UNIVERSITY OF ALBERTA

BECOMING AN ISLET CELL ALLOTRANSPLANT RECIPIENT

by

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in partial fulfillment of the requirements for the degree of
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DEDICATION

This thesis is dedicated to the most special people in my life:

-To my husband Greg who has been dedicated to my desire to accomplish this goal during some very trying times in our life. His love and support never faltered and were much needed.

-To my two wonderful and dedicated children, who, at one and a half and three, knew the words "proposal" and "thesis". Their happy smiles and great enthusiasm for everything gave me the energy to perservere.

-To my parents, and especially my mom, who sacrificed many hours and much energy to support me in achieving this goal. She has given me strength, motivation, self confidence, and endurance. She has always believed in me.

-To all my friends and family who have supported me and shown great interest in this endeavor, I can only say thank you from the bottom of my heart.

ABSTRACT

The purpose of this study was to describe what it was like becoming an islet cell allotransplant recipient. Using an exploratory-descriptive approach, unstructured tape recorded interviews were conducted with six islet cell recipients. Through ethnographic analysis, eight categories were found to describe the participants' experiences of becoming islet cell recipients. The categories included: (1) the context, (2) living with complications, (3) the decision, (4) post-transplantation, (5) benefits, bonuses, gifts, (6) doing it again, (7) ongoing concerns, and (8) effects on family and others, making it through.

The findings indicated that living with IDDM was an ongoing challenge that for these participants, resulted in diabetes related complications. Within the context of day to day living with diabetes, the decision to become a recipient was swift and for the most part unwavering. There were many benefits which enhanced the quality of the participant's lives. The most significant benefit was the ability to successfully manage blood glucose levels, which was in and of itself freedom giving. The benefits also increased their hope and ability to cope. Some have since seen deterioration of their health but most would not hesitate to go through the islet cell experience again. Family and others were also positively affected.

This research can help nurses and other health care professionals be more aware of the impact that this experience has on recipients and in recognizing this, be able to teach others about the experience. It was identified that support and encouragement, especially from health care professionals, was important throughout life as clients cope with diabetes.

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Chapter 1: INTRODUCTION

Insulin dependent diabetes mellitus (IDDM) is a serious disease usually developing in early to mid childhood. IDDM is controlled by insulin injections, restrictive diet, exercise, and a variety of life management skills. These controls, however, can be difficult to adhere to, especially for children, and the long term effects of diabetes, controlled or uncontrolled, can lead to serious complications including: renal failure, blindness, neurological problems related to altered sensation, and circulatory disorders, including heart disease and peripheral vascular disease. Many of the complications associated with diabetes are difficult to treat or manage, often resulting in disability, pain, and the need for long term medical treatment. Care of persons with diabetes-related complications is often costly and frequently has poor results or outcomes. Although there have been many improvements in the care and treatment of diabetes and diabetes related complications since the discovery of insulin 75 years ago, no cure has been found. The introduction of islet cell allotransplantation is a new and exciting frontier for the treatment and possible cure of IDDM. It is important, however, to understand how new technology, such as islet cell allotransplantation, has benefitted persons receiving the procedure. One thing that can help us understand the benefits of new technology is to ensure that recipients value the process and outcome, and that the outcome leads to a positive effect on the recipient's health.

My interest in this area stems from my clinical experience of working with many people with diabetes who fear the development of complications, or who are presently living with complications associated with diabetes. Some live in pain due to neuropathies or cardiac conditions, others live with blindness due to retinopathy, and still others live connected to a dialysis machine two or more times a week or to peritoneal dialysis four times a day due to renal failure. Many have more than one complication with which to contend. Some have expressed a sense of hopelessness at the prospect of having diabetes for the rest of their lives. Frequently, these patients ask about ways to prevent complications and about steps being made towards a cure for this disease. Any potential treatment brings hope to these patients.

In islet cell allotransplantation, human islet cells are transplanted from a donor into a patient with IDDM. At present the recipients must receive an organ transplant (usually a kidney) at the same time as the islet cells, or have a stable organ transplant in place. Since this procedure is still considered investigational, only those recipients already requiring immunosuppression are eligible for islet cell allotransplantation. Due to strict criteria and the need for ongoing funding, there have only been ten islet cell allotransplants done in Canada: three in London, Ontario (through a program from St. Louis, Missouri,) and seven at the University of Alberta Hospitals in Edmonton, Alberta, Canada. There have only been 260 adult islet allografts in IDDM recipients world wide (Ricordi, 1996).

Of those recipients, some have been completely off insulin for a period of time, and many have enjoyed euglycemia and the benefits of controlled diabetes. Still others have experienced relief, stabilization, and regression of complications and some have experienced the loss of the islet cell allotransplant, and/or have lost the other transplant (in most cases this is a kidney). No research has investigated what these changes have meant to these recipients.

As one might expect at this point, little is known about the short and long term benefits of this procedure. There is extensive follow-up in which several parameters associated with transplantation are measured. To date most of the literature is related to patient outcomes focusing on observable or measurable successes or failures of the transplantation. However, what is missing in the measurements is whether this procedure is seen as valuable by the recipient. Currently, none of the researchers in this area have recorded the recipients' experiences, expectations, outcomes, or how they view their lives post-transplant. Understanding the experience from the recipient's point of view will help identify the merit or value of this procedure.

Purpose of the Study

The expectations and experiences of islet cell allotransplant recipients must be understood in order to provide the best care possible and to direct further development and research in this area. Thus, the purpose of this qualitative study was to gain a deeper understanding of the experience of becoming an islet cell allotransplant recipient, and how that experience has affected the lives of the recipients.

Implications for Nursing

A better understanding of the patient's experience can help guide the preparation, teaching, and follow-up of other islet cell allotransplant recipients. The research may also identify effective techniques to support the patient and the family and it may increase the nurse's awareness of special concerns. The opportunity to relay other patients' experiences to a potential recipient may also help to alleviate some of the fear and anxiety that may occur when making this kind of health care decision.

Chapter 2: OVERVIEW OF THE LITERATURE

A review of the literature was done to provide a better understanding of the islet cell allotransplant procedure, what has been accomplished to this point, and to critically review research in this and related areas. There was very little relevant literature due to the recent development of islet cell allotransplantation. The first reported animal study only dates back to 1972 (Ballinger & Lacy, 1972) and the first human islet cell allotransplant in the world only dates back to 1974 (Warnock & Rajotte, 1992).

Much of the literature to date focuses on the process of islet cell harvesting, preservation, transplant procedures, and immunosuppression (Warnock, Kneteman, Rajotte, 1991; Warnock, Ellis, Rajotte, Dawidson, Baekkeskov, & Egebjerg, 1988; Warnock, Rajotte, Evans, Ellis, DeGroot & Dawidson, 1987; Warnock & Rajotte, 1988, 1992; Scharp, et al., 1991). Patient-centered information focuses on demographics, diabetes-related complications, glucose and HgbA1C levels post-transplantation, and any changes in presenting complications (Warnock, Kneteman, Ryan, Seelis, Rabinovitch & Rajotte, 1991; Warnock, Kneteman, Ryan, Rabinovitch & Rajotte, 1992). Potential outcome measures of success for pancreatic and islet cell allotransplants include reversal or prevention of diabetes-related complications, euglycemia, insulin independence (Scheinkestel, 1988), and improved quality of life (Morse, 1988; Nakache, Tyden, Groth, 1989; Nathan, Fogel, Norman, Russell, Tolkoff-Rubin, Delmonico, Auchincloss, Camuso, & Cosimi, 1991; Zehrer & Gross, 1990). Although there are some promising results based on these outcome measures they provide data which do not define or describe the patients' experience.

A few quality of life studies related to pancreatic transplants have been done using a quantitative approach. Gross and Zehrer (1992) found that the expectation of becoming "normal" following pancreatic transplantation may have altered the recipient's perceptions of their quality of life, but this speculation could not be confirmed. The researchers also thought that small improvements in health status may not have been identified due to the tools utilized. One other consideration is that most of these recipients received pancreatic and renal transplants. This makes it difficult to determine if quality of life changes are due solely to the pancreatic transplant, the renal transplant, or due to the cumulative impact of both transplants. Although a qualitative study may not be able to completely separate the islet cell allotransplant experience from the kidney transplant experience, it can allow the recipient to focus on the changes that have occurred in relation to diabetes and the associated complications of the disease, as well as the daily regimen required to control the disease. In this and other studies (Nakache, Tyden & Groth, 1989; Voruganti & Sells, 1989) quality of life has been equated with the patients' perceptions of health and the ability to function in daily life. The studies did not provide an opportunity for the participants to state their own definition of quality of life and therefore the results may provide misleading information. No research has been done that examines the patients' point of view of their experiences, expectations, or changes in quality of life related to the islet cell allotransplant.

In studies that have examined recipient experiences with other organ transplants, the literature reflects the physical outcomes, the psychological effects, and the effects on the family or significant other(s). Each of the different transplant procedures has identifiable benefits for the recipients and, in most cases, for the families. Most of the studies also refer to quality of life as a measure of improvement in the physical, mental, and /or social condition of the patient post-transplant. Spitzer (1987) suggested that in order to assess quality of life, a minimum of five attributes needed to be considered. These attributes included: physical functioning, social functioning, emotional and mental status, burden of symptoms, and the perception of a sense of well-being. The studies identified in the literature address some, but in most cases, not all of the above attributes.

Essentially, it was found that other organ transplant experiences were seen, overall, as a positive experience and one which made a difference in the recipients' lives. Mai, McKenzie and Kostuk (1990), found in a psychosocial evaluation of heart transplant patients that physical activity, return to occupation, and sexual activity had improved for these recipients as had their overall quality of life. Craven, Bright, and Dear (1990), found in their study of lung transplant recipients that most of the participants reported high satisfaction with physical and emotional well-being. Even for those who did not achieve the outcome they desired, they were much more satisfied with their lives than they were previous to the transplant. Most of the studies used lists or scales to measure the experiences and benefits of the transplant experiences. Some qualitative work has been done in this area however, which has allowed recipients to describe their own experiences and detail the benefits and concerns associated with the transplant. As Sensky and Catalan (1992) stated, "to a patient, an illness is an experience not easily reduced to a list of variables measured in the laboratory or clinic" (p. 1109). Meeberg (1992) in her study on living with a liver transplant, and Wainwright (1995) in his study on becoming a liver transplant recipient, found that the experiences of living with a liver transplant were overall very positive, but required an adjustment to the new level of health and to new roles that they could now assume or reassume. Both studies found that recipients were very appreciative of the donor family and expressed a desire to help others.

The benefits of these experiences were tempered however, by ongoing concerns related to rejection of the transplant, repeated hospitalizations, possible infection, effects of immunosuppressive drugs, constant monitoring, uncertainty about the future, and body image (Beer, 1995; Frey, 1990; Hayward, Kish, Frey, Kirchner, Carr, & Wolfe, 1989; House & Thompson, 1988; Juneau, 1995; White, Ketefian, Starr & Voepel-Lewis, 1990). House and Thompson (1988) also found that initial euphoria about receiving an organ could lead to anxiety and depression if problems began to develop. Overall, the findings of studies which look at the transplant experience of the recipient have identified positive outcomes tempered by some ongoing concerns. Though all of the studies contributed information about transplantation experiences, the literature that provided the greatest detail came from qualitative work. It was from this research that specific concerns about the experience of becoming an islet cell allotransplant recipient were identified. There was strong acknowledgement that further research of transplant experiences was necessary to further develop the programs and to better understand the care and needs of the recipients and their families.

Research Questions

The research questions that will guide this study include: What is it like becoming an islet cell allotransplant recipient? How has islet cell allotransplantation affected the recipient's life?

Chapter 3: METHODS

As Field and Morse (1985) state, "qualitative methods should be used when there is little known about a domain, when the investigator suspects that the present knowledge or theories may be biased, or when the research question pertains to understanding or describing a particular phenomenon or event about which little is known" (p. 11). As evident from the literature review, little is known about this research topic. Therefore, a qualitative exploratory descriptive research approach was used to answer the research questions. This provided an initial inquiry into the phenomena (Field & Morse, 1985) and provided insight into human behavior and the meaning of that behavior from the individuals perspective (Aamodt, 1982).

Sample

Purposeful sampling (Morse, 1991; Chenitz & Swanson, 1986) was used in this study. Informants were selected based on the needs of the study, not on preset variables or demographics. Informants who had an islet cell allotransplant were interviewed. Of the seven patients who received the islet cell allotransplant from the local program, four agreed to participate. Of those who did not participate, one was deceased, one had moved away and had not left a forwarding address, and one person had received a liver-islet transplant but rejected the liver soon after the transplants. Due to the small number of actual islet cell recipients, to gain adequate depth or saturation of data to answer the research question, these individuals would need to be approached directly and so were accessed through their doctor's office. The office staff was asked to send an introductory letter to each participant (Appendix B) outlining the study and how to find out more information if they wished to participate. They were asked to reply by a specific date if they did not wish to be contacted by the researcher or if they did not wish to participate in the study. It was assumed that participants were permitting the doctor to release their name and telephone number to the researcher if they did not contact the doctor's office staff by the stated date. The researcher then contacted each participant by telephone, explained the study, expectations, and inclusion criteria and then asked if they would be interested in participating. Appointments were set up for the participants and researcher to meet on a one on one basis and the participants then were required to read and sign a consent form. After the first informants were interviewed and the data were analyzed, it was important to the researcher to have one or two more participants who could possibly help strengthen the study by ensuring that the researcher was not missing anything in the data. Arrangements were made to interview one patient from another islet cell transplant program. Here again, the doctor from that program had his staff contact the participant and the patient verbally agreed to have me contact him directly by telephone. Arrangements were made to do a telephone interview. During this interview, a friend of this person identified herself as an islet cell allotransplant recipient and was interested in being interviewed as well. Subsequently, both participants from the second program were interviewed by telephone, providing the researcher with a total of six participants. The sample size was not determined by numbers of participants but by the quality of data obtained from each participant. The important aspect of this research was that the categories from the data came to the point where additional informants did not provide any new information, and I was able to answer the research questions (Morse, 1991).

Inclusion Criteria

To be included in the study, informants must have been:

1. an islet cell allotransplant recipient at least two months before being in the study,
2. able to speak and understand English, and
3. able to articulate their experiences.

The need to have the recipients at least two months past their transplant date was to allow for postoperative healing and a preliminary adjustment period. Each participant needed to be able to speak and understand English so that the researcher could understand what they were saying and so that transcription from audiotapes would be possible. The participants' ability to articulate their experiences was essential to obtain a clear and full understanding of their lives as islet cell allotransplant recipients.

All the participants in the study were asked if they wanted to receive a summary of the research results when the study was completed. All of the participants requested this information and provided the researcher with a mailing address.

Data Collection

Unstructured formal interviews, using a general interview guide, was the primary method of data collection (Chenitz & Swanson, 1986) (see appendix A). The first question asked of each participant was about living with diabetes before receiving the islet cell allotransplant. This was used to stimulate the conversation and set the focus of the interview, yet allow flexibility and openness for the participants to share their complete and unique experiences (Field & Morse, 1985). Other questions were asked to probe more deeply into these experiences.

Data analysis of the first interviews provided guidance in outlining the questions for the second interviews. These questions were prepared to allow for further exploration of the participants' experiences, to verify the data obtained in the first interviews, to contrast and compare the data from one participant to the other, and to explore ideas that may have been presented by the other participants but seemed to have potential significance to all the participants. These more in-depth questions were also used to verify concepts and themes. It was important to remain flexible and adjust questioning to the focus of the interview (Strauss & Corbin, 1990).

All informants were interviewed at least once. A second interview with four informants was required to complete the data collection and to clarify or validate the data. Interviews were 90 to 150 minutes long. Each participant wanted to continue the interview beyond the time frame originally agreed to, in order to share his or her story. All interviews were audiotaped and were conducted in person or by telephone as selected by the informants. The tapes were transcribed verbatim and reviewed for accuracy.

Fieldnotes were kept to supplement the interview data and were added to the typed transcripts. They were written soon after the interview to capture the setting, mood, and emotion of the interview. It was important to capture the salient points to ensure complete analysis of data.

It was recognized that my reflections about the data, informants, and the research process could influence the study if not dealt with appropriately. I therefore kept a research diary to allow for personal expression of beliefs, assumptions, and ideas. The diary also helped to increase my awareness of biases and made it easier to set these aside when analyzing data. The data were collected between February and August, 1996.

Data Analysis

Data analysis was done concurrently with data collection using ethnographic techniques. The analysis determined the direction of the study and the focus of the questions. All aspects of the data, including interviews, fieldnotes, and diary entries, were analyzed to provide a rich description of the experience of receiving an islet cell allotransplant.

Ethnographic analysis is a means of determining the parts, the relationship between those parts, and how they all come together to make a whole (Spradley, 1979). Data were manually analyzed by categorizing and comparing data, along with memoing and diagramming to identify concepts (Field & Morse, 1985) and themes.

Categorizing provides a means by which masses of raw data or symbols can be broken down into manageable parts. These categories can then be analyzed to discover relationships between these categories (Aamodt, 1982). Each paragraph and line of an interview was coded, representing ideas, themes, or concepts. These codes were compared and refined to form major categories. Data were then filed by these categories. The categories were substantiated in the interviews, transcripts, and fieldnotes. At first there were many categories representing the large amount of data, but with each subsequent interview, more specific categories began to emerge and several categories began to blend together to make one category. As categories became more defined, the data were compared to test the validity of the category and to determine if any information was missing, unclear, or miscoded. Categories were then compared to determine if they were distinct and contained either exclusive information or a story line. As data analysis continued it became evident that there were similarities and differences in the stories that the informants shared. By using more in-depth questioning, data was compared from one informant to another and also from one interview to the second interview with the same informant. Information shared by one informant provided questions to ask other informants. Then the additional responses were compared and contrasted to obtain a clear picture of the experiences. At this point it was evident that the categories were filled with deep, rich descriptions of the experiences, and that there were linkages between these categories.

Through the comparison of categories, themes began to emerge. Themes are a number of categories linked together into relationships and are assertions that have a high degree of generalizability (Spradley, 1979). Themes allowed for the story line to emerge that best described the experience of these six people.

Memoing and diagramming were done throughout data collection and analysis. This helped the researcher to remain objective while allowing themes to creatively evolve from the data. Memos allowed the researcher to reflect on events, and hypothesize about themes and relationships. Diagramming helped to give visual clarity to ideas that emerged and helped simplify difficult concepts or the connections between the concepts.

Credibility and Consistency

Complete and thorough data analysis is fundamental in identifying the deeper meaning in the informants' experience. The importance of rich thick data and achieving the point of saturation during analysis is fundamental to the credibility of the research.

"Truth value" or credibility is the measure of how well the researcher has captured and interpreted the informants' experiences (Sandelowski, 1986). Credibility in this study was enhanced by :

a) interviewing the informants more than once, to clarify and expand on data, and

b) maintaining a diary and stating personal biases, assumptions, and concerns to help decrease the risk of "going native" or "becoming so enmeshed with subjects that investigators have difficulty separating their own experiences from their subjects" (Sandelowski, 1986, p. 30).

In this study, the goal was to capture the life experiences of the informants including any variations so that the "audience views its findings as meaningful and applicable in terms of their own experience" (Sandelowski, 1986, p. 32).

