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THE UNIVERSITY OF ALBERTA

THE EXPERIENCE OF WAITING FOR A HEART TRANSPLANT

by

Linda Margaret Buzzell ©

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
MASTER OF NURSING

FACULTY OF NURSING

EDMONTON, ALBERTA
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Signed: Linda M. Buzzell

19 Beacon Crescent,
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Date: Oct 12/90

HOW MUCH LONGER???

Sitting by my kitchen window, staring at the rolling motions of the waves of the river.

With its natural beauty passing before my eyes, I am unable to move around the land surrounding my home.

No longer having the breath to walk along the river bank filled with secrets.

Having no more defense against anguish, anxiety and worrying thoughts.

My body and spirit constantly battling to find, one day, the health and welfare of my BEING.

I am weary of living at half-strength, my daily actions being restricted more and more.

Continuing on my route interlaced with uncontrollable obstacles, I stumble and weakly get up, hardly having the strength nor energy.

Hope, Faith and Eternal Love are my guides and companions to continue this fight so that I may receive this precious GIFT which will return me to vitality and a new LIFE.

Diane Bourgault
L'Islet-sur-Mer
Waiting for a heart-lung transplant for
22 months now.
June 1990

(Reprinted with permission from Ms. Bourgault and the National Organ Transplant Society)

UNIVERSITY OF ALBERTA

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 **THE EXPERIENCE OF WAITING FOR A HEART TRANSPLANT**, submitted by **LINDA MARGARET BUZZELL**, in partial fulfillment of the requirements for the degree of **MASTER OF NURSING**.

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Dennis L. Modry

Date: October 2, 1990

ABSTRACT

This study examined candidate's and support person's perceptions of the experience of waiting for a heart transplant. The candidates and support persons' subjective knowledge and understanding of the experience was the information sought. Data were collected over nine months from eleven informants using ethnographic methods of unstructured interviews, field notes, informant diaries, participant observation, and a personal diary for recording subjective impressions.

The findings resulted in the discovery of the various stages of waiting through which transplant candidates passed while they waited for a heart transplant. These stages were described by the candidates as: Waiting to be Accepted, Getting Ready, Being Ready, Being On Hold, and After Transplantation. In addition, adaptation behaviours and methods of coping with the uncertainty of transplantation are described.

Description of these processes, which have not been previously reported, begin to inform us how candidates and support persons perceive their transplant waiting experience and how they learn to adapt to this experience in their day-to-day living.

ACKNOWLEDGEMENTS

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CHAPTER I

INTRODUCTION

Statement of the Problem

> Waiting occupies a significant place in [our] ... experience. ... In a sense, it is so familiar a topic that we feel we know only too well what the meaning of waiting is. And yet, we would have difficulty describing the experience of waiting in a particular situation. (Fujita, 1985)

There are many different kinds of waiting. We wait for summer holidays, for the results of an examination, for a gift from a special person, or even for death. On the one hand, waiting may mean an inefficient use of time, a period of anxiety and loss of productivity. On the other hand, it may mean a critically important period of time when anticipation may be used to nurture awareness, understanding, and expression.

What we are waiting for is important. The "what" of waiting influences how we wait. But the latter does not, or should not, influence the former (Fujita, 1985). The "what" we wait for may be viewed with excitement, happiness, and general feelings of positiveness or with fear, anxiety, or anger.

Waiting is a significant part of the life of patients. They wait for appointments, tests, diagnoses, and prognoses. For some, waiting takes on even greater significance. For persons selected as candidates for heart or heart/lung transplantation, and for those who help and support these candidates, transplantation or the prevention of death is the obvious 'what' that is expected and the *raison d'être* of their waiting experiences. Yet, little is known about this important period in their life.

While the physiological changes associated with end-stage heart disease are well understood, the psychosocial adaptations required by the candidate and support person to their life situation are less well defined.

The literature on the psychosocial aspects of cardiac transplantation, when examined, reveals significant gaps. Only one study has documented patient perspectives of their illness. Knowledge about the effects of waiting is, in general, conjectured. Little is known or described about the waiting behaviours, practices, and beliefs of transplant candidates and support persons. Of particular importance to nursing is an understanding of the perspective of the transplant candidate and support person at this critical period in their life.

The nurse cannot state explicitly what each candidate and support person can expect to experience; nor may the literature be drawn upon for implicit practice procedure. The literature on waiting, when examined, reveals that little attention has been focused on the needs of patients and their families as the candidate proceeds from diagnosis through surgery into the recovery phases (Mishel and Murdaugh, 1987). By and large, descriptions by patients of their personal experiences have not been studied.

Transplantation patient management continues to be on the frontiers of medical science today. Nurses have a multi-faceted role to play in this highly technologically oriented world. They must have a knowledge and understanding of their patient and the family experiences in order to meet these needs in an holistic and caring fashion.

Purpose and Rationale

The purpose of this study was to discover how heart transplant candidates and their support persons perceived and described the experience of waiting, for themselves and for each other. That is, how did they conceptualize waiting, what meaning did waiting have for them, and how did they cope with or manage waiting for a cardiac transplant in their day-to-day living?

Transplant candidates and their support persons are conceptualized as possessing a unique subculture. They are singular in that they are the only group of patients for whom the "dance with death" may end with viable, extended life. Culture informs behaviour and there are rules and norms which may be discovered to instruct behaviour in certain ways (Aamodt, 1981; Spradley, 1972). It is through examining the described behaviours of the transplant candidate and support person, from their perspectives, that, as nurses, we become informed of the meaning of this experience.

Research Questions

The original research question was: What are the experiences of a transplant candidate and their support person as they wait for a heart transplant? The questions that evolved as the study progressed, and guided data collection and analysis were:

1. Do transplant candidates and their support person(s) actively construct their social world during the waiting periods?
2. What behaviours do they develop to cope with the effects of waiting for transplantation?
3. What meaning does the waiting period (process) have for the candidates and support person(s)?
4. Can these perceptions of the subculture of the subjects be translated into a cultural description that other professionals will understand?

CHAPTER II

REVIEW OF THE LITERATURE

Much has been written about solid organ transplantation. Surgical techniques, uses of various anti-rejection protocols, selection criteria, allocation of scarce resources, and the quality of life after transplantation are but a few of the topics frequently addressed in the literature. However, to date very little research has focused on the adaptation process which the recipient candidate and support person(s) undergo while waiting for the transplant surgery to occur.

In this chapter the literature on waiting for and the adaptation process to a cardiac transplant will be addressed. For the purpose of this discussion the literature has been divided into 4 categories.

1. The evaluation of transplant candidates and the process whereby they are selected to be recipient candidates. The available literature suggests that psychosocial variables need to be assessed in order to be certain that there will be a desirable outcome in cardiac transplant surgery. This is identified as being a very important factor when one takes into consideration the paucity of organ resources and the expense involved in the allocation and management of these resources.

2. Psychosocial studies, prior to 1980. These studies dealt with the psychiatric complications of heart transplants. During the late 1960s and 1970s (prior to the advent and generalized use of cyclosporine A as an immunosuppressant agent in the treatment and prevention of rejection), cardiac transplant surgery could be said to have been in its infancy. Morbidity and mortality statistics following surgery were high, with 40-50% of patients dying before the first anniversary of their surgery (Freeman, Watts, & Karp 1984). Each surgery was preceded by the rigorous selection of candidates, and further intensified by strict clinical management protocols aimed at the protection of the patient from both infection and rejection. Because of this rigid isolation, coupled with the high degree of steroid usage for the management of rejection episodes, there were many incidents reported of post surgical psychoses or of stress and anxiety experienced by candidates and support persons (Lunde, 1969).

3. Psychosocial studies, since 1980. In the past ten years, the life expectancy of transplanted patients has been enhanced and the one- and five-year survival rates can be estimated at 80-90% and 75% respectively (Canadian Organ Replacement Register, Non-Renal Transplant Data, 1989). In spite of this improved

survival rate, very little research has looked at the adaptation processes required by both recipient and family members as they progress through the transplantation ritual. While infection and rejection continue to remain a grave concern for any cardiac transplantation team, it has become evident that the early protocols contributed to the anxiety surrounding evaluation of patients for transplantation. In addition, the many unknowns of tissue immunology added to the uncertainty surrounding organ grafts and their survival.

4. Uncertainty, as it relates to transplantation. The unpredictability of organ donation is acknowledged throughout the literature. This factor is recognized as being stress-provoking, with expressions of anxiety being described as the natural emotional response.

Evaluation and Selection of Candidates

With the development of viable techniques to undertake heart transplants, inexperienced surgeons through out the world attempted to perform heart transplants. Following the high mortality rates as a result of this surgery, the interest in transplantation subsided until the advent of cyclosporine A. The development of this immunosuppressant brought about a renewed interest in heart transplantation. Copeland (1984), in his address to the 4th International Society for Heart Transplantation, expressed concern that unless extreme attention was paid to such issues as cost payments, standards of practice, program protocols, and surgical and team expertise, there would be a repeat of the earlier history of heart transplantation. He recognized, however, that heart transplantation was moving out of the experimental area, and he, along with others, led the debate about these areas of concern.

Central to the debate on heart transplantation was the issue of patient selection and program evaluation protocols. This concern had previously been brought to the forefront with the statement that "clinical effectiveness and usefulness are dependant upon careful and appropriate patient selection, expert surgery, postoperative care, immunosuppression, patient education, and liaison with the patient's permanent physician for subsequent lifelong care" (Evans,1984).

In 1985 Evans, in the National Heart Transplantation Study report, recommended specific patient selection criteria. He emphasized that consideration be given to those factors that were recognized as exerting an adverse influence on the outcome after cardiac transplantation. These factors are incorporated in the inclusion/exclusion criteria that are found in Appendix A.

Patient selection is a process which typically occurs in the following manner. Patient records and possibly a psychosocial history are transferred to the transplant centre, or the patient is referred to the centre and given a physical and psychosocial evaluation. Following this assessment phase, a candidate review session is held which is designed to both assess whether the candidate has a reasonable chance of surviving cardiac replacement and achieving satisfactory rehabilitation, and to share with the patient and family sufficient information to allow them to make an informed decision as to whether to proceed with the surgery (Christopherson, 1987).

Candidate selection has become more refined over the years. In the 1970s, candidate selection occurred to provide the best possible outcome for the experimental surgical procedure. In the 1980s, candidate evaluation and selection has become one of the standards of program excellence, and serves as a means of ensuring program success, as well as a mechanism of objective allocation of scarce and costly resources. In addition, these criteria have become more consistent among major transplant programs in the U.S. and Canada.

Psychosocial studies, prior to 1980

The three principal papers from this time period that addressed psychosocial concerns and needs of candidates and families are by Lunde (1969), Kraft (1971), and Christopherson (1979). Although the first two papers include several case histories and are anecdotal in nature, they do reveal areas for future investigation. The authors emphasized, for those involved in the clinical practice of caring for heart transplant recipients, a concern for recipient quality of life.

Lunde (1969) comments

> It is sometimes difficult to explain the risks of this procedure to a person who has no concept of a phenomenon such as tissue rejection. In addition, some people have already decided they want this operation done and, for seemingly magical reasons, they believe they will be immune from complications.

He went on to discuss the complications of being a potential recipient. The waiting period until a matching donor becomes available was seen to stretch beyond the initial feelings of elation and even euphoria after having been selected, and to give way to depression and anxiety. He went on to suggest that, as surgery becomes more radical and more vital organs are exchanged, "distortions of personality can be expected, since personality and self-image are so closely tied to body image."

Kraft (1971), referring to Lunde's earlier work, emphasized the need for studies of body-image (pre- and postoperatively) and family interactions. Kraft saw psychiatric complications as centering about organic reactions to procedures and drugs, more than about personality changes and psychogenic psychoses.

This was a critical paper, as it has had a profound impact on nurses, social workers, and psychologists attached to cardiac transplant programs. Kraft described the patients in heroic terms with surgery providing them with the opportunity to contest the inevitable. This view of a manful struggle against odds of a heroic proportion persisted into the 1980s, with little perception of the need for intervention with candidate or family. In fact, one is almost left with the feeling that non-interference is the preferred mode of action. The role of nursing appears to be supportive of the struggle rather than seeking ways and means to ameliorate the event for either candidate or support persons.

Christopherson, (1979) however, discussed the need for patient counselling. She acknowledged that, in the enthusiasm which surrounds the technical capacity of cardiac transplantation to extend life, it was easy to overlook the psychological and social demands the procedure makes on the recipient and his or her family. Christopherson stressed that there were several client characteristics associated with a good surgical outcome. These characteristics included the presence of strong family support for the transplant procedure, identification by the patient of meaningful tasks he or she would like to accomplish if extra time were to be gained as a result of transplantation, and an awareness of the risks, limitations, and benefits of cardiac replacement. Christopherson described transplant recipient candidates as developing a pattern of dealing with the reality of their illness. This development can be assisted by transplant team members to help the patient to deal with the stresses of the perioperative period. Although the emotional support of staff members to the patient and family are identified as being invaluable, the nature of the emotional support needed is not outlined. Christopherson affirmed that waiting can be an exceptionally difficult time for recipient and support persons, and described the time period after having adjusted to being accepted as a candidate until transplantation as 'purgatorial limbo'.

In this early literature, inferences have been made about the stress and anxiety of the 'difficult time' in what we have come to know as 'waiting for a transplant'. As the decade passed, the stresses of the perioperative period on both recipient candidate and family became evident. While physical relocation of candidates and family members and the concomitant stress of waiting for organ donation were perceived as an inevitable necessity for all programs, the science and the technology of transplantation remained the dominant feature of research studies. This was the experimental era of human heart transplantation surgery and is perhaps best expressed by Lunde (1969), "at this point in time, no matter what the nature of the patient's disease, the chances for survival, measured in months are almost as good without this operation as with it."

Psychosocial studies, since 1980

With the availability of cyclosporine A as a therapeutic agent to assist with the management and/or prevention of rejection, cardiac transplantation began its move from the era of experimental to approved therapeutic surgery for patients with end stage heart disease. As the long term survival of patients was enhanced by this medication, more patients were referred to transplant centres, more candidates were accepted onto transplant lists, and more and more time was spent waiting for the seemingly scarce organ donation. Thus, the waiting period became an extended time period where families and candidates were expected to manage, although adjustments and coping skills were recognized and frequently described in the literature.

Allender et al (1983) identified six stages of psychological adjustment to heart transplantation, based on their experience with 25 patients. The six stages were: evaluation period, waiting period, immediate post-surgical period (perioperative), first rejection episode, recovery period, and hospital discharge. During the 'waiting period', the authors describe anxiety as increasing as the candidate's physical condition deteriorates, with survival until transplantation being the primary constant worry. These authors suggest that how a patient will react to stress can often be predicted from his or her reaction to other stressful situations prior to heart transplantation and from the results of psychological testing. While they recognize that more effective intervention and patient management can be planned, no distinct recommendation is made for programs to follow.

Freeman et al (1984) commented on the descriptive nature of the few studies on cardiac transplantation that had appeared in the psychiatric literature up to that time. They discussed eight case studies which, they believed, underscored the importance of pre-operative evaluation. These pre-operative evaluations were to provide a baseline for comparison with postoperative mental status and to acquaint the patient and family with the transplantation team. In addition, these histories were used to illustrate how ambivalence, family pathology, excessive dependence, substance abuse, noncompliance, anxiety, depression, psychosis, and cognitive dysfunction can have a major impact on a patient's course. Although the authors do not elaborate, they postulated that some relationship exists between psychiatric factors and postoperative outcome following cardiac transplantation. The outcome was possibly mediated by immune factors.

