Psychosocial Aspects of Transplantation

There is little discussion in the literature of the psychosocial aspects of life following liver transplantation. However, somewhat more literature is available if one also considers the work done relating to heart, lung and kidney transplantation.

In most articles, a number of different psychosocial concerns of transplant recipients are discussed. This review is organized in relation to various psychosocial considerations. In each section, the descriptive articles are discussed first, and then the research studies are assessed. The six most frequently identified psychosocial aspects of transplantation are: (1) changes in body image; (2) fear of rejection; (3) complications and concerns regarding medications; (4) hospital-related concerns; (5) uncertainty about the future; and (6) changes in family, social or vocational roles and related income losses. The literature on each of these topics is considered in turn. Subsequently, positive psychosocial aspects of transplantation for recipients are briefly discussed.

Psychosocial Concerns after Transplantation

Changes in Body Image. Of the 24 articles reviewed, concerns about changes in body image were mentioned most frequently. Craven, Bright and Dear (1990) described psychiatric, psychosocial and rehabilitative stressors associated with lung transplantation, and briefly mentioned that changes in body image were adjustments that lung transplant recipients had to make. However, they did not elaborate and no research was cited, so it is unclear just what the recipients faced in terms of changes in body image. Futterman (1988) also indicated that body image changes can be one source of physical and/or emotional stress for cardiac transplant recipients. As in the previous article, this statement seemed to have been based on personal experience rather than on research, and was not developed any further. Sheets (1989), in a descriptive article about liver transplant recipients, mentioned that alterations in body image and self-concept are potential sources of either short-term or long-term difficulty, particularly for adolescent girls. The changes said to cause such difficulties were "acne, hirsutism, weight gain, and fullness in the face" (p.887). However, no research was cited to corroborate this statement.

Surman, Dienstag, Cosimi, Chauncey, and Russell (1987) wrote an article on psychiatric considerations pertaining to liver transplantation. In their experience with liver transplant recipients, impairments in body image were uncommon. However, they did state that an altered body image was a factor leading to depression and noncompliance in one adolescent transplant recipient under their care. Similarly, Lough (1986) stated that changes in physical appearance resulting from immunosuppressants can have an affect on adolescents, as they feel different than their peers. In Platzer's (1987) article on the topic of body image, one section was devoted to a discussion relating to transplant recipients. She stated that nurses must be aware that recipients of organs sometimes have an altered body image and have trouble integrating the idea of someone else's organ being in their body.

Problems of dealing with changes in body image have also surfaced in research studies on transplant recipients. Packa (1989) studied the quality of life after heart transplantation using a questionnaire with mostly open-ended questions which had been used in other studies and had acceptable reliability and validity. It was administered to 22 subjects to assess their physical, emotional, and social functioning. A unstated number of subjects "indicated that the emotional adjustment to changes in life-style, body image, selfesteem, and others' perceptions of them as heart transplant recipients was the most difficult of the adjustments to be made after transplant" (p.19). The specific changes in body image were not described in this article, so beyond identifying that changes occur, little knowledge was gained about the changes in body image that heart transplant recipients experience.

McAleer, Copeland, Fuller and Copeland (1985) mailed a questionnaire to transplant coordinators of various transplant centres to determine what problems these coordinators noticed in heart transplant recipients during initial hospitalization and then after hospital discharge. The patients themselves were not surveyed. Seventy-two percent of the 11 respondents reported that recipients have problems adapting to changes in body image at the time of initial hospitalization. However, the second hand nature of these data leads one to question the validity of the results.

In research studies on stressors experienced by renal transplant recipients, body image is addressed, although it is not always labelled as such. White, Ketefian, Starr and Voepel-Lewis (1990) in a study of 55 renal transplant recipients found that change in physical appearance that affects one's social life received one of the highest stress scores on a questionnaire. The authors first addressed the stressors that received the highest scores for concern and then later discussed the stressors reported as being the most difficult, but it was unclear what the differences were between the two categories. Because of the way in which the results of the study are presented, the findings are not clear.

Sutton and Murphy (1989) administered a stressor scale with reasonable reliability and validity to 40 renal transplant recipients. They learned that weight gain was given one of the highest scores for stress. Interestingly, the stressor "feeling that the kidney is not part of your body," which also relates to body image, was ranked as one of the lowest stressors.

Lough, Lindsey, Shinn, and Stotts (1987) mailed a questionnaire to 104 heart transplant recipients. Alterations in appearance of face and body, particularly hair growth and acne, were symptoms reported as "extremely upsetting" by 25% of the 75 individuals who responded.

Tymstra and colleagues (1986) held in-depth interviews with eighteen liver patients and/or their relatives either before, after, or both before and after, the patient received a transplant. The researchers wanted to determine the psycho-social impact of the liver transplant program. They identified that liver transplant recipients experienced changes in their physical appearance, a side effect of their medications, which the recipients found rather frustrating and upsetting. However, the researchers stated that patients accepted these difficulties with little complaining because the recipients believed that side effects were better than the prospect of death that they faced prior to transplantation. In the article, the specific changes that recipients experienced were not described, and no direct quotes from the interviews were used. Both types of information would have been helpful in promoting understanding of this issue.

House, Dubovsky and Penn (1983) conducted psychiatric evaluations and chart reviews of 34 liver transplant recipients. They stated that only three recipients, two adults and one child, expressed any difficulty integrating the donor's organ into their own body. Also, concerns about changes in body image were infrequently mentioned by the recipients.

In conclusion, both clinical descriptive articles and research papers indicate that changes in body image are sources of concern for some transplant recipients. However, the extent and nature of the concerns of recipients is far from clear. Additional, in-depth investigation is obviously warranted.

Side Effects and Cost of Medications. Immunosuppressant drugs and the other medications transplant recipients must take on an ongoing basis have many side effects which may cause distress. Also, the strict medication regimen which must be followed, along with the cost of these medications, are potential sources of stress to transplant recipients. Such concerns have been documented by many authors, in both clinical articles and research articles.

In one recent article, the recovery phase of liver transplantation was described. The authors stated that side effects of medications, particularly changes in physical appearance, were a concern for patients (Bass, Bindon-Perler & Lewis, 1991). In another paper, the impact of the side effects of immunosuppressive medications was said to be a great adjustment faced by lung transplant recipients (Craven, Bright & Dear, 1990). Futterman (1988) stated that drug-induced mood swings can cause physical and emotional distress for cardiac transplant recipients. Surman and colleagues (1987) looked at psychiatric considerations related to liver transplantation. They stated that in the postoperative period, organic brain syndrome, depression, and anxiety are some of the main problems that arise related to drug therapy. House and Thompson (1988) also supported the contention that psychiatric sequelae of transplantation can be largely attributed to the medications taken by recipients. Once again, these articles are not research based.

However, various concerns relating to medications have also been documented in research studies. In Frey's (1990) study of stressors experienced by renal transplant recipients at six weeks posttransplant, both cost of medications and side effects of medications ranked among the top stressors. Similarly, in Sutton and Murphy's (1989) study, in which a stressor scale was administered to 40 renal transplant recipients, cost of medications was the most stressful item. Concern about long-term side effects of immunosuppressive medications was also one of the stressors which received among the highest scores in a study of 55 renal transplant recipients (White, Ketefian, Starr & Voepel-Lewis, 1990).

Lough, Lindsey, Shinn, and Stotts (1987) sent a mail survey to 104 heart transplant recipients and learned from the 75 respondents that a number of symptoms related to immunosuppressive drug therapy are experienced by these patients. Many of these cause considerable distress. Side effects found to cause high distress were: impotence, decreased libido, mood swings, and depression. However, the numbers of recipients reporting these various side effects were not provided. The results indicated that the symptoms experienced by a recipient do not seem to affect his or her quality of life.

Tymstra, Bucking, Roorda, Van Den Heuvel, and Gips (1986), in their interviews with 18 liver transplant recipients, found that side-effects of immunosuppressants were experienced by individuals to varying degrees. However, recipients seemed to make light of these problems as they felt that they were "part of the bargain." Foley, Davis, and Conway (1989) found similar results when they surveyed liver transplant recipients to determine recipients' self reports of symptom frequency, the distress caused by symptoms, and the effect on quality of life. The 26 respondents reported a low incidence of side effects from their immunosuppressant medications, and these side effects did not seem to be of much concern to them.

In summary, these various studies indicate that the medications transplant recipients must take on a lifelong basis certainly have side effects. However, the research is inconclusive regarding the amount of distress caused by these medications.

Changes in Roles and Income Losses. Changes in roles and loss of income were mentioned in ten of the articles reviewed. Craven, Bright and Dear (1990) discussed the problem of readapting to family, vocational, or social roles in relation to lung transplantation. They stated that people unfamiliar with transplantation sometimes have expectations that transplant recipients are cured, rather than having life that depends on their graft not being rejected. Also, these recipients faced the potential loss of long-term disability income as they were no longer considered to have an illness. Similarly, Hook, Heyse, Pawlak and Steckelberg (1990) mentioned the fact that social and financial concerns begin to resurface for cardiac transplant recipients once they faced hospital discharge.

Christopherson (1987) stated that dealing with disruptions in family functioning, and with the responses of friends and colleagues are two problems requiring adjustments. Allender, Shisslak, Kaszniak and Copeland (1983) comment that, upon discharge, heart transplant recipients must deal with shifts in family roles and responsibilities. Similarly, Watts and colleagues (1984) state that after discharge, heart transplant recipients face a period of adjustments. They say that adaptation to being well can present difficulties to recipients who have become accustomed to taking on a sick role. Moreover, some have to deal with debts incurred over the course of their illness which they previously had been too sick to attend to. O'Brien (1985) listed three main challenges facing heart transplant recipients upon discharge: (1) reversals in roles from the patient's pretransplant status, (2) dealing with others who still treat them as though they are ill, and (3) inability to find employment. Similarly, Lough (1986) mentioned the fact that numerous expenses and problems of finding employment can be a burden for heart transplant recipients for several years after transplantation. Because the foregoing articles seem to be little more than the opinions of the authors, one cannot place too much weight on their statements.

The research studies are of more significance -- although, as will be seen, the evidence they present is mixed. To illustrate, in Sutton and Murphy's (1989) study of stressors experienced by 40 renal transplant recipients, it was reported that "fear of not being accepted by friends and family" and "reversal in family roles with the children" were two of the stressors which recipients ranked as causing the <u>least</u> amount of stress.

In contrast, McAleer and colleagues (1985), in their survey of transplant coordinators regarding the psychological problems in heart transplant recipients, found that the results indicated that 81% of the coordinators reported increased family stress and 45% reported increased marital stress at the time of initial hospitalization. After discharge, 81% of the coordinators reported family stress as a problem. Other problems affecting family functioning were: depression and mood alterations (initially 100%, then after discharge, 72%), personality changes (45% after discharge), and impotency (63% after discharge). However, as mentioned previously in this review, because these results were not obtained by directly asking the recipients, they need validation.

Hyler, Corley and McMahon (1985) tape-recorded support group sessions for heart transplant recipients and their families, and conducted a content analysis of the discussions. They found that changes in roles and responsibilities, loss of income, and increased burden on the spouse after the transplant were frequently mentioned. The amount of stress caused by these changes was not ranked.

It appears that additional work is required to determine the frequency and amount of distress for transplant recipients caused by changes in roles and losses of income. The conflicting findings may be due to differences in the perceptions of transplant coordinators and transplant recipients, or to varying reliability and validity of the methods used.

Fear of Rejection and Complications. Fears of organ rejection, infection, and other complications were reported less frequently in the literature. Those concerns discussed in the nonresearch literature will be presented initially. Futterman (1988) stated that factors such as rejection and complications are two of the major threats that make cardiac transplant recipients uncertain about their future. Craven, Bright and Dear (1990) mentioned that dealing with the ongoing threat of organ rejection is a constant challenge to recipients of lung transplants. Bass, Bindon-Perler, and Lewis (1991), in their descriptive article on the recovery phase of liver transplantation, stated that they interviewed liver transplant patients. They learned that fear of organ rejection was one of the concerns expressed by recipients. However, these interviews were informal only, apparently conducted by the authors during patients' visits to the follow-up clinic. There was no standard format for the interviews.

In various research studies, fear of rejection and other complications have emerged as being important to transplant recipients. Sutton and Murphy (1989), in their work with renal transplant recipients, administered a stressor scale which had previously been developed by other researchers for use with hemodialysis patients. They modified this instrument to make it suitable for the transplant population. However, they did not retest the reliability and validity. The researchers found that fear of rejection was one of the most stressful factors for renal transplant recipients. Similarly, when Hayward and colleagues (1989) developed an instrument to identify stressors in recipients of renal transplants, they found that for the 60 people responding to the survey, two of the stressors with the highest rank order were: the possibility of rejection; and the possibility of infection. In Frey's study (1990) with 48 renal transplant recipients, the results were similar to those of the Hayward study and to the findings of Sutton and Murphy. In each case, the possibility of rejection was one of the highest ranking stressors. White, Ketefian, Starr and Voepel-Lewis (1990) in their study of 55 adult renal transplant recipients, also found that risk of infection and other complications was one of the stressors that received the highest scores.

Foley, Davis and Conway (1989) sent out a questionnaire with Likert scales to assess symptom frequency, symptom distress and quality of life of adult liver transplant recipients who had been alive for at least six months posttransplant and had been discharged home. For the 26 respondents, rejection and infection were low in incidence and caused little distress. The only explanation for this rather surprising finding was that recipients were using denial of these concerns as a defense mechanism in order to cope with the stresses of their chronic condition.

In general, there seems to be some conflicting data regarding the fear of rejection, infection and other complications of transplantation. More research needs to be done to learn why some recipients have these fears and others do not.