Consistency or auditability provides a means of examining the repeatability of a study. Because a qualitative research project's means of data collection is unstructured or only semi-structured, repeatability may not be possible. The important factor here is whether or not someone else can follow what was done. If someone else can use the collected data, fieldnotes, memos, diary, situation, and so forth, and still come up with similar outcomes, or if someone else can follow the process of decision making during the study, then consistency can be established (Sandelowski, 1986). In order to ensure repeatability, a detailed description of how the study was done, including the interview guide (Appendix A) has been included. Categories determined from the data, as well as excepts from the interviews supporting those categories, are provided in the findings chapter. As well, data have been reviewed by my supervisor and another researcher from another discipline to ensure that the categories fit the data. This reinforced my findings and thus reinforces the repeatability of the study. Analyzing and reanalyzing the data also ensured accurate interpretation of the data and this was reconfirmed in subsequent interviews with the same participant.

Consistency was sought by providing a complete and detailed description of the research method including the data collection and data analysis processes. Coding procedures during analysis were followed and double coding was done by the researcher and her supervisor periodically, and especially at the beginning of the study, to compare results.

Credibility and consistency are essential to establishing rigor. It is important then, that these areas be evaluated throughout the study. This was achieved by comparing and contrasting data contained in interviews of different participants as well as data contained in interviews from the same participant. The responses were the same or similar between interviews from the same participant, and most often, participants agreed with each other or shared similar experiences. This provided validation that the statements were accurate when describing the experiences of the six participants. All aspects of the research procedure and any problems or concerns were discussed with committee members.

Ethical Considerations

Persons who have been islet cell allotransplant recipients were asked to participate in the study. Due to the small number of recipients (four to date) in the study area, it was thought that there may be some difficulty in obtaining an appropriate sample unless each person was approached directly.

Since each recipient is a patient of the same physician, access to these people was obtained through him. Two main ethical considerations arise from this approach. First, because they are patients, all information about them and their medical treatment is confidential and cannot be accessed without their permission. Thus, direct contact by the researcher would be a breach in confidentiality, unless prior permission had somehow been obtained. Secondly, the issue of having the physician approach these participants directly could be seen as coercion due to the physician-patient relationship that exists.

The approach proposed by the researcher to prevent breach of confidentiality and coercion but at the same time access the potential participants was to have the doctor's office staff send a letter of introduction (see appendix B) to the patients on my behalf, and have the participants contact me or my supervisor by telephone if they required further information, either in writing or on tape. They were also able to contact any of the people listed on their letter of introduction if they wished to participate and be contacted by the researcher, or if they wished not to participate.

Once a person was interested in participating, an information letter (see Appendix B1) along with an informed consent form (see Appendix C) was to be sent to the prospective participant. In some cases this was carried out, but in other cases the participant verbally asked to have the information letter and the consent form brought to the first meeting instead of having it mailed out. The participants had received a verbal description of the study and what would be expected of them if they chose to participate from the researcher on the telephone, and wanted to get on with the interviewing. Once the person decided to participate, an appointment for the initial interview was set up at a mutually convenient time and place. At the beginning of the interview, the participants were asked to review the information letter and a signed informed consent (see Appendix C) was obtained. Informed consent requires the person to be knowledgeable about the study, and have voluntarily decided to be in the study (Field & Morse, 1985). When a telephone interview was requested then a taped verbal consent was obtained.

A taped consent was obtained by first stating to the participant that the interview and consent would be taped. Then the interviewer read out the statement of consent, addressed any concerns or questions that the participant had, and then had the participant state their name and repeat the consent back to the researcher, which indicated that they were willing to be in the islet cell allotransplant study. The consent was taped on a separate tape from the interview(s).

Confidentiality

Due to the small number of potential informants and the close relationships they must have with the health care team, they are a particularly vulnerable group and it is important that confidentiality of data be maintained.

The researcher and transcriber were the only ones to hear the tapes. The thesis committee only had access to the transcribed data with names of participants removed. The tapes and transcripts were letter coded, so that only the researcher knew the identity of the person providing the information on each tape. All information known to the committee, transcriber, and researcher about the participants was held in strictest confidence. In no way were the informants subject to negative consequences from their participation.

All data, tapes, transcripts, consent forms, names, addresses, and telephone numbers of the informants are kept locked in a cabinet and only the researcher has a key. Consent forms will be kept for five years and will be kept separate from the raw data (Morse, 1991). Tapes and transcripts will be kept for the required seven years as set out by the university regulations (University Standards for the Protection of Human Research Participants, 1993). Tapes will be destroyed after that time. All identifying information will be shredded at the end of the study, except the consent forms, as further study may be undertaken with the raw data. Consent for secondary analysis will be obtained from the appropriate ethics committee if this is undertaken.

Anonymity

The informants' anonymity will be protected to the best of the researcher's ability. Each participant is only identified by a code letter. All quotations used in the findings section, will be identified by the assigned code letter at the end of the quotation and the participants are aware that quotations may also to used in articles and presentations about the study. The addition of the informants from the second research centre also helped to increase the anonymity of all the participants since it would be unlikely that the program that the informant was from would be identifiable. As well, there are only a small number of islet cell allotransplant recipients so it is difficult to protect anonymity thus, only very general demographic information will be included such as age and gender. Occupation will not be discussed, but employment status will be included.

Risks vs. Benefits

There were no risks or apparent benefits to the informants who participated in this study. The participants may help guide those who are planning to embark on the same journey by sharing their experiences and story.

Each participant seemed eager to participate and wanted to help others who may be considering this treatment. They were all grateful to the donor family and some of the participants became teary eyed when talking about the gift that they had received but no one became distraught or had to end the interview because of their emotional state during the interview.

Ethical clearance was obtained from the Faculty of Nursing, University of Alberta, and the University of Alberta Hospitals Special Services and Research Committee, University of Alberta Hospitals, Edmonton, Alberta, Canada.

Chapter Four: FINDINGS

The purpose in this study was to gain a deeper understanding of the experience of becoming an islet cell allotransplant recipient which is outlined in this chapter. As well, a description of the sample and demographic information is provided.

Participants

The participants consisted of two men and four women. Two were married, two were co-habitating, and two were divorced. Four participants have at least one child of their own. Two have a full time job outside of the home, one runs a home based business, and three are currently unemployed. They all have IDDM which was diagnosed between the ages of five and sixteen, and they all describe their diabetes as "brittle" or difficult to control.

Categories and Findings

Eight categories which outline the experience of becoming an islet cell allotransplant recipient, emerged from the data (see Table 1).

Table 1. Categories Outlining Islet Cell Allotransplant Experience

(1) The Context
(2) Living with Complications, Life in the Balance
(3) The Decision, The Pendulum Swings
(4) Post-transplantation, Life Anew
(5) Benefits, Bonuses, Gifts
(6) Doing it Again, Looking Forward, Looking Back
(7) Ongoing Concerns
(8) Effects on Family and Others, Making it Through

What is important to note is that this transplant experience occurs within the context of living daily with IDDM, and its complications. As such, the experience of becoming an islet cell allotransplant recipient can only be understood from within this broader context of living with diabetes. It is within this context that the decision was made to have the allotransplant, and against which the success of the procedure was judged. In the following sections events surrounding the islet cell allotransplant are presented separately. It must be understood that these events did not occur in isolation but rather as part of a life process. Each category will first be defined and then discussed in more detail with examples from the data used to clarify and articulate more fully the participants' experiences.

The Context

The context refers to the participants' experiences of living with IDDM. It includes how they felt growing up with a chronic disease and illustrates the day to day, hour to hour, minute to minute demands of living with such a complex disease. The context brings to light how emphasis has to be placed on the diabetes when making any decision and how this constant attention to the disease is difficult to maintain. Living with diabetes and its everyday challenges is filled with ups and downs. These ups and downs centre around food, management of the diabetes, daily injections, and/or hospitalizations. Each participant describes the early years with diabetes in a slightly different way, where half of the participants remember taking the diabetes "in stride" or just accepting the situation, while the other half remember always having difficulties with control of diabetes.

> -It was difficult managing your sugars, managing your food, I always liked to eat other things and stuff, just the realization that you can't do that was hard especially for a kid. (Z)
>
> -it was very difficult...the hardest part was to take the insulin shots you know. (W)
>
> - I guess as a kid I just sort of took it in stride, but found, I guess people's reactions to me were sort of, a little bit disconcerting. I didn't like being put in the sort of focus that I was different than the other kids, that seemed to come across in some of the group things that I was involved in as a child. (T)

Each of the participants expressed how diabetes interfered with some aspect of their life and kept them from doing things both as children and adults.

> -my school work would fail a lot...I missed out on a lot of opportunities because of my diabetes, I couldn't go on trips and I was in the air cadets and couldn't go on air cadet missions...and so I missed out on a bunch of stuff. (Z)

One person described how he had been fired for not telling his employer that he had diabetes. Another participant talked about how having diabetes changed her career plans. Some talked about how they believed others perceived them, or how they were afraid to be perceived in a negative way, and for some, diabetes became a secret, only to be shared with family and very close friends.

> -I stayed in the confines of being, trying to be as good a diabetic as I could when anybody was watching sort of thing and, nobody said anything about the diabetes, no body said anything about what I was eating, I didn't draw attention to it in front of people,...I wouldn't say that I was low because I wouldn't want someone to say you're low you should stop dancing or you should stop skiing and you should go down to the ski lodge and get something to eat because I wouldn't want anyone to know. (Q)
>
> -you don't want to walk down the street and just blurt out that you're a diabetic. It's one of the diseases that people automatically think that, being a diabetic you're not good for anything, you're to blame because you ate too much sugar...don't stand around a diabetic because they might automatically throw a fit. Don't go near a diabetic because you might catch it. And so people don't want to face, don't want to say I'm a diabetic. They really shy away...you hear the horror stories of people laying in the middle of the street and people thinking they're drunk. Well I've been that "drunk" person in the middle of the street, downtown, and if there wasn't one person that helped, you'd basically just lie there.... (Z)

Most remember a time when they paid little attention to their diabetes and see that as the time when most of the damage to their eyes, kidneys, and overall health probably occurred.

> -it was a very brittle diabetes, I think the first years maybe weren't too bad but in through my teenage years it was tough, I was always, always swinging high or low and I'm sure there's a real stretch in there where I didn't pay much attention to looking after things properly...always rolling into the hospital at some point, and the later part of my life it never, never really did get easier (T)
> -my diabetes was always out of control, it was up, up, up, never down, it was always high and I went into a coma about nine times. I just cheat a lot, and maybe that's what caused it. (P)

This lack of attention to their diabetes was not for the purpose of self destruction but was mostly due to a lack of association between poor glucose control and what that could mean years down the road for their health.

> -And then as I got older as a teen, I very rarely tested. That's what I try to hit to teens now is your ramifications down the road. (X)
> -I was very young so, I never paid that much attention to the diabetes. I just knew that I had it and that I had to take care of myself but never did, so, I was being like any other girl you know, not thinking, I wasn't thinking that I had diabetes. (P)

All of the participants talked about how certain aspects of living with diabetes were major areas of ongoing concern, were time consuming, and/or were frustrating. The primary areas included: eating, timing of meals and medications, glucose testing, and control of blood glucose levels.

Eating is associated with more than food and satisfying hunger for these participants. Eating is a constant reminder that they have diabetes and that over indulgence means not only loss of control, but can contribute to the development of complications.

> -...Well I enjoy food so I guess eating can sometimes mean trouble...well it's certainly a big part of everybody's life, I mean many of the social gatherings or any kind of celebration is usually around food and so you know, when you're trying to be very good and following things it's very restrictive, because, if you're as brittle as I am, any deviation from things and you're fluctuating a lot. (T)

Timing of meals, medications, and glucose monitoring was seen as part of managing their diabetes, but was also a big component of planning their day. Every aspect of the day revolved around the timing of meals, snacks, and medications. There was always concern associated with planning around special events, and if there was uncertainty in scheduling for the day.

> -with the diabetes as it is and managing everything you are always trying to preplan or foresee how your day is going to go and it doesn't necessarily go the way you think it is but, you always sort of have to prejudge things, make sure you have snacks ready and you know and your timing is better. (T)
>
> -I don't mind taking the insulin, I don't mind taking a needle that much, it really isn't that big a deal, the worst part about it to me is the time

> consumption. To take a needle, and to test and all that stuff. (Q)

Control of blood glucose levels was the biggest area of concern for all of the participants. Normal blood glucose was equated with control. Abnormal blood glucose was usually equated with complications. The expectation was that control of the blood glucose levels would come when food, insulin, and all aspects of caring for the diabetes were in place and on time. This however, was not reality, and so there was a great deal of frustration associated with trying to control the blood glucose. That control was a "constant pursuit".

> -It (normal blood sugars) just balances things out, it's just when you're dealing with the extremes all the time, I mean we cope with them, it's just not fun, they take your day out, you have a real low and that can set off your whole day. You feel terrible, and sometimes your stomach gets upset so you don't feel like eating the rest of the time or, you just want to lie down and sleep and it's just not appropriate, you're at your job, you've got to work and sort of stuff so it really affects things...you know what good control is and there's no way that you can achieve it. And it did get frustrating. It's not until you're older and you say okay, this is feedback and I can absorb it this way or that, but it's still not easy to deal with. (T)
>
> -I always had problems and, the frustration factor was really paramount, it wasn't so much taking the needle it was doing it and taking it and not having the satisfaction of having some control, it was just a fight, and, it kind of made me mad and it worried me at the same

> time. And I always had this thing about how long can I go like this, I'm taking my insulin, I'm doing what I'm suppose to be doing, how long am I going to go like this and things are going to fall apart. (Q)

Along with the daily responsibilities of living with diabetes, there was a need to be able to cope. Coping was often connected to control or striving for control of their diabetes but there was recognition that there are many factors that contribute to life's outcomes, over which they had little control. Here coping was essentially surviving in whatever way they could.

> -'cause you look back and think well probably that some of the stresses and things and life circumstances at the time you're just coping the best you could. So, maybe that's just an excuse but, (laughs). I think, that's the way it works, and I think that's the way it works for a lot of people who deal with other illnesses as well. You know working from day to day and just living and it's just a lot of factors that contribute to it. I mean you just don't have control of all of them. (T)
>
> -Coping, means more when everything is bad and shutting down, just hanging on by the skin of your teeth you know....just barely getting by. (Q)

Some of the participants talked about feeling guilty, either in relation to how they cared for themselves in the past or how it affected the rest of the family.

> - Where I felt the guiltiest was how it affected the family. Not so much myself. There's a lot more guilt associated with what the family has put up with. (X)
>
> - I think you're always sort of well, I think you feel responsible for yourself, there's always that guilt. And I think you start to feel guilty about oh, why didn't I take better care of myself than what I did or why did I do that, but I think the other side of it that comes around for me is that I think, it seems like you're always coping, and you're probably doing the best you can most of the time, and who knows why, or whatever. (T)

Some of the guilt was associated with the act of "cheating". Here the participants described how eating things that they were "not suppose to have" or eating in excess of the diet plan was considered cheating. Some of these "cheating" episodes were so significant that they continued to occupy the person's thoughts from time to time and were very vividly recalled. There was such negative connotations to the word and the idea of cheating that it was equated with being a "bad" person or a "bad" diabetic.

> - (the term "cheating") comes from other people first, and then internally, this little voice is telling you oh, you shouldn't be eating that or, you know. It was difficult because, you think especially when you're young and your hormones start changing and you have these cravings and you're hungry and you want to feel satiated and your body's giving you messages that are opposite to what's really

> happening, I mean your sugars are really high but you feel really hungry, so what's going on? So you're dealing with that a lot, and it was always there about cheating. It's not a nice word. But it is heavy, it's a moral judgement all the time. (T)
>
> -I just don't even keep chocolate or anything, you know what I like is I like double bubble bubble gum and I've gone through spurts where I will not allow myself to touch it but, um, once in a while I allow myself to have a piece of double bubble. That's my cheat, I love it....I remember being in the hospital and dying for something else to eat and a friend brought me up a tiny little pack of shelled sunflower seeds, and I ate them at night, I laid in bed and ate them in the dark and I dropped some on the floor and some where in the bed and I was in a panic that they were going to catch me and I hid the wrapper and that was a cheat. And they're not ever worth anything except a fat. A couple fats, you know, and I still feel guilty about that, you know. (Q)

Most of the participants talked about how they wanted a cure and/or feared the complications of diabetes. Each participant managed their fears and hopes in their own way, one by preparing for what he thought would be the worst and another by hoping that a cure would come before the complications occurred or before their time ran out. "Z" prepared for blindness:

> -I'd always accepted that diabetes, the first thing to go was eye sight, blindness, that's why I'd prepared for blindness, I hadn't prepared for dialysis, kidney disease. Those were something I didn't really know

> about as far as one of the side effects and complications of diabetes. (Z)

"Q" anxiously waited for a cure:

> -I'm sure somebody told me that I would be cured, that there would be a cure in five years. I don't know who told me that, I don't know if I just dreamed it, I don't know if they told me that and I believed it, or I was in denial because I wanted it so bad. I always thought if I take care of myself, if I just give this blasted needle, I will be healthy enough to have that cure when it comes. If I can keep myself from having complications when I have that cure I will be scott free. When I realized, started realizing that that wasn't going to happen, I think I started having some emotional problems about it, I didn't really talk to anybody about the way I felt, and I didn't realize I had a problem until years later when I was right in the middle of the complications, and then I felt I'd been lied to and cheated...That was the thing I was fighting against the most my self (developing complications) that there would be a possibility, cause I wanted to be cured before I got complications. (Q)

Emotionally some of the participants identified how they were more moody or had more dramatic swings in their emotional state related to their diabetes and specifically to the changes in blood glucose. "I do know that I get irritable if I'm hypoglycemic, and if I'm tired then that just makes it worse." (X)

One woman found that the female hormones also affected her blood sugars and consequently her moods, and she also found that she had more severe premenstrual symptoms with diabetes.

> -With the insulin and diabetes and sometimes you're feeling really low and really high and so the grouchiness is there and premenstrual stuff is more extreme. (T)

"Z" experienced loss of libido related to long standing diabetes and described the emotional impact that that had on his life.

> -diabetes causes a diabetic after a certain period of time for their libido to go, okay, kidneys don't do that, kidneys have got nothing to do with that. Once the libido goes, then if you have your wife or your girlfriend well, "don't you find me attractive anymore?" Um yeah I do but it's not that it's not that way and so emotionally you're thrown into an emotional roller coaster because, number one you can think of yourself as not being able to get an erection anymore, less of a man, not able to love anybody anymore and having that person with you imply the same thing. So emotionally you look at that and think what the hell am I put on this earth for? Why am I here? This diabetes I didn't cause it myself, I didn't do anything to deserve it. So emotionally it can not only mentally, emotionally it can all come back, so you have to really be strong. (Z)

Everyday that these people live with diabetes is a challenge. They have faced many ups and downs with both courage and fear, but have still been able to experience the normal joys and sorrows of life and of living. As the years passed, all of these participants began to develop complications of diabetes. The impact that these experiences had on each of their lives will be presented next.

Living With Complications, Life in the Balance

Living with complications, is living life in the balance. The day to day life of living and managing diabetes related complications was a constant balancing act. The complications were many: neuropathy, retinopathy, nephropathy, cardiac and/or large vessel disease, and any other condition which could be attributed to a history of long-standing diabetes. Each participant has been affected by one or more of these complications. Each has experienced retinopathy, and three of the participants have had significant loss of vision either temporarily or permanently. Two participants have neuropathy, one has cardiac disease, one has a serious history of infections and leg ulcers, one had problems with large fluctuations in blood sugar that resulted in episodes where she lost consciousness, and two are not able to sense when they are hypoglycemic. All of the participants have also had complete renal failure and subsequent renal transplants. Five of the participants each received a kidney from cadaver donors and one received a kidney from a living related donor.