O'Brien (1985), a social worker who had assessed 180 patients, 100 of whom underwent heart transplantation, outlined five stages through which a heart transplant patient progresses. Stage I is the time when the patient learns that there is no further medical help that can control the disease symptoms and that, without a new heart, life expectancy is very short. Feelings of confusion, fear, and disbelief are common and may lead to anger, despair, and denial. O'Brien (1985) stated that, if there has been a steady downhill course to the illness, many patients, with a sense of helplessness, may have moved along to an acceptance of an early death. Patients with a sudden onset illness, usually younger, have had little time to make the mental adjustments to their condition before moving into the next stage of their illness, assessment as a possible heart transplant candidate.

The author also described some of the profound social changes which have seldom before occurred in the patient's life and which affect the whole family. These are seen as the inability to work, the loss of earnings, the loss of status, and a reversal of roles. The descent into dependence is in marked contrast to normal life, with its future plans and aspirations. At this stage, a sense of humiliation is often felt, with feelings of poor self-esteem and inadequacy, leading to social isolation. She further stated that this is a period of anticipatory grieving for the inevitable death of the patient.

Stage II begins when the patient is admitted to hospital for assessment and evaluation. The interval between referral and admission may have given the candidate time to consider the issues involved: the need to accept an organ from another human being, the inevitable death of another person which makes heart transplantation possible, the sense that for them to gain another has lost, and, finally, that heart transplantation carries risks and uncertainties. The author described anxiety as being the dominant symptom expressed by most patients during this stage: anxiety about what is going to happen, what is expected of them, or over the need to meet and talk to a new set of people in an unfamiliar hospital. However, the most overriding anxiety is about being given a decision as to whether they have been accepted into the program, and that this can mask the real feelings about the operation. These 'real feelings' may be natural fears of the possible surgery, or less natural beliefs and concerns about their sex, race and emotions being identified with the donor heart. For the first time in their illness, patients can contemplate a future in good health, and this leads them to ignore obstacles.

O'Brien (1985) described this period as the most important time for cardiac transplant team members to work with the patient and provide factual information, while allowing the expression of natural feelings of fear and uncertainty. It is a time for discussing practical issues, such as arrangements for the family, finances, and work commitments of the partner.

Stage III is the waiting period. All patients, in retrospect, describe this as the most difficult period of all. It is not uncommon for the stresses of this period to be felt by all of the family members and for relationships within the family to be affected. Patients begin to doubt the decisions made earlier and wonder if death will arrive before a donor organ. This state of doubt enhances the feelings of dependence which started during the assessment period and deepens with the anger and frustration associated with insecurity. Above all, during this period patients have to draw upon their own inner resources to cope with and manage this uncertain period of time.

Stage IV begins at the time of surgery. Aside from normal levels of anxiety expected before surgery, there is a sense of relief and excitement. The immediate postoperative period is usually uncomplicated medically but is an intensely emotional one. The paramount feeling becomes the celebration of life and is shared between the patient and his or her family and other transplant patients and their families.

Stage V focuses on the discharge home and rehabilitation. This last stage stretches over a long period of time and may continue for many patients over a number of years. Anxiety is experienced at leaving the safety of the hospital. After the joy of returning home, there are adjustments to be made. Reversed roles may no longer fit. Many patients may have a job waiting for them; for others, transition to good health does not equal a return to work. The inability to find work may cause bitterness and resentment. No patient knows how long he or she is likely to live. Long life is not the expectation of a heart transplant patient, although all hope for it. Rather, it is the quality of health which gives life a richness not experienced during the illness.

This paper was a valuable contribution to transplantation literature and opened avenues for further consideration. Of particular importance was the awareness that much that was written continued to be from the perspective of the care-giver, anecdotal in nature, and while valuable from the clinical viewpoint, needed to be augmented by the candidate and support person's perspective of the meaning of the various stages of waiting

McAleer, Copeland, Fuller, and Copeland (1985) described six psychological adjustment stages associated with heart transplantation. These stages were very similar to those outlined by O'Brien, with the first rejection episode being separated out as a stage on its own. Eight problem areas were categorized, based on observations made on their own transplant population, and a questionnaire was developed and sent out to other centres seeking information to substantiate these findings. On the basis of this survey, the problem categories identified included mood alterations, marital stress, coping with chronic pain, changing body image, family related problems, compliance, impotency, and decreased libido. In this study, the authors indicated that, because the patient population had yet to be studied intensely to identify how candidates perceived their own problems and how those problems evolved during prolonged survival, there was much more to be learned in the management of the transplant population.

Mai and Burley (1985) and Manninen and Evans (1985), in a review of the literature, identified several areas in need of study. The most important of these was the need to focus on social support networks that include persons other than family and household members. Despite the absence of systematic studies, the presence of a social support system was recognized as important to the recovery of heart transplant recipients, although support networks were not specifically seen as a means of providing assistance with the waiting period.

Kuhn, Davis, and Lippmann (1988), using data from a two year study of 65 transplant candidates, discussed the emotional adjustment to cardiac transplantation. Patient adjustment was seen as depending on several factors: personality characteristics, specific nature and symbolic significance of the illness and its treatment circumstances, previous illness experiences, and level of emotional support. Emotional adjustment to cardiac transplantation was viewed as a phasic process, during which patients grieve loss of health, freedom, control, appearance, physical comfort, and self-image. Milestones, as previously delineated in the article by McAleer et al (1985), were seen to influence the adaptive task of each stage.

Kuhn et al (1988), used case vignettes and patient quotes to illustrate typical reactions to the different stages of emotional adjustment. For instance, the waiting period is described as "dancing with death." Once the joyous relief of having been accepted wears off and prolonged waiting begins, the adaptation task begins. Patients must adjust to loss of control while facing impending death. Anxiety progressively increases as physical health deteriorates. As they worry about dying while waiting, patients often become frustrated, irritable, and depressed. Nocturnal insomnia with daytime sleepiness sometimes develops, out of a fear of dying at night.

Kuhn et al (1988) made five major recommendations to try to reduce this stress. These recommendations were: 1) give patients time to make adjustments, 2) be accepting and encourage verbalization of feelings, 3) ensure adequate emotional support, 4) provide contact with other transplant patients, and 5) make mental health services available.

Kuhn, Brennan, Lacefield, Brohm, Skelton, and Gray (1990) stated that it is the transplantation protocol which may be the cause of emotional distress in most patients, with the evaluation phase being the most distressful. They likewise speculated that, with the current shortage of donor organs, the waiting period might soon be equally or even more distressing. They supported this contention by reporting study results in their program whereby of 55 patients accepted as transplant candidates, 26 experienced emotional difficulties during this phase, 34 had subjectively distressing experiences (mostly anxiety) and 21 exhibited behavioural problems.

Based on the review of the psychosocial literature both prior to and after 1980, it is recognized that heart transplant patients and their family members undergo a process of adjustment not only to the surgical procedure but also to the waiting period. In addition, we are able to understand that the management of the waiting period prior to transplantation is one of the more critical phases of the transplantation process for the patient and one which has significance for the care giver. However, there are no studies specifically reporting the patient's and family's perspective of this process.

Uncertainty, as it relates to transplantation

A possible key to the understanding and management of the waiting period is an understanding of the meaning and management of the uncertainty that candidates and recipients face while they are waiting for an organ donation. Budner (1962) defined uncertainty "as a cognitive state created when an event cannot be adequately structured or categorized because sufficient cues are lacking." Uncertainty occurs when the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes (McIntosh, 1976). Suls and Mullen (1981) proposed that events with elements of uncertainty may be exceptionally stressful. They state "the inability to distinguish undesirable events that one can do something about from undesirable events that one can do nothing about, may be more debilitating than the undesirability of the events themselves."

Mishel and Murdaugh (1987), using a grounded theory approach, looked at the adaptations by family members of patients with cardiac conditions who undergo heart transplantation. These authors suggest that there is a substantive theory that describes how family members gradually modify their beliefs about organ transplantation and develop attitudes and beliefs to meet the challenge of living with continued unpredictability. Unpredictability refers to the unknowns involved in heart transplantation. The theory consists of three main concepts - immersion, passage, and negotiation - which parallel the stages of waiting for a donor, hospitalization, and recovery. The initial dream (that life will return to normal after transplantation) is reformulated to fit the reality of the medical-technological treatment environment.

Immersion is described as occurring during the wait for a donor heart, when the unknowns centre on whether a heart will become available before the patient dies. Immersion consists of a series of behaviours in which one family member, usually the partner, pledges self to the welfare of the patient. All of the partner's cognitive activity is directed toward planning for the patient's welfare; all affective activity is a reflection of the patient's emotional state. The patient and the family must do nothing to influence organ availability. Three categories of immersion are described as occurring concurrently: freeing self, symbiosis, and trading places. The partner frees the self from home tasks, childrearing, work, and social commitments and transfers all attention to the patient. Symbiosis is used in its broadest sense to include parasitism or antagonistic symbiosis. Patients benefit from the close union because they are taken care of by their partners. Partners suffer because they lose their sense of self. Trading places involves taking on many of the traditional roles and behaviours the patient performed prior to illness.

Passage is initiated by the surgery when the candidate moves from eventual death toward another chance at life, and the partner moves from immersion toward independence. Passage contains three categories: catharsis, vacillation, and awareness. Catharsis referred to the expression and reliving of stressful events by the support person in order to discharge the tensions experienced during the immersion phase. Vacillation is caused by the unpredictable complications that occur during the first 6 weeks after surgery. As the initial belief "that all will be normal" begins to weaken, the support person begins to develop and use unpredictability and hope maintenance methods to buffer outcomes. These methods prevent partners (support persons) from being overwhelmed by the unpredictability of events and enable them to gradually integrate the realities of post-transplant existence. Awareness occurs when the belief in the return to a normal life has finally been put to rest. Changes in the patient, coupled with seeing the complications and effects of medications on other transplanted recipients, culminates in recognition of the patient's vulnerability.

Negotiation refers to the dynamic interaction between patient and partner. Although the data was only elicited from the partner, the partner and often the patient, realized that a new lifestyle must be structured that considers the patient's vulnerability and unpredictable future.

The stages described by Mishel and Murdaugh (1987) are consistent with the earlier reports of Christopherson (1971, 1976, and 1987) and O'Brien (1985). What is clearer in this study are the mechanisms used by families to adapt to the waiting process. Coming to terms with living with continual unpredictability requires establishing a view of the world in which stability is not assumed as normal, and the partner and the patient never again view themselves as invulnerable.

Summary

A review of the literature on the patient and family adaptation process while waiting for a cardiac transplant reveals that little is known with certainty about the period. The lack of definitive findings seems to be due in part to the early attention paid to the recording of surgical techniques, the acknowledgement of the experimental nature of the surgery, and as success mounted, to the importance of anti-rejection protocols and studies related to immune system responses.

The early literature reflected the concerns that cardiologist and cardiovascular surgeons had with the suitability of proposed candidates for this select procedure. Eligibility criteria excluded patients with certain medical conditions, as well as psychosocial problems such as drug addiction, alcoholism, suicidal tendencies, mental retardation, absence of social support, and a history of medical noncompliance. As a consequence of this emphasis on the selection of the pretransplant candidate, it appeared that, once acceptance was gained, the candidate and family were best ignored while they waited for surgery. They were assumed to have been satisfactorily analyzed and not in need of further attention. Early transplantation (after acceptance, a characteristic of the first decade of the surgery) may also have tended to mask the adaptation processes that participants underwent.

Although some information of a psychological nature is beginning to emerge, there has been little systematic data collected on this relatively circumscribed population (Hecker, Norvell, and Hills, 1989). Normative data on personality functioning, family support, and attitude toward health care and transplantation are seen as areas of inadequacy.

With enhanced survival following transplantation and the establishment of many transplant centres, it now has become evident that there is shortage of cardiac organ donors. The result of this is that the waiting time between being accepted into a transplant program and the date of surgery has extended from weeks to anywhere from an average of 6 months to a year.

As a result of the present apparent cardiac organ shortage, transplant team members are now in the difficult position of supporting patient and family members through a prolonged waiting period prior to transplantation. Nurses on cardiology floors, coronary care units, in emergency departments, attached to out-patient departments, and transplant clinics are expected to understand and cope with the extreme feelings exhibited by candidates and families. Frequently they are exposed to patients whose anxiety alters behaviour, such that unrealistic hope is expressed in the same moment as displays of severe despair, anger, and helplessness.

Because of the lack of systematic study, there are gaps in our nursing care repertoire. We do not know what informs the behaviour of this patient population or what the meaning of this waiting experience is. Furthermore, patients and family members have not been asked how they perceive this event and what meaning it has for them. It would seem likely that this population would be most likely to inform us as to the meaning and effect of waiting for a transplant.

In light of the above, this study was designed for the purpose of examining inductively, the subjective experience of transplant candidates and their support persons. Such an approach permitted the exploration of the meaning of waiting, the definition of various stages in the waiting process, the kinds of waiting, and the behaviours that assist candidates and their support persons during the waiting period.

CHAPTER III

METHODS

In this study the purpose was to discover how heart transplant candidates and their support persons perceived the experience of waiting for themselves and for each other. That is, how did they conceptualize waiting, what meaning did waiting have for them, and how did they cope with or manage waiting for a transplant in their day-to-day living? From the outset it was recognized that the experiences of heart transplant candidates and their support persons have not been comprehensively and systematically investigated and that, with the exception of the work by Mishel and Murdaugh (1987), little was known about the topic. Consequently, a first level (Diers, 1979) factor searching method for the study was selected. "Factor-searching or naming studies are descriptive in nature and occur at the exploratory or formulative stage of theory development" (Field and Morse, 1985).

Therefore, ethnography was used to elicit answers, which were contained within the subjective perceptions of the informants.

It was operationalized using the techniques of interviewing, participant observation, and informant diaries. As with life events which are not predictable or controllable, it was recognized that these inductive methods of inquiry would best permit 'life' to unfold as it willed. Naturalistic research permits the informant to describe and the researcher to observe the many facets of the same person in one context and/or one facet in a variety of contexts over time. Implicit is the mutual interplay of person and environment variables (Lazarus and Folkman, 1984). As data collection and analysis progressed concurrently, the investigator was able to provide direction to the subsequent interviews, thus making choices which enhanced the thick description.

This chapter is presented in the following manner: 1) description of the qualitative methodology (ethnography), 2) the research techniques and sampling, 3) data collection and analysis, 4) trustworthiness of the data and 5) ethical considerations.

Ethnography

Ethnography, as defined by Spradley (1970, 1979, 1980), was the primary method used for this study. Interviewing and participant observation were used to collect data for ethnographic analysis. Informant diaries, patient medical records, and researcher field notes augmented the data base.

An ethnographic approach is a way of collecting, describing, and analyzing the ways in which human beings categorize the meaning of their world (Aamodt, 1989).

Ethnography is a means of gaining access to the health beliefs and practices of a culture. Descriptive ethnography assists the professional nurse in understanding the patient's behaviours by "setting out to identify the social complexities that lie near the surface of a society." (Field and Morse, 1985). Cultural knowledge is transmitted to the ethnographer, as reported by the informants. The affective dimensions of waiting are communicated to the investigator and understood from the emic perspective (Aamodt, 1982; Davis, 1986; Field and Morse, 1985; Kay, 1982). Interviewing techniques were used as the primary method of eliciting thick descriptions for data collection.

Sampling and Research Techniques

Sampling

This study used a convenience sampling technique. Subjects who met the criteria were selected in the order that they were accepted onto the transplant list and agreed to participate. Evaluation and selection criteria for candidates are outlined in Appendix A.

Key informants met the following subject criteria:

1. recipient candidate and support persons had been assessed and accepted onto the centre's transplant list;
2. informants were over eighteen years of age;
3. informants spoke English;

4. an informed consent for support person (Appendix B) or for recipient candidate (Appendix C) was given;

5. informants were willing to answer questions and provided information in an informal give-and-take situation.