Concerns Related to Hospital Care. A number of authors reported psychosocial concerns relating to hospital care. Bass, Bindon-Perler, and Lewis (1991) stated that liver transplant recipients expressed concern regarding decreased independence during routine clinic appointments. Sheets (1989) contended that feelings of lack of control and changes in normal methods of coping are stressors for liver transplant recipients that arise during their hospitalization. Hook, Heyse, Pawlak and Steckelberg (1990) suggested that cardiac transplant recipients experience fear and anticipation about leaving the protected hospital environment. Allender and associates (1983) mentioned that during the recovery period, heart transplant recipients may have difficulty coping with the lack of ability to control their recovery. Later, once they are ready for discharge, they often have anxiety about not having nurses available day and night. Similarly, O'Brien (1985) stated that heart transplant recipients experience anxiety about leaving the safe hospital environment. Craven, Bright and Dear (1990) asserted that lung transplant recipients frequently feel very attached to the transplant institution, and doubt their ability to survive independently. These researchers also reported that lung transplant recipients encountered numerous expectations of them by medical staff, which they had difficulty dealing with. However, there was no elaboration on this statement. It is unclear just what expectations were experienced as stressful by lung transplant recipients.

In a research study (Hyler, Corley & McMahon, 1985) of concerns expressed by patients in a support group, heart transplant recipients had a number of hospitalization-related concerns. They were unsure of how much independence was expected of them, and how much they ought to have done for them. Also, some expressed concern about being cared for by people who were not familiar with heart transplantation. During one session, shortly after the death of two patients, great dissatisfaction was expressed regarding relationships with medical and nursing staff. It was implied that the recipients believed that the health care professionals could have done more to help the two who had died. Hyler and associates did not go into detail about what exactly was meant by each of these concerns, since the purpose of the study was to determine the frequency of concerns mentioned. It seems evident, nevertheless, that patients do have real fears about leaving the hospital environment. More research is required to determine just what these fears are and how frequently they occur.

Uncertainty about the Future. Uncertainty about the future is the last category of stressors mentioned in the literature. In a descriptive article regarding cardiac transplant recipients, Hook, Heyse, Pawlak and Steckelberg (1990) cited research regarding the perceived vulnerability and unpredictability of the future. Futterman (1988) stated that life is very different for cardiac transplant

recipients than it was prior to their transplant. There are many threats to their health, which cause the recipient to live in a state of "perpetual uncertainty." Futterman went on to say that the reaction to such stressors may be anger, disappointment, or depression.

A few researchers have reported similar findings. In Frey's research (1990) on stressors experienced by renal transplant recipients, the stressor which had the highest mean score was the possibility of repeated hospitalizations. This could actually be classified as a stressor related to uncertainty about the future, because it indicates that recipients were unsure about their future health. Hayward and associates (1989) also studied renal transplant recipients and found that uncertainty about the future was ranked among the greatest stressors. Similarly, White, Ketefian, Starr and Voepel-Lewis (1990) stated that uncertainty about the success of the transplant received one of the highest "stress" scores in their research with adult renal transplant recipients. Hyler, Corley and McMahon (1985) audiotaped sessions of a heart transplant patient support group. Concerns about health maintenance were the ones most frequently expressed. This worry of how to maintain health is likely related to feelings of uncertainty about the future.

Positive Psychosocial Impact of Transplantation

In spite of all the challenges facing transplant recipients, there are also some positive psychosocial aspects of transplantation mentioned in the literature. Tymstra and associates (1986) reported that liver transplant recipients appreciated life more after their transplant and that they had greater awareness of everything around them than they had before. Although they had to deal with disappointments and set-backs, recipients accepted these difficulties with little complaining because they felt their difficulties were better than the prospect of death they faced prior to their transplant. Bass, Bindon-Perler, and Lewis (1991) discussed the recovery phase of liver transplant patients. Three positive aspects of the experience of transplantation mentioned by some of their patients were: the opportunity to be with family members and friends, being given a second chance at life, and having the capacity to enjoy life once more.

Another positive psychosocial impact of transplantation expressed by many transplant recipients is their improved quality of life following transplantation. This topic has already been addressed.

Limitations of the Literature

The major problem with much of the literature in which psychosocial aspects of transplantation are discussed is that it is not research-based. The observations made have come from the researchers' personal experiences with transplant recipients. This does not invalidate the ideas. However, it would be helpful to have research to confirm the existence of these challenges in the minds of transplant recipients themselves.

In addition, even in the research studies, better descriptions of the methods used to conduct the studies would enable others to more easily replicate the research and further test the hypotheses. Similarly, if researchers included assessments of the reliability and validity of the instruments they used, it would facilitate others' decisions of whether to use these same tools.

Another shortcoming of some of the literature is that many authors' comments are based on their experience with transplant *recipients*, and little was mentioned about what the recipients' were like prior to their transplant. Consequently, a number of the patients' concerns after transplant may have been much more serious (even if of a somewhat different nature on occasion) prior to the transplant. This is likely true with regard to concerns like body image, role changes, income losses, and uncertainty about the future. This point is made clearly by Mai, McKenzie and Kostuk (1990) in a study of psychiatric problems pre and posttransplant. They assessed 27 cardiac transplant patients both preoperatively and twelve months postoperatively to look for psychiatric diagnoses. Fourteen patients were diagnosed with psychiatric problems prior to their transplant (generally either anxiety or depression), but only five had such diagnoses after having a transplant. All those who had a psychiatric diagnosis posttransplant had also had one previously. This study puts a new perspective on the cross-sectional studies that indicate that transplant recipients have various problems. It is possible that many individuals had similar problems prior to their transplant. Thus, there may not be a causal relationship between the transplant itself and the problem.

It is difficult to compare the literature relating to psychosocial aspects of transplantation for three reasons. The first is that recipients are studied at varying time periods after transplantation. Some research about psychosocial aspects of transplantation is based on recipients who were in hospital at the time, while other articles pertain to transplant recipients who have been discharged for varying periods. It is reasonable to expect that recipients' concerns will change over time. Thus, it is inaccurate to make comparisons between data obtained at different time frames.

Second, often the subjects used in the research are not described. It is possible that factors such as medical diagnosis, age, sex, marital status, number of children, educational background, type of job (i.e. professional versus labourer), and family roles, may influence the physical and psychosocial stresses associated with transplantation. By not examining these characteristics, researchers may be missing important variables.

A third reason for the lack of comparability is that the label one author assigns to a certain psychosocial variable often differs from the label another author has given it, though they refer to the same problem. All these factors decrease one's ability to make comparisons between research studies in order to obtain an overview of what life is like for transplant recipients.

Summary

There have not been many research studies examining life after liver transplantation, quality of life for liver transplant recipients, and psychosocial aspects of transplantation as a whole. Research on the psychosocial aspects of liver transplantation has not kept pace with that on the physiological aspects, although the former is no less important.

Because so little is known about what liver transplant recipients themselves think and feel about their lives, the focus of this study was on the transplant recipients' descriptions of their lives after liver transplantation. By thoroughly examining the recipients' own perspectives, the findings from this study provide new insights into their feelings and attitudes, and establishes a solid foundation for future research on this topic.

Chapter 3: METHODS

Rationale for Qualitative Methodology

The purpose of this study was to obtain descriptions of the lives of liver transplant recipients at the times when they were interviewed. As evident from the literature review, there has been no comprehensive, systematic research done on this subject. Therefore, a descriptive study was necessary to determine what the important issues are for liver transplant recipients.

The approach used was that of "factor naming" or "factor-searching." "Factor-searching or naming studies are descriptive in nature and occur at the exploratory or formulative stage of theory development" (Field & Morse, 1985, p.8). It would have been invalid to begin by trying to measure the significance of various factors to liver transplant recipients. The important factors are, as yet, unknown, and unsubstantiated assumptions would have had to be made. Therefore, this exploratory-descriptive approach was the most suitable method. Such an approach allows the researcher to collect, describe and analyze data which provides insight into human behaviour, and the meaning individuals attach to their behaviour (Aamodt, 1982). The researcher seeks to understand and develop concepts about the behaviour and beliefs of a group of people, that is, a cultural system, from the view of the individuals involved

(Aamodt, 1991; Field & Morse, 1985). Those who have received a liver transplant may be viewed as having a specific culture.

An organized description of the experience of liver transplant recipients is helpful for nurses since, "Such information...provides a map, if not a master plan, for recognizing and evaluating the needs of individuals and groups of individuals and putting into play strategies for quality human experience" (Aamodt, 1991, p.50).

Various methods of data gathering can be used for an exploratory-descriptive approach. Unstructured interviews were chosen as the primary method for this study. The reasons for this are twofold. First, unstructured interviews give the informants free reign to say whatever is most important to them. Second, this sort of interview avoids the problem of "putting words in the informants' mouths." The interviews provided detailed descriptions of what life is like after liver transplantation for analysis. One informant had a diary that she allowed the researcher to read and relevant information was transcribed so that it, too, could be analyzed.

Sample

A convenience sample of those individuals who had a liver transplant and were being seen at the liver transplant follow-up clinic at a major city hospital were selected as informants for the study. Criteria for the selection of informants were as follows. They had to be:

1. recipients of a liver transplant,

2. transplanted at least three months prior to the time of the interview,

3. 18 years of age or older,

4. fluent in English, and

5. not in hospital at the time of the study.

The three month time period identified in the second criterion was included so that the researcher would be speaking with recipients who had some time to adapt to life after transplantation and were beyond the acute stage of recovery. The age limit was enforced as it was thought that the description of life provided by adolescents and children might vary from that given by adults. Fluency in English was essential for two reasons. Firstly, informants had to be able to express themselves clearly in a language understood by the researcher. Secondly, since interviews were audiotaped and then transcribed, informants' voices had to be heard clearly from the audiotape. Informants were living at home at the time when they were interviewed, as the purpose of the research was to determine what recipients' lives were like once they were discharged and getting back to their usual routines.

For this study, sample size could not be predetermined -- but it was found that seven informants were needed. This sample size was dependent upon the quality of data gleaned from each informant. After each interiew, a content analysis was done, and ten categories describing the recipients' lives were developed. The principle of saturation was followed. Saturation of data categories is the point at which additional informants do not provide any new information which the researcher has not already obtained. Accordingly, the researcher decided that the sample size was adequate when the data obtained were sufficiently detailed to enable the researcher to answer the research question. The informants were therefore chosen in an ongoing manner, as they were needed, and data analysis was done concurrently so that the researcher would know when the categories in the data were saturated (Morse, 1986).

The researcher attempted to obtain approximately equal numbers of male and female informants to eliminate a potential gender bias. The liver transplant patient coordinator agreed to ask prospective informants if they would allow their names and phone numbers to be given to the researcher. Those who were interested in the study were then given an information sheet that briefly described the study (Appendix A, p.134). A few individuals were contacted by telephone by the transplant coordinator, so did not receive the information sheet. If they were interested in speaking with the researcher, the information sheet was read to them when they were contacted.

After hearing what the study entailed, those individuals who were willing to be part of the research were scheduled to be interviewed at a time and place of their choice. At the first interview, the study was again explained to informants and an informed consent was obtained once they were satisfied with the explanations and had all their questions answered (Appendix B, p.135) (Field & Morse, 1985). Each informant was given a copy of the consent form.

Two informants who lived three or more hours away from the transplant centre had interviews conducted over the telephone. For those informants, consent was tape recorded on a separate cassette from the interview, and the informant was mailed a copy of the consent form.

Secondary selection was used to obtain the best informants. That is, all eight volunteers were interviewed, but the selection of primary informants was done after the interviews commenced (Morse, 1991). Only one interview was deemed unsuitable for the study, and that person was designated a secondary informant. Although willing, the individual was not talkative and thus did not provide much data. The interview was not analyzed as were the other interviews, but it was retained as a secondary source to help validate the findings of the study. Those seven individuals who were good informants continued in the study as primary informants. Two primary informants and one secondary informant read the findings of the study at a later date to help validate the descriptions obtained from the data.

From the review of the literature, the researched anticipated a rather bleak outlook for individuals who had received a liver transplant. Thus, after the first three or so interviews, in which all the informants were so positive, the researcher began to wonder if she had just chanced upon a few optimistic individuals. The liver transplant coordinator who was approaching recipients was asked whether she thought the informants accurately represented the population from which they were drawn. She thought that they did, but the researcher also asked her to try to obtain informants who had had postoperative complications, and she did so. Nevertheless, the later informants reiterated the same thoughts as the previous ones had.

All of those who agreed to participate in the study were asked if they wished to receive a summary of the research results upon completion of the study. Those who did wish to have this information provided the researcher with their mailing address.

Demographic Information

At the time of the initial interview, demographic data were obtained (Appendix C, p.137). The primary informants were four women and three men, ranging in age from 41 to 64 years of age. Informants had between nine and eighteen years of education. Three had university degrees. Five informants were married, one was single and one widowed. All lived within the province where the study was done, but they lived varying distances from the transplant centre, between ten minutes and five hours away by car. Four lived in large urban centres, one in a smaller city, and two in rural communities. Two individuals were working full time in the same occupation they had had prior to their transplant. Two were working part time, two were retired, and one was a homemaker. One of the retired individuals did volunteer work, as did the homemaker. The medical diagnoses of five informants prior to liver transplant was primary biliary cirrhosis, one had sclerosing cholangitis, and one had viral hepatitis. The medication regime for the informants was similar. All were on cyclosporine and prednisone, and all but one also took azathioprine daily. Other medications, such as calcium and diltiazem, were also taken by a couple of informants. The length of time since transplant for the recipients at the time of their interviews ranged from five months to twenty-eight months.

Data Collection

Each informant was interviewed one or two times. The number of interviews was determined by the amount of data collected during each interview, the informants' eagerness to talk, and the number of questions the researcher wanted to ask. The location for each interview varied according to the preference of the informant. One interview took place in the informant's home, one was in the informant's office at work, and three were held at the transplant centre, as that was preferred by, or most convenient for, these individuals. Phone interviews were used for two individuals who lived three or more hours away from the city.

The interviews began with the statement by the researcher, "I'd like you to tell me what your life is like now that you have had a liver transplant." The interviews then proceeded in the direction the informant wished to take. Although interviews were unstructured, they still had a tacit agenda in line with the research question (Fetterman, 1989). Four prompting questions were utilized for the first two interviews to get informants talking at various points throughout the interviews (see Appendix D, p.138). After those two interviews were analyzed, more prompting questions were compiled from the experience gained in those initial interviews (see Appendix E, p.139).