Each of these participants developed complications of diabetes between the fifteenth and twenty fifth year after the onset of the IDDM. The first major complication that each developed was retinopathy. Although the degree of retinopathy varied, each required some medical intervention to treat or stabilize the condition.

> -it would have been (in my) early twenties when the retinopathy showed up on an exam so I had the photocoagulation with the laser and that, knock on wood, has been stable now for oh eighteen, nineteen years. That was fairly intensive but that was kind of the first signs, was the retinopathy, and usually the small vessel disease goes together so it's the retinopathy and the kidney. (X)
>
> -I started having problem with my eyes, first in the right eye. I had to have laser and when I had the lasers, about three days later I couldn't see from that eye. So I went blind from the right eye and then three months later from the left eye, I also had glaucoma and I had surgery from that eye twice but they couldn't do anything, so I went blind from both eyes. I can see a little bit from my right side, but not much, just a little bit. (P)

At some point after the onset of retinopathy, each of these participants developed hypertension. Each was aware that in time they would develop renal failure and require dialysis, as a result of this hypertension. The participants all described how they felt ill, tired, and saw their health deteriorate over a period of a few months to a few years. "T" described this gradual deterioration:

> - I started having blood pressure problems and stuff. I guess I have to relate it back several years before my kidneys finally gave up all

> together. I guess at first I just kept thinking I had like the flu or something that wouldn't pass, and sort of pulling myself through, through the week and then sleeping most of the weekend. Just not any energy to get anywhere and then I took myself to the doctor and my blood pressure was up so the blood pressure medication started, I recall then not doing so well, feeling very affected by them as well. And it was just a general slow down. (T)

The transition from renal disease to renal failure occurred over time, and dialysis became inevitable. Life on dialysis was difficult: some had complications, some were physically ill during the dialysis, and all felt that there was little or no improvement in how they felt, in their level of energy, or their overall well-being.

> -When I was on dialysis the doctor told me I had to have my transplant right away because my heart was weak, it wouldn't support the dialysis. I had to take medication under my tongue, and I was always, dry all the time, they hooked up the machine and I started to vomit, and I had all these cramps and all that. (W)
>
> -during my dialysis, I was just so ill, even dialysis, nothing felt good, nothing felt good, I....was afraid of transplant and more surgery and the fact that I was so sick that I might not make it through them. But, I felt that while I was on dialysis my life was over. I was weak, I was sick, I was, I could barely walk, I had no energy, I was just so sick I very truthfully believed I was dying. (Q)

Two people also described how they were more confused and lacked clarity in both their long and short term memory while on dialysis.

> -just before the transplant I was feeling very muddled in my thinking, I couldn't put things in their time perspective, and so I was very very confused and I just couldn't sort of think of my history or put things in their proper order. (T)

Only "X" felt that she had done well on dialysis. She was able to work full time while on dialysis, but then needed to have someone else take on the responsibilities at home.

> -Personally I think it's (peritoneal dialysis) the way to go, because it's a lot healthier a little bit more physiologic, than having fluid and toxins build up for a day then having it all sucked off in a matter of a few hours and.. it's just too drastic of a change in too short of a time on hemo, I did have a couple of runs on hemo in sort of acute situations and I never felt well. ....things would build up and you'd just feel sick. My husband used to say I'd go in looking like a butterball turkey and come out looking like an old crow, cause they would just suck everything off and I'd feel sick after that so I would maybe have one good day, where as with the peritoneal dialysis I was very fortunate, I could go to work and do my thing and it would take half an hour, four times a day mind you, but half an hour just once at work and, it was a lot more portable and it could go where you wanted and I felt I think

> about....as well as anybody can feel on dialysis, and with kidney disease because you really do feel ill and weak most of the time but I think I did really well on the dialysis. (X)

Four of the participants actually felt worse while on dialysis, and three of those people feared that they would not live long enough to have a transplant, and so planned for their death.

> -I was planning, I was trying to figure out how I was going to get things in order, the things I wanted to get in order, that's what my plans were for dying, and how I was going to die and I made up my will and I picked out my songs and I said what I wanted done and I, I sincerely, honest to God believed I was dying, and I believed that no matter how much treatment or medical attention I got I didn't think it was going to work. And I thought if I lived it was going to be a very,....drawn out painful, ill, terrible illness. I would be unable to do anything or take care of myself. I felt totally unable to take care of myself, bathroom, talking, anything. (Q)

Some identified how difficult it was to accept that they had complications. It was difficult admitting that there was something wrong, which in turn made it more difficult to adapt to the changes that were necessary to stay alive. The health changes demanded that they dedicate most of their time to managing the health problems with which they were now living.

> -I was shown how dialysis works and it was very upsetting and hard for me to accept because I had always been such a steadfast and strong individual. For me to have to rely on a machine three times a week for four hours a session was very overwhelming. (Z)
>
> -I think I was denying things a lot, not wanting to accept it, I guess I was getting sicker and sicker. Also, I think at that time I didn't push myself to find out where things were at. I mean I had seen a kidney specialist and he says oh you have two years before you have kidney failure, and I sort of was pushing myself and it was four years before I really had it, and I didn't do myself any favours with that I don't think. Cause there was a real stubbornness and a pride there that didn't want to be sick...(didn't want to) have the image of yourself being sick, that you still sort of carried the image around that you're okay, that things are all right you still can do everything you can do, and then things start to slip and then you don't do as well, but a part of you doesn't want to accept it and a part of you doesn't want to accept the fact that there are other problems still going on. (T)

Two of the participants also talked about how trying to accept and live with complications led to depression which, for both, required the use of antidepressants. As "Z" noted, there was a "loss of sleep which eventually led to depression and anxiety, and taking mood altering drugs and sleeping pills made things a bit more tolerable, but not really".

Along with the problems of being on dialysis, and the weakness and ill health associated with renal failure, there was still a need to balance the diabetes and the renal failure. All of this led to increased food restrictions and significant demands on time.

"T" provided a clear analogy of what life was like and how difficult it was to balance the demands of her ever present health problems.

> -I always find that, diabetes and then throwing in all the complications that happen with diabetes is just juggling, it's always juggling, and even more so when you're on dialysis or with kidney failure, because your food restrictions really start to get narrow. I mean your cutting down your sugars, cutting down your salt, you know watching your fats and then the diabetes, watching your time and stuff, you're constantly trying to remember everything. And not that it's that difficult that you can't do it but it would be nice not to have to have all those concerns all the time. (T)

Complications and the demands of living with complications led to social isolation. Participants were too tired, too weak, and too ill to be able to get involved with activities in the community or even with their family or friends. There was a tightening of the social circle, and most of the participants just stopped going out at all.

> -I mean with being chronically sick you just don't have the energy to give to other people. So that I found that, I closed off sort of the social circle I had and became less involved in my community, and even in sort of family matters. So, I did less with kids in school, in

> participating at the school, home, school activities and that sort of thing, and I've attempted to do some of that this year but I found that I just haven't got the give, and so I get myself up and I come to work and I get myself home and try and get something made for supper, and the rest of the evening I'm pretty flat. And I just have no desire to get out and go, well part of me does, part of my head would like the idea of getting out and meeting some more new people and getting to know more people in the community, but physically I'm just drained and I you know, weigh the options, well I think it's home again tonight. And it's not even done consciously anymore. Basically, I even had to draw the line because sometimes you try to do something and you realize you can't carry through. You can't give your commitment to get involved, whether it's in a community league or little league or soccer or something because, you're going to phone half the time saying you can't make it. (T)

Two of the participants talked about how the need for close medical attention began to consume most of their life. They became dependents of the doctors and the health care system and the more problems there were the more dependent they needed to become. As "T" states:

> -I find it very, I know you have to see them to sort of keep everything in check and have another overview of yourself but, I just get weary of going to the doctor. And then when you run into more problems or have more complications you're there all the more. And, sometimes it

> doesn't seem like they're giving you any offering of anything that's going to solve your problems but, you're always going. I just get tired of it and you know, I'm running for blood work every other week now and it just, they're small little inconveniences but they sort of start to add up. And then your life is evolving around them and then you sometimes get into the habit of doing it and then realize that your not choosing to spend your time any other way, I can't do this because I have a doctor's appointment today. So it can be just restricting in that way, not that it can't be done, not you know, that you don't appreciate their knowledge and their offerings of what they can give you but at the same time it just starts to add up and plus waiting, I mean every specialist you go to see, I mean just the other day I had an appointment at 3:40 and it was 5:00 before I saw the doctor and I know they're busy and I know they have a load, but at the same time that's still cutting into my day, and if you've got, you know, several a month to do. And I don't think anybody complains too loud because they're so grateful to have a kidney, but at the same time often you're spending a morning there or several hours just waiting and often then your visit is only five to ten minutes long. They could phone me here and I could drive down and be there for the appointment time, but I go and I sit in the morning and then I'm just in and out, and you're often waiting for them. (T)

Along with accepting the loss of their previous level of health, each of these participants had to deal with the loss of other important aspects of their lives. Two participants saw their marriages come to an end due to what they believe was the deterioration of their health. Four of the participants either lost or left their jobs when fatigue and weakness became overwhelming. One participant who lost her job also felt that the job loss caused her to lose part of her identity. She also talked about the loss of some of her other abilities, how she lacked a sense of worth and felt increasingly vulnerable.

> -I lost a really good job over being sick. That was bad enough but that job was also my identity... I guess all my poor health takes away your control over your life and you feel very small. You feel so small and insignificant, overwhelmed, um, like when my heart stopped and different things like that, and machines are doing it all for you, and you can't talk, you can't go to the bathroom for yourself, you can't do anything, and you're just, you're peanuts you know, and, you can't do anything for yourself and really, medical doctors can't do it all for you. You grasp onto any hope you have. (Q)

Each of the participants refers to someone or something that helped them get through this time in their life. For most, it was help from others. The help came from family, friends, and/or professionals. One person specifically talked about faith and how her beliefs made the experience livable. One participant talked about having a "vision" that he was going to receive a kidney and how the hope of getting the islet cells kept him going. And one person felt that medical attention and being knowledgeable helped her get through the loss of her renal function, dialysis, and the waiting period before a kidney became available.

> -I had people around me who were very supportive in all the things that I was going through. And then with the islet cell transplant, there were no guarantees with that either, but just the thought of that made it so that I could hang on a little bit longer...and it really got me to go farther to do better than I was doing at the time. (Z)
>
> -...I've got my faith, and things don't just happen randomly. There's a reason for it and you're either going to learn from it or, you know, go on, and you're not going to be given stuff that you can't cope with. And I think that's important, you need some sort of belief or faith system. Cause other wise just being on earth would be kind of hopeless. You've got to have some sort of belief, I think. (X)

Following weeks or months of living with devastating complications, the time came for the kidney transplant. The prospect of a new kidney was exciting, frightening, and even overwhelming. Four were so ill at the time they were called, they feared that they would not make it through the surgery.

> - I didn't think I would make it for a transplant at all, I didn't think I would. And when I heard that I was getting a transplant, it came as kind of a shock, it came quite quickly, two months, and, I don't even think I was ready for it because I didn't expect it at all. And actually I think, I was pretty sick when I got it, but if I would have been more of a controlled dialysis patient, I think it would have been a lot easier. Even though I had complications, I still think it would have been easier, cause I would have been stronger. (Q)

Two participants had their islet cell allotransplants at least two years after their renal transplant. They described their life following the renal transplant but before the islet cell allotransplant as less than ideal with continuing fatigue and ill health. They felt that they could not have a "normal life".

> -I couldn't do anything, like when I used to go out, I used to get tired a lot,...I started to work in a dentist's office and I just stayed there for about a month and right away started feeling sick and I couldn't have, a normal life. (P)

Amidst all the problems, concerns, and the struggle to survive, four of these people made the decision to participate in an investigational study involving allotransplantation of islet cells. Two of the participants had well established and stable renal transplants of at least two years duration and were approached to also participate in a similar research study. How they came to be in the study and how they came to their decision will be presented next.

The Decision, The Pendulum Swings

The decision, or the pendulum swings is the experience of seeking out or being approached to participate in the islet cell allotransplant investigational study and making the decision to go forward as a research subject. It includes how and when the subjects were approached by the researchers, or when they sought out the experience, how they came to their decision, and what influenced their choice to participate. Here the participants were offered not only the chance to have a functioning kidney but also to potentially have more flexibility in relation to some of the day to day, hour to hour, minute to minute demands of managing diabetes. Not only were some of the participants being pulled from the "brink of death" by the renal transplant, but now they were also being offered a "bonus", a chance to have good blood glucose control, to possibly be insulin independent, and to potentially halt or even reverse some of the complications of diabetes.

Of the six participants, four were approached by their doctor, (either the endocrinologist or the nephrologist), and two sought out the experience by approaching one of the physicians on the transplant team. Each person talked about how it was exciting to be considered for the islet cell allotransplant, though for some, the excitement was tempered with fear of the unknown.
As "T" notes:

> -I felt very enthusiastic about it, that there was some other hope going on with research, they needed a participant and I was willing, I thought it was a great idea to support them. (T)

But "Q" added:

> -you're scared, right, you're hoping so hard that you're scared. (Q)

Along with the excitement of this new possibility, came a quick decision to participate. Each person met with an endocrinologist from the research team, reviewed the procedure and the protocol that was expected post transplant, and essentially decided at that point to participate in the research. Reasons that the participants gave for participating in the research included: just being part of research, treating the diabetes, and helping others. Other individual influencing factors also affected the participant's decision to take part in the research study. One woman stated that "it didn't seem I had a lot to lose" by going through with the islet cell allotransplant. The same participant liked the people involved with the research and talked about how she trusted them and thought highly of their abilities. One person wanted to be one of the first islet cell allotransplant recipients in the world and to be "a leader in the field". He also felt that it was his own responsibility to get involved. He did not believe that this was a "miracle" but that success came from his willingness to be involved in research.

> -I believe also that a lot of people fool themselves with believing that something is God sent, and they literally jeopardize their life because they're waiting for something like this and their not doing anything themselves to help it. And so those people that want to get an islet cell transplant, or any research, cancer research or any kind of research out of a hospital or medical institution um, it's not God, it's research. You're going to have to go down and put in your two bits worth. (Z)

In contrast to the above statement, one participant talked about how faith or having a belief gives you hope and strength. She felt that you had to believe before you could have hope "and not necessarily that things will come out hunky dory, but you can cope with what comes your way". (X). She also expressed that her decision to participate in the research was not influenced by her faith, but that the faith gave her the strength to make the decision.

Every participant talked about how important and exciting it was to be part of research. Their contribution would help make a difference in the fight against diabetes and that this contribution would be made during their lifetime.

> -And I thought you know, just to even to be (part of) a research project, so maybe I die in the next year...at least I've made a difference. (Z)
>
> -I've always told them, if I can be a guinea pig to get closer to a cure I'll do it. (Q)

As well as fighting the disease, most of the participants talked about how participating in the research could help others as well as themselves. There was a special interest in helping children and a desire to keep others from suffering.

> -It's very important because it can help other persons....you know the doctor's going to find a cure for diabetes, you're going to find something to alleviate the pain of other persons and the children. (W)
>
> - the thought that I'd contribute to some research that was going on, and the opportunity to, to be in some way, that someone down the line wouldn't be going through diabetes. Cause it touches home, I've got diabetes, my brother has diabetes, you know and, I'm always hearing of somebody else coming up with it and I know it's a struggle. (T)

The opportunity to improve the way that diabetes was and will be treated was very important to most of the participants. As well, they hoped that they would benefit personally, and talked about the islets as a possible bonus, a potential cure, a means to come off of insulin, and a stabilizing force that would help make the renal transplant more successful, or keep their diabetes under tighter control.

> -I thought if it works it would be a bonus, if it didn't then I'm not out anything. (X)
>
> -I've always waited for the cure and the possibility of islets was the next best thing...I (wanted the islets to) give me enough help that the kidney will do well and I'll do well. (Q)
>
> -I thought it was going to be where I didn't have to use any more insulin. (P)

Along with the reasons for participating, the recipients talked about how they came to the decision and what they thought about as they waited for the transplants. Waiting provided the opportunity to reflect on their hopes and expectations, the perceived pros and cons of the experience, what the responsibilities would be after the islet cells were transplanted, what concerns they had, and whether they should reconsider their decision.

Although none of the participants stated that they had expectations of the islet cell allotransplant, most expressed hopes of success ranging from better control of the diabetes to a full cure.

> -I was hoping it would take the need for insulin away, and control the diabetes. (Z)
>
> -I hoped that the islets would actually cure me of everything....I was

> very open and thought that anything was possible. (Q)

When asked if they had weighed the pros and cons of their decision to participate, all but one of the persons interviewed had not evaluated their choice to any great extent. Most of the participants believed there was little or no risk and so felt it was an easy decision. One participant indicated she would have accepted the islet cells with immunosuppression even without kidney disease and failure. She believed that the quality of her life could only be enhanced with a successful islet cell allotransplant and went on to say, "You know some how when you look at your life and you think, diabetics don't have this long life span, so maybe you could have quality of life". Others expressed their quick decisions in the following ways:

> -I didn't have any fears, I knew in my mind that that was what I wanted to do. So I didn't think, I just wanted to get them, but I never went over and over it, I just wanted to have it done....my life was already a mess so I said it's better to try it to see if I get better. (P)
>
> -the cons were the extra time in hospital, and the studies afterwards, everyday, not only for my kidney transplant but also the islet cell transplant, and the different blood tests and stuff that had to be run and the time that had to go with it, but the pros far out weighed the cons. (Z)

All of the participants were aware that there would be some ongoing responsibilities associated with having the islet cell allotransplant. Each participant was asked to read and sign a contract and consent form. Two of the people talked about how important it was to be dedicated, that it was a big responsibility, and that they should not waste the opportunity.

> -...information sheets about the protocol, what they expect, what the risks are and you sign it, and they tell you that at any time you can cancel out, change your mind,...and they tell you that they would like you to keep in touch minimum of a year if possible, and to keep all your statistics, all your blood values, keep track of your insulin, be in close contact with them, and to respect your transplant and take the best care of it possible. To try to maintain your sugars and stay under the best control possible. (Q)

One person also talked about how he believed that he would need to be public about his experience. He believed that the research team expected this from him and he felt that he could handle the stress associated with these expectations.

> -To be the first or one of the first to have the transplant was an opportunity I couldn't turn down. Being in PR work or public relations work that I'm so accustomed to, it fit. I could deal with the stresses of keeping it hidden, not telling anybody about it. We couldn't have any media release for nine months. The way it needed to be handled in the public eye, it needed to be handled with reporters, news reporters, newspaper, everything, all the facets that came with news media

> releases. Dealing with patients and, patients asking when they would receive it, and how, and I felt that, not only could I handle all that I could also handle the fact that, I would benefit from it myself. So everything kind of keyed in to fit together. (Z)

Even with the research teams' expectations, the detailed information provided, and the investigational nature of the islet cell allotransplant, none of the participants reconsidered their decision to have the transplant. That is not to say that some of the participants did not have concerns however. Four participants talked about being afraid at some point after they had agreed to have the islets. For example, one was concerned that the islets may cause a mass in her liver and was worried about liver damage.