Informants were not excluded if their partner, support person or recipient candidate, did not choose to participate in the study or if one or the other, or both were unable to maintain a daily diary.

Two months were required to achieve the minimum number of study subjects. Six to eight sets of informants were included in the study to ensure that three informants would be transplanted within a four to six month period of time. The final sample consisted of three dyads (candidate plus support person), three candidates whose support person did not wish to be interviewed on a regular basis, and two candidates without support persons. At the completion of the study, three candidates (males) had been transplanted and discharged home, two other candidates (women) had been transplanted, two candidates (women) had died while waiting for a transplant, and one candidate (male) was still waiting for a transplant.

Biographical Characteristics

The four men and seven women who constituted the initial informants for the study ranged in age from 31 to 61 years of age. The seven women included four transplant candidates and three support persons. All of the women were married and had children, the youngest being 9 years and the oldest 35 years of age. Three of the women had grade 12 education, one was a university graduate, and the remaining three had achieved grade 10. Each of the women had been working full time prior to the onset of the last illness episode. For the four women who were candidates, it was this episode which led to their referral to the transplant centre for assessment. Two of the women were without active spousal support persons. For the remaining two women candidates, one husband was not interested in participating in the study and the other husband felt unable to articulate his feelings initially, although he became interested later and shared his opinions and feelings quite eloquently.

The men ranged in age from 32 to 61 years of age. They were all married; each was a transplant candidate and all had their support person present. Only one of the spouses did not wish to participate in the study. While one candidate described himself as being in semiretirement before coming to the transplant centre for assessment, the remainder described themselves as full time workers up until the time of their last major illness and all looked forward to returning to work after their heart transplant. The individual who was semiretired described himself as a good supervisor of his own business and did not anticipate giving up that activity. Three of the men had achieved grade 10 and one had completed grade 8.

Interviewing

In-depth interviews with subjects and support family members were the major data collection method used in this study. Interviews were conducted at least once with subjects and their support persons together and at least three times with subjects and support persons alone. Candidates who did not have a support person or whose support person was not interested in participating in the study were also interviewed at least three times. Of the candidates who died, one was interviewed once and the other twice. Interviews were audiotaped, transcribed and analyzed before proceeding to the next round of interviews. Categories or domains identifying kinds of waiting were identified.

A major attempt was made to conduct interviews away from the hospital setting. All but five of the interviews occurred out of the hospital. It was felt that this arrangement would assist with 'entry' for the interviewer. The informants would be on home ground and feel more relaxed and therefore feel freer to disclose their personal viewpoints. At-home interviews would also serve to conserve the energy of the informant, particularly that of the candidates, and provide privacy for the interview.

The first round of interviews was unstructured, with the informant asked to describe what waiting was like for them. Rounds two and three of the interviews were more structured. Themes that had been detected during analysis of the first interviews were tested with descriptive, structural and contrast questions (see Appendix D). Informants were encouraged to move from universal statements to specific incident statements (Spradley, 1979). A schematic work-sheet was shared with informants during round three to assist with the verification of the analysis. Informants were always asked if there was anything they would like to add to assist in filling in thin areas of the interviews. Dyadic and triadic card-sorts were done. Informants sorted cards on kinds of waiting, ways of waiting, activities while waiting, and variables affecting waiting. The purpose of the card sorts was to narrow down and clarify categories or themes. This process accomplished several things. In narrowing the categories hard decisions were made by the informants and the researcher. Information about the categories was validated when there was internal consistency among the informants and the researcher. During the card sorts informant comments were also recorded and transcribed to ensure that meaning was captured. The card sorts appeared to be fun for the participants and added further breadth to data gathered as they verbally clarified and described each item, accepting or rejecting the card's placement in the schematic worksheet. The results of the card sorts have been condensed into table 1.

In the final round of interviews, informants were presented with the developing taxonomy derived from the previous interviews. Verification and a refinement of the information received in the previous interviews were conducted with individual informants.

In addition, one volunteer informant had been on the transplant list for 18 month and was used as an 'expert' on waiting by the investigator to verify findings.

Participant observation

Participant observation in the acute care setting and out patient clinic area augmented the interviews, with attention being focused on verbal and non-verbal behaviours in response to the waiting period, hospital admissions, and clinical reporting of deteriorating health state. Detailed field notes of observations were kept.

The level of participant observation used in this study was observer-as-participant; that is, most of the researcher's time was spent observing and interviewing, with no reference to the professional role in the transplant program, as suggested by Field and Morse (1985).

Clinic visits by the informants provided the investigator with valuable observational opportunities. During these visits, the researcher was able to observe the group interactions between the informants and other transplant program members. Additional social interactions between the informants and clinic staff could be noted. Of prime importance was the ability of the researcher to check observations made with professional colleagues, particularly as the study advanced.

Field notes

Personal field notes were written following each interview of the impressions formulated during each interview session. Occasionally, with the final round of interviews, notes were made during the interview session. As this was a verification and reaffirming period, the researcher felt that note taking would not inhibit the interview process. This indeed appeared to be the case, as the informants frequently prompted the investigator to take note of what was being said, even though the session was being taped.

Informant Diaries

Three informant diaries were kept and retrieved by the researcher. Two belonged to recipient candidates and one belonged to a support person. Other candidates and support persons kept varying forms of what were described as 'journals' and frequently their contents would be shared with the investigator. However, the journals were not relinquished to the researcher.

While maintaining a diary was not a necessary aspect of informant participation the ones that were submitted proved to be invaluable. They provided unprompted and non-directed information into the day-to-day activities of the informants. Occasionally they were used as a means of directly approaching the researcher with questions or opinions that had not been addressed during the interview process. Most frequently they were revelatory of the mood and feelings that the writer was experiencing at the time of composition.

Data Analysis

The purpose of analysis was to separate the ethnography (the data, the cultural description) from the thematic or linguistic analysis (Hammersly and Atkinson,1983). The interview transcripts were read while listening to the tape to check for accuracy of transcription. Three copies were then made, with the original being placed in a separate file for safe keeping. The first copy was highlighted. The second copy was numerically coded with numbered fluorescent dots of various size and colour, a method described by Murdock (1971). The third copy was disassembled, and coded quotations were stapled or taped onto coded index cards and then put into folders according to categories (e.g. small pink dot # 13 Stress - 'it's more stressful for the transplant person ... I can cope with a lot.'). As themes reoccurred, sub-categories evolved until the investigator felt that the subject was exhausted. Throughout the analysis, memos or annotations were made on the second copy. They were brief and frequently represented possible connections or ideas to be pursued in the following interviews or ideas to be developed and explored with colleagues and advisors as possible linkages.

Field notes contributed to the analysis by permitting the researcher to document the form, kinds, and types of social phenomena observed (Field and Morse, 1985). The subjective nature of the impressions expressed in the field notes was recognized.

The emphasis in the second round of interviews was on eliciting similarities and contrasts in the 'thin' areas of data. The interviews were then analyzed in the same manner as before. As this process, continued it became evident that there were: 1) kinds of waiting, 2) behaviours which assisted with waiting and 3) factors which affected waiting. The sorting of this data served to saturate the pre-formed categories from round one. At this time, categories were reviewed and compared with each other to determine that they were mutually exclusive. Hunches about relationships were discussed with informants, professional colleagues, thesis committee members, and, in particular, with the transplant social worker, physiotherapist and nutritionist, in order to gain further insights, test tentative propositions, and validate impressions.

During the third and final round of interviews, findings were presented to the informants. Subjects were asked to sort the cards that had been developed. These were made up of single words or short phrases and represented the categories or themes that had emerged. The informants were asked to sort the cards first into whatever formation they wished. Commonalities and differences were searched for by the researcher. This activity seemed to be accomplished with considerable ease and decisiveness by the informants. Likewise explanations of similarities and differences was readily forthcoming.

The informants were again questioned as to whether there was anything further that they might wish to add. The analysis of this data proceeded as before. The critiquing by the informants of the categories and ideas expressed by the researcher served to refine the level of analysis.

Trustworthiness of the Data

The scientific approach to qualitative inquiry emphasizes the standardization of language, rules, and procedures for obtaining and analyzing data, so as to ensure replicability and validity of findings and presentation of results (Sandelowski, 1986). In qualitative research, measurement refers to the series of judgments made by the researcher about collected information, in relation to its truthful representation of the desired content, its comparability with known information and its verifiability across subjects and across situations. Guba (1981) and Lincoln and Guba (1985) suggest that four factors may be used to assess the rigour of the qualitative investigation. They are 1) truth value 2) applicability 3) consistency and 4) neutrality.

Truth Value

Truth value of the findings of the study is established when consideration is given to both the context of the setting and to the informants with whom the study is concerned. The fundamental assumption underlying the data collection was that the informants knew their world and that this knowledge is truth as they perceive it and grounded in the reality of their experience. In this study, the social context was appropriate. The only informants considered were candidates and support persons waiting for a heart transplant at the medical centre. Contact was made through the transplant out-patient clinic once the candidates had officially been accepted onto the transplant list. Interviews were conducted in a quiet, well lit, comfortable conference room or in the privacy of the family home. Privacy and uninterrupted interview time were planned for by scheduling interviews in advance, at times which were mutually agreeable. The unstructured format of the interviews permitted the investigator to explore the informants' perspective of the situation. In addition the nurse investigator had current transplant patient management experience and, in a sense, spoke the language of the transplant candidates and support persons (informants).

Field and Morse (1985) suggest that it is useful to verify data from several sources. The investigator was able to do this through discussion with another transplant coordinator (seeking affirmation and looking for dissimilarities) and by discussion with the clinic manager who had also developed a close relationship with the informants. When commonalities of behaviour were perceived to occur across data gathered in these different ways, the validity of the information was increased. When confirmation was not achieved the researcher was able to discuss this further with the informants; differences were pursued until a reasonable explanation of the event was obtained. It is through prolonged engagement and persistent observation that the researcher is able to become immersed in the culture and be certain that the context is thoroughly appreciated and understood. Persistent observation adds the dimension of salience to what might otherwise appear to be little more than a mindless immersion (Guba, 1981).

Applicability

Applicability of the findings occurs when they 'fit' into contexts outside the study situation, when the audience views the study findings as meaningful and applicable in terms of their own experiences (Sandelowski, 1986). Informal peer debriefing, exposing the investigator's thinking to the questions of peers, and dealing with their responses occurred with members of the heart and lung transplant team who worked closely with the patients and their support persons. This was an important perspective and the researcher looked forward to confirmation or debate of expressed ideas, especially amongst the cardiology nursing staff who had frequent contact with the candidates (during hospitalizations) and their support persons. Clarification of meaning for researcher and staff was the frequent outcome of these sessions.

Consistency

Consistency is concerned with the replicability and dependability of the data collected. It is the responsibility of the researcher to provide (thick description) data that makes transferability judgments possible on the part of the potential applier (Lincoln and Guba, 1985). The reader is, in effect, a type of auditor, looking for accuracy, examining the product (i.e. findings, interpretations, and recommendations) so that the end result may be accepted as establishing confirmability. Prolonged engagement provides the researcher with sufficient time to learn the culture, detect and take account of distortions in the data, and, most importantly, for trust to develop. The development of trust is a process whereby the researcher demonstrates to the informants that their confidences will not be used against them, that pledges of anonymity will be honoured, and that hidden agendas are not being served. Persistent observation adds the dimension of salience to what might otherwise appear to be little more than mindless immersion (Guba and Lincoln, 1981).

The purpose of persistent observation is to provide the researcher with the opportunity to identify those characteristics and elements in the situation that are most relevant to the problem or issue being pursued. Prolonged engagement provides scope and persistent observation provides depth and thus enhance the data collection process.

Neutrality

Neutrality is a concept of objectivity seen from three different perspectives. Confirmability is the first criterion of neutrality. Confirmability is achieved when auditability, truth value, and applicability are established (Sandelowski, 1986). Secondly, objectivity can be said to exist when an appropriate methodology has been employed to maintain an adequate distance between observer and observed. Finally, objectivity exits by eliminating artificial lines between subjective and objective reality, when the inquiry is value free and speaks for itself. Multiple methods of data collection (field notes, informant diaries, unstructured interviews, and participant observation) were built into the research design to provide as broad an information base as possible in order to ground the information in reality.

The inductive, reflexive character of ethnography, where the process of analysis involves the simultaneous development of constructs and indicators to produce a 'fit' between the two, assisted the researcher with the development of meaningful generalizations. The longitudinal nature of the study and the number of informants involved helped to prevent the data collection from becoming context-bound. The research design was such that only the relevant perceptions reoccurred in the oral text of the informants. Confirmability refers to the interpretational objectivity and hence neutrality of the data. Comparing the emerging perspective of the informants with lay articles by transplant recipients, professional articles on life following transplantation, and literature on spouses' experiences living with a transplant candidate, was used to further establish trustworthiness in the data and collection process. Trustworthiness of the data was also met when the findings were presented to other transplant program members not in the study, and were recognized by them as part of their lived experience. The four criteria used by Guba and Lincoln (1981) to assess the rigour of qualitative research were met in this study.

The researcher was the sole interviewer in this study and was responsible for data analysis. It is for this reason that the description of the relationship that developed between the informant and investigator is to be discussed, because it understandably affected data collection. The description of this relationship is essential in order that the validity of the study may be adequately judged (Sandelowski, 1986).

The information for prospective research subjects (Appendix E) and the fact that the study had been generated from questions that had arisen for the investigator over the preceding two and a half years while working as a transplant coordinator were discussed with prospective participants. This disclosure was of interest to these people because they had heard various stories about the time period they would have to wait for a transplant. Thus, the scene was set and this provided a quick entry for the researcher and allowed credibility to develop rapidly. The investigator had been there and knew what others had experienced. The investigator was able to establish from the outset that trust would evolve over time and with frequent contact as a participant observer. The discussion of this role was very important. Trust did indeed develop and frequently the informants would seek out the investigator to further discuss 'their research' together. Being able to observe the investigator in a working setting provided a situation of normalcy for the informants. They were able to judge for themselves whether or not they wished to share their hopes and fears with this person who wanted such intimate details from them.

The opinion of the researcher is that the development of a close relationship between herself and informants assisted in developing an open communication pattern, whereby much unknown or previously unarticulated information was gathered. The investigator also believes that the longitudinal nature of the study, combined with the analytical process and methods of ethnography, provided structure for the investigator and for the informant and prevented meaning from being assumed. Because heart and heart/lung transplantation has many inherent risks and uncertainties, the researcher recognized that the ties between self and informant would be very strong and would therefore require deep committment and careful professional behaviour.

Ethical Considerations

Ethical approval for this study was obtained from the Ethics Review Committee of both the University of Alberta Faculty of Nursing and the host institution. Written consent was also obtained from each of the informants who participated in the study (Appendix B and C). All participants in the study had the right to refuse to answer any questions and to withdraw at any time during the study. They were especially informed that by taking part in the study, they would in no way influence their chances for a transplant and that, should they choose to withdraw, they were in no way telling us that they did not wish to have a transplant. Informants were also told that if they were unable to keep or maintain the daily diary, they could participate in the study through the interviews alone. Likewise, it was also explained that should either the candidate or support half of a couple not wish or be able to participate, this did not automatically eliminate the other from the research study.

Anonymity, informed consent, confidentiality, and lack of coercion were the other ethical issues addressed in this study. Anonymity was guaranteed in the informed consent. To further insure that informant consent was voluntary, a standard information sheet about the research project was offered to the informants and reading time of one week provided before they were approached to participate (Appendix E). It was recognized by the investigator that a breach of confidentiality is always a possibility, particularly when a small population is being researched. Coercion is likewise a possibility, as people in life-threatening positions may find it difficult to believe the no penalty disclaimer in the informed consent. The fact that four people felt free to not participate in the study served to alleviate this concern.