Interviews were 30 minutes to 80 minutes long. All interviews were tape recorded and subsequently transcribed. Only the researcher was able to identify which informant provided the information on each tape and transcript as they were numerically coded to ensure confidentiality. Following each interview, the researcher recorded information describing the setting, the appearance and behaviour of the informant, as well as any subjective impressions the researcher had about the interview or the informant. The data collection was conducted between mid-December, 1991 and the end of February, 1992.

Data Analysis

Content analysis of the data was done manually after the interviews were transcribed. The data were examined for content relevant to the research question, and any phrases, sentences or anecdotes that pertained to the experience of living with a liver transplant were identified as units of analysis. As indicated earlier, the individual units of analysis were organized into categories arising from the data. This was initially done by attaching a label, or code, to each unit of analysis identifying the subject matter. Units of analysis were later arranged into categories by commonalities in subject matter. (Categories are listed and described in Chapter 4: Findings.) The important descriptors of living with a liver transplant became evident after the first five interviews, although the best label for each category was not developed until later when the categories were more complete. Interviews were conducted with two more informants to clarify and saturate the categories that arose from the data.

Theoretical notes, or memos were written by the researcher about the data and the categories to record her thinking processes regarding the data. These memos also assisted the researcher to identify important information not clearly spelled out in the data (Field & Morse, 1985).

Data analysis was ongoing throughout the course of the study. Each interview was analyzed as soon as it was transcribed. This analysis guided the researcher to ask the appropriate questions in future interviews. For example, after the first two interviews, and regularly thereafter, the researcher analyzed the transcripts to determine which questions were most effective in eliciting the desired information, so that these questions could be used in future interviews and the poorer questions were avoided (i.e., those which seemed to be leading questions, and closed-ended questions which elicited mostly "yes" or "no" responses). From the data, summary descriptions about recipients' lives were formulated. These descriptions were given to two primary informants and one secondary informant during the course of the study to validate their accuracy.

Trustworthiness of the Data

In experimental studies, one is concerned with the reliability and validity of the data. These concerns relate to whether the findings of the study are replicable, and the results valid. When employing a qualitative method for research, these same issues must be addressed, but some reinterpretation of the terminology is necessary "in order to better fit the assumptions of the naturalistic paradigm" (Guba & Lincoln, 1981, p.103). Four dimensions of the trustworthiness of the data are used: (1) truth value, or credibility, is parallel to internal validity; (2) applicability to external validity; (3) consistency, or auditability, to reliability; and (4) neutrality, to objectivity (Guba & Lincoln, 1981). The manner in which each of these four criteria was met in this study is as follows.

Truth Value

The truth value of a qualitative study is the degree to which findings actually represent the reality of the phenomena involved. Both the environment in which interviews are conducted and the informants themselves influence the truth value of a study (Guba & Lincoln, 1981).

The location of each face-to-face interview was determined jointly by the informant and the researcher. In some cases, an informant preferred to have the researcher come to his or her home or office. Other informants found it more convenient to meet the researcher at the transplant centre. Each of these interviews was scheduled in advance, and was conducted in a private room so that there would be no interruptions and the conversation could not be overheard. These techniques assist with the establishment of rapport with each informant and help to develop trust, both of which add to truth value (Field & Morse, 1985).

Phone interviews were also conducted at a prearranged time. Unfortunately, because these individuals were at home, each interview had at least one interruption, even though informants knew that privacy was desired. Interruptions were either in the form of the doorbell ringing, or by a family member entering the room and talking to the person on the phone. However, these interviews may have had a benefit for truth value that the face to face interviews did not have, in that the informant did not have to look at interviewer and could not see the tape recorder, and so may have felt more at ease talking about personal things (Field & Morse, 1985). For example, one individual felt comfortable enough to discuss sexuality posttransplant with the interviewer.

Because the individuals who participated in the study had each had a liver transplant, they could certainly talk accurately about the reality of living with a transplant. Informants' responses were assumed to be trustworthy, as there was no benefit to them if they were to lie. Moreover, their responses were compared with the other informants' responses, those of secondary informants, and those reported in the limited amount of literature available. Responses were also evaluated in terms of their face validity by the researcher, the transplant coordinator, and colleagues familiar with the field of inquiry (Field & Morse, 1985). The thesis supervisor, nursing colleagues, pastoral care workers who dealt with liver transplant candidates and recipients, and a peer support group also examined and discussed parts of the interviews and the categories developed from the data. They served as objective reviewers of the truth value of the findings.

Since interviews were unstructured, informants had the opportunity to describe what their lives were like without being restricted to answering questions to which they might not be able to relate. Irrelevant or unimportant questions were not asked. Also, the nurse researcher had cared for one of the informants as well as other liver transplant recipients while they were in the hospital. Thus, she was familiar with the language and terminology used by the informants, and was able to establish a rapport with them quite readily.

Credibility was established in two ways. First, during several of the later interviews, selected phrases obtained from previous informants were mentioned to subsequent informants being interviewed to see whether they could relate to, or would agree with, what the other people had said. It was found that they did agree. Hence the statements were validated as being accurate in describing the specific population under study. Second, the findings derived from the data were given to two primary and one secondary informant to see if the researcher's perceptions of the data fit with the way the informants viewed their own lives. Those categories were confirmed as being appropriate (Guba & Lincoln, 1981).

Preexisting biases may influence the credibility of the results (Guba & Lincoln, 1981). For this study, the researcher had no specific expectations of what informants were going to say about their lives, nor any specific hypotheses to prove. Also, since there is limited research available on the topic, the researcher had no biases from reading previous research. Therefore, preexisting biases were not deemed to be a problem which would invalidate the results.

After the transcription of each audiotaped interview was completed, each cassette was played while the transcription was reviewed. By this means, the accuracy of the printed interview was checked against the original data, and any errors were corrected. Furthermore, all inferences were checked against the data to ensure that there was a basis for them.

Applicability

The credibility of a study influences its applicability, since data which are meaningless have no generalizability. A benefit of qualitative studies is that real life is represented. In a scientific study, attempts are made to control the situation, and generalizations are context-free. To do this in qualitative research, where one is dealing with human behaviour, would make the findings somewhat artificial and idealistic when attempting to apply them to uncontrolled, realistic settings in which a context is necessary (Guba & Lincoln, 1981).

A qualitative research study has theoretical generalizability, which is based on similar meanings rather than on an exact replication of substance (Brink, 1991). The findings of this study were not quantified. Rather, common themes emerged from the data that enabled the investigator to develop a description of what the lives of the informants were like after their liver transplant. It should, therefore, be possible to apply the findings to other contexts which they fit (Guba & Lincoln, 1981).

Consistency

Consistency, or reliability, in qualitative research is part of validity and refers to whether random variation influences the stability and consistency of results, and thus to whether the study could be replicated (Guba & Lincoln, 1981). A study cannot have internal validity without having reliability. Therefore, by demonstrating a study's validity, as was done previously, reliability is also evident.

In order to promote replicability, a detailed description of how the study was done, including the main questions asked in the interviews, has been provided. Also, examples of interview data and the categories developed from it are documented in the findings section of this report. As mentioned previously, data were reviewed by individuals with no vested interest in the study. They agreed that the categories fit the data, which reinforced the replicability of the findings. Talking with a few informants several times and analyzing and reanalyzing the data over a period of time enabled the researcher to determine the elements of the interviews that were the most important and salient characteristics of the data.

Neutrality

Neutrality, for a qualitative study, means that the data are "factual and confirmable" (Guba & Lincoln, 1981, p. 125). As such, many of the methods for determining truth value also apply to the pursuit for neutrality. The data were validated by various informants, by the transplant coordinator, and by peers. This helped to ensure that the interpretations of the data were not only seen by the researcher, but were also evident to others.

Similarly, the unstructured interview format served to minimize subjectivity. Questions were developed primarily from informants' own words, rather than from a specific viewpoint that the researcher was trying to prove.

Ethical Considerations

Both the Ethics Review Committee at the Faculty of Nursing, University of Alberta, and the one at the host institution granted ethical approval for the study before any informants were approached.

Obtaining Informants

The liver transplant recipient coordinator approached liver transplant recipients, either at the transplant follow-up clinic or by telephone, to ask if they would be willing to let their names and numbers be given to a researcher who was desiring to learn about the lives of liver transplant recipients. This was done to minimize the risk of coercion.

Informed Consent

At the time of the first interview, the study was explained to all informants, and when they felt they had all their questions answered and had no concerns about the study, they were asked to sign an informed consent form (Appendix B, p.135). As mentioned previously, for telephone interviews, a consent was taped on a separate cassette from the interview, and the individual was sent a copy of the consent form by mail.

The consent form provided details about the study and addressed the issues of confidentiality, anonymity, freedom from risk, opportunity to ask questions at any time, the ability to refuse to answer questions at any time, and ability to withdraw from the study at any point an informant chose. Each participant was given a copy of the informed consent form.

Confidentiality

All audiotapes and transcripts were kept locked up when not in use. Informants' names, all other names, and identifying attributes were deleted from the transcripts. Informed consent forms were kept in a place separate from the data. The informants were told that details about their lives would be altered in the final report if there were distinctive details that might enable readers to trace who they were. Each transcript, audiotape and the one diary used were labeled only with the subject number assigned to that informant. The subjects' names and their associated numbers were listed in only one place, and this information was destroyed on completion of the study.

Benefits and Risks to Informants

Those individuals who took part in this study were aware that they would not receive any direct benefits from their participation. However, some found it encouraging to know that the researcher was interested in their lives and wanted to hear their stories. Also, all informants expressed the thought that they wanted to participate so that the information could be used to help future liver transplant recipients. The risks to the informants were minimal. One potential risk was that some might have become distressed when talking about their lives. Although several informants became teary, or a bit emotional, when speaking about the donor from whom they received their liver, none were so distressed that they wished to discontinue the interview and resume it at a later date, or to drop out of the study altogether.

Transplant recipients who agreed to talk to the researcher were made aware that they would neither receive preferential follow-up treatment, nor would they be penalized if they chose not to participate. None of the individuals who were asked if they would be interested in being interviewed declined.

Summary

Seven informants, four women and three men between the ages of 41 and 64, were the primary informants for this study. The major method used for data collection was unstructured interviews. A content analysis was done of the data, and from this, a description of what life is like after liver transplantation was developed. Steps were taken to ensure the results were truthful, applicable, consistent, and neutral. Similarly, possible ethical concerns that might have arisen regarding this research were resolved prior to beginning the study.

Chapter 4: FINDINGS

In this chapter, the findings from the research are presented. Ten categories, or descriptors, were identified through content analysis of the data. These are as follows: (1) Thinking about the Transplant, (2) Mental Activity, (3) Physical Activity, (4)Health/Normalcy, (5) Caring for Health, (6) Implications of Medications and Medical Procedures, (7) Appreciating Life, (8) Evolving Relationships, (9) Awareness of Donors, and (10) Moving Ahead.

Together, these categories summarize what the lives of liver transplant recipients are like. They will be described in order. The order of discussion of these categories is somewhat arbitrary, as the informants did not deem any single aspect of their lives more important than any other. A definition of the category descriptor will first be given, and then discussion of it will ensue, with examples from the data interjected to provide further clarification and illumination. At the end of each quotation, the code number of the informant who made that comment is indicated in parentheses. Recipients numbered one, two, five and six were female and those numbered three, four and seven were male.

Thinking about the Transplant

Thinking about the transplant experience is defined as remembering, reflecting, considering, and/or having an opinion about going through the process of having a liver transplant. Included in this category are any statements made by informants regarding their feelings about having the transplant, beliefs about why their transplant was a success, and thoughts about the significance of their transplant.

Feelings about Having a Transplant

All of the informants voiced thoughts about their transplant. Although the in-hospital period, and/or their recuperation at home, was viewed by some as having been difficult, none of the informants regretted their decision to have a transplant.

> - *[do I have any regrets about having a transplant?] Oh no, none at all. It was not a picnic for sure but it wasn't as bad as I thought it would be...It's an ordeal. It really is,.. especially if you have complications. But...it means your life. If it means your life,...you just don't have a choice really...I've been asked, would I go through it again? And,..of course I would. (5)*
>
> - *no regrets at all! I would do it again in a minute. In fact,...if I knew then what I know now about the recovery*

process, it probably would have been even less of a decision to make at the time. (3)

Some thought that not only did they have no regrets about having a transplant, but that it was actually a positive experience, even a miracle, and were glad they went through it.

- I wouldn't change a thing. I'd go through it...you feel so different after that it's sure well worth it. (2)

- you gain a lot by going through the experience. (3)

Beliefs Regarding Success of Transplant

Recipients all had beliefs about what had made their transplant successful. They credited their recovery to such factors as: positive attitude, education, faith in God, excellence in medical and nursing care, and physical fitness.

- I think the combination of positive attitude and education is all you need and you'll go through it. And to me, that was the main thing. (4)

- I think that..if a person doesn't believe in God, it would be more difficult. (5)

- [my family and I] have just an immense appreciation for medical technology and for good quality medical care. (3)

- I happen to..absolutely, firmly believe that the only reason I'm alive today was because I worked out before my transplant. (7)

Significance of Transplant

For each of the informants, the transplant was a significant event. The transplant period was thus a point in time to which the rest of their lives were related. They all compared their present lives to what they had been like prior to the transplant, whether their lives had changed or remained much the same. However, even though having a liver transplant was one of the most important events in the recipients' lives, it seemed to have diminished in importance the farther away recipients got from it.

> *...it was probably the most significant experience that I've ever had in my life...it was very dramatic and...it was a big deal at the time. Right now, I'm not sure if it really feels like it was a big deal all the time (3)*

Another individual expressed that he did not want to keep thinking about having a transplant, that he wanted to get on with his life.

> *I don't want people coming and saying, "Oh, how terrible to have to go through that." I want [my transplant] back in the past someplace and leave it there, go on. I don't want any special treatment. (4)*

For some, the thing which prevented them from forgetting they had had a transplant was their abdominal scar.