> -I was worried initially that if they're putting this mass in the liver, you know, down the road, was there going to be some other mass growing there or could there be problems with it...But to me, it didn't seem like too much of a chance. (X)
>
> -it's pretty technical (consent form) and, sounds like you know, they go in your liver and it sounds very scary and, you can end up with liver damage or you can loose your kidney and there's a chance about this and a chance about that, that's really very intimidating. But all in all I figured I had everything to gain and nothing to loose. And I guess I didn't really believe that my kidney transplant would be successful unless my diabetes was under control. I guess that's the big clincher. (Q)

> -I was afraid, I was afraid but, I said, I'm going to try it, that's all I thought. (P)

For these people, they saw this as a chance for the pendulum to swing in a positive direction and so they decided to go ahead with the transplant. Only one participant had no hesitation when her decision was made and believed that this was a wonderful thing that was going to happen to her.

Most of the participants were quite ill and dependent on dialysis to keep them alive when this chance to become a recipient was offered to them. However, all of the participants stated that they were not afraid to turn the team or the offer down. Only one had some concerns that if he turned the team down he may jeopardize his health coverage, but did not want to turn down the offer anyway. All of the participants stated that they did not feel pressured to participate, nor did they feel vulnerable about having to make the decision at that vulnerable period in their life.

Once the decision was made to participate, each person had to wait and see if the blood work supported their eligibility for the study and then they had to wait for the surgery. The waiting was filled with uncertainty: four of the participants did not know if they would get the islet cells until the day of the kidney transplant. Five of the participants were awake for the islet cell allotransplant, and felt that the opportunity to see the islets inserted was exciting, and they were glad to have had the experience. All of the participants stated that it was a painless procedure that was over in minutes. The insertion of the catheter into the liver, for the islet cell infusion, was done under general anesthetic either at the time of the kidney transplant, or the day before the islet cell allotransplant for the people who had an established kidney transplant. All of the participants were told that this would require a small incision, but for two of the recipients, the incision was "very long" and unexpected. This was upsetting for both of these people at the time, but neither regrets receiving the islet cells. Once the procedure was over, the wait began, to see if there would be a "new" life post-transplant.

Post-transplantation, Life Anew

Post-transplant, life anew, is essentially what life was like after the kidney/islet or islet cell allotransplant. This includes: what the experience was like immediately after the transplant, what the follow-up and protocol involved, what limits they had imposed upon them, either from themselves, or from the researchers, as part of an investigational study, how they reacted to the islets, what hopes they had for themselves and the research, how they viewed the future or what their outlook on life was now, and what contributions they have made to others since the transplant.

Following the kidney/islet or islet cell allotransplant, there was a period of adjustment and settling in. Each recipient required adjustments in immunosuppressive drugs. Their drugs had to be titrated up or down, changed, or, in the case of the two recipients who received their islets well after their kidney, added. For one of the post kidney/islet recipients, the addition of a new immunosuppressant caused a reaction which included; cramps, pain in his legs, and severe illness that made him "feel like dying". Any problems associated with the kidney, such as rejection episodes or infections, required other adjustments in medications, and also added to the stress on the islet cells. Time was also needed to allow the islet cells to settle in and establish a good blood supply.

Initially there was stringent testing, at a minimum, hourly blood glucose monitoring, and gradual weaning from insulin and glucose intravenously to subcutaneous insulin so that the islets could rest. All of the kidney/islet recipients required a longer hospitalization than would have been required for the kidney alone to allow for the closer monitoring and gradual weaning from intravenous insulin to subcutaneous insulin.

> -well initially they try and keep the islets from being stressed...So initially I was in hospital two weeks, kidney wise I think I could have left after one week, but the two weeks was for the islets, and to avoid any undue strain, or placing any sort of undue burden on the islets they keep you on dextrose and insulin infusions. And initially, I think because of the damage and maybe the islets lysing when they're inserted there's a big sort of an insulin snow (large amount of insulin released at on time), there was lots of insulin, released, oh gosh they were giving me D50, syringes full just to get my blood sugar up. You know the process of transferring or transplanting there's lots of insulin released. And that was probably just for the first day or two, and then so that the islets wouldn't have to work and to give them time to kind of nestle in and get accustomed to their new environment, and as I understand it developing a blood supply, takes a fair bit of time. So for the first two weeks it was these infusions and, constant monitoring, 27 times a day blood sugars, finger pokes. That was something else, you didn't sleep because there were always finger pokes. And it was just a gradual sort of weaning of the infusions, one was dextrose, one was

> insulin, and then starting to inject insulin again with the idea of not forcing the islets to right away start carrying the whole burden. (X)

The protocol and follow up that the recipients were expected to follow required dedication, determination, and commitment. Two people described how they were testing their blood glucose many times per day in the early days and weeks following their islet cell allotransplants, "I was testing sixteen times a day", and all of the participants continue to test their blood glucose levels at least four to eight times per day. Two of the participants continue to phone in their blood glucose results daily to a automated recording system which then tells them how much insulin they need to take the next day. Three other participants continue to keep written records of all their blood glucose results and submit this data to the islet cell research team on a regular basis.

> -now I'm on my about 414th day and I still keep track of all my values...Part of the responsibility, you have to keep track of your date, times, values, weight, temperature, medication, activities, anything that you change or deviates from your normal day...I photocopy my pages and send them off...I don't think you can let up on the protocol. (Q)

Along with home glucose monitoring, each participant was expected to have other lab tests done, the most common of which, was the Sustacal® challenge test which tested the function of the islet cells. The participants were also asked to be available for further testing at any time and to see the endocrinologist on a regular basis. One participant stated that she "didn't realize you would still keep the stringent monitoring" after the islet cell allotransplant and felt that it required self motivation to continue as a research subject. Another participant talked about how important it was to take the experience "one day at a time" and how the constant testing was reaffirmation that this was a day at a time, as a subject in a research study. Although the participants all believed that follow-up was necessary, two people voiced concerns about the amount of stress placed on the islet cells during the Sustacal® challenge test, and some people would have preferred a more specific outline of the expectations, tests, and procedures with the understanding that if there were any problems there would be changes made to that outline. Along with testing and follow-up, there were also some limitations that needed to be considered by each before participating, and participants felt that the research team should have made them aware of these.

Five of the participants talked about limitations and the need to maintain a routine following the transplants. The limitations included those suggested by the islet cell research team, as well as those that were self imposed.

One participant stated that she could "eat a greater variety of foods without affecting her blood glucose levels, but she could not eat more food". Another participant stated that he was "told to limit fats and simple sugars but to go ahead and experiment with larger servings".

> -A better variety of food, but the amount it can not be a large amount, it has to be a small amount. (P)
>
> -they wanted you to manage a diet plan...to just watch the amount of fat and real sugar, but other than that, your carbohydrates, if you want three

> of toast in the morning instead of two well you go right ahead. (Z)

Although most of these participants felt they had more flexibility in managing their diabetes, four of the participants actually maintained the same or an even more rigorous routine than they did before the transplant.

> - I do have a lot more leeway with it, but I still, I don't know if it's years of following a CDA diet and the routines, but I still get up in the morning, you know same time every morning and do my thing and the insulin, and have breakfast and I pretty well stick to the same meal plan, you know, unless you're going out or unless it's a special occasion or something. (X)
> - Well there's still a large protocol, and the testing, for myself anyway, and I'm still on insulin, so that's still a factor because your constantly testing and doing. But I don't know if I went off the insulin I would probably still be testing anyway. (Q)

"Q" also stated that the demands of the routine were still there especially because she was still on insulin. She stated, "people think it's going to give them freedom from the life of diabetes, well for me, it really hasn't done that". The ongoing need to live with limitations and follow a routine had an impact on the participants reaction to receiving the islet cells.

The individual reactions to receiving and living with the islet cells illustrates how this experience has affected each of the participants. The main reactions to this experience have been both emotional and reflective. One person talked about how he was now going to be able to contribute in some way again,

> -I guess my feeling after the islet cell and kidney transplant was that I was going to live, and I was going to be good to society in some way, again. (Z)

and others talked about feeling blessed, fortunate, surprised, euphoric, and privileged.

> - surprised that it was you or, it was such a gift and you wondered why it was you. And I could feel myself feeling, almost over privileged. Sometimes when I talk to other diabetics about what was happening, and whether it was really coming from them or it was my own perception, a resentment, that someone was able to get it and they were not. And so I felt, maybe cautious at times, sometimes about telling people. As much as I am enthusiastic about it I also felt maybe I was trying to be too, empathetic towards the other person...And I just found that at times I was checking myself, cause I at times I felt I can't share this with anybody else, it's not like a piece of cake you can divvy up, or whatever. But almost, maybe it was just more almost unworthy, why was I so lucky this was happening to me? (T)
>
> -I feel very blessed and fortunate because there's so many of us out there and to be able to have been one to have received it is, overwhelming...I was really euphoric, I was just so excited that I got them, I just felt like it was a total gift and I realized that they create opportunities...just the

> whole fact that I was chosen and able and it worked out, and the timing...I felt very privileged and I still feel that way. (Q)

One person believed that, although the islets were not a cure, they made her take better care of herself. She also believed that in some ways the islets were more trouble because of the extra monitoring and ongoing concern about damaging the islets.

> -You know it's encouraging, sure. Yeah, I just don't want people to get the misconception,...that it's an instant cure and then you can go out and forget about diet and forget about everything, you get this little islet cell transplant and, you see in a lot of ways, it's a lot more trouble for me since the transplant than before, because you know, I'm watching and I'm monitoring and, I'm thinking if I don't take care of myself, other than the complications, I might be damaging the islets. (X)

Another person also voiced fears about damaging the islets and was concerned that she would be letting others down if that were to happen. She also felt that maybe it was better that she lost her kidneys when she did because she was able to get the islet cells.

> -I'm scared to damage them, plus I don't want to let anybody else in the program down that's worked so hard to get me the islets, I have a feeling of responsibility...at the time it didn't look like I was going to loose my

> kidneys for a long time, now that's not fortunate that I lost them, but maybe it was better in the long run that I lost them when I did, because the timing was right, I managed to get the islets. (Q)

Along with the reactions to having had the islet cell allotransplant, most of the participants expressed hopes for either themselves, the program or both. The main hopes that these people had for themselves were that the islet cells would prevent, decrease or stop complications, stabilize their current problems, prevent rejection of the transplanted kidney, and cure the diabetes or at least make them insulin independent.

> -If I can maintain near normal blood sugars then hopefully I won't have such awful complications down the road...If I can keep the blood sugars good, which seems to be what the islets are helping me to do, them I hope to prevent complications. (X)
>
> -I certainly had a hope that I would be off of insulin and I hoped that it would last forever... (I hoped) things would stabilize and I wouldn't have to worry about things going wrong...so I saw it certainly as an opportunity to keep things stable at that level at least and carry on. (T)
>
> -What I would have liked, or would still like is to go off insulin, so I'm a non-diabetic, so I have a hope of never rejecting, or would have a better chance of not rejecting. (Q)
>
> -If I reject I can loose the kidney and islets. If I loose the kidney I loose the islets but, I think if my diabetes is a mess I could go into rejection. (Q)

The participants also expressed hopes for the program which included; developing the ability to transplant islet cells without the need for immunosuppression, giving islet cells before the person has diabetes related complications, simplifying the process and opening up the program so more people could benefit from the islet cell allotransplant, and making islet cells available to all persons with diabetes.

> -I hope it becomes an easier process so it costs less and they know more so more people can take advantage of it, and preferably before they have their complications. What I really hope for is immune system research. (Q)
>
> -Maybe down the road there'll be...ways of transplanting islets where you won't have any sort of immune reaction. (X)

The islet cell allotransplant experience provided not only hope, but a possible future and a new outlook on life for most of the participants. When they were living with complications and especially when on dialysis, many talked about death. Following the transplants, they had a future to think about. They began to plan or look forward to their life. Although most of these participants were cautious about planning, they felt that they had a reason and a need to look forward. One participant felt he managed best looking at life "one day at a time", and five years into the future was as far as he wanted to think ahead. Another participant however, was planning for retirement and hoped that she could stay active and be relatively healthy into her later years.

> -I'd like to live to be a good old age as long as I'm relatively healthy...I want to stay active...Work is a large part of my identity and I like working...The health part I don't think about it, I don't worry about it. I guess, occasionally, you know when things maybe don't go quite the way you want, or if you're not feeling well, you might dwell on it but, you know you take it as it comes and you do what you can and,... there's no point in staying at home and brooding about it you're just going to make yourself sick in that way. So, I think you need to get out and do things and plan. Have to go buy RRSP's today cause I'm planning on having a good retirement. (X)

Another person talked about how she was "looking at the future now" but had not been able to before, and how even "the little things" were an important part of her future.

> -I want to do things, I want to get up and I don't want to be slowed down, I want to get back to work, I want to take my kids for a walk, I want to, I've never travelled, I'd like to travel, I don't know, that's the big stuff. I'd just like to walk over the snow bank at my house. (Q)

Along with looking at the future "Q" had a need to regain control, set boundaries, get organized, and make plans. She felt a responsibility to get her life together even if it was a little at a time.

> -trying to take some control in my life. Trying to get well enough, get

> organized enough and maybe get enough days out of the hospital to do some volunteer work or something, or maybe take a course. I'm trying to set some boundaries in my life, have some control over my life, organize my life. I feel that with that growth maybe I'll even date in the future, or maybe, I will do volunteer work, maybe I'll do something. I don't know, maybe I'll get a job. That seems too hard for me right now. But I'm getting my self confidence back and I can see making plans for the future. I haven't got the specifics planned, but I'm starting to think that I should make some plans anyway. I'm not thinking about...death is not what I'm thinking about...I want to do something with this gift, this second chance, and I feel for myself and for the people that helped me get this gift, I think it's my responsibility to get my life together. Otherwise there's no use in having it, and it doesn't have to be in a massive way, just small little successes along the way. I'll take them, I'm not going to shoot for the moon, but, well maybe I will, but a little bit at a time is just fine. (Q)

"P" talked about having a "better" future, that she "wasn't going to be sick all the time" and that her blood sugars would be "under control". Having a sense of future was again an important component of the participant's lives and thus there was a need to try and repay the islet cell and renal transplant programs in some way.

Although none of the participants felt pressured to "repay" the program or the doctors, they wanted to show their appreciation and say thank you for the gifts they had received. All but one of the participants have done some public speaking or have spoken with the media, and one person has done provincial fund raising by riding his bike all over the province. Most of the efforts of these people have been to raise awareness about the program, to share their individual stories, and to support fund raising efforts.

> -I've learned a lot more about diabetes because of it, and now I'm talking to people about it and I like to think that that's sort of my payback. (X)
> -I showed people that the money that the Alberta Foundation for Diabetes Research had raised had actually gone to a good cause...I'm a person that received that money from that tin that you put that money in and I want to come and say thanks. (Z)

Two participants also stated that they hoped by taking part in the research they were doing something that was good for others.

> -I have always had in my mind that I'm doing this because I want a cure for others. (P)
> -I want to do as much as I could for myself, my children, and as much good for other people. (Q)

The need to contribute something back to the program grew from the positive experiences that all of the participants enjoyed following their islet cell allotransplants. The positive experiences following the islet cell allotransplant will be the focus of the next section, bonuses, benefits and gifts.

Benefits, Bonuses, Gifts

Islet cell allotransplantation was a powerful and life changing experience. The positive outcomes, that is the benefits, bonuses, and gifts could and did occur at various points, and in various contexts of the participants' lives. The positive experiences affected many aspects including: diabetes management and control, freedom, flexibility and timing of regime, coping, physical health, emotional or mental health, social involvement, and feelings about what the experience meant to each of them.

The greatest benefit shared by all of the participants was in the management and control of their diabetes. Control was equated with normal blood sugars, and feeling better, physically and mentally, and thus, increased their ability to live with diabetes on a daily basis.

> -Control of the diabetes was a lot easier...instead of the diabetes ruling you it was more the tables turned where you could rule the diabetes. (Z)
> -...it's certainly made the management easier, a lot easier, just knowing you've got the good blood sugars makes a difference. (X)
> -it sort of gives you a chance to experience life as maybe more normal, so that is something you sort of want...(life management was easier) in comparison certainly. (T)

Normal blood glucose levels meant "balance", "stability", "bliss", "smoothness", and "feeling better", resulting in a "nice or big release" from the struggle or challenges of living with diabetes.

> - ...for years I had been struggling with I don't know if that's the right word, challenged by diabetes if you like, and with the islet cell transplant it was, it was just a phenomenal change, just the smoothness of it, not having the really high sugars or the really low sugars, it was just such a nice ride it was two years of bliss really, in that regard it really was. Well it just seemed to balance things out and it took away the uncertainty of your day, cause you're never sure of what was going to transpire. And...you know you sort of could rely on yourself, so that was a great part of it. (T)

"Q", "T", and "X", also described how normal blood sugars gave them a sense of control and provided positive feedback which encouraged them to continue to do their best to care for themselves, and motivated them to monitor their progress. As two of these participants stated:

> -when the sugars seem to be doing well you had that positive feedback so that you didn't mind checking your blood because you were hoping for another good result. (T)
>
> -I'm a lot more diligent and compliant...it gives me motivation, I like to see the nice numbers. (X)

Although the normal blood glucose levels were positive, "Q" strongly attributes the better glucose control to the islet cells and not to the support that a close relationship with the team provided, or the diligence with which she monitored and reported her blood glucose levels. She described how her blood glucose levels fluctuated a great deal before the islets and stated "without the islets they would still be all over the place", even with close monitoring.

Along with simplified blood glucose control, the functioning islet cells were also perceived or believed to slow, or decrease the complications of diabetes.

> -I felt things were much more stable that I didn't have anymore real worries about my eyes going some more and circulation seemed to be improved. (T)
>
> -the biggest difference is getting normal sugars, taking less insulin, knowing that maybe you have a grip on complications and not letting them get away on you. (Q)

Two participants also believed that the islet cells would help prevent complications or at the very least keep things stable.

> -...I mean I dealt with the eye problem and the kidney problem and I really hoped that things would hold because I still have my feet and hands and full sight, or pretty good sight. So I saw it certainly as an opportunity to keep things stable at that level at least and carry on. (T)

For those who achieved insulin independence, life changed dramatically. There were no longer the time and organizational demands of being on insulin. "T" described this transition with the following analogy:

> -I always find that diabetes and then throwing in all the complications that happen with diabetes is just juggling, it's always juggling...and with the islet cells there was just one ball, you were playing catch, you weren't planning on juggling five or six. (T)

"T" was able to clearly articulate the dramatic difference that the islet cell allotransplant made in her life. As she spoke, it became clear that most of us could learn to play catch, but not all of us could master the skills needed to be an accomplished juggler. It became apparent that persons with diabetes and especially those with diabetes related complications had to constantly strive for perfection in the way that they managed their lives, and that even letting up a little could result in everything "crashing down" around them. As "T" stated, "diabetics deal with extremes all the time, I mean we cope with them, it's just not fun". She talked about how normal blood glucose results helped to stabilize everything so that the constant watching and striving for perfection was no longer necessary all the time and hence, the opportunity to just "play ball". She and most of the other participants talked about the greater flexibility in their lives', and how they were no longer controlled by the clock and the necessity to eat and take medication and do things at certain unchangeable times. Ironically, having more control of the diabetes, gave them more freedom.