Confidentiality of the data collected, diaries, audiotapes, and transcripts was maintained by giving each subject a code number. The names of the informants, their code numbers, and colours were listed in only one area and the information was destroyed at the end of the study. All the information was stored in a locked office. Tapes, diaries, and transcripts will be destroyed after five years.

CHAPTER IV

FINDINGS

Data analysis in this study resulted in the discovery of the various stages through which transplant candidates and their support persons passed as they waited for a transplant, of the behaviours that assist candidates and their support persons during the waiting period, and the defining of various kinds of waiting in the period prior to transplantation. In this chapter a description of the day-to-day living pattern of candidates and support persons will be provided, stages of waiting will be discussed, and adaptation behaviours will be described. The kinds of waiting, incorporating both uncertainty and hopefulness, will also be discussed.

Day-to-day Living

Transplant candidates and their support people develop and survive or live in a special world that they manufacture for themselves. It looks familiar to an outsider and much of their activity appears natural to us. For example each day is constructed to meet family demands for school, work, housekeeping, and leisure. In all cases in this study, clinic, and, hence, doctors appointments became a part of the routine of the day and, while they were seen as the reason for being in the transplant centre, they were also incorporated into a larger whole, which was seen as everyday living.

For all informants, the overriding need for a transplant has brought about a temporary relocation of the family home, and thu[illegible]stment of family financial priorities and [illegible]ies. In some instances there was a role reversal where the traditional male bread winner has been required to take on the housekeeping, nurturing tasks of the wife, while the female became the principal income earner, family organizer and book keeper. In other cases it was the traditional female role that had to be relinquished, such that cooking, housekeeping, and nurturing were reluctantly handed over (due to failing health). In either case, role reversal was viewed, at the least, as a loss of independence, and, for some, as a loss of control and self esteem. Typical candidate expressions include "We are so tired, nothing is working for us. I know it's all my fault we're here." For all informants it meant an increase in dependency on the support person, and, while such statements would be made as "I'm used to being a house husband, I have been for the last three years," other statements, such as "Losing my driver's licence and not being able to drive myself was not only an indicator of loss of energy; it has made waiting harder now, it was terrible," were indicative of the feelings aroused by having to live in an unpredictable state and losing independence.

A new environment was superimposed on the families in this study as all needed to relocate to be nearer the transplant centre. This environment consisted, first, of the new town in which they had relocated and, secondly, of the medical centre, the outpatient clinic and laboratories, the personnel, and, finally, the customs and mores which were in some way attached to the transplant program itself. These latter consisted of the values, beliefs, and customs that had developed and were passed from one group of transplant patients to another. They involved views on hospitalization, the transplant list, and clinic appointments, to name but a few. The following quotes are examples of statements made in interviews which are reflective of some of these values and beliefs: "Ask for Dr. X to do your biopsies, his are always smooth," "Don't ask to go home for a weekend; they will put you at the bottom of the list," or

> I don't know if it is worthwhile to be in good shape here or not, because if you are in good shape, I don't know if you will get that transplant. If you are not in good shape ... It's a very tough thing to talk about.

Incorporated with the beliefs were the behaviours which transplant candidates and support persons adopted, such as the jargon, ' I've got pitting ankles, and wet lungs' or the black humour, 'don't forget to step on the gas when you go home'. The various activities with which they occupied themselves while they waited included mall strolling, playing cards, and just visiting with each other and talking. Interwoven throughout their day is the routine which develops because of participation in the transplant program. The value and place of routine in the daily lives of candidates has a specific meaning and place. It appears to have almost a ritualistic quality. It definitely is a means of handling waiting and is part of the coping mechanism which helps to manage the stress of the uncertainty of organ donor availability or unwanted death. As one informant commented:

> Routine - It makes me feel good inside. You see, this is very important. I don't work now. I sometimes wish I could, but I also know what I am going through. Like I'm fine in the morning. I can get up at 7.00 a.m. and I'm good until about noon. Mentally I'm sharp. I am thinking right. I am doing fine, but of course as the afternoon approaches, this is life, I slow down. I get tired a lot easier, and I want to sleep. I look forward to lying down on the couch. and just snoozing for an hour, hour and a half. If I don't do that, what happens is that I find that I am not as sharp. My mind doesn't think quite as fast as it normally would. I can't come up with answers properly all the time. And that's not good. I'm happy in the mornings. I like to have the freedom to come to the hospital when I want to. I have the freedom to lay down and sleep if I want to. If I feel like going over to the neighbour's place for coffee, I can do it and it makes me feel good inside, and if you feel good mentally, I have a piece of the control.

Another candidate said "a routine is important, it brings order out of the chaos of your life, it keeps me from going nuts," while another said "Having my kids here has been the best thing for me. They're in school, they need to be fed and clothed so I have to keep to fairly regular, normal routine. That keeps my life in order."

Home Setting

The home setting referred to the living arrangement that each of these candidates made as they moved into the hospital locale in order to be within ready commuting distance, should a donor organ be available to them. As each subject's new home was very specific to individual needs and could be used to identify the informant, none will be described, although all were visited in the course of the interview process. What was important was that each home revealed the attempt to settle in the transplant centre. Family photos, special items of small furnishings, toys, and hobby materials were among the things brought with them to aid in the settling-in process. Lack of financial resources was also apparent in some circumstances. This was evidenced by the lack of furnishings, amusement items such as television, radio, or books, and toys, and in one instance, food supplies were almost non-existent. One support person described finances as being the worst worry after wondering about when the heart would come. "I would say financial, money wise. That bothers him a lot. ... We still have payments in X and we are spending here too." Only one family after transplantation thought the locale of the transplant program was better than their past situation and gave voice to the idea of permanently relocating. When queried about this thought, there seemed to be a fear of not having 'expert' medical care on hand, should any problems arise once the patient and family returned home.

The Waiting Area and the Out-Patient Clinic

Central to the day-to-day living of every transplant candidate was the out-patient clinic area. All activity governing their lives was seen to emanate from the out-patient clinic. In the early days of their arrival in the transplant centre, the clinic was viewed with trepidation and endowed with sinister power. It housed 'them' (doctors, transplant coordinators, and anyone else who might try to exert control over day-to day living). As one candidate expressed it, "The first thing that hits, I suppose is the loss of control over your life." As each candidate and support person became acclimatized to the routines of the transplant program, and developed confidence in the management of the candidates, this viewpoint changed. The clinic area almost became a social drop-in centre, with the business of the clinic being an aside.

The waiting area was an open seating arrangement, attached to the out-patient laboratories on the main floor of the hospital, but on a corridor with minimal traffic. This area could seat 16 people and was used on Tuesday and Friday mornings from 7 am until noon by the program participants. The transplant clinic was run by a clinic manager, assisted by the transplant coordinator on call, and attended by at least one of the three cardiologists attached to the program. The pulmonary physiologist and the transplant surgeon also attended clinic on a regular basis. In addition, the transplant dietician, social worker, and physiotherapist would, from time-to-time, be involved.

The clinic proper consisted of a large open area, adjacent to the waiting room. It contained five examination rooms which were used by the transplant program and five other examination rooms which were used by other programs. Of importance to note is 1) that other programs and their patients were located in the same area; 2) that both the waiting area and the clinic itself had large open areas where conversations could be overheard or partially overheard; and 3) that privacy could be gained only by isolating yourself in an examination room and closing the door. There frequently was a patient being weighed just outside these doors, or one standing at the counter waiting for requisitions. Several patients were observed to have developed the tactic of just hanging around the phone areas. The physicians used these phones to seek consultations for the patients they were seeing, ask each other advice about a problem they had just discovered, or as a referral number where they could be reached while they were in clinic. All transplant program patient's listened to these discussions whenever they could. When this was discussed with the informants such replies would follow as, "You often learn things, and then you don't have to ask questions." This was a situation which broke the rules of confidentiality and placed patients in jeopardy with information that was taken out of context and applied with little understanding of the consequences. "I've been watching the x-rays every week myself and I can see a considerable amount of decrease in the size. This can only mean one thing, we have a match made in heaven." This is an example of a statement of misinformation. The informant had been experiencing mild to moderately acute rejection episodes which had been responding to steroid therapy. Because the immune system had responded to the treatment the heart size decreased. This was not a situation where a tissue match that had been 'made in heaven' could be said to exist.

The investigator frequently observed the informants and other patients as they attended clinic. Vigorous socialization occurred amongst candidates and support persons. It is during the clinic waiting time that dates are made for coffee sessions, plans are made for group activities, and reassurance is offered by transplant candidates to each other. Likewise, it is during this idle time that comparisons are made. Pills (their number, variety, reason for the change in dose, and side effects) are discussed and debated. Diet and weight are the next major topics for debate and, finally, exercise: how much or how little that can be done.

At one stage, unbeknownst to any staff member associated with the program, the candidates ran a lottery called 'Consultarama.' This referred to the practice of one cardiologist to send the candidates out for another opinion. The prize for the most consults was a dinner out. This event was not discussed with the researcher until she had indicated that data gathering was nearly over.

Attendance at the clinic provided direct feedback from the physicians and the coordinators as to current health status, either as reassurance that all was well or in the form of 'fixing it up.' The candidate or support person used this contact time to talk to nursing personnel, ask questions, voice concerns, seek verification of physician information, and, in general, do problem solving that was not perceived as being in the domain of the physician. All informants expressed the viewpoint that they were well cared for and were receiving the 'best medical care ever' from the physicians. These same informants also stated that the "docs are too busy, too distracted, and too far above the patient" to be knowledgeable or interested in their day-to-day living problems, such as finances, reactions of children to the move, homesickness, or feelings of despair and anxiety.

Confidentiality of patient information in this setting is very difficult to maintain. Each transplant or recent death is considered information to be shared. None of the informants were any less forthcoming about this topic than the other candidates observed in clinic. The other issue of contention which was observed between clinic staff and the program participants was the desire to know when and why participants were admitted to hospital. While curiosity may have appeared to be the sole driver of these voiced concerns, the researcher believes it was a demonstration of the feelings of collegiality which develops amongst program participants. This interest in the well-being of other program members became especially evident shortly after the participants were able to establish a formal, self-help support group.

Stages of Waiting

The findings in this section are derived from the research method used in the tradition of Spradley (1979). Ethnography has been used to elicit the affective dimensions of the waiting process. The informants described five distinctive kinds of waiting: 1) waiting to hear that they had been officially accepted onto the transplant list, 2) getting ready, 3) being ready, 4) being on hold, and, finally 5) waiting to go home. These five stages of waiting began to emerge from the data as the first round of interviews were further clarified during the card sorts, and were finalized in the verification interviews. From this data a pattern of the stages of waiting was developed and is presented in Table 1.

Waiting to be Accepted

Waiting to be accepted was that period of time which usually followed an in-hospital assessment of the candidate at the transplant centre. Following the assessment, a candidate evaluation committee would meet and all the assessment data would be reviewed prior to accepting or rejecting the candidate. This committee consisted of the three cardiologists, the transplant surgeon, the pulmonary physiologist, the transplant

TABLE 1. Stages of the waiting process. An outline of patient perceptions and behavioural adaptations to the stages of waiting for a heart transplant, as determined during this study.

Themes	Waiting to be Accepted	Getting Ready	Being Ready	On Hold	After Transplantation
Approximate Time Frame	2 - 12 Weeks	4 - 6 Weeks	3 - 6 Months	6 Months or Longer	2 Weeks - 3 Months
Transplantation	Ambivalent; Fearful; Sad	Ambivalent; Physically feels better: Questions need for transplant	Accepted; Optimistic; Positive attitude	Ambivalent; Doubtful; Resigned	Euphoric
Relocation	Information-seeking	Time of social readjustment	Adjusted; Immersed in transplantation culture	For some, financial difficulties begin to surface	Thinking about going home
Morale	Low; Depressed; Concerned with dying and donor availability	Vacillates; Easily affected by social contacts; Learning transplantation protocols	High; Hopeful; Feelings of invincibility	Low; Focus on dying and the person who must die for them to live; Feelings of hopelessness surface	High, but tinged with realism
Activity	Thinking; Planning; Worrying about finances; Wants information now!	Frantic physical and mental activity	Keeping busy; Routines well established; Socializing important	Declining physical and mental activity; frequent hospitalizations	Focused on physical fitness; Return to 'before illness' health state
Adaptation	None	Beginning to manage uncertainties	Well adjusted to relocation; Coping well	Coping mechanisms breaking down	Generally coping well; Influenced by medications
Support required	Information; Phone support from social worker and coordinators	Frequent contact with transplant team, especially social worker and transplant coordinators	Minimal maintenance support required from transplant team	Frequent direct intervention and support required from physicians, coordinators, social workers, and other transplant team personnel	Support of direct problem-solving nature required from physician, social worker, and coordinator
Transition Points	Accepted onto list	Self-acceptance of need for transplantation	Deterioration in health state	Death or transplantation	

social worker, the transplant recipient coordinators, and the procurement coordinator. As this committee did not have a standing appointment time, the logistics of bringing such a large group together meant that frequently 4 to 6 weeks would pass between meetings. If, for any reason, additional data was needed, a further extension of the time period between assessment and acceptance of the candidate could occur. Candidates were provided with information about the selection procedure but were not given an indication by the cardiologist as to whether they were likely to be accepted.

Waiting to be accepted was an emotional time fraught with anxiety. For the self-motivated and well organized candidate, it was a preparation time when research occurred into heart transplantation, financial resources available were arranged, and, in general, the candidate gained as much information as possible prior to making the move to the program centre. " My illness adaptation came in the assessment phase, I had to wait so long to hear whether I was accepted. Remember I phoned nearly every week wanting to know about housing, when to move the wife and kids ...." For other candidates, it was a time of frustration, a period of anger where energy was spent on worrying about dying before being accepted, and on what they described as 'self-pitying' behaviours, asking why they should be the victims of heart disease, and/or why they were the person needing a transplant. Real concern was expressed about relocating families and the hardships this would cause. "Is it going to be worth the effort?" was frequently a concern voiced at this point in time.

Another anxiety expressed at this time, which did not resurface on a regular basis, was the fear expressed by some of saying anything, in case they might be turned down. All informants described this period of time as being very stressful, regardless of whether they were a candidate or a support person.

For some candidates, this period of waiting was a short period of calendar time which passed quickly. For the candidates where four to eight weeks passed prior to being informed that they were accepted, it was a period of never before experienced frustration and anxiety. These candidates would describe this period as a "living hell" and equated and compared all events which followed with this time frame. Only one candidate and support person experienced a brief wait (two weeks) before being informed that they were accepted. All other candidates waited a minimum of 6 weeks and, in one instance, 12 weeks. One candidate had been previously turned down at another centre and, for this family, the wait to hear that the patient had been accepted into the program was a period of high anxiety. This informant stated "It was tough. I don't think I would want to see anybody have to go through that, because when you don't know for sure whether you're going to make it and you need a new heart, it makes it hard."

Getting Ready

Getting ready was that period of time which followed the candidate's acceptance onto the transplant list. This period of waiting lasted approximately six weeks and could be characterized as the time of readjustment and loss. It was also a time of real activity, in the sense that it might involve finding accommodation, arranging banking facilities, phone, pharmacy arrangements, and the other myriad activities that are required when a person relocates.