> *There's never a day that goes by when you sort of don't think about what you've been through, because you're always reminded by something like your scar, or something like that. (3)*

In summary, the experience of having a liver transplant was an event that affected the current lives of all the individuals interviewed. They reported that they could not think about the present without providing the context of what they were like pretransplant. Each person held beliefs about what it was that had made his or her transplant work. Some found that they were able to move forward from their transplant experience easily. Others had to make an effort to leave it in the past, and said that their scar made them ever-conscious of what they had been through.

Mental Activity

Mental activity refers to the functioning of, or relating to, the mind. The recipients' statements about their abilities to use their minds were grouped under this descriptor.

For most, mental activity was worst just prior to the transplant and for the first few months afterwards. Subsequently, mental functioning improved to the same level it had been pretransplant. For those whose disease process had been quite advanced before their transplant, their mental activity became better than it had been for a long time pretransplant, except for possibly some short-term memory loss.

> *...[my mental function] is just about back to normal...to be honest, it was a concern of mine very early after the transplant. I couldn't keep two thoughts together. I mean I...wouldn't have second guessed myself on whether two and two is four....I don't have the same problem, nowhere near the same problem. (7)*

One individual stated that his ability to engage in mental activity had diminished somewhat in the first few months posttransplant. He felt that he was now back to the way he had always been, in spite of occasional lapses of memory.

> *I still get that sense from time and time that I have lapses of memory. But...I don't feel like my abilities to comprehend, to analyze situations, to problem solve are any less, or any greater really, than they were before. I think I've just sort of come through it. I'm certainly about the same level. (3)*

A few recipients believed that it was their medications which had caused the temporary changes in their mental activity, which were taken in highest dosages in the first few months after receiving a transplant.

> *...my mind doesn't feel cloudy at all. Not anywhere like it did the first few months. And I knew at the time that...that's just a function of medication. And I wasn't sure whether that was*

> *going to continue. And...I probably haven't even thought of it till you raised the question now. But for the last few months,...I can't remember having any kind of a sense of being in a daze or being foggy at all. (3)*

Several mentioned experiencing short term memory loss, but were not sure whether that was attributable to their age, their disease process, or their medications.

> *- I find that I do have short term memory loss...and one other thing I find I have a problem with is often searching for words. I know what I want to say but I can't find the words. (6)*
>
> *- the only thing, and that could be a little bit aging again, just a little problem with remembering. Not today, but maybe three, four, five days ago. For people that I've only seen twice, there's no way I could even remember a name. It's just gone, and those kind of things either could be my medication, which I think has a bit to do with it, but it could also be the aging process as well. I couldn't put my finger on it for sure. But I do notice a slight bit that way. (4)*

Recipients who thought that they experienced memory loss accomodated for it in various ways. Some avoided activities which caused them mental difficulties. Others modified the way they did things.

> *I just make sure I have good plans and good notes so I don't vary off and the next day..start on something new and don't*

> *finish what I did before...again it's just a little bit of..adjustment, just been a little bit of modification. And I might have had to do that even if I hadn't the operation (3)*

Recipients reported that, on the whole, mental activity seemed to be at the worst for the first few months prior to the surgery when the disease process was advancing, and then immediately afterwards when they reported that their dosages of medications were the highest. However, after this period recipients did not generally experience any loss of mental function, other than possibly some short term memory loss, which they tended to attribute as much to aging as to their disease or their medications. To the extent that they had some slight memory loss, they were easily able to adjust for it in their behaviour.

Physical Activity

The term "physical activity" refers to bodily movement, being active, having liveliness. Comments by the informants which referred to their physical abilities to be active, to take part in things, were grouped in this category under two subheadings, "limitations" and "energy level."

Limitations

All of the recipients reported few physical limitations, or only minor limitations. A limitation for them was something that restricted them from carrying out desirable activities. They made a point of mentioning the activities that they could do, particularly if they had not been able to do them for a while before the transplant. Most of them believed that they were able to be involved in whatever they wanted to do, and that they had more independence than they had had since prior to their transplant.

- I can pretty well do anything I want to do now. It's just great! (1)

- I do a lot of golfing, a lot of curling in the winter and a bit of walking and bicycling (4)

- I don't know that I have any [limitations]...I'm skiing again. (3)

In some cases, informants expressed the feeling that, although they were back to activities they had not been able to do since prior to their transplant, they had occasional pain and muscle weakness, and they did not have the same endurance as they did before.

- I can still golf fairly well. I don't say I can go as strong and as long and as well as I did before, but I still do it. (4)

- I still haven't reached the point where I can really dig in because I don't have the stamina. I'm very weak in my hands

> *too; for whatever reason, I can't open jars anymore, where I used to be really strong. (5)*

However, the recipients recognized that they could not compare their physical abilities to those that they had had years before they ever got sick.

> *I think at some point I got like I wanted to be able to do what I did when I was 20. Well let's face it. I'm fifty. I'm not going to be able to do that. (6)*

In general, their lifestyles were less tightly controlled than prior to transplant. For example, they did not have restrictions on what they could eat.

> *I can eat any food. (1)*

Energy Level

In addition to describing specific activities they could and could not do, all but one of the recipients also discussed their new energy level or their lack of energy. Energy was interpreted in this study as the ability to be vigorous, such that daily activities could be carried out without extra rest.

Three basic observations can be made here. First, those who were carrying on their daily activities in a relatively normal manner prior to their surgery, reported that the transplant experience initially reduced their energy level significantly. However, after they recovered, they stated their energy levels were pretty well back to the way they had been prior to their transplant. Second, those who were virtually incapacitated prior to the transplant, indicated that even in the recovery period their energy levels were better than they had been before, and as they gained strength, their energy levels became dramatically better than they had been pretransplant. Third, all recipients recognized that their energy levels were going to be lower than they were five, ten, or fifteen years earlier when the recipients were younger. One individual expressed these sentiments:

> *[I've] never been a person to lay down and rest but..when I finish [work] I'll lay down for half an hour, rejuvenate myself and then I'm okay for the evening. If I'm home on Saturdays and I'm fairly tired, I'll have to have a half hour sleep in the afternoon, which I never did before. It just takes a little more energy to get things going. But considering the way I was prior to my operation, my energy level now is a hundred percent better than it was then. Cause then it was just a horrendous task to get up and have a shower, before you went to work...So right now, it's a hundred percent better. (4)*

For those recipients whose disease process was quite advanced by the time they received their transplant, after the surgery they were amazed at how much energy they had.

> *I've always got something to do and the energy to get up and do it... before, I used to have ideas of things I wanted to do and*

> *then..by the time I got dressed, had breakfast,..I didn't have the energy to do it. (1)*

All of those interviewed thought that it was essential that they obtained adequate rest and so they made sure that they got it. Some took a nap during the day if they felt tired, as this was seen as one of the most effective ways to maintain the optimum energy level possible.

> *I have to lay down,..sometimes twice a day in order to just get some...strength back. If I want to do something that is time-consuming, well, I have to kind of plan for it, pace myself. (5)*

The longer the time since transplant, the more energy recipients reported. At first, they found that they were just able to perform their own self care and required quite a bit of rest. Later, they stated that they were able to take up various sports again and perform their own house and yard work.

Recipients indicated that they were generally happy with their energy level. Relative to the amount of energy they had had immediately pretransplant, or the amount that they had expected to have had in the future if a transplant had not been obtained, current energy level was reported to be satisfactory at worst and miraculous at best.

Health/Normalcy

Closely related to mental and physical activities is the broader topic of health and normalcy of life. Health, as defined by the recipients, was the freedom from illness, along with the ability to do whatever they wanted to do. Normalcy was to be like the average person. Included in this section are the informants' thoughts about having a normal life, and not feeling that they are different from other people. Also included are statements about whether they felt that their lives had changed, and whether they thought about their health more often or less often than they had previously.

Feeling Normal

Informants all felt like they were normal in spite of having had a liver transplant. They compared themselves to other people around them, and perceived that they had the same level of wellness and susceptibility to disease as people in the general population.

- *I feel...like a normal person (5)*

- *I don't feel any different than anybody alse in this office probably does. (3)*

- *I think if I got the flu, I would be just..I would be as sick as they are. Like, I would think I wouldn't be any sicker because of having had the transplant...I'd be able to handle it the same as they handle it. I don't think of myself as being handicapped (1)*

All but one informant felt healthy, and considered themselves normal.

> *I just don't think I've got a health problem anymore. So I just consider it sort of business as usual and almost as if, in that sense, as if the last three years didn't happen. And they haven't slowed me down (3)*

The one individual who did not feel totally healthy said that, with regard to her liver, she was healthy, but that she had two other ongoing health problems that made her feel less than healthy. Most of the informants thought that they were healthy enough to do anything they wanted to do.

> *...when I think about it, there really isn't anything [I couldn't do]; if I wanted to, I could try anyways (1)*

In addition, just because informants had to have ongoing follow-up with health care professionals, and had to take medications several times a day, their perceptions of themselves as healthy did not seem to be affected.

> *- I don't think I'm unhealthy at all. You know, the fact that I take medication to keep my system in line...to me, it does not mean I'm unhealthy. (1)*
>
> *- I'm now back to normal and it's just straight ahead except for once a month going to get my blood work done. (3)*

Focus on Health

The recipients believed that their lives were not so focused around their state of health now that they were feeling better. They did not take this health for granted. It just was not in the forefront of their minds at all times the way it used to be.

- When we start feeling better and the actions come back, we don't even think of it. (1)

- now I don't think about my health so much anymore. (5)

Changes in Life

Some recipients indicated that, prior to their liver transplants, they had expectations that their lives would change after their transplant.

- I sort of had this notion [I'd] be back to normal, but I [was] not sure that [I'd] ever be the same. But...it's better than that. I mean, not only you're back to normal, but you're better than normal. (3)

- in a way sometimes I'm almost disappointed because...life is normal. (6)

- I don't think my life has changed a whole lot...it's pretty much life as normal. It's kind of amazing actually. (7)

Informants varied a bit on their views of how much their lives had changed posttransplant from the way they were before they became ill. Some thought that their lives were back to the same way they had always been.

> *...basically [my life] is very similar to what I was like prior to my having a transplant, before the critical period. Cause basically I can do just about anything now that I did before (6)*

Those who thought it had changed believed that the changes were very minor. When asked what he would tell a potential liver transplant recipient about life posttransplant, one individual stated:

> *you're just going to tone down your life a bit. It won't change a lot, but you've just got to be aware of that it's going to change slightly. But you'll have a very normal life. (4)*

This same individual provided a descriptive statement that effectively sums up the feelings of normalcy after a liver transplant:

> *I feel that a lot of people feel that when you have an operation like this, your whole world falls in and you have to create a whole new one. It's not true. It's just a little blip in your life and you overcome it, and you come back and do the same thing that you ever did before. You don't turn black and you don't lose all your teeth. You don't go blind and you don't have to have a wheelchair and all those things. (4)*

Caring for Health

Closely related to their feelings of health and normalcy were the recipients' thoughts about being well and maintaining themselves in a state of freedom from sickness. Remarks made about making health a priority, or thinking about health, were also included in this section. *Caring for health* was thus the descriptor given to all activities that were undertaken with the goal of wellness in mind.

Many activities to maintain health were no different than those any person who wanted to have a healthy lifestyle would do. This encompassed eating well, getting exercise, and getting enough rest.

- You try and eat...quite a good balanced diet...I don't use even yet a lot of salt. (2)

- I make sure that I get adequate rest. Like I don't allow myself to become overtired. And if I get tired, I go home and I'll have a nap. (6)

- I try and stay active even if I don't have an exercise regime. (3)

- you just tone your life down a lot. You don't go to bars and have a party, and you don't spend a lot of time in rooms that are smoky (4)

There were also aspects of caring for health that involved taking precautions because of being immunosuppressed.

- I do want to be careful and not pick up something...like if we were travelling, I wouldn't deliberately go out and eat in an

unclean place or do anything foolish. Like I mean, I think...I've learned to watch for things like that. Like to be careful what you're eating (1)

- Flu shots. Not only did I have one, I made everybody in my family get one too...I said "I don't mind...if they get sick, that's fine, but at least they should <u>try</u> not to get sick"..and they weren't real pleased with me, but it was not a big deal once they had it. (3)

As time elapsed from when they had their transplant, some individuals stated that they became less concerned about their health.

...you're further away from that first part...and. I don't think you'd do anything foolish but...it just doesn't worry you the same. (2)

Others continued to be very conscious of their health, and of how they could best look after it.

- I've always been aware of my health and my own condition but I think on the whole,..that is the number one thing in my life now. (1)

- I think you just watch life much more carefully. If you're out in the cold, you dress up. If you're out in the damp, you make sure that you're not going to get soaked and cold and chilled...As far as sun, I'm not supposed to be in the sun. So

> *when I'm out on beaches, I just lay around in the shade rather than out in the bright sun. (4)*

Those who had made changes in their lifestyle to live in a more healthy manner thought that the changes became just a part of their ordinary routine over time.

> *It becomes part of your life...You change your life around that problem and it just becomes part of you. And then...you don't think of it as being unusual or anything. (1)*

All the recipients who were interviewed maintained that they tried to live a healthy lifestyle. Some reported that their incentive was the desire to do all that they could to ensure that their transplant continued to keep them alive. Others said that healthy living was nothing new as they had always been health conscious.

Implications of Medications and Medical Procedures

Part of what recipients had to do to care for their health was to take medications at least twice daily, and to have bloodwork and other follow-up care on an ongoing, regular basis. They talked about taking their medications, and about living with, or thinking about, the side effects of these medications. They also had thoughts regarding the physical effects of the transplant, including having a scar from the surgery. The descriptor given to these data was *Implications of Medications and Medical Procedures.*

An implication of something means that there is a logical connection between the two articles being considered. *Medications* as used for the descriptor for this category pertained to the medications that the recipients had to take, the immunosuppressive agents in particular. *Medical procedures* referred to the transplant surgery itself, and to follow-up treatments such as check-ups and bloodwork.

Taking Medications

Recipients discussed various aspects of taking medications. Most stated that although they did not particularly like taking medications, they did not really mind it either, or at least recognized that there was no other option, and so accepted it.