Four of the participants spoke about the freedom they were able to experience with functioning islet cells. Although this degree of freedom was related to the duration and quantity of function achieved by the islet cells, it did not diminish the importance placed upon experiencing this freedom, all be it briefly. Freedom included: not having to take insulin, flexibility in the timing, amount, and types of meals, and the opportunity to focus on other things besides the diabetes and its constant demands. As "Z" commented, "your diabetes was basically on a back burner". And as "X" noted, there was no longer "that constant demand on you to make sure you eat here and do all that. I still carry stuff with me, I think that's ingrained and I still think that's a wise thing to do,...but, it's not such a big focus anymore".

Along with freedom, there was flexibility. Flexibility came with the timing of medication, meals, and the amount and type of food that one could eat. Five of the participants found that flexibility with the timing and types of meals they ate was significant since, for most of their lives they had to eat at specific times, eat only from the meal plan, and watch the amount that they consumed.

> -as far as meal wise I've got a bit more leeway thanks to the islet transplant, and the timing, ...I can quite often go a number of hours later, and I can also indulge myself, you know with a nice big muffin for an afternoon snack and I don't have a problem...but I think the timing is the real big one, you don't realize how significant it is until you can go without, or like that stretching and, again, when I was sick this past winter, you know, sort of fluids on the hour and the blood sugars didn't go out of whack. That was kind of an eye opener. (X)

"Z" explained the relief he felt when he was able to have that flexibility in his life. He stated: "it was a relief. It was like tie your hands up with a rope and stay that way for twenty years, and then just for the period of a month we're going to untie your hands and put your hands in an elastic band, that's the relief you get...Just the little bit of flexibility you get that was never there before, was finally there and it was great....I finally wasn't under the regime of being diabetic. I didn't have to eat six times a day at specific times...life was a little different for that period of time too, so it was really good".

Every participant talked about how the functioning islet cells helped to stabilize their health and thus made them better able to cope. Z stated: "There was the flexibility with having the islet cells there and then that made coping a lot easier, coping with the stresses of doing everything all the time". Being able to cope with the day to day demands of living was "great". The fact that there was less concern about hypoglycemia and there were fewer ups and downs in their blood glucose levels increased their energy levels and also contributed to their ability to cope. As "X" stated: "I think even just that, (stable blood sugar levels), contributes to well being, you're not up and down...I think you're better able to cope with running around or scrambling around...without running down". With the increased ability to cope also came a sense of security, "Q" stated: "I'm coping better with my health and what's happening with it...I have less frustration..., most of the fear, the fear is not the same". Thus, coping also contributed to or was made better by the physical, emotional or mental, and social changes experienced by the participants.

The physical benefits of having the islet cell allotransplant were many. Participants described how they felt "stronger", "healthier", "better", and more energetic. The persons who had islet cell transplants after their kidney transplants were well established, felt they had more energy only after the islet cell transplant, and that they now felt "normal". As "P" stated:

> -I have been feeling very good, it's better than before. When I was without the islet cell transplant, I used to feel very weak, because my blood sugar was always high and I felt very weak, and sometimes I felt like vomiting, I had headaches and I felt very bad. And now you know it's different, it's better, everything is better.

"Z" also described in detail how his energy level improved after the islet cell transplant. He felt that now the cells of the body could use energy more consistently because the insulin was always available, and so his energy level was consistent all day long, it was no longer up and down, it was a "straight line and you can feel that inside your body".

Three of the participants stated that their visual acuity was better after receiving the islets, and two of those people were islet cell recipients well after receiving their kidney transplant. As "W" stated: "I was blind in my left eye and now I can see through my left eye. My vision is better now". Three participants also noticed improvements with their circulatory problems. "T" stated that her "circulation seemed to be improved", "Q" attributed her ability to heal a serious foot ulcer to the islet cell function, "well, the greatest thing is that my foot has been able to heal because I'm achieving a lot of normal range blood sugars...which is just phenomenal", and "P" stated that she has better sensation in her legs and feet and that she "used to have pains in her feet too and now I don't have that". "T" also found that her "female hormones" settled down and she had less PMS related symptoms, "even the hormones seemed to have settled down a lot, so my symptoms weren't as extreme...like real fatigue and PMS and all the cramping and the blood flow and everything else".

There was also a sense of overall wellbeing after the islet cell transplant. The participants believed that the islet cells gave their bodies a break from the detrimental effects of the diabetes and the related complications. "Z" described this change in his body as regaining control:

> -physically I just found that my body was in control of itself again, instead of me having to put control into the body...an islet cell transplant controls the entire day...in a diabetic every hour is a change, with the islet cell transplant there's no change...you don't have that up and down feeling all the time, the islets just smooth everything out and you feel a lot better. (Z)

"T" described this change as a "reprieve from further deterioration", and believed that the islets also contributed to her quantity of life, by a couple of years, due to this time away or reprieve from the effects of the diabetes. "Q" described this change as a means to heal and to reduce or prevent disabilities:

> -it's obvious that it's helped because of the (healing of my) foot, that's a visual, obvious thing. I wouldn't have been able to heal otherwise, especially on steroids and anti-rejection drugs...I think most definitely...that all the complications and problems I've had since my transplants would have been much greater. I don't think I would have healed or maybe made it through some of the stuff if I didn't have the islets.

The physical benefits were easily identified and most were specifically attributed to the islet cell allotransplant by the participants. The emotional or mental benefits, bonuses and gifts were numerous and equally as important to the participants. The emotional benefits included: less worry, more "stable moods", "smoother emotions", "feeling good about yourself", and feeling "normal", with a "vastly improved quality of life". Five of the participants identified that after the islet cell transplant they had more stable moods or "smoother emotions". They attributed this change to the stable blood glucose levels and two people stated that erratic blood glucose levels really "played havoc with you physically and emotionally". As "T" stated, her "moods felt much more stable...it's just if your sugars are high and you start being crabby in certain situations well you handle it much differently than when you're at normal levels".

The physical and emotional benefits were strongly correlated. As "X" stated, the freedom and the good blood sugars were special, but that "maybe psychologically too, being special and feeling good about yourself has to have some sort of positive impact". This "feeling good" also helped "Q" feel like she was "normal" and allowed her to be "more involved" than she had been while on dialysis.

This improvement in overall physical and emotional wellbeing also enhanced quality of life. Most of the participants defined quality of life as "feeling healthy", "productive", and "being able to do what you want to do". One person also defined it as "not having to look death in the eye everyday", and another person stated that quality of life was strongly related to ones overall health. "X" stated that it was "hard to dissociate the kidney from the islets, but quality of life improved with both, and with the islets, the freedom you had and the good blood sugars were part of that experience". "Q" stated that the quality of her life "improved vastly" after her transplants and she no longer felt like she was "disintegrating" or "deteriorating" daily. As most of the participants viewed quality of life as both mind and body wellness the cognitive benefits were also part of their holistic view of health.

The mental or cognitive benefits included: "better ability to concentrate", feeling more "focused and alert", faster and better "ability to think", and believing this was a "miracle". This increased ability to think more clearly or concentrate for longer periods of time was, for many, clearly related to the islet cell allotransplant and the resulting decreased swings in blood sugars, as opposed to the kidney transplant.

> -Concentration for long periods of time. With the concentration of that, I found after the islet cells transplant for about a period of a year or a year and a half, I was able to do that constantly (showed me some very intricate work he was doing), for twelve, sixteen hours a day, now I find I can only do that detail of a technique for periods of three or four hours at a time then I have to stop and I have to let my brain rest and this has all got to do with diabetes, because it affects the concentration levels. (Z)
> -(because of the now normal blood sugars) I can think better, faster, you know and I don't get so upset or nervous. (W)

Social benefits, although not as extensive, were also very important to the participants. "Z" found that he had increased social contact following his transplants. This may have been related to his increased contact with the media because of the islet cell allotransplant which he believed expanded his social circle and allowed him to be more involved. However, "P" found that she was more involved with her friends since the islet cell allotransplant, and "X" stated that she continued to talk with her friends about her experience and shares information that she hopes might help someone else. "T" found that she had the energy to be more involved in her community and social activities, and "Q" was able to be more involved in family activities. As she stated:

> -just to be able to spend the day with them or to open the curtains and enjoy the day, before,...I felt too sick, my eyes were too bad, I couldn't stand up, I was too dizzy, just everything, I couldn't do it, so, it means a lot.

The benefits, bonuses and gifts experienced by each of these participants affected "deeper" aspects of their lives. They were able to hope again, believe in a future which was not there before, and had faith that they were not "going to be sick all the time", and thus could reengage in life.

> -with the kidney transplant and the islet transplant it was just like, oh my goodness, there's lots more to go for, there's still lots more ahead, so it was certainly much more positive. (T)

Along with having a future, most of the participants felt that they were "special", "privileged", "fortunate", or "lucky", to have received the islet cell allotransplant and that this in and of itself had been important.

> -it was kind of neat you know being one of the few people in the world to get off of insulin entirely, it was pretty special. (X)
> -you were surprised that it was you...it was such a gift and you wondered why it was you, and I could feel myself feeling almost over privileged. (T)
> - it's a big responsibility as well as an honour. I feel very privileged and I feel very fortunate that I was chosen...part of me hopes that miraculously the islets are going to cure me. (Q)
> -It was a good, a big thing. Because there are so many people that are diabetic and to take me you know, I don't know why they did but I was glad they did take me. (P)

The benefit of insulin independence was special to those that experienced this change in their lives, but for all of the participants, the normal blood glucose levels have been the real key to feeling better, to having better overall health, and to a better life. As "T" stated:

> -the two years that I had without insulin was really quite liberating, very liberating. It was almost shocking to sort of eat food and test your blood and have a normal reading and you know to have normal readings every time you do your blood test was really quite phenomenal.

"T" was very disappointed when she had to go back onto insulin but for "X" it was the glucose control that was more important, which she has been able to maintain with small doses of insulin.

> -it's just been a real learning opportunity and like I say, the control. Anything that's going to help your diabetes control has got to be good. (X)

"W" believed that the islet cells were a real benefit and that they changed his life. He has spent less time in hospital and has more time to himself since he received the islet cell allotransplant. "Q" and "P" also stated that they have experienced a tremendous improvement in their overall health and attribute this to having better blood glucose control since the islet cell allotransplant.

> -I really appreciate the gifts I've gotten, I really want to enjoy the quality of health I do have now...it seems silly, but it means everything just to have a good day. (Q)
>
> -once you feel healthy that's one of the best things, once you feel healthy, everything else is fine. (P)

The benefits, bonuses and gifts were many, and were important and life changing. They affected how the participants viewed their future and how they viewed the islet cell program. This experience as a kidney and islet cell recipient influenced how they would view this opportunity in the future and thus affected what they would do, if they could do it again.

Doing It Again - Looking Forward, Looking Back

"Doing it again - looking forward, looking back" is described as the response that the participants would have when asked the questions; "would you do it again?", and "would you recommend the islet cell transplant to others?" The impact that the islet cell transplant had on each of the participants' lives was significant enough to affect their response to these questions, and seemed to cause them to review what they experienced, and speculate on what may be in store for others in the future.

With unwavering certainty, five of the participants stated that they would be willing to have the islet cell allotransplant again. As "T" stated, "I wouldn't hesitate to have them again if I was eligible". She is hoping that she will be able to get another islet cell allotransplant at the time of her next renal transplant and she is "certainly looking forward to that". For all five of these participants, there was "absolutely no question" that they would go ahead with the islet cell transplant again.

For one of the participants however, there was a great deal of hesitation and uncertainty about having the islet cell allotransplant again. She was fearful that the islet cells somehow contributed to the chronic rejection and loss of her kidney transplant and she does not what to jeopardize another kidney. She stated:

> -If I was asked to do it again I don't know if I would. You know it would take a lot more soul searching than it did the first time around, especially if I'm thinking well I need another kidney and chances with the second kidney, the life usually isn't quite as long as with the first transplant, I'm

> thinking well, if you add islets on top of that, I don't know what I would do. (X)

On the other hand, she does "not regret having the islets, but if there is any chance that another shot of islets would interfere with the life of a second transplant I wouldn't, no". Interestingly, she does want to maintain the islet cell function she still has until she receives her next kidney transplant and beyond. She does not "see any necessity to boost the number of islets" to make her insulin independent as she feels she has very good control of the diabetes and her C-peptide levels and HgbA1C levels are good. I did ask her what she would do if she lost the islet cell function between now and her next renal transplant and she stated that she did not know, that that was a "tough one", but that she would like to see "a stable transplant first, wait for them to work on the...islets and then go for some more". Her greatest concern was jeopardizing another kidney. When asked if she was concerned that the islets she has functioning now would jeopardize her next kidney she stated, "yeah, but the way that I look at it ...was that there is really no guarantee that a second kidney won't reject...so I've got the islets, I'd like to at least hang on to one thing, I'll keep them".

As far as recommending the islet cell allotransplant to others, five participants stated that they would recommend the procedure and one person stated that it was too personal a decision for her to recommend it to anyone else. Although the five participants would recommend the islet cell allotransplant, they also expressed the importance of being well informed before making the decision. The participants wanted new comers to the program to know that: it may be "risky to the renal transplant", that they may "have a longer incision than originally planned", and to "really stress the protocol" so that they would know how much "time, dedication and discipline was required" to be in the program. Overall, there was great enthusiasm for the islet cell allotransplant experience and a desire to not only benefit from the experience again themselves, but to share this experience with others. The enthusiasm for what had happened to each of the participants, was tempered by the reality of the situation however, as they lived with ongoing concerns.

Ongoing Concerns

Ongoing concerns are those that the participants lived with from day to day related to diabetes, the kidney/islet transplant, the islet cell allotransplant or life issues which were affected by their experiences. Although there were many positive aspects to having the islet cell allotransplant, each of the participants has experienced new or ongoing problems related to their health that continue to be, or are again a concern.

Most of the participants were afraid of the development or the progression of diabetes related complications and one person talked about how she feared living through the same experiences again.

> -my big thing is the fear of complications...I have a fear of what I've gone through already and I've a fear of the future or reoccurrences, I still have fear that if I get out of control I'll lose my kidney, lose my feet, lose my eyes. (Q)

Two people talked about how control of the diabetes was the key to preventing complications and to keep this experience from happening again. They believed that normal blood sugars contributed to a better life and the more normal the blood sugars the better off they were. They were concerned that lack of control of the blood glucose levels would have negative effects on their health. Two of the participants also had to deal with the loss of sensitivity to low blood sugars. Without that "safety net" as protection, very frequent blood glucose monitoring is necessary to try and identify any low blood glucose levels. "T" found that she was frustrated after she had lost the islet cell function because of erratic blood glucose levels and she took the blood glucose levels personally. She stated that it was hard to think of this as feedback, it was just negative, and she continually asked herself, "what did I do wrong now?" Essentially, all of these people placed a great deal of value on normal blood glucose readings and were concerned whenever there were fluctuations. Most equated normal blood glucose levels with well being and good health.

Two people also discussed a more global concern about the lack of knowledge and understanding that society has about diabetes. They expressed frustration about how some people still think that insulin is a cure, or at least a way to control diabetes, and therefore, people with diabetes do not have as many concerns. One person also expressed how most people do not even know that there are complications associated with long standing diabetes. Along with the concerns associated with the diabetes, the participants also had ongoing concerns about the kidney and islet cell allotransplants.

The kidney and islet cell allotransplant concerns relate to the effects of the two transplants on each other, effects of the transplants on other organs, and the rejection of one or both of the transplants. At the time of interviewing, one participant had lost kidney and islet function, one had lost islet cell function, two were experiencing chronic rejection of the kidney but continued to have islet cell function, and two continued to have islet and kidney function with the assistance of small doses of insulin. For the one person that lost islet cell function, he was disappointed but had not expected the islets to last and was now hoping to be eligible for a second transplant. The person who lost islet and kidney function was very disappointed by the loss of both of the transplants. She stated that she really grieved the loss of both, but that the kidney was the "big thing at the time", and that she now realizes how important the islet cells were to her. The two who were experiencing chronic rejection of the kidney but continued function of the islet cells viewed their experiences quite differently. One person believed that the islets had nothing to do with the chronic rejection. He saw it as a separate issue but was not even sure that he was in chronic rejection since increasing his water intake seemed to normalize his kidney function. For the other person with chronic rejection, her feelings were quite different. She was not sure, but thought that the islet cells were possibly causing an accelerated rate of chronic rejection of her kidney.

> -so far I don't know that there's been a down side or any ramifications although some people think that the diabetics that get the kidney and the islets tend to have a more aggressive chronic rejection of the kidney. And I'm afraid that's my case now. You know the chronic rejection seems to be very much more accelerated, than diabetics that don't get the islets...And, a couple of the studies I've heard of relate more in animals or whole pancreas, but that there was a relationship between sort of like an increased immune response or an increased

> immunogenicity with the two being transplanted. So now that I am in more of a chronic rejection, I'm wondering if the islets had something to do with it. (X)

For the people who continue to have functioning islet cells, any high or erratic blood sugars make them fear that the islet cells are going to reject. Those with kidney function are always concerned about rejection of their kidney.

One participant stated that he was concerned that the islet cells were making his liver work too hard and he has had problems with excess blood production since the islet cell allotransplant.

> -Sometimes I feel like my liver is working too much, because before the islet cell transplant I didn't have that problem with my blood. Now, I have to go every six months or every four months to take away that blood. Maybe it's because they introduced something in my liver. (W)

Rejection of the transplants is, or was, the main concern for all of the participants. The loss of the kidney and/or the islet cells was something that they thought about a great deal and that they all feared. Rejection was also identified as a relatively common occurrence and could be brought on by even a simple cold.

> -Well I've got significant damage because of my rejections...which causes me a lot of trepidation, and of course the concern as other transplant patients, of going into rejection just getting a simple

> cold...Rejection is quite common, it's a scary thing. (Q)

Along with the concerns about rejection, one person talked about how she was concerned that the medications to prevent rejection could also damage the islet and kidney transplants and how any change in her health status or medications scared her. Some of these concerns also carry over when looking at the islet cell allotransplant on its own.

When asked about concerns relating to the islet cells alone, the participants shared some very significant ideas about the experience, the follow-up, and the program. Only one person felt that persons coming into the islet cell program, especially after a stable kidney transplant, should be cautioned about the specific immunosuppressive risks. She felt that they should probably worry about the need for increased immunosuppression with the introduction of the islet cells and as "X" stated:

> -is that going to have any effect down the road on your kidney should you go into rejection and need more immunosuppressive drugs. Quite often if you use one once, you can't use it again down the road so that might limit your choices and chances if you go into some sort of rejection with your kidney. That would be my big concern I think.

She did go on to say that she did not regret having the islet cells but that would be a concern now if she was going into the experience after a kidney transplant. Interestingly, this concern was not expressed by either islet cell recipient who actually received their islets after a stable kidney transplant.

One person expressed concerns about how the follow up testing affected the islet cells. He was concerned that the Sustacal® challenges that were done monthly to confirm the level of function of the islet cells were actually stressing the islet cells too much. As "W" states, "the cells are going to get tired", and he feels that test is not necessary all the time. Other concerns about stressing the islet cells were expressed by "Q", who was concerned that rejection episodes of her kidney, the immunosuppressive drugs, and any other health problems, also stress and damage the islet cells. The islet cells were seen as very important and for the most part, the recipients who still had functioning islet cells were afraid to lose them.

Concerns about the program were also very important. Two concerns were shared; one dealing with letting the program down, and the other with the lack of support for the program. It was very important for the program to be recognized as worthwhile and participants worried that if they were not successful recipients, then the program would be seen as unsuccessful.