The candidates and support persons commented frequently on the loss of familiar surroundings, lack of personal belongings, and on missing close family members and friends who were perceived as a sources of support, understanding, and diversion. Loss of independence, privacy, and control were the most frequently described emotional feelings. These feelings contributed to the overall uncertainty that the informants experienced and described readily. The beeper, the clinic visits, and the constant checks and enquiries made into their health state were not viewed as being a concern for their well-being but rather as a means of supervising their activity.

Getting ready was also a time period of frantic activity. Some of this was generated by the beeper itself. The beeper is a radio-activated call device, given to the candidates to ensure that they were always available for contact by the coordinators when they were out of the house. This was particularly important in the early part of their stay in the transplant centre, when candidates were new to the area and well enough to be out and about the town. The beeper was the emergency back up system, to be used to call these patients in for their transplant when they could not be contacted at the home phone number. All the candidates and support people expressed having a sense of urgency about everything they did; for example, "if I start this, will I have a chance to finish before I'm beeped," or "what if I don't get done in time?" The beeper was thus viewed as an armed extension of the clinic staff: a means of checking up and controlling their habits. It was the enemy that could call them at any time, interrupt social occasions, and invade their privacy. It was also an object of distrust and needed to be tested. It was during these first few weeks that coordinators would receive calls at all times of the day or evening, when 'the system' was checked by the candidates. Above all, in the early weeks, the feeling about the beeper, as expressed rather succinctly and wryly by one candidate, was "I guess I really resented being on a leash sometimes."

Unless the candidate was hospitalized at this time (one only), these living arrangements were done, at their insistence, by themselves. Support persons were consulted, but they expressed, as well as the candidate informants, the need for the candidates to feel that they were doing something useful and were, in a sense, continuing to make decisions. This expression of independence allowed candidates to maintain some control and make practical or concrete efforts to deal with the day-to-day issues in their lives. These were seen as very important activities by the candidates but often produced unexpected feelings of alienation and were points for argument with the support persons. Such statements as "I hold back because I don't want to say anything because I know he doesn't mean it, but it does get to me. There will be times that he will say 'Why don't you go home? I don't need you here, and I can handle it myself.' stuff like that, which he never would say." were examples of the control which support persons needed to exert.

Often the activities which candidates chose to do were reflective of the role reversal that had taken place. For example, one gentleman decided to be the person who would do the grocery shopping. He would select various recipes from cook books, buy the ingredients, and then tell his wife to do the cooking. When asked about this he said "I never had time before and, besides, it keeps her on the hop." His wife was incensed and wondered how he knew where "the buys were" and felt that he was just trying keep her busy, a self-admitted goal of the candidate. Another activity which frequently created havoc in households was the laundry. The questions of how frequently one should wash, what clothes went into the machine, the brand of soap to be used, and, last, but certainly not least, who should do the wash all provided grist for heated discussion.

With the relocation to the transplant centre, time hung on the hands of both support persons and candidates in this early period of their waiting. All day-to-day living tasks which occupied time were jealously guarded through the right of previous ownership. When this was discussed with support persons, some of the benefits of such enforced closeness could be identified. Such statements as the following would be made: "We have never gone shopping before, now we are going every day as long as he feels good and I do. We don't shop, we don't buy, we look. We enjoy our time together."

It was during this period of time that financial concerns became an issue. Considerable time was spent by both candidates and support persons worrying about money. Frequently they would need to be guided towards the social worker for assistance with management of a budget and/or assistance with alternate sources of funding. It became very obvious, throughout all the interviews, that, although information had been forwarded as to likely costs that would be incurred, the over-riding issue of needing a transplant did prevent candidates and support persons from viewing this problem in a realistic light. Where funds had been promised by various community agencies, their erratic delivery also enhanced feelings of anxiety and further emphasized the sense of loss of control over their own lives.

Other emotional expressions made by candidates at this time were feelings about the loss of privacy. They felt they wanted to talk to transplant team members privately; they were not used to group activities, sharing their feelings with outside others, and felt "naked in the goldfish bowl" (their term for the waiting area). Many questioned again whether they had made the right decision, that is, agreeing to go on the active transplant list, especially if they felt they were in reasonably good health.

Candidates recognized that good health was a relative thing, and that they were classified as having class IV heart disease according to the New York Heart

Association classification system. None had been able to work, even part time, for the preceding six months and some had been off work for as long as three years prior to being referred to the transplant centre for assessment. Informants who felt that they were in this stage of relative 'good health' found looking at other less well candidates, waiting in clinic, and being examined in the same fashion very difficult.

> It is difficult, I find it difficult sometimes coming to the clinic and, of course, as you know, I have made some good friends . . but, you get to sit and you get involved with other patients and all I've heard from other nurses, ... is that it is good to talk to other patients and get their feelings. Sometimes I disagree with that wholeheartedly. I like to talk to people who have gone through the transplant. But I find it difficult to sit and talk to other people that are waiting on the transplant list also, and I am not being greedy or selfish, but the mind is a very complex thing and it's very difficult sometimes to sit with somebody else that happens to be approximately your height, approximately your weight, and God only knows if he's your blood type, and I realize that those are the three things that are important. And that makes it tough for an individual. And I'm not saying that it affects me really bad. I wouldn't let it anyway, but it still works on the back of your mind. So that's the tough part about coming to clinic.

This was also a time of less positive thinking; the frustration of being ill enough to need a transplant was readily translated into anger of the 'why me' sort. The uncertainty of getting an organ frequently manifested itself in the expression of such statements as "what if

I die; is it really worth it?" or "am I putting my family through all this bother for nothing?".

The critical point which seemed to bring the getting ready stage of waiting to an end was the final recognition by the candidates that they were really in need of a transplant. All informants stated that, prior to this point, the impact of their need for a transplant had not been acknowledged. This is emphasized by comments such as: "You have already been told by your family doctor, then a cardiologist, then you are sent here for referral, but even after you have moved here it doesn't seem real;" "when the coordinators start teaching, it really hits home, hey that's me you are talking about." It was this acknowledgement and acceptance of their current health state and all that it meant that permitted the candidates and their support person to pass onto the next stage of waiting.

None of the candidates or support persons were able to pinpoint exactly a point in time when this transition occurred, but all agreed that if they had to target a point, it was this final acceptance that they really needed to be there that was the transition point between the Getting Ready stage and the next stage Being Ready.

Being Ready

This period of waiting, lasting for the next three to five months, was frequently called 'the honeymoon phase' by the transplant team members and by the candidates themselves. This was not because all was well in the candidate's world, but because the team members and program as a whole were viewed by them through rose-coloured glasses. Attendance at clinic was now viewed as a positive activity; it was part of the routine that had been established. The waiting area now became a convivial setting where notes on the progress of recently transplanted patients could be compared, and such mundane topics as weight gained or lost, or adjustments to medications could be discussed. In fact the clinic waiting room seemed to become almost a drop-in centre or, at least, one constant gathering place where participants would branch off for social times in the hospital cafeteria.

There were informal attempts to control newer patients (candidates) by the older patients. One informant said "I really ignore all that B.S.; if you listened to it you would go crazy. I don't want to hurt anyone's feelings so I just pretend to listen, but that doesn't mean I agree." However, very little time was required for these newer patients to merge in with the old hands and very soon the point was reached where they too would have to occasionally be paged to return for their examination.

Individual health states became very important for the candidates and reassurance was sought on all fronts. This was a very noticeable characteristic of this stage of waiting. The clinic visit served to reaffirm to the support person and the candidate that all was well for surgery, that the transplant team was still interested in them even though they had been there for awhile, and that they were still very active candidates, even though there were other patients who were sicker than they were. The clinic staff would repeat the criteria for being a recipient and that would satisfy them for the moment. It became very evident that confidentiality of information was very hard to protect. Candidates felt it was their universal right to know as much as possible about each other and, particularly, about who was in hospital.

One of the myths that surfaced frequently was the belief that those candidates who were in hospital would get transplanted sooner. Of course, in some instances this did occur, because the hospitalized patients were much sicker. However, the researcher was frequently asked if this were true, and it was necessary to point out that this didn't always hold true. Candidates were reassured by staff that it is far better to be reasonably well and go into surgery in the best possible shape, than to be a very sick person who might easily die before a donor became available.

The constant badgering of the transplant nurses for information about other patients was seen by staff as a very tiring aspect of working with patients, and often annoyed the nurses. On one occasion, a candidate had to actually be asked to leave the clinic area and to wait in the sitting area, in order for the nurse to quietly discuss a patient concern with the attending physician. The candidate was observed to be annoyed and expressed the opinion that it was their right to know who was in hospital so that they could visit and support that patient. Explaining that if the patient wanted visitors, they could ask for them was to no avail, and always the response would be "Of course they want to see us! We know how they are feeling. Only we know what its like to be waiting."

Much emphasis was placed on being fit by the candidates. Although being fit was mentioned in the On Hold stage, it was more frequently emphasized in the Being Ready stage. Fitness did not seem to be directly related to the day-to-day health state, as one could be 'fit' and still have an off day. It applied to physical activity, to having a routine, and a positive mental attitude, and to having specific daily goals which could be accomplished by the candidate. While physical activity was important, being fit also meant taking care of oneself. This meant having afternoon rests, a good night's sleep, eating smaller meals (not to necessarily lose weight but to aid digestion). All this was seen as helping the transplant team, demonstrating compliance, and taking out extra insurance in that, if you were fit, you would make it to the operating room for the surgery.

Independence from the support person was also imp [illegible] this time. Candidates would say such things as [illegible]e shopping I make her make me up a list and out I go. I can still drive us" or "If she wants to go to a movie or have a ladies night out, I think that's great. I can manage on my own. I am not a baby."

From an observational point of view, the candidates probably were at their physical best during this period of time. The experienced transplant cardiologist were often able to improve these failing hearts and their physical activity would improve, for a short while. In the case of two of the candidates, this improvement in health remained right up until the time of surgery. The candidates frequently slept better, had less hepatic congestion, less pulmonary and peripheral oedema, were able to tolerate food and fluids, and thus, in many instances, felt better than they had in months. Candidates were very adept at describing their physical state to physicians and coordinators and were proud of the medical vocabulary that they possessed.

It was not difficult for either candidate or support person to think positively in this period of waiting. They had received the opportunity of talking to successful transplant patients; they were often told by these same patients that everyone has complications but "look at us now!" Perhaps most importantly, because they felt good, they often were able to convince themselves that none of the post-transplant problems would be theirs. Likewise, considerable effort was spent on the part of the coordinators in encouraging the candidates and support persons to have hope, to plan for the future, and to live each day at a time.

Frequently heard expressions at this time would be in the nature of "this has been really great for me and my family, we have gotten to know each other really well" or "it has been a real positive experience for our marriage, we have drawn closer together." More than one candidate viewed this time as being very positive for themselves. "I really got to know myself, it was a positive thing." "I never knew I had these resources, my family says I am more understanding, more patient." The beeper became a friend, a reassurance that provided freedom rather than a restriction. Family members had usually established patterns for visiting and making phone calls. Candidates and support persons would be most positive about the support they were receiving from distant family. In fact, three of the candidates stated that they had never known how popular they were until they had moved away.

Pre-operative teaching was completed by this time, and candidates and support persons felt that this was the time they used to express their frustrations, to air their questions, and to feel out the system. Many of their thoughts on organ donation were talked about during this period of time and what would make a match for them was always asked by both candidates and support persons. During this stage of waiting, candidates and support persons did not talk about dying or organ donation in concrete terms: "that issue has been dealt with." All but one candidate denied thinking about the uncertainties ahead. To be unsure about the future was interpreted as not having a positive mental attitude and preventing success. Thinking positively, associated with maintaining high morale, being fit, and keeping to a routine, were the important tasks to be accomplished.

Keeping busy was an important activity for both the candidates and their support persons. The development of a routine to which they adhered was frequently mentioned by both parties. The routine gave purpose to their life, provided a plan of action which could be followed and assisted in maintaining morale. "Keeping to a regular routine is very important. It's part of the maintaining control thing. It helps you to feel and look normal. Keeps you from being a sick person. I'm just a person going about my daily duties. Maybe that was the selfish part of me but I cared a lot about that. It was almost a compulsive need."

For many informants, having a routine allowed them to plan for the future, create daily goals to be accomplished, and live each day at a time. This latter philosophy was not espoused by the candidate who spoke most adamantly about having a routine and thinking positively. "Living one day at a time is difficult when you are the kind of person I am. I like to have things planned ahead, I don't like surprises, I can't live one day at a time, It's a nice saying." Another candidate felt that having a routine kept them from "going nuts, you can't let waiting dominate your life." For this person, routine helped "to put up a front, you know back here [meaning in the brain] the future might not come, you are in a kind of limbo, but a routine helps a lot. Just planning one day at a time makes you believe there will be another day and another day. Pretty soon you believe it." Another viewpoint was "Having dreams, being hopeful, fantasizing what it would be like to live a normal life, that's part of the routine too. After supper, we talk about when we all are back home."

Keeping busy during this period of waiting meant that both mind and body were occupied. Physical activities (for example, going for walks, shopping at a mall, getting meals, doing the housekeeping) even though they might require frequent stops for rests, were reaffirmations, for both the candidate and the support person, that the candidate was well and was making a special effort to be in good shape for surgery. One patient measured his fitness by the number of times a pause was necessary when climbing a specific number of stairs; another took great pride in announcing that it was still possible to push snow. The researcher knows that these must have been momentous efforts of will, because, in each case, the surgery was observed and, when the old (huge and severely damaged) heart was removed, the surgeon commented on the debilitation of the organ.

Several changes in attitude were also observed by the researcher during this period of time. Many of these changes would be commented upon openly by the candidates or support persons themselves. There was an expression of trust and confidence in the care being received. From the initial "I don't have much choice, do I?", the researcher frequently heard comments being offered to other, newer candidates of the following nature: "You can really trust them, they really care about us, they tell it the way it is."

It was during this period of time that testing seemed to stop. Frequent intervention on the part of the transplant coordinators waned because it was not needed. Phone calls to coordinators became almost non-existent. Coordinators would often be reassured by the candidates that the beepers were still working: "Just waiting for your call!" Beeper miss-fires were accepted as just that and conversations would be brief or of a social nature. Candidates and support persons looked relaxed; they knew the jargon of the clinic, had observed its operation, witnessed a few people get transplanted, and, while they may have had a quick hospitalization for further medication adjustment, on the whole they were managing very nicely on their own.

The one factor which had considerable influence at this time was the presence of hope. It varied in expression from "I've never been uncertain, I do not permit myself to not have hope. If I didn't have hope I wouldn't be here" to "before I talked about the future for others; now I know I have hope for myself. I know I am going to make it." or to "You know I am a great visualizer. I have had lots of time to think. It's not so much what-ifs but how much can I cram into my future.

I spend hours thinking about what I am going to do, where I will be. Dying is not a possibility for me. And that is Hope."

Being ready was a period of time when candidates felt reasonably well, had adjusted to the relocation, and had overtly conquered their anxieties related to organ donation and their own survival. It was a period of time when the candidate and support person entered into social relationships with others, believed that there were future goals that were attainable for themselves, and experienced feelings of hopefulness.

Being on Hold

At about the sixth month period of waiting for the transplant, there was a transition which candidates and support persons identified as happening, when they began to doubt that a transplant would occur. Even if the candidate remained relatively healthy and did not experience frequent brief hospitalizations, feelings of uncertainty reappeared and doubting of the possibility of a transplant occurring were voiced. Several events were identified as triggering off this change and were described as the indicators of when you moved from Being Ready to the kind of waiting which was described as Being On Hold. These events included false alarms, numerous transplant surgeries being done, and deteriorating health with subsequent hospitalizations.