> *...having to depend on medication...kind of...cramps your style a bit. You have to carry it with you when you go somewhere. But the alternative isn't so great. (5)*

The recipients thought that being on medications was a small price to pay for having their health, and accomodated it into their daily routine.

> *It becomes part of your life. Just like taking those pills every morning at nine, and every night at nine. You just do it. I think anybody who's had an illness and anybody...who's been*

handicapped or anything. You change your life around that problem and it just becomes part of you. And then...you don't think of it as being unusual or anything. (1)

The recipients stated that taking their medications became "second nature," "something you just get used to." They also mentioned ways they had worked out to help them remember to take their medications at the appropriate times. One woman said her family had bought her a watch with an alarm on it which she set to ring at the right times. Another individual talked about putting his medications for the next morning in his briefcase at night so he would not forget to take them to work.

Side Effects of Medications

All recipients reported experiencing some side effects from their medications. Hair growth was one which was frequently mentioned. Some individuals actually liked the growth of extra hair. Others found it a nuisance but even they thought it was something they could adapt to, and did not consider it really a problem.

- I like all my hair now. Cause for awhile it was getting so thin before (1)

- I have a real black mustache and my eyebrows have turned black too, for whatever reason. You know, my hair is pretty grey, but my eyebrows have come in really black and thick. I have to have them [waxed] also. So, that's one of the side effects. And my

> *arms...had long hair on them...so I just shaved my arms also. So that's one of the side effects also,...it's not a serious thing. (5)*

Other physical changes that were reported by one or more recipients that they attributed to their medications were: a puffy face, and/or overall weight gain, "I have these fat cheeks (5);" a change in facial complexion, "I've got a complexion of a teenager (7);" slightly dulled vision, "my eyesight is a little less acute (4);" a weaker voice, "my voice isn't quite as effective as it was before, the medication seemed to have affected the muscle tone (4);" changes in their nervous system, "when I do fine work, I find that my hand will flutter a tad (4);" and feeling "hyper" -- "I'd get quite hyper and...I would be flapping around (6);" thin skin; elevated blood pressure; and decreased libido. However, the recipients found that the longer the time since transplantation, as their dosages of medications decreased, the less they experienced side effects.

> *- It's getting better...because the dosages are changing. Some are dropping, and...that's..what I have found is the biggest thing; 'till you finally get levelled all out in your medications...you have your different side effects and things like that (2)*
>
> *- the hair produced on my face and that has really...cut back so much since the cyclosporine has gone down in the dosage. (1)*

Body Image

The recipients denied having difficulty adapting to a new body image, which was changed by having the surgical scars and experiencing the side effects of medications.

- *I weigh more now than I've ever weighed in my life. But somehow, it doesn't matter as much. (3)*
- *[having a big scar] doesn't bother me a bit...it's just..not as noticeable as it was, you know, three or four months ago. It seems to be getting less. But no, that doesn't bother me one bit because...I'm not bikini material for one thing! And so, you know, it doesn't affect me at all. (5)*

Long-term Prognosis

Some recipients mentioned a concern about the long-term effects of being on medications. However, they did not let themselves become preoccupied with such worries.

I know full well that there are some long term side effects from the medications that aren't terribly great...I know that, but I'm not going to spend a lot of time thinking about it...I'll do what I need to do to live as healthy as I can to make sure that I don't have those problems. But if I do, I do. And if I...end up with cancer because I've had cyclosporine treatments, 10 years from now or what not...well, you know that would be really tragic personally...but on balance, I'm not sure that was a bad

> *tradeoff. So I'll be prepared to live with that stuff if it happens. Like I'm just not going to spend a lot of time thinking about it. And...if I have a problem, I'm going to check it out. There's no doubt about that. But...I'm not going to worry about stuff that might happen with extended use of cyclosporine or prednisone or Imuran or...whatever. (3)*

Thoughts about rejection were dealt with in the same way by informants. They did not let themselves think much about the possibility of rejection.

> *I have absolutely no thoughts about whether rejection's going to come or...am I going to get through the next one year, two years, three years, five years. I just don't think about those things. I don't think in those terms. (3)*

As time passed after transplantation, the recipients had a sense of security that rejection, or any other complication, either would not happen or could be overcome.

> *- I know that rejection is a very great possibility. But I always think the longer you're down the road from the operation, the less chance of it (4)*
>
> *- I think that [rejection] can happen...but I guess I've got, maybe it's a false sense of security, but I have this sense that if rejection sets in, I can get it treated. And mean I...never thought beyond that...I just kind of assume that it's fixable (3)*

Several recipients stated that they were not afraid of rejection, and thought it was a waste of time to worry about it.

> *What do I think about rejection? I'm not afraid of it, I'm not living my life in fear,...if it happens, it happens. I mean, I can't live in fear and change my whole lifestyle because it may happen. I mean, I may get hit by a car tomorrow too. (7)*

They had a certainty that if there were any complications developing in their bodies they would be picked up by the physician when they had their bloodwork done and then treated appropriately.

> *...once a month, I go and have that bloodwork done and I know if something's happening, we take care it and I don't worry about that. (1)*

The recipients expressed great confidence in the abilities of the transplant team to look after them.

> *I myself have all the confidence in the world in the staff in there [the transplant centre], and the transplant team (1)*

Thoughts about Follow-Up

All the recipients had bloodwork done regularly and follow-up appointments with a physician from time to time as well. Those whose transplant was recent and those who had recent complications had more frequent blood tests and checkups than the others.

As with their medications, most of the individuals in this study seemed to have adopted these prodedures into their lifestyle. They were not bothered by having to have ongoing follow-up, nor did they think it meant they were unhealthy.

> *I consider my medications and my bloodwork and visits as just something I do and...I don't do them because I'm sick. I just do them because I'm supposed to do them as a follow up and that's it. (3)*

It was evident that medications and medical procedures had implications for what the lives of liver transplant recipients were like. However, although many of the implications were negative, they seemed to be accepted by the recipients as the price paid for their health. They did not seem to let themselves be bothered by the side effects of medications or by the potential for organ rejection. They had confidence that the follow-up care provided to them would allow for early detection and successful treatment of any potentially serious complications.

Appreciating Life

In spite of all the implications of medications and medical procedures, the recipients were happy with their lives. They said they had a much greater appreciation of life than they had before their transplant. They clearly recognized the worth or quality of life, and were sensitive to, or aware of, life. Many felt that they did not take as much for granted, and were able to get more joy out of their activities.

> *- I continue to live my life pretty much like I did before but I appreciate it more because it was nearly taken away from me. (5)*
>
> *- I've learned to enjoy [golf] much more. I don't become quite as competitive. I enjoy the fact of being there much more than I did before the operation. I think that brings out a lot more you know. (4)*

Recipients frequently stated that they noticed, and cherished, little things in life more than they had prior to their transplant.

> *Two years ago when asked some of the things I'd like to be able to do again -- and one thing I said was "be able to walk in the autumn leaves and make them crunch under my feet."...Now, I go for a walk like there is nothing to it. It's the little things that make the difference. (1)*

Some indicated that they reassessed their priorities and made modifications in their lives. For these recipients, the transplant was viewed as a positive event because of the changes in lifestyle it prompted. These individuals felt that such benefits from going through the transplant would have long-lasting effects on their lives.

> *You gain a lot by going through the experience...I revalued all my priorities and what I wanted to do, what I wanted out of*

> *life. Family responsibilities and family relationships and relationships with friends and personal relationships. All those kinds of things. You look at it all different...the world is just better afterwards....I don't think you lose that...I don't know if I'll ever lose that now. (3)*

A couple of individuals said that they had actually made these changes pretransplant, that it was their illness that had made them contemplate life more.

> *I think I [reevaluated my priorities] prior to my transplant...I did a lot of thinking....what I could live with and what I couldn't live with. (6)*

Others simply expressed joy at being alive, or at having a "second chance" at life as they put it. They perceived themselves as lucky.

> *I have been given a second chance and I want to make the best of it. I'm so lucky to have this extra time -- can't help but feel that it is "extra" time. (1)*

As with the individual just quoted, some believed that, in a sense they had been given "extra" time. Thus, they wanted to be productive and make the most of their time, and not waste it.

> *I tell you,..you appreciate each day, each day that you wake up and feel good..you just...really appreciate it; it's like a gift. And I try to do something each day. I don't like to waste my time because you know, I feel it was such a close call*

> *for me...so each day...I want it to be productive. I want it to be a good day and I try to do that, I kind of plan my days.* (5)

All of those interviewed were very happy to be alive. They had a positive attitude about their lives, and were appreciative of being given the opportunity of having a transplant. One man summed up his present life in this way:

> *I'm a pretty happy guy and you know, I'm glad that I'm still here and able to continue on with life,..I use the expression that "I've looked through the door but didn't step across the threshold," 'cause I was there a couple of times and I'm back, and I'm damn glad I'm back.* (7)

Evolving Relationships

Relationships with family and friends were discussed by all informants. As with most aspects of life, relationships are dynamic, rather than static. As such, they evolve over time; that is, they develop gradually, or are worked out. Whether the liver transplant recipients' relationships with others changed posttransplant or not, they nevertheless were continuing to develop. Hence, *evolving relationships* was the title given to this next category.

It seemed as though the reactions of friends and acquaintances to the transplant recipient often differed from those of family members. Therefore, they are discussed separately.

Friends

Some recipients felt that going through the transplant had brought them closer to their friends, while others stated that their relationships had not changed.

> *I think maybe I've become closer to some people because of the fact that they- you know, this operation was fairly "on the edge" and if I hadn't made it, then...I would have been gone. And I think because of that, we have a tendency to cherish our times together a little more...life goes on and you just ignore a lot of people and they ignore you. But when it gets down to the final brass tacks of it, it brings out the best in all people. And I have some closer friends because of it. (4)*

A number of informants commented that acquaintances were amazed to see them looking so well after the transplant, when they were used to seeing them jaundiced and ill in appearance.

> *- I have seen some of those people since and they're; they're just amazed...because...it's a totally different appearance. (3)*
>
> *- she was surprised to see how I looked; said I looked like I used to years ago. (1)*

The recipients were happy when people noticed, and commented on, how much healthier they were looking.

> *..when they comment, you just feel so much bubblier and happier and...you're out for more fun and everything else (2)*

Another change reported in their relationships was that many of their friends and acquaintances thought that the recipient would still be unhealthy after the surgery. Thus, they treated the recipients as though he or she had limitations and restrictions regarding activities. The recipients reported that acquaintances who were not emotionally close to them had more trouble than close friends believing that the recipient was well and not unhealthy. Some acquaintances continued to treat the recipient like a fragile doll.

> *She couldn't understand why I wasn't feeling more tired or uncomfortable. I told her I probably have more energy than I've had for years. She just shook her head. Then she said...that they should get going because I probably needed a lot of rest and was tired. (1)*

As a result of this, the recipients reported that they had to prove to those around them that they were able to cope with the demands of everyday living. But after their friends saw that they could function in the same manner as ordinary persons who had not had a transplant, friends began to treat them like normal persons.

> *..people still ask me how I'm feeling and how I'm making out in terms of follow up. And people that I work closely with-they're always concerned about that. But...I don't have to remind anybody anymore that I have no restrictions...I think most people have accepted that I'm back to normal. So I...clearly*

don't have any impression I'm treated any differently now than I used to be. (3)

A few recipients differentiated between older and younger acquaintances, stating that the older ones had more difficulty believing they were well after the transplant.

...ones that are probably the most amazed I think are your older people...I think they're always so surprised on how well I look and "..oh, you're back working." You know, this always seems to be the surprise. I get the feeling that they think well I should be sitting at home crocheting or, you know? Reading a book or something like this rather..I think, but that's more your [illegible] (6)

Ger [illegible] actions of friends to a liver transplant rec [illegible] to be as follows: initial surprise at the c [illegible] en concern that the recipient get enough re [illegible] much or work too hard; and, finally, grad [illegible] that the recipient could be treated as a normal person. It seemed to some recipients that it took longer for older acquaintances to reach this final stage of acceptance than it did for younger ones.

Family

Relationships with family members, particularly one's spouse and children also evolved over the course of the transplant experience.

For some recipients, their marital relationship improved or was strengthened by the experience. One recipient stated that prior to the transplant, she and her husband were not getting along very well because they were both feeling a lot of stress, and her husband was getting tired of the caregiver role. However, after the transplant she stated:

> *emotionally, we're just getting along that much better because I feel like he feels like he has a partner now -- not just somebody that he has to look over [sic]...it's definitely a lot better. (1)*

Another recipient thought that she and her husband had always had a strong relationship, but commented:

> *I'd say we probably have a very solid marriage and I think probably a lot of it has to do with-with the way we or we were able...to come together because of the difficulty rather than having it split us. (6)*

She believed that the transplant had benefited their marriage relationship.

> *I think it's brought us closer...we communicate I think on a much better level...we aren't playing games with one another (6)*

Yet, one informant indicated that she and her husband were having some problems in their marriage. She was feeling well enough to be independent, but her husband did not seem to want her to be.

> *I don't know if it would have made a difference had I not had a liver transplant. Possibly, because I think that he sort of enjoyed his role of caretaker and...I appreciate it, but I don't want to remain in that area, I want to move on. And he can't seem to understand that. (5)*

Other informants, while stating that their marriage relationship had not changed much after the transplant, nevertheless indicated that their spouses were protective of them. These individuals, however, interpreted such concern as evidence that they were loved, rather than feeling that their independence was being smothered.

> *There are times when my wife gets concerned, like when I got back to work she was afraid I was overdoing it... They're normal concerns I think that people would have, given a similar set of circumstances. I don't think that they're paranoid concerns. I think they are,..normal and all they're doing is showing their love for you anyway...I don't think it's what I'd call a problem. (7)*

The recipients also mentioned this protectiveness when they talked about their relationships with their children, whether they were grown up, or younger and still living at home.

> *- my kids [and I]..we've seemed like we've grown,...I'd say we're fairly close....They've got probably a little more protective from the time I was having the surgery (6)*

- my kids keep yelling at me that I shouldn't be doing what I'm doing. (5)

However, on the whole, family members treated the recipient like a normal person, rather than expecting him or her to be different, and to have limitations.