> -I really worry about letting the program down...everybody who's worked so hard and I don't want people to think that it's not a viable program. I really want it to be successful as a type of cure. That's really important to me. (Q)

The second concern about lack of support for the program was related to the nephrology department withdrawing support and no longer encouraging their patients to participate in the research. One participant who was back on dialysis and really wanted to receive islet cells again with the next kidney transplant had been advised against it. She emphasized how diabetes had affected and continued to affect her life and how even though the renal failure was important, the diabetes always had a part in everything she did.

> - I think maybe some of the other concerns sort of come from the out side. It seems with the kidney specialists, they really don't have a supportive role behind the islet cells which I find really unfortunate. And so that I think will start to show a little bit more and people will find that, that happens. And I guess that's what I was finding because along with the kidney being very important to me, the islet cells were very important to me as well, my concern with it I don't think was matched by the kidney people that were doing the surveillance with that. So it was interesting, cause, I guess your diabetes is always sort of foremost in your mind with planning and stuff. And even though the kidney maybe more important at the time, you still carry the importance of the diabetes with you. You still have to work it out. (T)

Along with concerns about the program moving ahead, some of the participants expressed concerns about personally moving ahead as well. All of the participants who were unemployed at the time of the interview expressed a desire to return to work in some capacity, though there were concerns by some on how working might effect their health. One person was concerned that going back to work would jeopardize his health and another participant was concerned that if she got sick after going back to work there may not be medical aid or support available to her. These were real concerns and fears about reentering society and the work force after a long period of illness and disability.

The ongoing concerns expressed by the participants were important and pervasive. No matter how well things were going for the participants, there were always concerns that had to be addressed. Along with the above concerns, other concerns expressed revolved around family issues and support which will be presented in the next section.

Effects on Family and Others, Making it Through

Effects on family and others, making it through, looks at how living with diabetes has affected not only the individual but also those with whom he/she has come in contact. These effects are interwoven throughout the persons lifelong experience of living with diabetes. Although participants recognized that the ability to make it through all of these experiences has depended on the support and love of others, they equally recognize that living with diabetes has led to losses and some hardships. The impact of diabetes on family and others will be looked at through the phases of living with the diabetes. The family response at diagnosis, the affect of diabetes complications, the islet/kidney transplant, and the present situations.

At the time of diagnosis, most of the participants remember some effects on their family. There was a need to learn about diabetes, diets, and medications, which led to lifestyle adjustments. Family members, and particularly mothers, had to learn a great deal and make the necessary adjustments to meet the needs of a child with diabetes.

> -my mom, when I was a kid, she had to go through a lot of different things, always going to the diabetes seminars and learning how to cook

> the food...she was the only one at home and it was really hard for her at that time because they didn't have the teaching and they didn't have the teaching facilities that they have now. (Z)

With the exception of one participant, other immediate family members were rarely mentioned except to say that they had to adopt the diabetic meal plan. "X" believes that her mom was too afraid of diabetes and so her older brother assumed the responsibility of educating her about her diabetes.

> -my brother was the one who actually took me to the doctor and kind of educated me with the things you are supposed to do and there weren't really classes as such that I can remember...my mom has never been very knowledgeable, I think she was very afraid of it so my brother did most of the educating. (X)

"Q" remembers that although her parents wanted her to be as normal as possible, they also were very protective of her.

> -my parents also picked up on that and they wanted me to be normal so they treated me as normal as possible...however, they always had an underlying fear that something would happen to me and they protected me from a lot of things. (Q)

As these children grew up, married, or entered relationships and tried to have what we would consider to be a normal life, they eventually developed complications of diabetes, and relationships started to change. For some, relationships with family and others became closer and the participants believe that it was the love and support of these people that got them through the difficult times.

> -I had people around me that were very supportive with all the things I was going through. (Z)
>
> -Wonderful support from you know, everyone...you need support. (X)
>
> -Socially I've had a lot of support, both from old family and friends, and I've made a lot of really wonderful friends...that part is definitely the plus side. (Q)

For others, the complications not only meant loss of health but also the loss of relationships. Two participants believed that their marriages ended largely due to their health problems. "Q" stated that losing her marriage because of her health really "embittered" her and although "Q" and her ex-husband have struggled to be amiable, it has been very difficult.

> -most people including myself feel that it (the divorce) was directly related to my health...I couldn't keep a house the same way anymore, we started fighting, I wasn't working, money was tight...He's always kind of stayed in the picture and helped out. (Q)

"Q" also believes that she lost her best friend because of her health problems.

> -And my then best friend told me she just couldn't handle the stress of all the major things that were happening in my life. She just couldn't handle it. (Q)

Two other participants also believe that their spouses were very affected by the situation at the time. The spouses had to assume all of the responsibilities during this very difficult time and for a while, put their own lives on hold.

> -I'd come home and that was it, I couldn't do anything, so he was doing all the grocery shopping, cleaning, you name it, everything, cooking. So it was a real burden on him too, just, you know, I would come home and conk out, and then he'd have nobody to share the usual sorts of things and activities and problems. (X)
>
> -at one point when I was quite sick before my first transplant, my husband was not living his own life. He was sort of waiting for things to happen, either for me or to me or whatever, and I'm pretty sure he put his life on hold and then I think we finally had a conversation about it and he finally realized that he had to sort of still go on with plans and hopes and dreams for himself. Maybe it wasn't for us but, and so I think it was a turning point for him to realize that he had to still keep going with his life even though things looked devastating for me at the time. What I think he was waiting for was sort of, things were on hold until I was better and then we could all do things, and so it took a part of realizing that they still had to carry on with their life and that things were still going to happen with me one way or another. (T)

Three of the participants believed that their children were negatively effected by their deteriorating health. They describe their children as "living under stress", "neglected", and as kids who have "lost out". As "Q" stated about her children: "they take care of me more than I take care of them, and I think that's really hard".

> -I think kids end up damn near looking after themselves a lot more...And my daughter, there's a lot of stress for her to deal with, and she's just learned to cope with it and sort of ride along and fortunately she seems to be the kind of kid that's sort of tucked in her own little head, which may be her saving grace, I guess. (T)
>
> -I think for the kids, I think they're the ones that have lost out. Sure we're big people and we sometimes can't cope, but I don't think it was fair to the kids. (Q)

One participant realized, after the fact, that her daughter, who seemed to be coping with everything so well, really was hiding away her feelings, and at one point finally allowed her feelings to emerge but by that time, she had to deal with a severe depression which required hospitalization and treatment. "X" stated, "four years later, and she's still coping with it. Doing much, much better, but I think she was the one who really suffered for it". And "T" stated that she sees her daughter needing more but she "can't give it and she feels bad".

As well as individual effects, the family as a unit also had to deal with issues. Most of the participants identified hardships that the family had to endure on account of their health problems. These participants were concerned about how the family was burdened and often unsupported during a very difficult time.

> -As the patient you do what you need to do, but it's the family that feels they're helpless...I think it's probably harder on the family...Everyone was miserable and in pain, in their own little closet cause they didn't want to hurt anybody else. You think you're protecting the rest of the family in shielding them, but you're all just making it worse for everybody. (X)
>
> -I think they (the family) ended up being neglected because it was kind of focused on me all the time. (T)
>
> -It's been really hard on them, my whole family...I don't feel like a burden, I feel like it's hard on their hearts. (Q)

Three of the participants talked about how they felt guilty when their health problems directly affected their family and others. The ever present health problems cut into time for vacations, and limited involvement with their children and activities.

> -Where I felt the guiltiest was how it affected the family. You know I didn't do a lot of things that I think I maybe should have. There's a lot more guilt associated with what the family has put up with, than with how I treated myself, because it affects other people. (X)

"T" believed that people don't really know what it is like to live with diabetes until you actually have to live with it. She stated that diabetes is "a pervasive thing, it's into everything" and because of the nature of the disease and the health problems, she was left to make a lot of decisions that effected the entire family. "Q" stated that even though her family loves her she feels she has no control around them and now that she is feeling stronger she finds that she has to set boundaries so that her family does not engulf her or keep her trapped in a sick role.

Once the transplants were completed and the islet cells were working, most of the participants stated that the islet cell allotransplant had a positive impact on the family. For "Z", he found that his mom worried less about him when the islet cells were working. His mom had always worried about him living alone and having an insulin reaction or that he would get sick and no one would find him. After the islet cell allotransplant, his diabetes was more stable and he experienced fewer blood glucose swings so his mom felt he was safer during that time. "X" believed that the islet cells affected her family in a positive way. Her daughter bragged about her mom having the islet cell allotransplant and "she was really excited when I was off insulin and it was kind of a family project, like what are the numbers and everybody follows the progress". "Q" felt that the islet cells gave her family hope. She stated: "I know it does my family good to see the good days".

For the participants that either have decreased or lost islet and /or renal function, they are now having to face a new or reoccurring set of concerns that again is affecting their families. "X" has had to face not only her own losses but also has had to tell her daughter that her kidney will soon stop working and that she will have to go back on dialysis. Her daughter wants to donate one of her own kidneys to "X" and this has created more concerns since "X" believes that her daughter is trying to "fix" her mom, but in doing so, "X" fears that it could "make or break" her daughter. "X" is concerned that her child is trying to assume too much of the responsibility for 'mom' and notes, "she's felt far too responsible for me as it is". "T" has also expressed concerns about her family and she feels that even though they have been coping, part of that so called coping "maybe by denying stuff".

Most of the participants believed that individual and/or family counselling or professional support did or would have helped them get through the experiences of living with complications and the transplant experience more effectively and with a lot less problems and issues to deal with during or after the crisis was over. Two participants recommended that a psychiatrist or a social worker be involved from the time that complications were diagnosed to work with the patient and the family. The participants identified the need for someone to help the family face the problems and work through the feelings and emotions associated with diabetes, complications and transplantation. It was recommended by three of the participants that a nurse or nurse clinician would be a great help in pulling all the information together and explaining the situation to the patient and /or family. The participants identified the importance of having health care professionals who they could go to, to ask questions and for support.

> -...it doesn't have to be a doctor, it could be a nurse or nurse clinician or whatever term it is, but somebody who does have a little clearer picture of yourself. That's the other thing I think, trying to have somebody that is following you that does have a clear picture of yourself, now maybe some people utilize their general practitioner but

> I've been going to so many specialists that I haven't even been seeing my GP, and so it would be nice to see somebody that tied in a little more seriously all the avenues that you're looking at, if it's kidney and it's heart and it's diabetes, somebody who could pull it a little more together, because specialties really do stay chunked in their sort of corner, I guess I'd feel a little more whole if it was somehow encompassed more, or somebody had a handle on everything fitting together. But sometimes you get feeling disjointed because you're just seeing different guys that don't put an emphasis on this or you know, the kidney guys really concerned about the kidney, not too concerned about the islets or whatever, so it would be nice to sort of get a feeling that you were looked after all together. (T)
>
> -...somebody who could dedicate the time to be kind of a counterpart in it. I think that really helped and kept me going because it's hard to be dedicated, test and record and do this and do that. So I found that kept me on track, which I think is important. (Q)

As "Q" also stated,

> -keep the patient happy and I think the happier, the more they'll work on the protocol to give it their best foot forward...the more contact the more results they're going to get.

The intricate relationships that the participants had with their families others, and especially the health care team, were very important and influential in how they coped during the different phases of their lives.

Summary of the Experience of Becoming an Islet Cell Allotransplant Recipient

Living with IDDM began at an early age for each of these participants. At the time of diagnosis, the need for diet, insulin, and urine testing were presented to each of these people and their families. Home blood glucose monitoring did not exist, and most of these participants stated that they essentially felt good and consequently did not pay much attention to the diabetes and the importance of watching it closely. "Cheating" was a major part of their vocabulary from very early on in life and wanting or eating certain foods was equated with being "bad". As the years went by the quiet, destructive nature of diabetes became more and more apparent. A complex disease that potentially results in serious complications, became a reality. Each had some degree of retinopathy, and as a result, one participant is blind and the others have had some laser treatment to stop the development of new blood vessels. Each participant has lived with the devastating effects of renal failure, endured the demands of renal dialysis, and some feared that the end of their life was near. Although one person did relatively well while on dialysis, the others all described the urgency with which they required a kidney transplant and how they were never sure if that opportunity would come in time. Following the loss of renal function and subsequent dialysis four of these participants were approached to participate in a research project. They were presented with an opportunity that only few had experienced and many could only dream about or hope for. These participants were asked to be islet cell allotransplant recipients. Although they were told that this was an investigational procedure, it provided hope for all, as a possible cure for others, and it presented an opportunity to possibly win the "battle" against IDDM. The other two participants were presented with this opportunity after having had a kidney transplant that had been stable for at least two years.

Although none of the interviewed participants felt there had been much need to reflect on their decision, each expressed a desire to be part of research, most expressed a desire to help others, and all hoped that the procedure would help them in some way. If it worked it would be a bonus, a gift, or even an answer to their prayers.

The islet cells were transplanted the day after the renal transplant for four of the participants and at least two years after their renal transplant for the other two recipients. All described the procedure as essentially painless and most were grateful to be able to be awake to witness the momentous event. All the participants believe they have benefited from this procedure, none regret having taken this chance, and all but one would be willing to have the procedure done again. That one person was hesitant to have the islet cells again but hoped that she would be able to maintain the function of the islet cells she has while waiting for a second renal transplant.

Each participant described the relief and sense of control they felt throughout the time that the islet cells were functioning. The euglycemia had a tremendous impact in at least one of the physical, emotional and/or social components of their lives. Three of the six participants were completely off insulin for several weeks to two years. This experience of being insulin independent has, been "a release", given these people more flexibility, and has lessened the burden and responsibility of "juggling" all the components needed to control diabetes and the related complications so they could just "play ball". Some of the benefits have included; improved vision, decreased leg pain from neuropathy or intermittent claudication, improved ability to concentrate, improved to excellent blood glucose control, more flexibility with meal content and/or timing, and less demand on time dedicated to controlling the diabetes. The sense of being "normal" became more real.

The effects of the diabetes and especially the complications of diabetes had some serious effects on the families and relationships of these participants. The emotional, physical, and social losses of some of the participants were tremendous.

Each of these participants now have ongoing concerns related to their own health situation, and have some degree of uncertainty about the future. Some have lost the function of their islet cells and three of the participants are now dealing with the rejection of their transplanted kidney. The need to take immunosuppressive drugs have many concerns associated with it as well. Yet with all of this uncertainty, most are certain that they would do it again, and two participants are hoping to receive islets again in the near future.

The magnitude of this experience as not just an event but a part of the greater whole was very apparent as participants described their life with diabetes and talked about the desire for a cure or to just have control of their blood glucose to prevent or alleviate the complications of diabetes. As one person suggested, the diabetes was not a problem to live with, but the complications were devastating. The islet cell transplant gave them a chance at something better.

Chapter Five: DISCUSSION

In this chapter each category presented in the findings chapter is discussed, and the findings are compared with existing literature. As well, implications of this research for nursing practice, restrictions of this study, and suggestions for future research will also be outlined.

Discussion of the Findings by Category

The Context

Becoming an islet cell allotransplant recipient was best understood within the context of living with insulin dependent diabetes mellitus and the trajectory of this disease. The context provides us with a picture of the life long demands of living with IDDM, and offers us a deeper understanding of what living with diabetes meant to these participants. Here it becomes clear how the day to day, hour to hour, minute to minute demands of IDDM can be all consuming. Callaghan and Williams (1994) found that people who live with diabetes are required to be the managers of their illness because the management required is "a day -to-day, moment-to-moment issue" (p. 136). Similarly, Armstrong (1987) found that the "intricate, complex, and time consuming actions necessary to ensure that food, exercise, and insulin are in the right proportions to result in glucose homeostasis are among the most demanding daily regimens of any chronic disease" (p. 563). Not only is the daily management time consuming, but there is a sense of tedium associated with it, as one has no release from the ritual (Lundman, Asplund, & Norberg, 1988). This complexity is reinforced by Warren-Bouton, Auslander, and Gettinger (1982) who studied a group of nondiabetic health care providers as they tried, unsuccessfully, to follow the dietary, medication, exercise and testing tasks of day-to-day diabetes management over a period of four days.

Participants also identified the silent destructive nature of this disease, with its uncertain outcomes. Participants in a study by Callaghan and Williams (1994) discussed the impact of diabetes on their lives and also characterized their lives as lacking in spontaneity and filled with uncertainty particularly in relation to the illness trajectory and the threat of long term complications. Due to the silent pervasive nature of the diabetes, the participants also identified how it could, at times, be ignored without realizing the damage that might occur. Haire-Joshu (1992) identified that few, poorly compliant adolescents with IDDM realize that they are risking their future health, as few of them experience any immediate health consequences as a result of paying minimal attention to their diabetes regimen.

Every aspect of the participants' lives involved control. Controlling the amount eaten, controlling medications, controlling blood glucose levels, and controlling activities, was a constant pursuit for these participants within the context of trying to live their lives. Price (1993) also found that control was an important component in self management where one tried for control over the diabetes, the process of attaining or maintaining control, or the choice of an acceptable level of control and the activities that would allow them to reach that goal. Callaghan and Williams (1994), as well as Price (1993), found that blood glucose control was a central issue for participants in trying to attain control of their diabetes and their life. As Hernandez (1995) noted, the diagnosis of diabetes brings with it a regime that impacts the daily practices and lifestyle of the individual.

Control was often very difficult to achieve however, and so these participants talked about experiencing frustration, trouble coping, and feeling guilty about how diabetes affected the rest of their family, and about lapses in control and subsequent "cheating". Armstrong, (1987) stated, "worry, fear, and, guilt are not uncommon responses to the implications of diabetes. Major lifestyle changes and the drastic complications that may occur if "good" health behavior is not forthcoming" (p.561) can be very stressful for the individual, family, affect work, and decision making. Cheating was a term that participants equated with a "bad" person or a "bad" diabetic. Williams Hoover (1983) points out that "most patients are not out there wantonly cheating. They want those normal blood sugars even more than you do. What they are doing is trying and failing over and over again. It gets pretty discouraging" (p. 42). Haire-Joshu (1992) stated that "adequate knowledge does not guarantee that adults will adhere to the schedule that living with diabetes demands. In addition to readiness, willingness, and overall motivation, family support, and cultural factors are critical determinants of patient motivation and adherence" (p. 499). Although there is much written on the topic of compliance and adherence, few studies have looked at these issues from the patient's perspective. Roberson (1992), however, conducted a qualitative study that looked at the patient perspectives of compliance and found that compliance and noncompliance were influenced by a number of factors including; a complete understanding of their condition, socioeconomic factors, social concerns, fear or dislike of the treatment regimen, and the belief that God would guide and look after them in whatever they decided. Self management in this study seemed more a means of meeting personal life goals and situations rather than noncompliance. Essentially, the participants sought treatment approaches which were manageable, livable, and effective. There seems to be a need for flexibility and fluidity in managing chronic diseases such as diabetes to allow for adaptation to life events and situations. Price (1993) also found that self management experience and process is a total life experience not limited to tasks and cues related to physical needs.

Most participants talked about waiting for a cure, and/or feared the complications of long standing IDDM. Many studies identified the fears that people with diabetes have about the development and/or progression of complications (Armstrong, 1987; Callaghan & Williams, 1994; Haire-Joshu, 1992; Davidson, 1986).

The experience of living with diabetes is generally well supported in the literature and this study provides further support for the findings of other studies. Essentially, living with IDDM is an ongoing challenge where the participants face many ups and downs, fears, and successes along the way. As time passes, the efforts to be "normal" were met with even bigger challenges as the participants faced diabetes related complications.