False Alarms

False alarms were trips to the hospital for a possible surgery, with the surgery subsequently cancelled. Amongst three of the eight candidates in this study, there were five so-called false alarms. Each time, they were brought into hospital and worked up for their surgery, and one even reached the operating room, only to have the surgery cancelled. As one of these informants stated: "You can't help but be psyched up for it. I know I don't want a bad heart, but geez you really can't help but be depressed. I know it happens, but why to me?"

Transplantation of Other Candidates

During the study, numerous transplant surgeries were done after a prolonged period of eight weeks when no transplants had occurred. Two of the research candidates were transplanted, as well as other candidates, in this period, and every other candidate expressed joy and pleasure in the fact that some of their 'buddies' had received a transplant. However, following these surgeries, a state of depression and doubt descended on the remaining candidates and support persons and expressions which typified the On Hold kind of waiting were made. Informants would express themselves in the following fashion, "I've tried everything to make myself feel better but nothing is working. I don't even try to start because I know it is going to take more power than I can put out."; "There is so much stress on all of us and it makes me more worried every day."

Deteriorating Health

The third and final transition factor which seemed to exemplify the move to this time frame was deteriorating health. Deteriorating health meant decreased physical activity. Increasing right, left, or biventricular heart failure meant increased fatigue, physical discomfort from a distended heart, liver, and sluggish gut. Breathing became a supreme effort and walking any distance an impossibility. Even talking was difficult. Time became distorted and mental concentration diminished. Both candidates and support persons became more dependent on transplant team members.

During the On Hold period, complaints of further loss of independence were frequent. These complaints might involve the inability to drive a car, being dependent on a wheel-chair, or guilt about being a burden to the support person. Support persons would comment that they observed personality changes. As one woman stated "... can't handle people anymore, too many patient's in clinic really bother his nerves, or new people really bother us." These behavioural changes also made the candidate difficult for staff to nurse. The cardiology nursing staff took a great interest in transplant candidates who had previously been admitted to their areas. There was usually a good number of nurses who remembered the candidate and support person from the assessment period of waiting, if not from infrequent admissions. However, it was not unusual for the staff to query the suitability of the candidates as they deteriorated, or to doubt the motivation or will to live when the candidates were admitted. This was particularly evident when readmissions were frequent or prolonged or the candidate reached a state of extreme mental and physical deterioration but was considered still a suitable operative candidate by the cardiologists. None of these candidate informants had indicated that they wished to withdraw from the transplant list. The support person and candidate clung to the familiar and would be observed to pour out their thoughts to the nurses they knew and to totally ignore the ones they didn't. When questioned why this was, the usual response was "I trust them," or "I like them."

Being On Hold meant a return to or an increase in dependency. It was also accompanied by a period of self doubt and a general decline in well-being. There were increased periods of tiredness and a lack of ability to sleep. In addition to this loss of the sense of well-being that had persisted up until this point in time, there was usually decreased appetite and/or feelings of nausea, such that being able to eat was difficult. Neither support person nor candidate verbalized an understanding of these signs and symptoms of end stage illness. Denial appeared to be the mechanism in use. The clinic physicians would frequently palpate the abdomen, inform the patient that the liver was enlarged, gently tell them that their "gut" was congested and that things were slowing down, but this did not really seem to sink in at the time of clinic visit.

However, when a support person was interviewed, such statements would be elicited as "He is really worrying about his weight and if he will make it" or "He is getting edgy, very edgy, won't admit to being scared because he believes it's a man's role to be strong and positive, but I know he is worrying and that makes it hard for me." When candidates were interviewed, such statements as the following were made: "There is a bit of scariness in there but it is the waiting that is really starting to get to me", or "For some reason, I am worrying now. When is the day going to happen? Is it going to happen? I've been getting stupid ideas in my head like what is my chance of getting another heart attack? Things like that are getting to me."

From the candidate diaries came some of the most revealing comments.

> I think we are almost ready to crack. It feels like we are pulling away from each other because I have no car, no money, no help from home. All this is just making me close up again. I really feel that I'm putting people through things they don't have to go through

or

> Well I'm worse than yesterday, B/P is real low, and I'm dizzy all the time now. Headache, am more tired, weak, just awful. Went to the hospital they stop some meds, hopefully that will help. I know I'm getting worse just by the way and things I do. I can't do them as long or I don't even try to start because I know its going to take more power than I can put out.

Physical deterioration, combined with a lengthy waiting period, were the triggering factors which moved candidates into the On Hold phase of waiting, which was characterized by depression, self-doubt as to ability to survive until the transplant, and ambivalent feelings about the worth of the transplant itself. Further loss of independence, decreasing financial resources, and frequently reoccurring hospitalizations served to underline the length of time that candidate and support person had been waiting, and all of these factors together undermined morale.

It was at this period in time when most concern about the competence of the program was expressed by the candidates and their support persons. Staff involved with the program would be frequently questioned about donor availability, or asked who had been transplanted the other night, when there might not have been a transplant for several weeks. Staff were also frequently asked "Just who decides who gets the heart?" This period of being On Hold was a stage of waiting which continues until death or transplantation occurs.

After Transplantation

Following transplantation, candidates and support persons had a further 3 to 6 months to wait prior to being discharged home from the program. Discharge home was dependent on the course of their post-transplant recovery and followed criteria for discharge established by the cardiologists.

Following the immediate post-operative course, everyone was euphoric. The candidates, possibly because they were on high dose steroids, were still very elated over their surgery. The support persons were happy because the surgery had occurred and their family member was discharged (safe) from hospital. Both groups had very unrealistic views of the future and when asked to look backward to the stressful time which had just passed, were very benevolent in their attitudes: "You guys [meaning the program personnel] are really great, and waiting is just something you have to do."

Summary

These findings are summarized in Table 1.

The experience of transplant candidates and their support persons as they wait from the time of being evaluated until two weeks after transplantation has been presented in this chapter. This waiting period was discovered to be a process made up of stages of waiting. These stages were well defined by the informants, possessed distinct characteristics, and have unique implications for nursing practice and suggest areas for future research efforts. Transplant candidates and their support persons held significant beliefs about the waiting process and the meaning it had for their lives.

CHAPTER V

DISCUSSION

The purpose of this study was to examine the meaning of waiting, from the perspective of heart transplant candidates and their support persons. An inductive approach was taken because an analysis of existing literature on the waiting period prior to transplantation revealed that there was only one study relating to the adaptation process that candidates and support persons have to make while awaiting a transplant. This failure to examine the meaning of waiting, from the perspective of the transplant candidate and support person, had left a significant gap in patient management knowledge.

The findings from this study indicate that transplant candidates and their support persons develop a world view that is particular to themselves. A system of routines and beliefs arise to protect and assist them in reaching their combined objective: transplantation. The management of uncertainty and its concomitant anxiety are interwoven throughout their lifestyles. Together and individually, the candidate and support person adapt and manage effectively, provided that the deterioration in health state is slow, that the recipient responds to significant medical intervention, that death is only a distant possibility, and that morale (in the form of hope) is sustained. When this is no longer the case, adaptation and coping mechanisms appear to deteriorate and outside support is required.

The purpose in this chapter is to discuss the findings from this study from the time a candidate and support person are accepted onto a transplant list until the candidate is transplanted. The discussion is organized in the following manner: 1) discussion of the research methods, 2) discussion of the findings, 3) implications for nursing research and nursing practice, 4) summary.

Research Methods

The ethnographic method, as explicated by Spradley (1970, 1979, 1980), was used in this study because it allowed the researcher to explore the meaning of the waiting process with transplant candidates and their support persons. By eliciting and analyzing the words used by candidates and support persons and examining their frame of reference in categorizing events, an understanding of transplantation culture was gained.

Culture in this instance refers to the "acquired knowledge that people use to interpret experience and generate social behavior" (Spradley, 1970, 1979, 1980). Hence it was necessary to understand thoughts, feelings, interpretations, and actions from the perspective of the candidates and support persons as they experienced the process known as waiting. To develop a concept of meaning, a theory of meaning and a specific methodology designed for the investigation of meaning is necessary. Ethnography provides that theory and methodology. The use of the emic perspective, multiple methods of data gathering, and the ability to clarify perceptions between informant and the researcher as they occur are the distinct assets of the ethnographic methodology.

The findings in this study do not represent the beliefs of any one individual but are reflective of the beliefs of all the subjects who participated in this study. While individual beliefs and contradictions may become obscured, individual variations are explained in the manner recommended by Aamodt (1982) and by Field (1983). Inference is not eliminated when studying culture revealed through speech, but it is the responsibility of the ethnographer to draw the generalizations and state these in clear, concise language.

Data Collection Techniques

In this study, data were collected through unstructured audio-taped interviews, participant observation, observer field notes, and patient diaries. Nursing observations and notes on clinical charts were consulted to verify or illuminate patient perceptions, when necessary.

The use of unstructured interviews permitted the linguistic themes of the informants to develop and be explored. As more data were collected, themes were tested and kinds of waiting experiences for both candidate and support person evolved. An analysis of the parts of waiting revealed that waiting for a transplant is a process whereby, in addition to personal experiences, certain activities and events which occur are interpreted and given meaning by the candidate and support person.

Unstructured interviews, combined with participant observation, allowed for verification of the meaning of the process through the use of probing questions to discover relationships and contrasts among and between informants. As the study advanced, triangulation (Field and Morse, 1985) occurred with the researcher conferring with professional colleagues to verify both observations and inferences.

All but five of the interviews were conducted in individual candidate homes. All informant homes were visited; however, at the request of some informants, interviews were also held in a private hospital office. This request was made most frequently for convenience, although, in one instance, it was to ensure privacy from the candidate and, in another instance, from the family support person. Interestingly enough, both of these interviews were concerned with the same themes - morale. Each person did not want the other partner to be aware of how difficult it was for them to maintain an atmosphere and feeling of hope. These were highly emotional interviews, with the distress of each partner being very apparent. In the first case, the researcher suggested that the candidate seek assistance from the social worker in dealing with this issue; in the second, the support person was directed to the support group. Considerable effort was being made by transplanted patients and their support people to assist waiting patients and families. Evans (1985) and Mai and Burley (1985) have identified that prospective transplant families and candidates achieve some degree of help from such groups.

At-home interviews placed the informants in familiar surroundings and provided space to move around in. While this did permit the informant to be more relaxed and self-disclosing, it was not a guarantee of an interruption-free session. Incoming phone calls, curious children, spousal inquisitiveness, and the need to socialize by offering tea and cookies were frequent sources of disruption. Thus, privacy was frequently sacrificed. The inference made was that, by not organizing privacy as requested, the informant was not comfortable with the interview process or its content.

As time progressed, it became apparent that this was not a valid assumption, as opinions expressed by study members in these very open sessions were very similar to ones expressed in totally private settings.

A conclusion drawn from this observation was that candidates and support persons were very capable of expressing themselves in an open and straightforward manner. This had been a previous observation and confirmed the researcher's opinion that informants were able to express what they felt and were willing to discuss the truth, as they perceived it to be. The use of self in ethnography, of course, leaves the researcher subject to 'reflexivity' and suggests that researchers need to be conscious of their role as actors and of their own internal state (Aamodt, 1983; Reinharz, 1979).

The interviews also provided candidates and support persons with the occasion to reflect on their own beliefs and experiences, with many commenting that this was a first for them. All of the candidates stated that they viewed the interviews as a positive experience. They saw it as an opportunity to share their singular knowledge of an 'awesome experience' with others. For some of the informants, it was a very emotive time when, frequently tearful, they verbalized their fears, concerns, and despair over what they perceived as wasted life. For others, it was an opportunity to speak positively about the future, express appreciation for care received from transplant personnel, and, above all, affirm their faith and hope in their own transplant outcome.

As a participant observer and interviewer, it was difficult to remain detached, unbiased, and non-affirmative in action. However, a very conscious effort was made to neither lead the conversation nor offer suggestions that might be construed as problem solving. The reactive effect which the researcher can impose and experience (Denzin, 1970; McCall and Simons, 1969; Wax, 1971) during the interview process is a potential limitation of the unstructured interview and participant observation. At no time did the observer/researcher feel so closely bound in the interview process that objectivity was lost.

The use of theoretical sampling and consultation with professional colleagues of observations and responses (an integral part of the ethnographic method) also assisted in ensuring that the potential effects of the researcher were limited. It is through sharing this information that the researcher is afforded the affirmative confirmation whereby the colleague announces "I know just what you mean" or "That sounds just like" or "I can just picture it happening that way." These are considered to be reflections of the reality of the experience-reporting and validators of the objectivity of perceptions by a researcher (Guba and Lincoln, 1981; Leininger, 1985; Van Maanen, 1983; Sandelowski, 1986). Such statements are indicative of the themes and patterns that have emerged from the descriptive ethnography portrayed by the informants.

The use of informant diaries proved valuable, although only three were maintained and made available to the researcher. They were a mechanism of continuing the dialogue with the researcher. Frequently they would start with a salutation to the researcher, or often direct questions would be asked of the researcher with statements such as "you have really made me think about .... and here's my answer" being quite common. Another value of the diaries was that they assisted in confirming the trustworthiness of the open interviews. Comments made in the diary, under what the researcher was assured was exclusive ownership, rarely were unique. Thus the audit trail described by Guba and Lincoln (1981) was established.

None of the candidates who died had maintained diaries. The researcher was thus saved the ethical concern of possessing personal materials of the deceased which the family might have requested back, in spite of having signed an agreement that all such materials were the property of the researcher.

As broad generalization was not the goal of this study, attempts were not made to quantify the data. The convenience sample was selected, in the order that candidates and support persons were accepted onto the cardiac transplant list and agreed to participate in the research protocol. They were representative of a single institution's program. No one, under the age of 18, was approached to participate. All informants had to be able to express themselves verbally in the English language, but being able to read and write in English was not a prerequisite, although each informant was approached to keep a diary. It was recognized from the outset that many people find it difficult to maintain a daily diary and that the informants would be no different in their behaviour. Therefore, a diary was not viewed as a requirement for participation in the study. It is recognized that the findings of this research can only be applied to other candidates in transplant programmes with similar characteristics.

The findings from this study do permit theoretical generalizability as aspects of the emergent concepts can be applied to the experiences of other candidates and support persons. The utilization of secondary informants in the cardiac transplant clinic was another method used to elicit data against which to measure the findings, and to check that the concepts made sense. The applicability of these findings may be relevant to other patient groups who demonstrate anxiety and experience the stress of uncertainty, while waiting for treatment for a prolonged period of time.

Finally, it must be recognized that this study was exploratory in nature, designed as a first step to developing an understanding of the experience of cardiac transplant candidates and their families as they wait for surgery to take place. Continued research is needed to further develop the initial understanding of the implications of waiting for a transplant, for both the candidate and the support persons, developed in this study.

Discussion of the Findings

This study was unique because, to the knowledge of this investigator, there had been no previous ethnographic investigation of the perceptions of the experience of waiting for a heart transplant, from the perspective of both the candidate and the support person. In fact, there has been only one study reported which expressed a concern for the adaptations made by candidate and family as they experience the waiting process (Mishel and Murdaugh, 1987).

Mishel and Murdaugh (1987) suggest that family members gradually develop attitudes, beliefs, and behaviours to meet the challenge of living with the continued unpredictability of waiting for an organ donor. The findings from the present study support this contention. The beliefs and behaviours expressed by the candidates and their support persons were similar to the descriptions provided by these authors. The unique finding from this study is a description of the trigger points which occur within the waiting time period, delineating a transition from one stage of waiting to another. These trigger points are being accepted onto the transplant list, self-acceptance of the need for transplantation, deterioration in health state, and finally, death or transplantation. The waiting period was seen to be made up of a series of distinct stages, linear in progression, and terminating either in death or transplantation.