- I don't think that they treat me like an invalid. (5)

- My children...they consider me healthy cause they're close to me and they've seen what I've gone through and everything. (1)

- from time to time, [my kids] will make comments about the fact that I'm sort of normal, I'm not lying on the couch in the evenings anymore (3)

For the liver transplant recipients interviewed, those friends and family who were emotionally closer to the informants, and spent more time with them, at first were amazed at the change in the recipients and tended to "baby" recipients, but after they got used to the recipients being well, they treated recipients normally. Acquaintances who did not know the person as well were more likely to be amazed at the changes in the recipient, and to think that he or she was more fragile than the ordinary person and needed to rest more and restrict activity. For marital relationships, the stress of the transplant experience generally seemed to strengthen the marriage.

Awareness of Donors

All of the liver transplant recipients interviewed thought about the donor from whom they received their organ, although some were more acutely aware than others. When one has an awareness of something, it means that person has knowledge about it, particularly "in a keenly responsive way" (Random House Dictionary, 1980). Included in this category were the recipients' thoughts about being thankful for the donor, writing letters to the donor family, having a foreign organ in their body, wondering about the donor's characteristics, and encouraging organ donation.

Thoughts about Donor and Donor Organ

For some recipients, their awareness of the donor was interwoven with sadness since they knew that someone had had to lose his or her life in order for the recipient to live.

> *I know it gives me kind of a lump in my throat sometimes when I think about it, because I know somebody else has lost their lives for me to feel this good. (1)*

Those who felt sadness about the donor found it helpful to write a letter to the donor family to express their gratitude, and to try to make something positive out of the tragedy.

> *I wrote a letter...to the family of my donor. It took me a long time...to get just the right words and so I really struggled over it. I don't know who they are. But..I wrote the letter*

> *and I gave it to [the transplant coordinator]. And so, that made me feel a little better....I was able...to say what I felt about this donor...I was able to let them know how appreciative our whole family is...of this donor. (5)*

For others, the awareness was less emotion-laden. One person thought about the donor mainly because there had been a size discrepancy between the recipient's body and the size of liver that had caused some complications.

> *...the only reason I think about the donor is because of the fact that the liver was substantially smaller than my liver (7)*

Although none of the recipients were bothered by the fact that they had an organ from someone else in them, one recipient stated:

> *...sometimes it seems weird (3)*

But he added:

> *it doesn't feel like a different person's liver. You'd never know really where your liver is anyway and/or what it feels like (3)*

Another person said that having someone else's organ was not a concern, but cared only:

> *...that it still is clickin' away like it's supposed to. (4)*

Several of those interviewed wondered sometimes whether they had acquired some of the donor's characteristics. For example, one individual said he had joked with his physician that maybe he had put on weight because the donor had been overweight. Another informant wrote in her diary:

> *Wonder if I got the liver of a very young person -- who has lots of vim and energy. And if that has any reflection on me and my behaviour. Who knows what may lay down the road for me!! No one really knows yet what happens 15-20 or 25 years ahead for liver transplants. Maybe, I will have a very young body!! (1)*

Another person commented that she wanted to have a productive life so that the donor's contribution to her would not be in vain.

> *I think in a way maybe now even inside you think you're going to make the best cause you're given the hope. He's given you that chance (5)*

<u>Thoughts about Organ Donation</u>

All the recipients were very conscious of the need for organ donors and stated that they had filled out their own organ donor card and promoted organ donation to others when they had the opportunity.

> *...one thing that I've done, and I make sure everybody that I can urge to do it has done it, that's to fill out their donor card....on their licence....I don't religiously go around and make sure people have done it. But any opportunity, I really promote it, and mine's filled out. And if I should die, they can have whatever they want and if they can use it, that's great. (3)*

One individual went even further than this, stating:

> *I think that there should be some ongoing program, a much stronger one than they have now to, almost at the same level as donating blood. To get people to become so extremely aware of the importance of this. (4)*

Recipients felt that they were a living testimony of the success of organ transplant, and said that when other people saw that they were doing well it sometimes caused those people to have more awareness of organ donation and transplantation.

> *...they see me looking healthy like this and they realize just how important research is...and having their donor cards...on their driver's licence filled in....I hear that many times you know, that people will be doing that now because they see what happened to me. (5)*

It appeared that liver transplantation increased awareness of both recipients and their friends and families with regard to donors and the need for organ donation. Recipients put their increased awareness to action by signing their own donor cards and encouraging others to do the same.

Moving Ahead

The last category of data discussed by recipients pertained to their plans, their optimism regarding the future, and their desire to help others either financially or by volunteering their time. All such thoughts were given the descriptor *moving ahead*. To move can mean to be going or passing "from one place to another with a continuous motion" (Webster's Ninth New Collegiate Dictionary, 1983). Ahead denotes a forward direction.

Making Plans

The recipients had varying views on making plans. Some liked to plan ahead and make lists of things to do because they did not want to waste any of their time now that they were able to be active and take part in things.

> *...[the future] is more a positive thing now. Like, I think about what I'm going to do next week or some project I'm going to tackle. Before, I didn't really want to pick any big projects because there was times, no kidding, it would cross my mind, "Am I going to be around to do this? Am I going to be around to see the end of this?" And of course, I didn't start any huge projects. I didn't even want to plan a trip for next August, because why think that far ahead? I might not even be up to doing it...Where now, it would be great if I could plan that trip for nine or ten months from now, I would leap into it and want to do it. (1)*

Another recipient felt confident enough about the future to buy a new house, even with the additional financial burden that this entailed.

> *I have enough confidence in where I am and where I'm going that...even going out and buying a new house... I don't consider that risky in the sense of where my health is at. (3)*

Others thought that they wanted to live one day at a time because they could not know what the future would hold. These two recipients did not seem as confident about the future state of their health.

> *- it's just on a day to day basis that I plan things (5)*
>
> *- you never know from day to day, do you really? -- so you're just going to make the most of every day you have (2)*

For those who stated they were still recuperating, the future was seen as a time when they could get back to their regular level of activity.

> *...what we've told people is that, at least temporarily, we can't do some of the things that we have done in the past, simply because physically I can't do it,..or circumstances are such that it can't be done this year, but maybe next year. (7)*

Others had specific ideas about things they wanted to do. Quite a few indicated that they desired to travel.

> *I'd like to be a grandma and all the rest of the things that go along with it I suppose. And I'd like to do some travelling (6)*

Being Optimistic

All the recipients, even those who were less sure of their health, were optimistic about the future.

- I'm looking forward to doing lots of things...I'm sure not worried about the future. (1)

- the future for me is good or better than ever. (3)

Several indicated that their confidence and optimism increased as time after transplantation passed.

I don't have any of those kinds of fears about what might happen in the future, having gone through that, everything worked out well, and I have this comfort level that everything's fine....I know that the longer you go on, the longer the time elapses from the point of the transplant the less chance of rejection, the less chance of it not working out. And I'm just about at the one year mark now and I think that when I get to the one year mark, and feel as good as I do now,...and I wouldn't want to say it, but I almost have the feeling that rejection can't happen because I've passed this magical one year mark. (3)

Making Decisions

A few recipients indicated that in moving ahead with their lives they had some decisions to make.

- I don't know, I think maybe I should go back to work. And I think, where would I work? (1)

- I'm just seeing how well I can manage my home, because I have my own home...and if it is too much, that's the next thing to

> *think about...selling [my] home and having an apartment or something. (2)*

However, the need to make decisions was viewed in a positive light instead of as a problem. It signified to the recipients that they were well, and had enough energy to make such decisions. Prior to their transplant some reported that had felt too exhausted and hopeless about the future to want be involved in decision-making.

> *I'm more sure in what I want. Sometimes, I know I used to think, "Why ask me? I probably won't be around to see the outcome." So I didn't really care about being asked about something. (1)*

Ability to Move Ahead

Several recipients talked about how they were able to move ahead with their lives. One credited it to her faith in God. Another attributed it to positive thinking.

> *- I guess I don't really fear anything. I figure the good Lord doesn't give you any more then you can handle and I thoroughly believe that...if you have faith and you believe that, I think you can handle just about anything. (1)*
>
> *- Accept the fact that this happened and push forward from that point. Get your mind positive. Think positive. (4)*

Helping Others

For many individuals, part of what they wanted to do in moving ahead was to help others. Two of the recipients interviewed did volunteer work. Another mentioned being more conscientious and generous about making financial contributions to charities than he had been pretransplant. Several discussed their willingness to talk with liver transplant candidates or anyone else they thought they might be able to help.

> *- I've noticed...that...donations to charities - I'm more generous now than I ever was before...it's because..I can afford it, but also I just have this feeling that it's important. (3)*
>
> *- I'd like to share my experiences with whoever I can. Particularly answer any questions of anybody...who's waiting for a transplant...if I can be of help anywhere, I'd like to. (1)*

The liver transplant recipients who were interviewed reported looking to the future with optimism. Some were confident enough about their health that they made long range plans, while others preferred to live day to day. Overall, after going through the transplant, and being given another chance at having a future, recipients seemed to want to make the future better for others.

General Comments

Informants for this study did not all live in the city with the transplant centre. Some were from rural areas and from other cities. Yet there seemed to be no difference in their reported outlooks and descriptions of life. In other words, their family locations relative to the transplant centre did not appear to be a factor influencing their recovery in any significant way.

Similarly, although the recipients differed as to age, sex, education and marital status, no distinguishable variations occurred in their recovery experiences or attitudes because of these differences. Surprising uniformity existed in this regard.

No mention was made in this chapter with regard to the _timing_ of recipients feelings and responses, that is, the order in which they felt that certain things had happened. The timing of changes seemed to vary for the informants, possibly depending on the length of time they were ill, and the severity of their illnesses pretransplant.

Summary Description of Life After Liver Transplantation

From the perspective of the recipients interviewed, a description of the nature of liver transplant recipients' lives can be generated. The transplant was viewed as a significant event, and the recipients had no regrets about having had it. But the recipients reported that they wanted to move on from there and not dwell on the past. Mental activity seemed to improve compared with the pretransplant and/or immediate posttransplant states, and any ongoing lapses in memory and concentration were generally attributed to aging. Physical activity seemed to be much better. Most of the recipients thought that they had few, if any, limitations of activity. For those who were quite debilitated prior to the transplant, their energy level, even in the recovery stage, was much better than it was before the transplant. For those recipients who were relatively healthy pretransplant, energy level was slightly reduced during the recovery stage, but seemed to improve so that it was back to or better than where it was before the transplant.

The recipients reported feeling healthy, and not spending time worrying about their health. But, they did try to maintain a healthy lifestyle. After receiving a liver transplant, it seemed that the recipients moved from focusing on illness, or lack of health, to focusing on health or simply accepting health as the norm. Taking medications, dealing with the side effects of medications, and incorporating follow-up regimens and the effects of medical procedures into their lifestyles did not seem to bother the recipients, as such routines were viewed as the price paid for health. The liver transplant recipients in this study greatly appreciated life and did not take it for granted.

It seemed that relationships with friends, acquaintances and family evolved over time. It was reported that friends and acquaintances went through periods of amazement and skepticism before accepting that the recipient could be treated as a normal person. On the whole, the family members did not have the same difficulties in accepting that the recipient was able to lead a normal life. Marital relationships generally seemed to be strengthened as a result of the transplant experience.

The recipients reported a much greater awareness of the need for organ donors than they had prior to their transplant, because of being dependent on a liver that originally belonged to someone else. However, the recipients did seem to have a problem integrating the idea of a foreign organ into their own persona.

The recipients indicated that they viewed the future with optimism, and made plans on either a day-to-day basis, if the recipient had concerns about his or her health status, or on a long-term basis if the recipient was confident about his or her health. The recipients also reported the desire to make the future better for others.

Chapter 5: DISCUSSION

In this chapter, a brief general description of life after liver transplantation is provided. Then, each category presented in the findings chapter is discussed. Where appropriate, the findings are compared with existing literature. Some concluding remarks complete the chapter.

Discussion of the Findings by Category

Thinking about the Transplant

Three things became evident from this research. First, liver transplant recipients were found to have positive feelings about their transplant, and some even considered transplantation to be a character-building experience. They felt that their pretransplant expectations of what their lives would be like posttransplant were either realistic, or more pessimistic, than their experiences proved. Thus, they were not disappointed with what their lives were like posttransplant. These findings may indicate that the pretransplant assessment and work-up that each of them received prepared them adequately for what they went through.

In published research, there is no discussion of liver transplant recipients' reflections about their transplant. Thus direct comparisons cannot be made between the present study and past findings. In the only research in which limited attention was given to this matter it was noted that depression was common in the transplant recipients studied (Tymstra, Bucking, Roorda, Van Den Heuvel & Gips, 1986). However, of the seven recipients interviewed for this current study, as well as the two secondary informants who provided some input, none indicated that they felt depressed in any way. In fact, they all had positive feelings about their lives.

Secondly, none of the seven informants regretted having the transplant. For some, their only regret was that they had not had it sooner, either because transplantation was not available locally earlier, or because he or she had taken some time before deciding to proceed with the surgery. Even those for whom recovery had been difficult were glad to have had the transplant.

Third, the recipients interviewed all held beliefs about what had brought them through their transplant successfully. Thus, it is important to recognize that different people have different ways of obtaining support.

Mental Activity

There are two aspects of the findings regarding mental activity that need to be discussed. The first pertains to cognitive functioning. With respect to cognitive functioning, it was noted that the recipients of liver transplantation interviewed for this study reported fewer difficulties than noted by other investigators.

For instance, Wolcott, Norquist and Busuttil (1989), reported that although recipients did quite well on a number of measures of cognitive function, on several tests they concluded the recipients had "persistent focal cognitive dysfunction" (p.3563). Tartar and colleagues (1988) found that recipients obtained normal, or close to normal, cognitive functioning within two to three years after their liver transplant, but stated that they had "deficits implicating cerebral dysfunction requiring visuopractic capacity" (p.210), that were present three years posttransplant. In the present study, all of the recipients mentioned that at one point or another during the course of their illness or transplant they had had some concern over their impaired, or as some put it, "foggy" mental functioning. However, after their disease process was resolved and their dosages of medications were reduced, these problems were eliminated, although some reported ongoing short-term memory loss. But, they felt such memory loss may have been due to aging as much as anything, and found it easy to adjust for this problem.