Living With Complications, Life in the Balance

Diabetes related complications are a painful reminder of the devastating effects that diabetes can have on the body and the lives of those with the disease. Living with complications, especially life threatening complications, is living life in the balance. Each day, even every moment can be difficult, and for most of the participants, it was a struggle to even hold onto life. There are many potential complications related to diabetes and commonly they occur sometime after fifteen years with IDDM (Haire-Joshu, 1992; Lodewick, 1984; White & McNatt, 1992), which was the situation for these participants. The types of complications associated with long standing IDDM, along with the symptoms, sequela, and the relationship to diabetes management, are all well documented in the literature, as is the research associated with the prevention and treatment of these complications (Davidson, 1986; Haire-Joshu, 1992; Hoops, 1990; Skyler, 1987; Wang, Lau, & Chalmers, 1993).

The literature offered little information on the experience of living with diabetes related complications from the patients' point of view. In fact, only one research article was found that specifically dealt with this experience. Ternulf Nyhlin (1990) conducted a qualitative research study which specifically looked at the experience of people living with diabetes related complications, however, most of the findings centered around general emotions and concerns rather than how a specific complication impacted the participants' lives. Turnulf Nyhlin (1990) found that living with complications was a "continuous balancing process" (p. 1023) of dealing with uncertainty. Strauss, Corbin, Fagerhaugh, Glaser, Maines, and Suczek (1984) also found that the gradual changes implicit in the phases of a disease may be predictable, but that the timing and severity tends to be uncertain. Hilton (1992) found that uncertainty is threatening because a clear perception of what will happen is not possible and that uncertainty limits the sense of control and increases the sense of helplessness. Weems and Patterson (1989) also found that uncertainty was a major challenge for patients waiting for a renal transplant. They found that most participants asked the questions "when or will I get a kidney?". As well as uncertainty, these investigators also found feelings of ambivalence amongst the participants as they tried to decide if a transplant would be the best thing for them. Strong ambivalent feelings were also present when thinking about who the prospective donor might be since that person would have to die in order for the participant to receive a kidney.

The development of diabetes related complications was a turning point for these participants. Though complications progressed at varying rates the effects were, for the most part, quite devastating. Jacobson, Lawrence and Hauser, (1985) found that the often experienced failure of attempts to control the diabetes and the resulting complications may be a source of despair, anger, and frustration. It became apparent that persons with diabetes related complications had to constantly strive for perfection in the way that they managed their lives. Since perfection is essentially unattainable, there was often frustration, associated with trying to manage the diabetes, or there was just a sense of "why bother" and giving up. Kyngas and Barlow (1995) found that guilt about diabetes control was common and often extended from unrealistic goals and expectations. Williams Hoover (1983) in her article on patient burnout strongly articulates the perfectionistic demands of trying to manage diabetes, "from the moment a person develops diabetes, for 24 hours a day, 365 days a year, for the rest of his life, he is responsible for managing the unmanageable, controlling the uncontrollable, and coping with the incurable-his diabetes" (p.41).

The deterioration of the participants' health occurred over time leading to retinopathy, then renal failure, and the need for renal dialysis. Wulsin, Jacobson, and Lawrence (1987) stated that patients with long standing diabetes are sometimes afflicted with multiple complications and live with an increased risk of death. Most of the participants found life on dialysis to be difficult and felt they had no improvement or were worse on dialysis, so much so, that some feared that they were dying. Beer (1995) found that even though the patients in her study accepted the need for dialysis, they had considerable difficulty adjusting to the loss of control and the disfiguring changes that occurred to the body. Juneau (1995) states that one of the psychological issues prior to transplantation is fear, fear associated with dying before or after the transplant, pain, or of not living long enough to get an organ. These findings were also supported by Porter, et al. (1991) in their case study of three patients waiting for a heart transplant.

Along with fear, two people also felt they were more confused and lacked clarity in their memory while on dialysis. Acceptance of complications and particularly dialysis was difficult which eventually led to depression for two of the participants. Essentially, it was difficult admitting something was wrong which in turn made it more difficult to adapt to the changes needed to survive. Juneau (1995) found that a prolonged stress response can lead to anger, depression, and withdrawal. For some of the participants, depression and withdrawal were certainly factors influencing their ability to cope with complications.

Complications had to be balanced with the diabetes leading to increased demands on time and energy, and ultimately to social isolation. Hoothay, DeStefano, Leary, and Foley-Hartel (1990) also found that the diabetic with end stage renal disease faces additional dietary limitations, a more complex medical regimen, and dependency on machines for survival. As well, in a case study conducted by Peace (1995) the feelings of isolation that occurs is best reinforced through the words of the participant who was on hemodialysis, "I feel like I'm on an island surrounded by water and I can't swim, I can't get away from it" (p.42). Participants also described how they were too tired, too weak, or too ill to be involved with social activities. The subjective feeling of fatigue is common and can be caused by anemia, anxiety, stress, changes in circadian rhythm, depression, frustration, role conflict, or ineffective coping (Srivastava, 1986).

This increase in demands was also affected by the need for close medical attention which began to consume their lives. Two participants found that the constant need for medical attention led to a dependency on doctors, nurses, and the health care system. Losses in other aspects of the participants' lives were also a direct result of their deteriorating level of health. Loss of relationships and jobs also meant loss of ability, identity, and sense of worth, which increased the feelings of vulnerability for some of the participants. White and McNatt (1992) found that long term dialysis often disrupts an individual's career and family life due to physical symptoms and time demands of the treatment.

The participants identified how having support during this difficult time was the reason that they were able to continue on during some of the worst times in their lives. The support came from family, friends, professionals, faith, and/or hope. Support was widely identified in the literature as a key component in the ability to make it through this experience and to continue on (Callaghan & Williams, 1993; Haire-Joshu, 1992; House & Thompson, 1988; Weems, & Patterson, 1989).

In time, the prospect of a kidney transplant was exciting, frightening, and even overwhelming, and four of the participants, who were so ill, feared that they would not live through the surgery. Porter, et al. (1991) found that along with the joyous relief of being put on the transplant list, patients feared long waiting lists, and experienced frustration, irritability, and depression while waiting and worrying about dying. Juneau (1995) also found that the continued unavailability of a suitable organ can lead to anger, depression, and withdrawal.

White and McNatt (1992) also identified how overwhelming it can be to try and cope with renal failure, testing, making transplant decisions, and usually having to assimilate new information all within a short period of time.

Two of the participants had their renal transplants before their islet cell allotransplants and they described their lives as less than ideal due to continuing fatigue and ill health. This finding is contrary to the findings of Evans, et al. (1985) who stated that transplant patients' quality of life was comparable to that of the general population. However, Sutton and Pelletier Murphy (1989) did report that post-transplantation issues including dietary and medical restrictions could still be in existence, blood pressure may still be a problem, bones may be weak, sexual function may not return and medications may produce unpleasant side effects.

Only one participant felt she did quite well on dialysis. This is different from the study conducted by Beer (1995) where half of the twelve participants in that study felt well enough on dialysis to not feel the need for a transplant and the other half felt that long term dialysis was almost too much to bear and that a transplant could not come soon enough. This difference may be due to the fact that statistically, people with diabetes do less well on dialysis and with end stage renal disease than the rest of the population (Brennan, 1991; Haire-Joshu, 1992; Narins & Narins, 1988).

Essentially, the findings of this study, in relation to living with diabetes related complications, supports the preexisting literature, but there are obvious gaps in this area of study since there is very little in the literature that addresses the experiences of living with diabetes related complications. Specific losses, identified by the participants, were not emphasized in the literature which would make you wonder if this was unique to this study or if it has just not been well addressed in other studies to date. Interestingly, the two participants who received their renal transplants prior to their islet cell transplants actually described their lives as less than ideal due to continuing fatigue and ill health but this was not supported in the research literature. However, most of the research conducted in this area has been quantitative in nature and has, for the most part, compared the quality of life of the recipients before and after the transplant, but did not address the effect that the transplant had overall. Most of the literature did not address the day to day functioning and experiences of the participants but rather looked at the overall picture.

The Decision, The Pendulum Swings

The decision, or the pendulum swings, was the experience of seeking out or being approached to participate in the islet cell allotransplant investigational study and making the decision to participate. Not only were some of the participants being pulled from the "brink of death" by the impending renal transplant, but they were now being offered a "bonus", a chance to have the good blood glucose control that had been, for the most part, so elusive, a possible chance at insulin independence and the potential ability to halt or even reverse the complications of diabetes. All the participants talked about how it was exciting to be considered for the islet cell allotransplant, but how, for some, that was tempered by fear of the unknown. Porter, et al. (1991) and Craven, et al. (1990) found that the patients' relief at being put on a transplant list is often replaced by fear due to the prolonged waiting period. House and Thompson (1988) stated that "many patients become quite frightened when they learn a part of their body is failing and that they need a transplant to survive" (p. 535) and that fear is often related to the unknown.

Interestingly, participants took very little time considering this offer and quickly decided to participate. This was not a life or death decision like it usually is with other transplants, this was a choice that could enhance their life beyond what a renal transplant would be able to offer. Reasons for participating in the research included: being part of research, treating diabetes, and helping others. Individual reasons included: feeling that they did not have much to lose, liking the research team and feeling that they could be trusted, wanting to be a leader in the field, and willingness to be involved. One person also believed that faith helped in the decision making process. The use of prayer and "bargaining with God" were identified in the literature as tools used by patients to help during the waiting process (Christopherson, 1987; Porter, et al., 1991). While transplantation is often seen as an ordeal, hope and a supportive system of beliefs play a significant role (House & Thompson, 1988). There is essentially no literature that addresses the process of deciding to become a transplant recipient. Hathaway, Strong, and Ganza (1990) specifically asked why transplantation was chosen but did not look at how the decision was made. They did report that renal transplant recipients in their study expected to: be off dialysis, feel better, be more active, return to work, have more dietary freedom, have more free time, live longer, and be more physically healthy and that these were the primary motivators for having the transplant. There seems to be an assumption that transplantation may be the only choice in a life or death situation, or the decision has already been made prior to the point where the researchers are investigating an area of interest such as waiting for a transplant or the post-transplant experience. As well, no literature was found that addressed the refusal of a transplant and how a person and/or family made that decision. Literature that mentions the decision making experience at all, simply refers to the fact that indeed a decision had been made to go ahead with the transplant (House & Thompson, 1988, Porter, et al., 1991) or mentions that the patient is empowered to make the decision to go ahead with or refuse the transplantation (Christopherson, 1987).

The excitement about participating in research grew out of the opportunity to make a difference in the "fight" against diabetes and being able to actually make a contribution in their life time. There was a desire to help others as well as themselves and to help keep children and others from suffering. The chance to improve diabetes treatment as well as personally being able to benefit was very important. The hope was that the islet cells would be a bonus, a potential cure, a means to be insulin independent, a stabilizing force for the renal transplant and the diabetes, and a possible means of keeping diabetes under better control or to reverse or stop complications.

Waiting for the transplant provided the opportunity to reflect on their hopes and expectations, the perceived pros and cons of the experience, what responsibilities would befall them after the transplant, think through any concerns they had, and think about whether they should reconsider their decision. House and Thompson (1988) and Porter et al. (1991) identified that even when the decision had been made to proceed with transplantation, the long waiting period may result in frustration, anxiety, irritability, hopelessness and depression. This was not the case for those waiting for the islet cell transplant, where in fact, the anticipation of receiving the islet cells actually helped some of the participants make it through the waiting period and the dialysis experiences.

Only one participant had reevaluated her decision to any great extent. Most of the participants saw this as low to no risk and so felt it was an easy decision. Most saw this as an opportunity to improve their health and the quality of their life. Christopherson (1987) points out that the hopes and expectations of transplantation often hide the lack of understanding of transplant limitations. Two participants talked about how important it was to be dedicated, that this was a big responsibility and that they should not waste the opportunity. What is significant however, is that these thoughts came after the transplant experience and did not influence their decision to participate.

With all the expectations, and the investigational nature of the islet cell allotransplant, none of the participants reconsidered their decision to participate. However, most expressed fear about what the experience would be like and the unknown effects of the islet cells. Even with this uncertainty, the participants saw this as a means for the pendulum to swing in their favor and so decided to go ahead with the transplant.

At the time that the opportunity for the islet cell allotransplant was offered to these participants, they were very ill and some would have considered them potentially vulnerable. Retrospectively however, none of these participants felt that they would have had a problem turning down the offer to participate if that had been their decision. None felt pressured to participate.

Once the participants had been considered for the study, they had to wait to see if the lab tests would support their eligibility and then they had to wait for the surgery. Eligibility criteria included a diagnosis of IDDM, a stimulated C-peptide level of <0.3 ng/ml, indicating that the islet cells are not functioning adequately, and having had or waiting for a renal transplant. As well, the surgeon must be able to harvest a pancreas from the same donor as the kidney (Astle & Yam, 1990; Budinger & Donnelly, 1994). The waiting was filled with uncertainty and four of the participants did not know, until the day of surgery, if they would get the islets. Fear of the unknown or uncertainty is common in chronic illness especially during the crisis stages of the illness. Uncertainty can limit the person's sense of control. If a person cannot decide what to do, or the resolution is not apparent, fear, excessive worrying, and anxiety can result (Hilton, 1992).

After waiting for the transplant, the procedure turned out to be painless and brief, but very exciting. The islet cells were instilled using a percutaneous approach and no general anaesthetic (Budinger & Donnelly, 1994). Then the waiting began again as participants speculated about whether there would indeed be a new life post-transplantation.

Post Transplantation, Life Anew

The experience of becoming a transplant recipient has given many people a new or better quality of life (Christopherson, 1987; Nathan, 1991; Lough, Lindsey, Shinn, & Stotts, 1987; & Wainwright, 1995). This new life was also experienced by the participants when they received the kidney-islet or islet cell allotransplant. The new life came about gradually as the participants adjusted to changes in their bodies, and as the immunosuppressive agents were adjusted. The period immediately after a transplant can be unstable and filled with uncertainty as the recipients wait to see if the organ will reject and medications are titrated to meet their individual needs (Bartucci, Loughman, & Moir, 1992; Budinger & Donnelly, 1994; & Christopherson, 1987). This adjustment period was also needed to allow the islet cells to settle in and establish a good blood supply. Along with the settling in period was stringent testing and gradual weaning from insulin and glucose intravenously to subcutaneous insulin, which allowed the islet cells to rest. This is supported by Budinger & Donnelly (1994) as they describe how immediately after transplantation, insulin is administered prophylactically to protect the islet cells while they establish a blood supply, and how it is the first two weeks after transplantation that is the most critical. The islet cell allotransplant recipients also required a longer hospitalization to allow for the closer monitoring and gradual weaning from the intravenous insulin.

Once released from hospital, there was a strict protocol that recipients were expected to follow which, in keeping with other transplant experiences (Christopherson, 1987) required dedication, determination, and commitment. Blood glucose monitoring was essential and frequent. These results were recorded and reported to the research team on a regular basis. The home glucose monitoring was also supplemented by lab testing for both the renal and islet cell transplants. The islet cell function was monitored by a Sustacal® challenge test and the recipients were asked to be available at any time for further testing and to see the endocrinologist regularly. Although the recipients were given a new chance at life, this was tempered by the need for frequent monitoring and follow-up. The demands of living with diabetes were either added to or replaced by the protocol requirements of the research.

Along with testing and follow up, there were also some limitations that needed to be considered. Surprisingly, the limitations that the participants imposed upon themselves seemed more restrictive than the limitations suggested by the research team. Although most of the participants felt they had more flexibility in managing the diabetes, four of the participants actually maintained the same or an ever more rigorous routine than before the transplant. There was a concern for some that they might damage the islet cells if they were not careful and that having the islet cells increased their commitment to self care. This attitude toward self care was also supported by Wainwright (1995) in his study of post liver transplant recipients.

The main reactions to receiving the islet cells have been both emotional and reflective. The participants talked about being able to contribute in some way again, and about feeling blessed, fortunate, surprised, euphoric, and privileged. One person even believed that the loss of her renal function may have been a blessing because she was able to get the islet cells which have improved her life.

Most of the participants expressed hopes for themselves and the islet cell program. The main hopes that they had for themselves were that the islet cells would prevent, decrease, or stop complications, stabilize their current problems, prevent rejection of the renal transplant, and cure the diabetes or at least make them insulin independent. Hopes for the program ultimately were to find a cure, but even before that they hoped that the islet cells could be transplanted without the need for immunosuppression, that people with diabetes could get the islet cells before they developed complications, that the program could be opened up to more people or to all persons with diabetes. The islet cell program gave these participants hope, a future, and a new outlook on life. They were able to plan and look forward to life. Some were more cautious than others about thinking and planning ahead, but they were all looking at the future. Looking at the future could be the little things or it could mean planning for retirement but, it was a factor that most of the participants had given up on before the transplant. The sense of future gave at least one participant the strength to set boundaries, get organized, make plans, regain control, and get her life together. Research conducted by Ternulf Nyhlin (1990) also found that people living with complications of diabetes believed it was senseless to make plans for even the near future. Whereas those who were transplant recipients talked about the future, set and accomplished goals, and continued to move forward with life (Christopherson, 1987).

The new life that these participants felt they had been given, brought about a sense of responsibility to the programs and doctors for all that had been done. There was a real desire to try and repay the program and to show their appreciation for the gifts that they had received. The efforts of the islet cell recipients have been to raise awareness about the program, to share their individual stories, and to support fund raising efforts. They wanted to do something for others by doing something for themselves. This is in keeping with the findings of Christopherson (1987) and Wainwright (1995) who found that transplant patients talked about wanting to help others because the transplant team had helped them and they had an overwhelming desire to give something back to their families and the health care providers. The need to contribute back to the program seemed to grow from the positive experiences that all of the participants enjoyed following the islet cell allotransplant experience. These positive experiences were seen as bonuses, benefits and gifts.

Bonuses, Benefits, Gifts

As previously mentioned, islet cell allotransplantation, like other transplants, was a powerful and life changing experience. Most of these changes were seen as bonuses, benefits, and gifts. The positive experiences affected many aspects of the participant's lives including: diabetes management and control, freedom, flexibility and timing of regime, coping, physical health, emotional and mental health, social involvement, and feelings about the experience and it's meaning to the participants.

Although the ultimate goal of this procedure may be a cure, the greatest benefit shared by all the participants was in the management and control of the diabetes. Control increased their ability to cope with diabetes on a day to day, minute to minute basis and was equated with normal blood glucose levels and feeling better, not only physically, but mentally. Normal blood glucose levels meant a more balanced life, and increased stability. There was little to no struggle or challenge to living with the diabetes.

The new found control was positive feedback which encouraged and motivated some of the participants to take better care of themselves and monitor their progress. The better blood glucose control was attributed solely to the islet cell function regardless of the closer monitoring, management, or follow-up. Physiologically, blood glucose control should be regulated when the islet cells are functioning since the islets of Langerhans contain not only the insulin producing cells or beta cells, but they also contain the glucagon-synthesizing alpha cells. The islet cells also synthesize small amounts of somatostatin which is released from the delta cells and is also produced in large quantities by the hypothalamus. The beta cells release the insulin, the alpha cells release glycogen to counteract the insulin release and vice versa, and the somatostatin works to suppress either the alpha cell or beta cell secretion to keep the blood glucose level consistent (Marieb, 1989).

Participants perceived or believed that the islet cell would slow, decrease, prevent or stabilize diabetes related complications. The most dramatic changes however, were for those who achieved insulin independence. There was no longer the demands of balancing diabetes with the demands of living and the normal blood glucose levels decreased the demands of watching and striving for perfection.