O'Brien (1985) and Allender, Shisslak, Kaszniak, and Copeland (1983) identified stages in the transplant process, and recognized the waiting period as being a significant time period for candidates. However, they did not describe the waiting period after acceptance into the program as being more than one step in the transplantation process. In this study, it was evident there are different kinds of waiting, with activities which are distinctly identifiable in each phase and others which are common to all stages of waiting.

The behaviours which were common were those which enhanced a positive attitude, fostered hope, and provided feedback to the candidate that all was well and he or she was fit for surgery. It is of interest to note that candidate perception of health state differed from that of the care-giver and support person. Care-givers viewed the candidates as patients as they presented physically in the clinic. The shortness of breath, the loss of appetite, the decreased physical activity, the haemodynamic status were the areas of focus. In contrast, the candidate and support person's viewpoint was influenced by a combination of the report from the physician and the candidate. Personal observation of the candidate's wellness with reference to day-to-day physical decline, influenced the support person's appraisal of the fitness state.

'Being fit' had a significance not previously described in the transplant literature. It included a largely attitudinal component which incorporated a sense of well-being. This was demonstrated by statements of compliance regarding medications, diet, exercise, and rest and was further emphasized by beliefs which supported high morale and the conviction that "there is a heart out there for me." Being fit equated to and was as important as having a routine established. A feedback loop appeared to be established which permitted candidates to incorporate all positive signs and convert these to a spirit of hopefulness. Mishel and Murdaugh (1987) reported that issues beyond the waiting phase are not important, until candidates and support persons are sure that the patient will receive a heart and survive the surgery. Death was not denied ("of course, it can happen"); rather, the emphasis was on thinking positively and being hopeful.

The candidates and their support persons were prompt in establishing a routine to their daily lives. This was viewed as demonstrating compliance. Routine was also used to provide a sense of normalcy in day-to-day living and symbolized independence and a sense of control, and, therefore, allowed goal-setting and allowed hope in the future. For each person interviewed, regaining personal control was seen as the major factor which assisted in the normalization of their lives and with the management of the uncertainty of waiting.

Uncertainty, a perceptual state, occurs when internal or external stimuli are vague or unclear (Lazarus and Folkman, 1984; Mishel, 1984; Suls and Mullen, 1981). Averill (1973), suggests that most people prefer predictability, regardless of the effects; that humans would rather know that the odds are against them, than not know the odds at all. Uncertainty and unpredictability in determining the chances for an organ transplant contribute to the perception of waiting as stressful, and may impede coping efforts.

In the Getting Ready stage of waiting, control was seen to be in the hands of the transplant team personnel. Loss of control was felt to be caused by the illness, enhanced by relocation to the transplant centre and symbolized by the tie to the beeper. The beeper was the epitome of uncertainty; one never knew when it would go off and it was, of course, a symbol of the uncertainty of receiving an available organ for transplantation.

Personal control was recovered at the transition point of acceptance. Candidates described themselves as settled in. The routines of hospital, clinic life, and their personal patterns of living, which had merged to be accepted, were perceived as the norm. The candidates and support persons had developed attitudes and beliefs which they saw as helping them to cope with waiting. They were comfortable with their surroundings, had few questions to ask, and, above all, felt independent. Informants had become immersed in their culture (Aamodt, 1989).

It was at this point that changing attitudes and behaviours indicated that a socialization process or adaptation to the situation had occurred. While Christopherson (1979) states that candidates develop a pattern of dealing with the reality of the illness and are assisted by transplant team members, this pattern was not described. This researcher would suggest that the pattern is the socialization process which allows a return to structured normalcy and thus the regaining of a sense of independence and control, which is essential to the maintenance of self-esteem.

While it might seem inappropriate to associate a sense of physical well-being with a patient with end stage heart disease, it was important to recognize that this concept was an adaptation mechanism developed to assist with the waiting process and to support this adaptation response in the clinical setting. Positive verbal feedback from physicians and nurses was incorporated into the candidate's attitude about the team effort. The concept of 'team' included the candidate and support persons, as well as the professional team members. When positive feedback was received, this seemed to reinforce a feeling of high morale, enhanced hope, and, in some manner, confirmed to the candidate, that by being compliant, they were participating in the work of the transplant program. Enhanced self-esteem on the part of the candidate, at a time when it could have been at a low point, was an additional gain from this feeling of *esprit de corps*.

In this study, candidates and support persons appeared to minimize the perceived threats of deteriorating health, possible death before transplantation, and loss of morale by developing a belief system, pattern of behaviours, and a system of day-to-day living that created an atmosphere of challenge by focusing on the possibility of success, rather than failure.

The initial two phases of waiting, which consisted of the Waiting To be Accepted and the Getting Ready phases described in Chapter IV, were perceived as a time where loss of control and independence were combined with grieving for past life and with lowered self esteem, so as to generate overwhelming feelings of powerlessness and hopelessness. Until the candidates accepted and made adjustments to these perceived losses, they continued in this state of fearfulness and ambivalence. Adaptation was a slow process, which varied with each candidate but was universally described as reaching a transition point which they defined as acceptance of the situation. The situation was, in this case, their own realization and acceptance of the need for a heart transplant.

A possible explanation of this transition may be found in the coping mechanisms which were developed by the candidates and their support persons to overcome some of the stressors described previously. Lazarus and Folkman (1984) view coping as a process whereby the dynamics and changes which occur are a function of continuous appraisal and reappraisal of the shifting person-environment relationships. Coping is a cognitive process which applies to all stressful encounters, and changes in coping may occur rapidly or may continue to occur for hours, days, weeks, or even years.

The development of a daily routine was a coping mechanism which permitted candidates to achieve personal goals and provided a sense of control over their personal destiny. Self-esteem was enhanced with these measures, permitting them to deal assertively with fellow candidates and with members of the transplant team. Being fit, a state achieved through diet, exercise, and compliance with medications, promoted a positive self-image in what could conceivable be viewed as a very sick body. This ability to develop a positive self-image was very important and was central to the informant's self concept and perceptions of self-esteem. Attendance at clinic assured that the physiological needs were met, and compliance with medical regimens promoted feelings of security and safety. Anxiety was, in some way, reduced through the development of predictable patterns of behaviour. This was reinforced by what the informants perceived as predictable patterns of management of the candidates by physicians and transplant team members.

By focusing their behaviour on the elements that they could control (diet, medication, exercise, and rest), by establishing a routine to their lives, and by setting realistic short-term goals, candidates were able to reappraise their situation and to find predictabilities in their environment, which assisted them in developing strategies to cope with the stress of waiting.

As they moved into the Being Ready phase of waiting, transplant candidates and their support persons began to identify with other members of their group. They developed a specific identity and described themselves as members of a specific sub-culture. In describing themselves as different from or as members of a special group, they perceived that their social support and feelings of belongingness would come from the membership. This, in turn, helped to lessen the feelings of loss of identity and belongingness which were natural outcomes of the dislocation to the transplant centre. For the candidates, loss of role-function was a common factor and perhaps in this situation which was shared by other candidates the role loss was de-emphasized or seen as a norm.

Thinking and planning for the future was a distinct characteristic of the Being Ready phase of waiting. Thinking about the future took place in the presence of hope. It was in direct contrast to the ambivalence felt toward the transplantation process expressed by candidates during the Getting Ready phase of waiting. Lynch (1965) states that hope is energized by a belief in the possibility of getting somewhere and in the possibility of reaching goals. The 'somewhere' and the goals can be as many as the wishes and things we propose to ourselves. Miller (1983) suggests that hope also provides dynamism for the spirit, thereby saving people from apathetic inaction.

Thinking and planning for the future are coping mechanisms which could only be brought into use during this phase of waiting, because they hinge on the physical state of well-being that had been achieved for the patient by the cardiologists (with the patient's cooperation). The presence of hope was very dependent on the health state of the candidates.

However, the researcher would suggest that in making such comments in reference to themselves as: "I expect to be the best transplant," "live the longest," or "be out of the hospital the soonest," candidates were, in fact, developing a health trajectory path as described by Corbin and Strauss (1984), which included goal-attainment and self-actualization. The course of chronic illness has been conceptualized as a trajectory path because of its linear movement.

All of the subjects in this study had suffered from progressively deteriorating heart disease. They could be described as being in the end stages of chronic illness and, consequently, both they and their support persons had involved themselves in its management. Both parties had experienced the downhill course of the candidate's heart disease and welcomed the opportunity to be hopeful.

The On Hold stage of waiting, triggered by deteriorating health, was accentuated by passing time and signalled by a return to pre-acceptance anxiety, ambivalence about the surgery, and depression expressed in feelings of hopelessness and loss of a sense of self-worth. During this stage of waiting, candidates and support persons saw their well-established routines deteriorate. They were unable to associate declining health with predictable hospital admissions. Each admission seemed a surprise, and the hospitalizations became sources of anxiety and symbols that time was running out. It was during these admissions that candidates might receive ambivalent care from nursing and medical staff. While some staff were able to support the candidate and support persons in these periods of despair, others were unable to engender a spirit of hopefulness. Because hope was difficult to sustain in patients and because it was difficult for the health care team to be consistent in their approach in managing the candidates and support persons, these findings would suggest a further avenue for study and a need for education of health care team members.

Implications for Practice

There are many implications for nursing practice that can be drawn from the findings of this study. While some of these findings are of specific interest to nursing, they have general applicability to all health care providers with an interest in the management of transplantation candidates.

An awareness of the existence of a transplantation culture, a knowledge of the meaning of the waiting process, and an understanding of the adaptation mechanisms used by transplant candidates and their support persons offer a conceptual framework against which to direct both the art and the science of nursing.

All informants in this study were overwhelmed by the implications of the need for transplantation. All were able to identify and articulate their experiences and needs. Each informant was able to describe patterns of practices and systems of beliefs which indicated that an adaptation mechanism was in place to assist them in

coping with the uncertainties of transplantation. Nurses have a responsibility to familiarize themselves with this process of adaptation, to recognize the cues that are provided by the candidates and support persons, and to nurture these behaviours, in order to assist the patient in sustaining hope and in managing the uncertainties of transplantation.

The most difficult phase of waiting was seen as being a time when candidates and support persons were unable to sustain hope, due to frequent changes in what they perceived to be their normal routines and perceptions that they were the recipients of ambivalent caring on the part of the transplant team hospital-based care givers. Nurses, as primary care givers, are in a position to most directly influence and support positive care giving attitudes. Sensitivity to the special needs of this clientele should provide an impetus for discussion, when designing individual care plans.

It should likewise be the responsibility of transplant centres to provide the background education for personnel who care for these patients. This educational information should be up-to-date, and incorporate theoretical as well as practical management perspectives. For example, this program should discuss strategies for inspiring hope in patients.

Hope is essential in sustaining candidates and support persons throughout their waiting period. This area of expertise in nursing appears to be poorly developed or understood from the practice perspective. "Hope doesn't spring eternal - sometimes it has to be carefully mined and channeled" (Miller, 1985). Nurses and other health care professionals could benefit from theoretical information sharing and discussions surrounding this topic.

A concept central to the core of nursing care planning has been the individualizing of patient management. Care should be taken in the assessment of individual coping strategies. An awareness of these effective mechanisms would permit the nurse to support these efforts with appropriate timing of the interventions, rather than through a generalized approach based on assumptions of anxiety, fear of dying, and feelings of hopelessness.

Implications for Research

This qualitative study has closely examined the meaning of waiting for transplant candidates and their support persons. Waiting has been identified as an adaptive process which develops, progresses, and regresses over the time period prior to transplantation. While the adaptive mechanisms are highly individual and dependent on previous coping skills, they also appear as general (common) overt behaviours which can be interpreted by transplant management personnel. These behaviours act as signal devices to indicate position on the waiting path trajectory and should trigger intervention or non-intervention responses on the part of the care givers. Several questions for future research have thus been raised. First and foremost: are these findings repeatable with subjects who are in a similar position? Secondly, do these findings replicate themselves for any group of patients who must manage uncertainty, unpredictability, and a prolonged waiting period prior to treatment? Finally, what exactly is the meaning of hope and how does nursing nourish and sustain this vital ingredient in transplant candidates and their support persons?

Summary

This study explored transplant candidate and support person perceptions of the effects of waiting on themselves and each other. Existing research on this topic was limited and almost absent. The belief systems and behavioural adaptations of informants were examined from an emic perspective. Waiting was seen to be an adaptive process which could be described verbally and which possessed specific characteristics at each stage along the way.

The findings of this study would indicate that waiting is a process to which transplant candidates and their support persons make behavioural adaptations in order to manage the associated stresses of coping with uncertainty. The meaning that this time period has for the informants is influenced by the transplant candidate's health state, by the ability of the candidate and support person to maintain a high morale, and by their combined efforts to establish a degree of normalcy in their day-to-day living.

In establishing a daily routine which incorporated the transplant clinic, the frequent hospitalizations and the dislocation to the transplant centre, transplant candidates and their support persons were able to recover a sense of control in the management of day-to-day living. They developed a system of beliefs and practices which assisted them with waiting and helped identify them as belonging to a specific culture.

In developing a cultural identity, transplant candidates and support persons regained a feeling of being in control of their lives. In addition, they were provided with an additional mechanism which assisted them with further behavioural adaptations necessary for the management of the uncertainty of the waiting period.

Likewise, the findings in this study indicate that the informants are reliable reporters of their perceptions and that they are able to provide verbal clues as to their adaptation to the waiting process. There are distinct and prolonged time periods when very little intervention of a supportive nature is required from transplant team members. There are other discretely identifiable periods of time where consistent and predictable support from care givers is required.

The original question that guided this research was: What are the experiences of transplant candidates and their support person as they wait for a heart transplant? The answers to this question have been discussed throughout this thesis and included the stages to the waiting process, and the behavioural adaptations made by candidates and support persons as they experience this process.

REFERENCES

Aamodt, A.M. (1981). Neighbouring: Discovering support systems among Norwegian-American women. In D. Messerschmidt (Ed.), Anthropologists at Home in North America: Methods and Issues in the Study of One's Own Society (pp. 133-149). New York: Cambridge University Press.

Aamodt, A.M. (1982). Examining ethnography for nurse researchers. Western Journal of Nursing Research, 4, 209-221.

Aamodt, A.M. (1983). Problems in doing nursing research: developing a criteria for evaluating qualitative research. Western Journal of Nursing Research, 5, 398-402.

Aamodt, A.M. (1989). Ethnography and epistemology: Generating nursing theory. In J.M. Morse (Ed.), Qualitative Nursing Research. A Contemporary Dialogue. (pp. 29-40) Rockville, MD: Aspen.

Allender, J., Shisslak, C., Kaszniak, A., & Copeland, J. (1983). Stages of psychological adjustment associated with heart transplantation. Heart Transplantation, 11, 228-231.

Averill, J.R. (1973). Personal control over aversive stimuli and its relationship to stress. Psychological Bulletin, 80, 286-303.

Budner, S. (1962). Intolerance of ambiguity as a personality variable. _Journal of Personality_, _30_, 29-50.

Canadian Organ Replacement Register, Non-Renal Transplant Data (1989). Government of Canada.

Christopherson, L.K., & Lunde, D.T. (1971). Selection of cardiac transplant recipients and their subsequent psychosocial adjustment. _Seminars in Psychiatry_, _3_, 36.

Christopherson, L.K. (1976). Psychological and Social Aspects of Cardiac Transplantation. _British Journal of Nursing_, _149_, 34-36.

Christopherson, L.K. (1979). Cardiac transplantation: need for patient counselling. _Nursing Mirror_, _149_, 34.

Christopherson, L.K. (1987). Cardiac transplantation: A psychological perspective. _Circulation_, _75_, 57-62.

Comaroff, J., & Maguire, P. (1981). Ambiguity and the search for meaning: Childhood leukemia in the modern clinical context. _Social Science and Medicine_, _15b_, 115-123.