This finding is different from the findings of Tartar and associates (1989) who reported that memory was intact in the recipients examined. It is possible that the recipients interviewed for the present study only perceived themselves as having short-term memory loss, but in actuality had no more difficulty in this area than anyone in the general population. Overall, they did not think that they had problems with cognitive function.

Physical Activity

The recipients interviewed for this study were very satisfied with their physical abilities. They were all unequivocably of the opinion that their levels of physical activity were very satisfactory, and certainly were much better than their pretransplant condition. This finding concurs with that of Küchler and colleagues (1991), who indicated that recipients' evaluations of their physical conditions increased significantly posttransplant. The authors did state that these ratings were not as high as those of healthy controls.

The present study provides different findings regarding physical activity than those of Robinson and associates (1990). As reported in Chapter 2, these researchers found that about half of the 31 recipients they studied, who were all at least three years posttransplant, had subnormal function in at least one extremity. Many also indicated some accompanying weakness, pain, lack of coordination, or restriction in movement. Several patients also required the use of assistive devices for various activities of daily living. In the present study, several recipients mentioned having occasional pain, slight muscle weakness, or lack of endurance. But their posttransplant condition was so much superior to their former condition that they did not feel these were significant or that their physical activity was limited.

The differences in reported results may well be a function of the different methodologies used in the two studies. In Robinson's study, recipients were asked to respond to a questionnaire that listed various adverse effects that recipients may have experienced on occasion. No attempt was made to measure the degree of distress caused by these symptoms. Thus, the reason that respondents even identified these things may have simply been because they were listed on the questionnaire. The symptoms may never have caused them any significant distress and accordingly may not have been serious issues in their minds or experiences. In the current study the researcher specifically attempted to avoid the possibility of putting ideas in recipients' minds. Open-ended questions were used, whereby recipients were left free to mention what was of importance to them, rather than being asked to respond to what the researcher thought might be of significance to them. Moreover, the recipients in the present study were between six months and two years posttransplant, as opposed to more than three years posttransplant as in the Robinson study. Although it is conceivable that more physical problems develop the longer one goes past a transplant, the recipients interviewed for this study who had had their transplant for more than two years felt that they were still improving, and not getting worse.

Health/Normalcy

If there was any one aspect of their lives which liver transplant recipients emphasized above all others, it was the fact that they felt healthy and normal, or better than what had been their "normal" for quite some time before the transplant. They did not feel handicapped or different from the general population, and they did not want to be treated any differently. All except one (as described in the previous chapter) felt healthy and did not perceive their follow-up care to mean that they were unhealthy. One woman compared her surgery to someone having an appendix out, and stated that just because that person had to have surgery did not mean he or she was unhealthy afterwards.

Many recipients expressed amazement at how normal their lives were. Some said that they had read everything they could find about liver transplantation prior to their own surgery, and much of the literature talked about the problems recipients faced. Thus, prior to their transplant, they felt that somehow they would not be quite the same afterward, even though they were told by the transplant coordinator that their lives would be normal. These individuals were therefore rather pleasantly surprised by their posttransplant condition.

Three recipients mentioned that, prior to their own surgery, they had met a previous recipient who looked very healthy and normal. This increased their own hope for a normal life posttransplant.

Similarly, they said that after their transplant, occasional contact with other liver transplant recipients who had gone through the recovery process ahead of them helped them feel that their own recoveries were normal.

Caring for Health

The recipients all took some precautions regarding their health. As time elapsed after their transplant, most did not feel they had to be vigilant to preserve their health, but rather felt they were simply trying to live in a healthy manner. Those who continued to be a little more concerned about maintaining their health status watched what they did a bit more carefully than did the others. But, even these individuals felt that their heightened awareness of being careful became, or already had been, just part of their routine. For example, with regard to staying away from people who are ill, one man stated that he had always tried to do that, so it was not a change.

Caring for health has rarely been mentioned in the literature from the perspective of recipients. Hyler, Corley and McMahon (1985) found that the most frequently expressed concerns by heart transplant recipients in a support group were those relating to maintaining health. What has been noted in the literature is that recipients have to be taught about lifestyle restrictions (e.g. Sheets, 1989). However, the findings from this present study may indicate that teaching for liver transplant recipients should be focused on healthy living, such as eating a balanced diet, and following an exercise program, rather than on lifestyle restrictions. This suggestion was also made by Hyler and colleagues who stated, "Teaching sessions should emphasize the positive aspects of daily health care and encourage the patient and the family member to view it as a matter of routine" (p.455). This provides a more positive focus than dwelling on restrictions; there is no need for recipients to curtail their normal activities in order to have a healthy lifestyle. Any precautions that are required can be incorporated into their day-to-day routines.

Implications of Medications and Medical Procedures

There are three main aspects of life posttransplant that should be considered with regard to the implications of medications and medical procedures. First, there is the question of compliance. A great deal of work has been done on the subject of compliance of patients with various therapeutic regimes (e.g., Sackett & Haynes, 1976). However, for the transplant recipients who took part in this study, compliance was not even an issue. When talking about having to take medications twice daily or more often, recipients all volunteered that they had never missed taking their medications, although most had temporarily forgotten, and been a few hours late at times. They had incorporated their medication schedules and follow-up routines into their lives, modifying their lives where necessary to make the regimens fit. They did not let the difficulties of having to take their medications at the right times, or of always making sure they had their medications with them, become an annoyance to them.

A second important finding relates to side effects of medications. In articles about transplant recipients, the distress caused by side effects of medications has frequently been mentioned (e.g. Bass, Bindon-Perler & Lewis, 1991; Craven, Bright & Dear, 1990). However, in research studies, where many side effects were listed by transplant recipients, researchers came to the conclusion that the side effects did not affect quality of life (Lough, Lindsey, Shinn & Stotts, 1987), were minimized by recipients (Tymstra, Bucking, Roorda, Van Den Heuvel & Gips, 1986), or were not a source of great concern to them (Foley, Davis & Conway, 1989). These research findings concur with those from the study discussed here. The side effects of medications were accepted with few complaints. Recipients made comments about how they did not really like their "fat cheeks" or the extra weight they had gained. However, they tried to view the side effects in a positive manner. For example, one lady stated that when she had a puffy face, "it ironed out the wrinkles." They also said that most of the side effects disappeared as the dosages of medications decreased, and so felt that they only had to endure them for a short time.

Finally, there is the issue of body image. Changes in body image posttransplant, which frequently result from the side effects of medications, have received considerable attention in the literature. As discussed in Chapter 2, authors have had varying views of the importance of this issue. However, the recipients interviewed for this study were in agreement that their body image was not affected by the transplant experience. Neither the scars from their transplants nor the side effects of medications were of great concern to them. This finding is consistent with literature pertaining to adult liver transplant recipients.

In the two research articles in which body image of liver transplant recipients was addressed, both groups of researchers indicated that concerns with changes in body image were rarely mentioned (House, Dubovsky & Penn, 1983; Tymstra, Bucking, Roorda, Van Den Heuvel & Gips, 1986)). Body image posttransplant, related either to integration of a foreign organ or to bodily changes caused by the transplant surgery or the medications, did not appear to be a major problem. This finding may have been different if the samples in studies had been composed of adolescents. In descriptive literature regarding psychosocial aspects of transplantation, problems with changes in body image after an organ transplant are often mentioned in relation to this age group (Lough, 1986; Sheets, 1989; Surman, Dienstag, Cosimi, Chauncey & Russell, 1987).

Appreciating Life

All the recipients interviewed had a deep appreciation for life. It may have been that they had a heightened awareness of life because of the risk of death from their disease or their transplant. Little things became more important and were not taken for granted. Priorities were reassessed. They wanted to make the most of every day they had. Recipients felt that going through their illness experiences and/or having a transplant had actually benefited them in this way. This is a finding that has not previously been reported. It does not appear to have been studied directly, although some researchers who have measured quality of life have possibly assessed this appreciation of life indirectly.

Evolving Relationships

Findings from some research studies suggest that stresses in relationships may be experienced by transplant recipients (McAleer, Copeland, Fuller & Copeland, 1985; Sutton & Murphy, 1989). The current study sheds light on this issue. First, as with the deeper appreciation of life, evolving relationships were viewed by a number of recipients as a benefit of transplantation. For most of them, the stress resulting from the crisis situation of a transplant caused them to develop deeper, more meaningful relationships with family members and friends.

There is, of course, the potential for new stresses because of the changes the recipient goes through from pretransplant to posttransplant. One husband had a difficult time adjusting to increasing independence of his spouse after her transplant. One might initially think that this finding relates to the comment made by one of the respondents in the study of the psychosocial impact of a liver transplant programme done by Tymstra and colleagues (1986, p.308). The person said that the transplant experience made good relationships "twice as good," and poor relationships "awful." This result is, however, more consistent with the studies by Hyler, Corley and McMahon, (1985) and O'Brien (1985), in which the findings suggested that role changes can be a stressor. It is evident that how relationships evolve will depend upon such factors as how family members respond to the role changes that may occur after one has a transplant, on the temperament of the individuals involved, and how well all individuals involved communicate their feelings to one another and are willing to work them out.

A second issue, in the same context of relationships, relates to the frustration recipients experienced regarding the reactions of friends and acquaintances to them following their transplant. It took a while for such people to get over their amazement about the positive changes in the recipient. Recipients found that they had to prove that they could be normal before others would begin to treat them that way.

Awareness of Donors

When the first few recipients who were interviewed mentioned the donor from whom they received their liver, the researcher did not consider such thoughts significant in describing what living with a liver transplant is like. However, as more people were interviewed, the awareness of donors kept coming up, and it became obvious that such awareness was an important part of life after a liver transplant.

In published articles on life posttransplant, the donor is generally mentioned only in relation to discussion of integration of a foreign organ (e.g., Packa, 1989; Platzer, 1987). Two recipients did wonder if they had acquired some of the donor's characteristics, but for most of the recipients in this study, the awareness of donors was broader than that. It encompassed three things: (1) a great appreciation of their donors, (2) a sadness that the donor had to lose his or her life in order that the recipient might live, and (3) an awareness of the shortage of, and need for, donor organs.

The recipients who expressed the most sadness about the donor having to lose his or her life were the ones who had written a letter, or letters, to the donor family to say "thank you," and to let the donor family know how they were doing. This was one way these recipients tried to repay the donor family for their gift of an organ, and the recipients felt good about having done that. All the recipients were proactive in terms of informing others of the need to sign their organ donor cards and doing this themselves. This was another way of expressing their gratitude. They wanted to ensure that others who needed an organ had the same opportunity to receive one that they had.

Moving Ahead

There are two particularly interesting findings in relation to the category *moving ahead*. The first pertains to the concept of uncertainty regarding the future for liver transplant recipients. Researchers who have had renal transplant recipients rank the importance of various stressors have indicated that uncertainty about the future is one of the greatest stressors for these patients (Hayward, Kish, Frey, Kirchner, Carr & Wolfe, 1989; White, Ketefian, Starr & Voepel-Lewis, 1990). There have not been any studies of this sort conducted with liver transplant recipients. The results researchers obtained by surveying renal transplant recipients were not consistent with the findings from this study. In keeping with the liver transplant recipients' general feelings of satisfaction with their lives, those interviewed were all optimistic about the future. Planning, being productive, and making decisions, all played a part in their futures.

There are two possible reasons for the differences in findings from this study to those from other research. Firstly, as mentioned earlier in relation to another category, the difference between this study and previous research may be method used to determine the degree of importance recipients attach to the stressor *uncertainty regarding the future*. When given a list of stressors and asked to rank them from greatest to least importance, recipients are forced to put a weight on the uncertainties they face. In comparison to the other stressors listed for their consideration, uncertainty about the future might be assigned quite a high rank, but within the perspective of their lives as a whole, this uncertainty might be very minimal, as is suggested by the findings from this study. In the research studies in which recipients were given a questionnaire to fill out, so in a sense, they were forced to respond in ways that may not have accurately expressed their true feelings.

There is a second potential explanation for the discrepancy between the findings from past research with those of the present study. The optimism that characterized all the recipients may have been simply that they were optimistic because they felt well, or it may have been due to their inner strength, or some personal attribute that sustained them. Various recipients expressed beliefs about how they managed future uncertainty. However, all recipients received their transplants in the same centre and were cared for by the same group of health care professionals. Thus it is also possible that their optimism came, at least in part, from their care-givers. Until the source of such optimism can be determined, it is important that nurses realize that they may contribute to transplant recipients' views of the future.

It was also noted that most recipients made a more conscious effort after their transplants to help others than they had previously. This took various forms, such as volunteer work or increased generosity to charities, but all recipients indicated that this was definitely part of what they wanted to do in moving ahead with their lives. They reported that they were more altruistic than they had been pretransplant. They seemed to have gained a broader perspective on life and realized that there was more to the world than just their own little part of it. Just as they had received what they felt was a gift in being given a second chance at having a future, they wanted to share this gift with others.

This finding makes intuitive sense, and has been described in earlier literature on reciprocity. Researchers have found that patients often desire to give gifts, tangible or intangible, to nurses to repay them for the care they have received (e.g., Morse, 1989). In the present study, recipients may be demonstrating this feeling of indebtedness to society as a whole. In light of this, perhaps a "buddy" system that pairs transplant candidates with transplant recipients could be developed. This could enhance the transplant experience for the new candidate by having a person to talk to who could relate to what he or she is going through, and could simultaneously enable transplant recipients to feel as though they were returning some of the help they received.

Concluding Remarks

In general, even though the recipients interviewed in this study had been through a dramatic, life-changing experience, they were able to emerge from it with a feeling of normalcy. The life-or-death experience did have important effects on their outlook on life, including their priorities, their relationships, and the joy they received from everyday things. Many of them had new attitudes about life, and a new sense of what was important in life. They manifested a deep sense of gratitude too. Not only were they thankful for every day that they lived, they were also grateful to their donor. They frequently expressed this gratitude by helping others. These values brought extra meaning and joy into their lives.