Copeland, J.G. (1984). Address to the 4th International Society for Heart Transplantation meeting.

Corbin, J.M., & Strauss, A.L. (1984). Collaboration: Couples Working Together to Manage Chronic Illness. Image: The Journal of Nursing Scholarship, 4, 109-115.

Davis, D. (1986). The meaning of menopause in a Newfoundland fishing village. Culture, Medicine, and Psychiatry, 10, 73-94.

Denzin, N.K. (1970). The Research Act: A Theoretical Introduction to Sociological Methods. Chicago: Aldine.

Diers, D. (1979). Research in Nursing Practice. Philadelphia; J.B. Lippincott.

Evans, R.W., Manninen, D.L., Vercast. T.D., Garrison, L.P., Jr., Yagi, J., Merriken, K., Jonsen, A.R., et al. (1984). The National Heart Transplantation Study: Final Report. Seattle: Battelle Human Affairs Research Centres.

Field, P.A. (1983). An ethnography: Four public health nurses' perspectives of nursing. Journal of Advanced Nursing, 8, 3-12.

Field, P.A., & Morse, J.M. (1985). Nursing Research: The Application of Qualitative Approaches. London; Croom Helm.

Freeman, A.M., Watts, D., & Karp, R. (1984). Evaluation of cardiac transplant candidates: Preliminary observations. Psychosomatics, 25(3), 197-207.

Fujita, M. (1985). Modes of waiting. Phenomenology + Pedagogy. 3, 107-115.

Guba, E.G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. Educational Communication and Technology Journal, 29, 75-92.

Guba, E.G., & Lincoln, Y.S. (1981). Effective Evaluation. San Francisco; Jossy-Bass.

Hammersly, M., & Atkinson, P. (1983). Ethnography: Principles in Practice. London; Tavistock.

Hecker, J.E., Norvell, N., & Hills, H. (1989) . Psychological assessment of candidates for heart transplantation: Toward a normative data base. The Journal Of Heart Transplantation, 8, Mar/Apr.,171-176.

Kay, M.A. (1982). Writing an ethnography of birth. In M.A. Kay (Ed.), Anthropology of Human Birth (pp 1-24). Philadelphia: F.A. Davis Co.

Kraft, I. (1971). Psychiatric complications of cardiac transplantation. Seminars in Psychiatry, 3, 58-69.

Kuhn, W.F., Brennan, A.F., Lacefield, P.K., Brohm, J., Skelton, V.D., & Gray, L.A. (1990). Psychiatric distress during stages of the heart transplant protocol. The Journal of Heart Transplantation, 9, 25-29.

Kuhn, W.F., Davis, M.H., & Lippman, S.B. (1988). Emotional adjustment to cardiac transplantation. General Hospital Psychiatry, 10: 108-113.

Lazarus, R.S., & Folkman, S. (1984). Stress, Appraisal, and Coping. New York: Springer.

Leininger, M. (1985). Southern rural black and white American lifeways with focus on care and health phenomena. In M. Leininger (Ed.), Qualitative Research Methods in Nursing (pp. 195-216). Orlando, FL: Grune & Stratton.

Lincoln, Y.S. & Guba, E.G. (1985). Naturalistic Enquiry. Beverly Hills, CA: Sage Publications.

Lunde, D. (1969). Psychiatric complications of heart transplants. American Journal of Psychiatry, 126, 368-373.

Lynch, W.F. (1965). Images of Hope, Baltimore: Helicon Press.

Mai, F.M., & Burley, J. (1985). Psychological aspects of heart transplantation. Transplantation Today, 16-21.

Manninen, D.L., & Evans, R.W. (1985). Effects of heart transplantation on family relations. Transplantation/Implantation Today, 44-46.

McAleer, M.J., Copeland, J., Fuller, J., & Copeland, J.G. (1985). Psychological aspects of heart transplantation. Heart Transplantation, 4,(2), 232-233.

McCall, G.J., & Simmons, J.L. (1969). The problem indicators participant observation research. In G.J. McCall & J.L. Simmons (Eds.) Issues in Participant Observation: A Text and Reader. Reading, Mass: Addison Wesley.

McIntosh, J. (1974). Processes of communication, information seeking and control associated with cancer: A selective review of the literature. Social Science and Medicine, 8, 167-187.

Miller, J.F. (1983). Coping with chronic illness. In J.F. Miller (Ed.) Coping With Chronic Illness: Overcoming Powerlessness, Philadelphia: F.A. Davis.

Miller, J.F. (1985). Inspiring hope. American Journal of Nursing, 85, 22-35.

Mishel, J.H. (1984). Perceived uncertainty and stress in illness. Research in Nursing and Health, 7, 163-171.

Mishel, M.H., Hostetter, T., King, B., & Graham, V. (1984). Predictors of psychological adjustment in patients newly diagnosed with gynecological cancer. Cancer Nursing, 7, 291-299.

Mishel, M.H., & Murdaugh, C.L. (1987). Family adjustment to heart transplantation: Redesigning the dream. Nursing Research, 36,(6), 332-338.

Murdock, G. (1971). Outline of Cultural Materials, Human Relations Area Files Press, New Haven, CN.

O'Brien, V. (1985). Psychological and social aspects of heart transplantation. Heart Transplantation, 4, 229-231.

Reinharz, S., (1979). On Becoming a Social Scientist. San Francisco: Jossey Bass.

Sandelowski, M. (1986). The problem of rigour in qualitative research. Advances in Nursing Science, 8, 27-37.

Spradley, J. (1970). You Owe Yourself a Drunk. Boston: Little, Brown.

Spradley, J.P., & McCurdy, D.W. (1972). The Cultural Experience: Ethnography in a Complex Society. Chicago: Science Research Associates.

Spradley, J.P. (1979). The Ethnographic Interview. New York: Holt, Rinehart, & Winston.

Spradley, J. (1980). The Cocktail Waitress: Woman's Work In a Man's Land. New York: John Wiley and Sons.

Suls, J., & Mullen, B. (1981). Life events, perceived control and illness: The role of uncertainty. Journal of Human Stress, 3, 32-35.

Van Maanen, J. (1983). Qualitative Methodology. Beverly HIlls: Sage.

Wax, R. H. (1971). Doing Fieldwork; Warnings and Advice. Chicago: University of Chicago Press.

APPENDIX A

Selection criteria for heart transplantation program candidates

For Inclusion:

1. Age - 0 - 70 years.
2. End Stage Heart Disease - New York Heart Association - risk class IV: patients who are unable to carry out any physical activity without discomfort. Symptoms of cardiac insufficiency or of angina may be present at rest and the discomfort increases with any physical activity.

   Exception - patients with intractable ventricular arrhythmias or with left ventricular heart failure caused by atherosclerosis may not yet be in risk class IV.
3. Life expectancy is estimated to be weeks or months with less than a 10% survival at the end of 1 year.
4. Agreement that previous medical or surgical therapy has been optimal and that no other therapy except transplantation offers realistic expectation of a functional improvement.
5. Absence of sepsis, irreversible liver damage, and other disease processes (for example: positive VDRL serology or HIV serology that might cause an early death or be seriously aggravated by transplantation).
6. Strong family support.
7. Demonstrates a strong will to live.
8. Demonstrates satisfactory intelligence, motivation, and compliance with past medical regimens.
9. Demonstrates a realistic understanding of what transplantation can do for candidate as well as the complications of the procedure.
12. Adequate financial resources.

For Exclusion:

1. Severe pulmonary hypertension - pressures greater than 6-8 Wood units.
2. Severe irreversible liver or renal dysfunction.
3. Active systemic infection.
4. Other systemic illness present.
5. Recent (less than 6 weeks) or unresolved pulmonary infarct.
6. Severe peripheral or cerebral vascular disease.
7. Active peptic ulcer disease.
8. History of significant behaviour problems (confirmed with a psychiatric consult), frankly psychotic, alcohol or drug abuse.

APPENDIX B

The University of Alberta

Informed Consent Form

(transplant support person)

Project Title: Perceptions of the experiences of waiting on transplant candidates and their families

Researcher:	Linda M. Buzzell Faculty of Nursing, University of Alberta, Edmonton, Alberta T6G 2B7 Phone: (403) 492 6847	Supervisor: Dr. M. Allen, Faculty of Nursing, University of Alberta, Edmonton, Alberta T6G 2B7 Phone: (403) 492 6411

The purpose of this research is to look at the transplant candidates and their support person's views of the effect of waiting on themselves and their families. If you take part in this study, you will do the following things. You will be interviewed on three occasions. These will be once when the person you are supporting is accepted as a candidate for transplantation, once while he or she is waiting for surgery, and once about two weeks following discharge from hospital after surgery. If your candidate is called for surgery before the second interview takes place then you will be interviewed just before the surgery is done. Each interview will take about 45 minutes to an hour.

One time you will interviewed together with your candidate. All other interviews will be with you alone. You will also be asked to keep a diary. In the diary you are to write down your thoughts, feelings and concerns related to the waiting periods. The total time for all the interviews will be about 3.5-4 hours. The amount of time to write your diary will be about 10-30 min. each day that you feel able to write in it. All interviews will be tape recorded and then typed. To make sure that no one knows which typed sheets are yours, a number will be put on these sheets instead of your name. The number and your name will be locked up. This will be destroyed once the study is completed. Any names that are said on tapes will not be typed. Information about you or your family will be disguised in all reports of the findings.

THIS IS TO CERTIFY THAT I ____________________________ agree to participate in this study. I understand that there will be no risks to me if I take part in the study and that participation in the study will not influence the chances of my candidate obtaining a transplant. I know that I will be interviewed and observed. These interviews will be tape recorded and the observations noted.

I understand that there will be no information that will identify my family in any published reports of this research. I understand that I may review the typed sheets from the interviews. I know that the diary will become the property of the researcher and will not be shared with other family members.

I understand that the typed material from this study may be used in future studies. If this is done, the research will first have to be approved by an ethics committee. I also understand that parts of the transcripts may be shared with students and staff nurses so that they will better understand what it is like to wait for a transplant. The data will be destroyed when it is no longer required for research purposes.

I also understand that I may withdraw from this study at any time, without consequence, by telling the researcher. I give consent for excerpts of the transcript to be quoted, even though portions may be excluded at my request. Questions about the research have been encouraged and my questions have been answered to my satisfaction.

I have received a copy of this consent form.

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Signature Witness Date

I would like a summary of the research findings at the conclusion of the study.

Name: ____________________
Address: ____________________
____
____

APPENDIX C

The University of Alberta

Informed Consent Form

(transplant candidate)

Project Title: Perceptions of the experience of waiting on transplant candidates and their families.

Researcher: Linda M. Buzzell	**Supervisor:** Dr. M. Allen,
Faculty of Nursing,	Faculty of Nursing,
University of Alberta,	University of Alberta,
Edmonton, Alberta	Edmonton, Alberta
T6G 2B7	T6G 2B7
Phone: (403) 492 6847	Phone: (403) 492 6411

The purpose of this study is to look at the transplant candidates and their support person's views of the effect of waiting on themselves and their families. If you take part in this study, you will do the following things. You will be interviewed and observed on three occasions. These will be once when you are accepted as a candidate for a heart transplant, once while you are waiting for your surgery, and once about two weeks following your discharge from hospital after surgery. If you are called for your surgery before the second interview takes place then you will be interviewed just before your surgery. Each interview will take about 45 minutes to an hour.

One time you will interviewed together with your support person. All other interviews will be with you alone. You will also be asked to keep a diary. In the diary you are to write down your thoughts, feelings and concerns related to the waiting periods. The total time for all the interviews will be about 3.5-4 hours. The amount of time to write your diary will be about 10-30 min. each day that you feel able to write in it. All interviews will be tape recorded and then typed. To make sure that no one knows which typed sheets are yours, a number will be put on these sheets instead of your name. The number and your name will be locked up. This will be destroyed once the study is completed. Any names that are said on tapes will not be typed. Information about you or your family will be disguised in all reports of the findings.

THIS IS TO CERTIFY THAT I ____________________________ agree to participate in this study. I understand that there will be no risks to me if I take part in the study and that participation in the study will not influence my chance of obtaining a transplant. I know that I will be interviewed and observed. These interviews will be tape recorded and the observations noted. I allow the researcher to look at my medical records for observations made about my response to my conditions and my care.

I understand that there will be no information that will identify my family in any published reports of this research. I understand that I may review the typed sheets from the interviews. I know that the diary will become the property of the researcher and will not be shared with other family members.

I understand that the typed material from this study may be used in future studies. If this is done, the research will first have to be approved by an ethics committee. I also understand that parts of the transcripts may be shared with students and staff nurses so that they will better understand what it is like to wait for a transplant. The data will be destroyed when it is no longer required for research purposes.

I also understand that I may withdraw from this study at any time, without consequence, by telling the researcher. I give consent for excerpts of the transcript to be quoted, even though portions may be excluded at my request. Questions about the research have been encouraged and my questions have been answered to my satisfaction.

I have received a copy of this consent form.

__________________ __________________

Signature Witness Date

I would like a summary of the research findings at the conclusion of the study.

Name: ____________________
Address: ____________________
____
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APPENDIX D
EXAMPLES OF QUESTIONS

Descriptive Questions

Descriptive questions allow the ethnographer to explore the setting, elicit a large sample of utterances in the informant's native language, and encourage an informant to talk about a particular cultural scene (Spradley 1979).

Can you describe what the experience of waiting for a transplant has been like for you?

Tell me what you mean by keeping busy?

Structural Questions

Structural questions are asked concurrently with descriptive questions. They are alternated in the interview with the descriptive questions, to compliment, rather than replace, descriptive questions. These questions often require an explanation and move the ethnographer further away from friendly conversation (Spradley, 1979).

When you talked about keeping busy I wasn't certain what that involved. What do you usually do to pass the time?

You say that waiting isn't the same now as it was before you settled in here. Can you tell me how it is different?

Contrast Questions

Contrast questions assist the ethnographer in discovering and restricting each subset of terms within within a contrast set.

We have talked about ambivalence and what it means to you. Can you tell me where it appears and when it does? Can you tell me when it does not appear and why not?

How has being down differed now in the On Hold phase of waiting from when you were waiting to be accepted?

APPENDIX E

Information for prospective research subjects

Project Title: Perceptions of the experience of waiting on transplant candidates and their families

Researcher:	Supervisor:
Linda M. Buzzell	Dr. M. Allen
Faculty of Nursing,	Faculty of Nursing,
University of Alberta,	University of Alberta,
Edmonton, Alberta	Edmonton, Alberta
T6G 2B7	T6G 2B7
Phone: (403) 492 6847	Phone: (403) 492 6411

The purpose of this study is to look at transplant candidates and their support person's views of the effects of waiting on themselves or their families. If we know more about what it is like for you to wait for your transplant, it will help in the future care of patients. If you take part in this study you will talk with the researcher three times. These will be at the time of your acceptance as a candidate for your transplant, while you are waiting for your surgery, and about two weeks following your discharge from hospital. One time, you will be interviewed together with your support person. All other interviews will be with you alone. If you are called for your surgery before the second interview takes place, you will be interviewed just before surgery. You will also be asked to keep a diary about your experience.

It is important to know that, if you take part in this research, you are, in NO WAY influencing your chances for a transplant. If you do not take part, or withdraw from the study, you are in NO WAY telling us that you do not wish to have a transplant. This will not affect your spot on the transplant list. The researcher has worked with transplant patients for many years. She knows that the ability or interest to maintain a daily diary may not be upheld. If you can't keep a daily diary, you may still take part in the study. All information will be kept private, between you and the researcher.

The daily diaries would be shared with the researcher.