In the recipients' descriptions of life with a liver transplant, the element of time was important, although it was not discussed specifically with regard to any one descriptive category. For example, recipients talked about the reduction of side effects of medications over time, and their increasing ability to pursue activities similar to people without transplants. But, they did not report a common critical path for their progress. Indeed, the defining of such a path was not a research objective of this study. All that can be said is that for those who were quite well up until their surgery, the recovery period was short, and it was only a matter of months until they felt completely normal. Others, typically those who had more health problems pretransplant, experienced a slower recovery and felt they were still improving two years posttransplant.

During the time when the findings of this study were being compiled, the researcher heard a heart transplant recipient speak at a symposium relating to transplantation. The heart transplant recipient's experiences and outlook were quite similar in many respects to those of the liver transplant recipients in this study. This may well mean that the description of life after liver transplantation in this research has theoretical generalizability to other groups of transplant recipients, particularly recipients of heart or liver transplants. The findings may also apply to some renal transplant recipients. However, it is quite possible that life for renal transplant recipients may be different since they always have the option of having dialysis if their transplant is rejected or malfunctions, whereas there are no artificial substitutes for hearts and livers at this time.

While the results of this study are very positive, health care professionals, and liver transplant candidates and recipients must be aware that not all liver transplant recipients recover successfully. The findings of this study will be most relevant to recipients who, like the ones interviewed for this study, have been discharged from the hospital and are able to live independently.

Chapter 6: CONCLUSIONS AND RECOMMENDATIONS

In this final chapter, implications for nursing practice drawn from the findings are discussed initially. Next, some limitations of this study are outlined. Suggestions for future research follow, and then a brief summary concludes the thesis.

Implications for Nurses

There are a number of nursing implications which can be drawn from the findings from this study. The first has to do with hope. Various researchers, such as one who studied patients with chronic heart failure (Rideout, 1986), have found that individuals who are hopeful remain more involved in life than do those who have less hope. In view of this, it may be helpful to liver transplant recipients to have the health care professionals who are caring for them maintain optimism regarding their recovery, even in the midst of complications. With this hope, coupled with the knowledge that their nursing care will likely yield rewarding results in the lives of recipients, nurses may be able to encourage recipients with the prospects that once recipients get over the acute phase of recovery, their level of physical activity and mental function will generally be superior to what they had in their pretransplant state. This may give recipients who are experiencing complications, and/or a decrease in energy, hope for the future. In turn, this may help them to be more involved in trying to recuperate.

Recipients may find it helpful to have the normalcy of life posttransplant emphasized to them. Literature that accents the positive nature of life for recipients could be provided for them to read if they wish to do so. Also, meetings between an individual who is about to go through a transplant with one who has been through it, and experienced positive results, could be highly beneficial. These suggestions are consistent with the well-known fact that one's thoughts, hopes, and expectations can have an influence upon one's health (Muhlenkamp & Broerman, 1988).

Secondly, the recipients in this study reported different ways of obtaining support. Thus it might be useful for health care professionals to find out what recipients' belief systems are, and what candidates rely on for their strength. By doing this, health care workers might be able to reinforce these beliefs while recipients are going through the experience of waiting for, and then receiving, a transplant. For example, if the individual draws their strength from a trust in God, then they could be encouraged to pray and to trust in Him. If the person feels that education helps them to face the transplant with more hope, then he or she could be kept particularly well informed of his or her progress and ongoing patient education could be emphasized. Such techniques could help both to personalize care and to improve the quality of health care provided.

Thirdly, this study provides some insight into what information recipients might find helpful in order to adapt to life after their transplants. They may need to adapt their lifestyles to accommodate therapeutic regimes and unpleasant side effects with a minimum of disruption. Recipients are regularly taught about the side effects they will likely experience from their medications. However, nurses could also let them know that many of the side effects may only be temporary. In addition, nurses could help recipients find ways of accommodating for troublesome side effects, such as waxing body areas where undesired hair growth occurs.

Adapting to changes in body image did not seem to be a significant problem for the adult liver transplant recipients interviewed for this study. Nevertheless, nurses could explore this issue with recipients to determine what their feelings are about their body image. Then, if that person does have concerns, nurses can help them adapt to their new body image, or can refer them to a counsellor.

Recipients who express sadness about their organ donor could possibly be helped to adapt to life posttransplant by writing a "thank-you" letter to the donor family (it must be done anonymously through the organ procurement organization). Thus, nurses need to be sensitive to the needs of recipients who may wish to write such a letter and inform them how they can go about this task.

Fourthly, nurses, and others who care for liver transplant candidates and recipients, could have a role in helping recipients make the transplant experience strengthen their relationships. Nurses could assist transplant recipients to view the stress as a temporary condition that can be used as a learning experience. Similarly, nurses may need to alert recipients to the fact that they may experience role changes posttransplant. However, the responsibility of nurses is not only to recipients, but also to their families. As such, nurses could also alert close family members of recipients to the fact that recipients likely will be able to be independent postoperatively, and will feel able to do things they perhaps have not done for some time. In addition, nurses could warn recipients of the reactions they may get from others once they are discharged and get back into their daily routines. The recipients could be told that such reactions may only be temporary.

Finally, the increased appreciation of life experienced by recipients can potentially profit those individuals who are around liver transplant recipients -- such as health care professionals caring for them in the hospital, family members living with them, or work associates relating to them. As people see the recipient recognizing and valuing little things in life more, or reassessing priorities, it can be an incentive for them to do likewise. If individuals choose to, they can perhaps acquire some of the benefits of the transplant experience without having to go through it personally. In today's world, where all too often the emphasis is upon material possessions, position, power, and prestige, the perspective of transplant recipients who value the simple, daily joys of living could be a valuable antidote.

Limitations of the Research

As mentioned in the findings chapter, there were no distinguishable differences between the responses and experiences of the recipients according to their age. However, it is also true that their ages were quite homogeneous as all were middle-aged. Their ages are representative of the average ages of adults receiving liver transplants at the transplant centre from which informants were obtained, but is conceivable that with younger people there may be differences in findings. For example, the emotions they experience may be different, as well as. the manner in which their relationships evolve, and their physical and mental activity. Thus, this is a limitation of the study, that the findings may not apply to other age groups, specifically young adults, adolescents, or children.

The small sample size can also be viewed as a limitation. However, as was noted earlier, the study was limited to seven interviews because, after speaking with seven good informants, it became clear that the same comments were being made by each one. Thus, to answer the research question, further interviews were not warranted.

As with any qualitative study, the small sample size does not enable one to make generalizations. However, the intent of such research is "to discover *meaning,* not to measure the distribution of attributes in a population" (Field & Morse, 1985 p.59). The findings were reaffirmed by the secondary informants and by the heart transplant recipient who was heard speaking about his life, which does provide more credence for the findings of the study than might otherwise be assumed.

Suggestions for Future Research

In future research, some of the limitations mentioned earlier could be addressed. First, a study that focuses on younger people and children would be useful to see if there are any differences from what seems to be a fairly uniform description of life after liver transplantation obtained from the older adults in this study. Such research might indicate whether recipients in a particular age group tend to have more problems in a certain domain, for example, mental activity, physical activity, or relationships.

In the present study, recipients reported minor problems with memory loss, but tended to attribute them more to age than to the transplant or to their medications. A study with children and youths, for whom memory loss is not normal, could help determine whether memory loss is merely a result of aging, or whether it is indeed related to the transplant or the therapeutic regimes. In addition, the same type of unstructured interview could be used with recipients of other organ transplants to see if there are any major differences in the lives of liver transplant recipients and recipients of other types of organ transplants. It would be interesting to note whether recipients of other types of organ transplants also have the same interest in promoting organ donation that was demonstrated in this study.

A related concept which could be studied is the length of time required for going through the recovery process. Thus a grounded theory methodology could be helpful to ascertain if there is a specific, predictable order in which experiences take place. Moreover, it could help pinpoint any similarities and differences between recipients of various transplants, such as the time it takes to overcome physical problems or return to normal mental functioning. Such process-oriented research could also address the issue of whether those who are relatively well prior to their transplant experience fewer changes posttransplant than those who are very ill pretransplant. Or, it could be employed to examine how long after a transplant recipients' physical abilities, cognitive function, and health status continue to improve before they plateau.

Summary

The purpose of this study was to describe what life is like following a liver transplant. An inductive, exploratory-descriptive approach was used because a review of the literature published prior to this study revealed little information detailing life after liver transplantation from the perspective of recipients themselves. Unstructured interviews with seven adult liver transplant recipients were used to compile a description of recipients' lives after their transplant. After a content analysis of these interviews, ten categories which provided a description of recipients' lives after their transplants were formulated. These categories are as follows: (1) thinking about the transplant, (2) mental activity, (3) physical activity, (4) health/normalcy, (5) caring for health, (6) implications of medications and medical procedures, (7) appreciating life, (8) evolving relationships, (9) awareness of donors, and (10) moving ahead. These findings indicated that life with a liver transplant seems to be much more positive than has generally been reported in the literature to date.

The recipients were very happy with their lives, and never regretted having their transplants. They were pleased with their mental and physical function and felt healthy and normal. They tried to maintain a healthy lifestyle, including the taking of prescribed medications and having ongoing follow-up care. They were not bothered by their therapeutic regimes, or the side effects of them. Nor did they have trouble adapting to their new body image. Recipients had a great appreciation for life and for the donor who had given them life, and most had closer relationships with friends and family because of going through the transplant experience. Recipients were more conscientious than they had been before their transplant about helping other people in need. As well, they were enthusiastic about signing their own organ donor cards and about encouraging others to do the same. In general, they viewed the future with optimism.

The conclusions from this research can assist nurses, and other health care professionals, particularly those who rarely see recipients after discharge, to improve the quality of care they provide to them. As nurses learn about what liver transplant recipients think regarding transplantation, how patients feel about themselves and their circumstances after discharge, and how they view the follow-up care given them, nurses may be better able to meet the patients' needs, and assist them to be better prepared for the future. Suggestions for future research are provided that could help in understanding the lives of liver transplant recipients.

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Appendix A

Information for Volunteers

Thank you for allowing your phone number to be given to me. My name is Glenda Meeberg and I am a graduate student in the Faculty of Nursing at the University of Alberta. I am doing a study of what people who have received a liver transplant think and feel about their lives. I would like to talk with you if you are willing to tell me about your experiences. Just because I will be phoning you does not mean that you must take part in the study. You can still choose not to be involved. If you have any questions you may contact me at 462-3188.

Appendix B

Informed Consent Form

Project Title: Living with a Liver Transplant

Investigator: Glenda Meeberg
3-120A, Clinical Sciences Bldg.
Faculty of Nursing, University of Alberta
462-3188

Supervisor: Dr. Anita Molzahn
4-105M, Clinical Sciences Bldg.
Faculty of Nursing, University of Alberta
492-6279

Purpose of Study: To learn about how people feel about their lives once they have had a liver transplant.

Consent: This form shows that I, ______________________________, agree to take part in this study. I also understand that:

1. I will have between one and three interviews with the researcher at the time and place of my choice. The interviews will take place either over the telephone or as personal interviews. The researcher may ask me to share information such as a diary. However, I do not have to if I do not want to.

2. Interviews will be about 60 to 90 minutes long. I am free to end interviews sooner than that. I may refuse to answer questions if I choose to do so.

3. The interviews will be tape recorded and then typed. My name will not appear on the tape or on the typed pages. The final report of this study may contain some of my words, but my name will never be linked with my words. If diaries are used, useful parts will be xeroxed and then typed. Names and identifying facts in diaries will not be put in the final report.

4. The tapes will be kept in a locked drawer when they are not being used by the researcher.

5. There are no risks to me from being part of this study. My care will not be changed by whether or not I participate. If I become upset at any time I will be referred to someone who can help me.

6. I will not receive any direct benefits from being part of this study. The information may be used in the future. It may help prepare other people for their liver transplant or help them manage their lives after their transplant.

7. I am free to drop out of the study whenever I wish. My medical and nursing care at the transplant clinic will not be affected by whether or not I take part in the study. To drop out I can phone Glenda Meeberg at 462-3188.

I have read this consent form and have received a copy of it. If this is a telephone interview, I understand that a different tape is being used to record my consent than will be used for the interview. I will be mailed a copy of this consent form. I have been given the chance to ask questions about this study. I am aware that I can receive a copy of the research results if I wish to.

Participant	Researcher	Date

Appendix C

Demographic Data

Interview date:__________

Subject Number_______ Age______ Sex______ Marital Status____________

Number and Ages of Children____

Number of years of Education_______________________________________

Occupation____

Currently Working?____Working before transplant?____Until when?_____

Date of Liver Transplant____

Previous Diagnosis____

Length of Time with Illness____

Current Medications____

____

Complications since Discharge______________________________________

____

Dates of Hospitalizations since Transplant_________________________

____

Distance (in hours) from Transplant Centre_________________________

Appendix D

Prompting Questions and Statements (First Version)

1. Describe for me what you do on a typical day.

2. If I was someone who was going to be having a liver transplant and was wondering what it was like afterwards, what would you tell me?

3. How do you feel about having to take medications every day so that your liver won't be rejected?

4. Do you think you would still have chosen to have a liver transplant if you had known then what your life would be like now?

Appendix E

Prompting Questions and Statements (Second Version)

1. What is your life like now that you've had a liver transplant?

2. Describe for me what you do on a typical day.

3. What sort of limitations do you have on what you can do, if any?

4. If I was going to have a liver transplant, what would you tell me to prepare me for what my life would be like afterwards?

5. What effect have the medications had on you?

6. What sort of side effects, if any, do you have from your medications? Do these bother you a lot?

7. What do you think about rejection and other complications?

8. Do you consider yourself healthy now?

9. What do your family and friends think about you and your health? How do they treat you?

10. Do you do anything special to protect your health?

11. What is your mental function like now?

12. Do you live your life any differently now than you did prior to your transplant?

13. How do you feel about having had a liver transplant?

14. Do you ever have any thoughts about your donor, or about having someone else's organ?