The increased flexibility meant not having to live by the clock, and ironically, having more control of their diabetes, gave them more freedom. Though the degree of freedom was related to the duration and level of function achieved by the islet cells, any degree of freedom was seen as important. Freedoms included not having to take insulin, flexibility in the timing, amount, and types of meals, and the opportunity to focus on other things besides diabetes and its constant demands.

Flexibility in relation to timing, amounts and types of meals, as well as flexibility in relation to medications was a very significant change in the lives of the participants since most of the time they had lived by the clock, ate based on a meal plan, and were always expected to watch the amount that they ate. Now, they were free from the strict regime associated with having diabetes.

Each participant talked about how the functioning islet cells helped to stabilize their health. In turn the fewer "ups and downs" in their blood glucose levels increased their energy levels and contributed to their ability to cope. Coping also increased due to the physical, emotional, and social changes and improvements, experienced by the participants. Sutton and Pelletier Murphy (1989) found in their study of renal transplant recipients, that coping increased when they believed that they could control part or all of the situation.

The physical benefits of islet cell allotransplantation were many and included: increased energy levels, increased visual acuity, improved circulation, improved ability to heal, improved sensation in extremities, decreased symptoms of PMS, and a sense of overall well being. The physical benefits of transplantation is well supported in the literature especially with the recipients of heart, lung, liver and kidney transplants (Christopherson, 1987; Craven, et al., 1990; House & Thompson, 1988; Mai, et al., 1990; Wainwright, 1995; White et al., 1990). As well, the effects of a better controlled blood glucose are well supported (Armstrong, 1987). Skyler (1987) reviewed several studies which looked at the effect of better blood glucose control on the microvascular complications of diabetes, including retinopathy, nephropathy and neuropathy. The studies indicated that retinopathy did in some cases improve, that early renal changes were reversed, and that nerve conduction velocity testing indicated an improvement in neurological function. As well, Bartucci et al. (1992) reported that patients receiving successful kidney-pancreatic transplants experienced less evidence of diabetes related nephropathy, inconclusive or negative results related to diabetes related retinopathy, and improved nerve conduction studies in patients with neuropathy. These studies essentially supported the reported improvements that participants in this study described following the onset of good blood glucose control. Overall, there was a sense of well being as the participants believed that the islet cells gave their bodies a reprieve from the detrimental effects of diabetes and related complications.

Not only were there physical benefits, but the emotional or mental benefits were numerous and equally as important to the participants. These benefits included: less worries, more stable moods, smoother emotions, feeling good about oneself, feeling normal, and a vastly improved quality of life. Most participants defined quality of life as feeling healthy, productive, and being able to do what they wanted to do. Studies which address quality of life post-transplant also support these findings (Craven, et al., 1990; Christopherson, 1987; Mai, et al., 1990; White, et al., 1990), however, most did not define quality of life from the participants perspective (Hauser, et al., 1991; Mai, et al., 1990). These participants believed they no longer had to look death in the eye every day. There was no longer that deterioration of the mind and body.

Cognitively, participants believed they were better able to concentrate, felt more focused and alert, and were able to think faster and more clearly. These changes were seen as miracles. The ability to think more clearly and concentrate for longer periods of time was, for most, clearly related to the islet cell allotransplant and not to the renal transplant. No literature was found that addressed these particular changes.

The bonuses, benefits and gifts experienced by each of these participants affected many aspects of their lives and these benefits brought out the ability to hope, to believe in a future, to have faith that they were not going to always be sick, and that they could now reengage in life. The feelings of being special, privileged, fortunate, or lucky were important.

Interestingly, insulin independence was very special to those who achieved that outcome, but for all the participants, the normal blood glucose levels were the key to feeling better, to having better overall health, and to a better life. The bonuses, benefits, and gifts were very important and life changing. These experiences as a kidney-islet or islet cell allotransplant recipient influenced how the participants would view this opportunity in the future and certainly would influence their decision if they had the chance to do this again.

Doing it Again-Looking Forward, Looking Back

A measure of the satisfaction that persons have with a particular experience is whether they would do it again or if they would recommend it to others. Due to the tremendous impact of this experience on these participants, it was important to ascertain their thoughts on this experience and whether it would be something they would want again in the future.

With unwavering certainty, five of the participants were willing to go through this experience again. There was "absolutely no question" or doubt in their minds. One participant however, approached that question with a great deal of hesitation and uncertainty. She was fearful that the islet cell allotransplant may have contributed to the chronic rejection of her kidney and she does not want to jeopardize another kidney. On the other hand, she does not regret having the islets, but does not feel confident about what they may do to a future transplant. She does plan however, to try and keep the islet cells she currently has functioning until she can have another renal transplant. This is interesting, since there is a disparity between what she is afraid of, and wanting to hold onto what she still has. She was uncertain about how she would feel if she also lost the islet cell function, but wanted to see a stable renal transplant and then wait until the islet cell program was further developed before she would go for more islet cells.

Most of the participants would recommend the islet cell allotransplant to others but, they felt that anyone going into the program should be well informed before making the decision to participate. The participants wanted others to be informed about the possible risks to the renal transplant, and they wanted the protocol to be stressed so that the potential recipients would completely understand the amount of time, dedication, and discipline that was needed to be in the program. The expectations of the islet cell program were not well understood prior to the surgery. The participants would have liked a more specific outline of the expectations as a guide to what to expect. Overall, however, there was great enthusiasm for the islet cell allotransplant experience and the participants wanted to not only benefit from this opportunity again, but also wanted it for others. Bartucci, Loughman, & Moir (1992) in their study of kidney-pancreas transplant recipients also found that 100% of those with a functioning graft would encourage a friend or family member with similar diabetic problems to undergo transplantation. The participants' enthusiasm for the islet cells however, was overshadowed by the realities of their personal situations and the ongoing concerns that each had for their health and their future.

Ongoing Concerns

As with other transplant experiences, the islet cell allotransplant recipients had to live with ongoing concerns related to this experience. Although there were many positive aspects to having the islet cell allotransplant, each of the participants had to face new or ongoing problems related to their health.

Concerns about the development or progression of diabetes related complications weighed heavily on their minds, and some feared having to live through the entire experience again should they reject their kidney. Because the participants believed that the key to preventing complications was blood glucose control, they feared the loss of the islet cell function. For those who had already lost islet cell function, the effects of diabetes on their body and their overall health was again a concern.

Concerns related to the kidney and/or islet cell allotransplant included: the effects of the two transplants on each other, the effects of the transplants on other organs, and the rejection of one or both of the transplants. The loss of the kidney and/or the islet cells was a major concern, and any symptoms or test results that were not seem as normal were cause for alarm. Fear of rejection is consistently reported in the literature as one of the main concerns that recipients have following any transplantation (Frey, 1990; Hathaway, Strong & Ganza, 1990; Hauser, Williams, Strong, Ganza & Hathaway, 1991; Hayward et al., 1989; House & Thompson, 1988; Sutton & Pelletier Murphy, 1989). Christopherson (1987) noted that "the onset of rejection has always been perceived by patients as hidden and insidious" (p. 59). This is of special concern to people with islet cell transplants. Budinger & Donnelly (1994) and Sutherland, et al. (1993) reported the major complication with islet cell allotransplantation is rejection, and more specifically that they are rejected more rapidly than other organs, and there are no good clinical markers for early detection of islet cell rejection.

Along with concerns about rejection were concerns about how the immunosuppressive drugs affected the transplants. Budinger & Donnelly (1994) identified that steroid induced hyperglycemia may be confused with the hyperglycemia of rejection. Any change in medication was an area of concern since an increase may be due to a possible rejection episode which in turn may also harm the rest of the organs or the transplants. One participant raised a concern about how boosting immunosuppression, in order to have the islet cell transplant, may be harmful to a stable renal transplant. However, the two people who actually received the islet cells well after their kidney did not feel that there was any need to be concerned.

Stress on the islet cells was a concern for some of the recipients. The Sustacal® test, which tested the function of the islet cells, rejection episodes of the kidney, immunosuppressive drugs, and other health problems, were identified as potentially harmful or damaging to the islet cells. These concerns may be very valid as it has been documented that stresses to the body such as rejection episodes and altering immunosuppressive drugs can harm the islet cells in both islet cell and pancreatic transplants (Budinger & Donnelly, 1994; & Weber, 1988).

Concerns about the program were also expressed. The first concern was related to letting the program down. It was very important that the program succeed and be recognized as worthwhile. There was a concern that if recipients did not do well, then the program would be seen as unsuccessful. The second concern was the lack of support for the islet cell program by the nephrology department in one of the centres. This lack of support was not found to be documented in any other centre that performed islet-kidney transplants and it may be specific to this one program. Either way, participants believe all options should be discussed, not just the ones that are deemed appropriate by certain health care professionals.

After such a long period of illness and disability, there were concerns and fears about reentering society and the work force. Although there was no literature that addressed these concerns specifically, Juneau (1995), when looking at psychological aspects after a renal transplant, found that the psychological benefits of being gainfully employed are immeasurable as employment can increase the person's sense of worth, self esteem and provide a sense of identity. She, however, did not address the psychological effects of trying to reenter the work place after a relatively long absence. Interestingly, Ternulf Nyhlin (1990), in her study of living with diabetes related complications, found that there was a desire to keep going and that practical solutions which made life easier and made it possible for one to go on working were important. The desire to keep going and to continue working was also identified in renal transplant patients. Stressors that these patients identified included job opportunities, time off work, change in work, and changes in social activities (Hayward, et al., 1989). Work seems to be an important component in the lives of most people and thus can play a significant role in the overall wellbeing of a transplant recipient.

Effects on Family and Others, Making it Through

For all participants, living with diabetes has had an impact not only them, but also on their family and/or significant others. For the most part, the ability to make it through these experiences depended on the support and love of others. Again this finding is well supported in the literature. Friedman (1986) noted that the "quality of family life is closely related to the health of family members" (p. 3). Similarly, participants in a study of hope and social support by Hirth and Stewart (1994), identified family, friends, and health professionals as individuals who provided them with support, which was integral to their ability to manage and carry on.

Not all participants had ongoing support, as some endured the loss of relationships due to the impact of the diabetes on their lives and the responses of others to those experiences. Although participants were able to make it through those losses, it is clear, as is reported in the literature, that loss of social support clearly has a negative effect on health. The effect of diabetes on family was also put into the context of living with diabetes. At diagnosis, families had to adjust to the change in lifestyle and the time related demands of controlling the disease. There was a need to assimilate large amounts of information, to try and be supportive, and to make the necessary adjustments to accommodate the demands of living with diabetes. The bulk of the responsibility seemed to fall on the mothers of these participants as they tried to meet the needs of a child with diabetes. In many cases, the family just adopted the diabetes way of life and in particular, the meal plan. There was in some cases a perceived over protection of the child with diabetes along with a desire to live a "normal" life. Christopherson (1987) states that "when the onset of illness is gradual, changes in patterns of family interaction and role assignment often occur" (p. 57). The need to take on more responsibility for the care of a child with a chronic illness, the increase in self care that is expected as a child gets older and needs to assume responsibility for the diabetes regime, and the shifting of responsibilities back to someone else when complications occurred are all representative of role adjustments needed throughout the context of living with IDDM.

In time, participants grew up and entered into relationships with a significant other. As life moved ahead, the complications of diabetes began to emerge and this affected relationships with family, friends and health professionals.

Some found their relationships strengthened by their experiences, while others found that the complications meant not only loss of health but also the loss of relationships. Support from the family has been identified as the most important factor in maintaining the psychological health of the diabetic with renal failure (Friedman, 1984; Pienning, 1984). However, House & Thompson (1988) found that during the period after discharge, separation and divorce increase in frequency if a spouse has had a transplant. Yet inspite of all the stressors, transplantation usually appears to have a positive effect on marital relationships. In this study, some marriages ended and friends removed themselves from the situation. Spouses had to assume all of the day to day responsibilities during this difficult time, and for a while, put their own lives on hold. Mishel & Murdaugh (1987) describe how spouses of pre-heart transplantation, immerse themselves into keeping the patient alive and comfortable and free themselves up from other responsibilities to attend to the patient. The partner's "life is on hold, with no roots, commitment, or involvement with anything other than the patient" (p. 334). Craven (1990) identified the waiting period prior to a transplant as "life on hold" for both the patient and significant other.

Children were also negatively affected by the deteriorating health of their parent. The children were described as living under stress, neglected, and having lost out. The children often assumed the care giver role, and they worried about their parent. Children are rarely mentioned in the literature in relation to transplantation or chronic illness of a parent. The cursory mention however, does identify how children can be forgotten during the stages of illness as one parent tries to manage with their health problems and the other parent, if present, focuses much of their attention on their ill spouse (Mishel & Murdaugh, 1987).

As well as individual effects, the family as a unit was significantly effected. The family was expected to endure hardships and burdens, often unsupported during these difficult times. For the person living with diabetes, there was often feelings of guilt associated with how their health problems affected the family and others, even though they had no energy to make the situation better. In a case study conducted by Porter et al. (1991) a participant stated that "it's harder on the family than it is on the patient because you have no choice, but they are going to survive even if you don't make it" (p. 29). The feelings of guilt are widely reported in the literature related to living with complications of diabetes and pretransplantation (Armstrong, 1987; Benning & Smith, 1994; Kyngas & Barlow, 1995). There was also a loss of control over their own health and life as well as demands to make health care decisions for themselves that would effect others around them.

Once the transplants were completed, participants believed that the islet cells had a positive impact on their families. There was less to be worried about as the participants' diabetes and health were more stable, thus it gave the families and others hope. This was also supported in the literature that addressed other transplant experiences where the transplant was stable and the recipient was able to reclaim their roles in the relationships with family and friends (Craven et al. 1990; Wainwright, 1995).

For some of the participants, the loss of the islet cell and/or renal transplant has now created new concerns that are affecting the family. There is a desire by some family members to fix the problem, others are trying to deal with a role reversal where the child needs to assume some of the parent's responsibilities, and still other families (as a means of coping) are denying the situation.

When looking back on the experiences of living with diabetes and especially complications, most of the participants believed that individual or family counselling, or more professional support would have helped them get through these experiences more effectively. Recommendations included: having a psychiatrist or social worker help the participant and family to identify and cope with feelings related to living with complications and transplantation, or have a nurse or nurse clinician work closely with the patient and/or the family to help pull all the information together, educate, and act as a support person. Clark (1994) identified that a major intervention for nurses is to strengthen the family unit by including and supporting them as well as empowering them to make decisions. Making decisions was an important and ongoing situation for the islet cell recipients, but health related decisions are best made when a person is well informed. It was found that health professionals were an important source of information regarding transplantation and patient health status as well as providing effective support in the form of encouragement. As well, being acknowledged as a whole person by health care personnel was found to be very important when trying to deal with uncertainty (Hirth & Stewart, 1994; Ternulf Nyhlin, 1990). Interestingly, Weems and Tate Patterson (1989) again found support was important, but unlike other studies that found the family or others as the most important support, these researchers found that it was especially meaningful for health care workers to be supportive and to offer encouragement. Essentially, relationships with family, others and the health care team were very important and affected how participants coped with health related experiences during the different periods of their lives. The intricacy and magnitude of these relationships very much influenced the experiences that the participants had living with diabetes and becoming islet cell allotransplant recipients.

Summary of the Discussion

Each participant in this study has ventured on an incredible journey. Living with IDDM was and continues to be unrelenting in its demands for attention. It is only within the context of these lives that life long pursuits, achievements, and heart breaks, from which grew the experiences of living with diabetes related complications, can be fully understood. The development and severity of complications remains uncertain and unpredictable. The only certainty is that when they do occur, complications will be devastating and life changing. Those who have developed life threatening complications live life in the balance, often struggling to hold onto life itself. The uncertainty often leads to despair, anger, and frustration. This contributes to a lack of acceptance and for some, depression.

The complications add to the struggle with balancing diabetes, and increasing the demands on time and energy. The added restrictions of renal failure make eating very difficult, and dialysis, though maintaining life, is an added source of suffering, and demands many hours of time, preparation, and monitoring. The decrease in energy levels and increased demands on time further increase the social isolation.

The decision to have the islet cell allotransplant provided new hope, a bonus that would swing the pendulum in their favour. The anticipation of being able to benefit personally, as well as contribute to research stimulates a quick affirmative response to participate, and a reason to hold on a little longer. This is an opportunity to make a difference.

The benefits of islet cell allotransplant are many, and are life changing and life enhancing. The follow up however, requires dedication, determination and commitment. The demands of living with diabetes are either added to or replaced by the protocol demands of the research. It is however, worth the effort and commitment. There was a sense of future that had been lost before the transplant.

The physical, psychological, and social bonuses, benefits, and gifts are numerous, but the greatest benefit is the ability to manage and control the diabetes. There is increased flexibility, stabilized health and increased ability to cope.

Amidst all of the excitement and support from family, friends, and the health care team, however, lives the realities of on going concerns. Concerns related to health, actual or impending organ rejection, further progression of complications, effects of immunosuppressive drugs, and the future of the islet cell program, weighed heavily on the minds of some of the participants. There is an attempt to balance the gift given with the still uncertain future.

With all of the demands of coping with IDDM over the years, the gift of islet cells comes as a welcomed relief for family and others. There is a positive impact and less to worry about for the family and friends, at least for awhile. Overall, islet cell allotransplantation is believed to be a very promising treatment alternative for people with IDDM.

Implications for Nursing Practice

The experiences shared by the participants in this study help to identify the important role that nursing can play in the care of people living with diabetes and those who become islet cell allotransplant recipients. In collaboration with the client, and his or her family, nurses can play an important role in helping to develop a life long means of managing and coping with diabetes. Each experience of living with diabetes does have commonalities but is also unique to the client and should be treated as such. Teaching the skills to problem solve will allow clients to manage and adapt far more readily than only teaching the facts.

Diabetes is ever present and must fit into every aspect of a person's life. A strong and open relationship developed over time between the client, family and nurse can ensure honesty, trust, and a supportive relationship especially in times of crisis.

During the development of complications, nurses can continue to provide support, empathy, and take an active role as client advocate and as coordinator of care. Living with complications related to long standing diabetes can, and is exhausting, frightening and confusing due to the demands of caring for oneself, family, and interacting with the health care team. The nurse can help by developing a plan of care, and coordinating activities to reduce the energy demands placed on the patient and family. This is also an important opportunity for educating the clients and helping them pull all the information together. Due to the acuity and diversity of problems that living with complications can present, clients often need help to put all the pieces together in order to understand how the situation affects them as a whole.

During the time that the client may be waiting for a transplant, nurses can continue to provide support, encouragement, education, and assist in identifying and obtaining resources. It is also important that the client also understand the regime that they will be expected to follow. Nurses can assist the client and family to prepare for the changes that a transplant will bring.

Participants shared a great deal of information about how the islet cell allotransplant program could be improved to better meet the needs of participants. One of the interesting outcomes of this study, is that the participants had already been exposed to many health care professionals and although they really appreciated the expertise of the transplant team, they still wanted someone else who could follow them through the experience and be there to help and support them. A nurse or nurse clinician was the most frequently mentioned professional who the participants believed could help fill the gaps in the system.

Nurses have a responsibility to be knowledgeable in their professional practice. Learning as much as they can about new treatment methods and how they can benefit the client will strengthen their practice, increase the client's confidence in the nursing care provided, and provide background information that can help in the development of new knowledge. Participants identified that specialized care tended to be fragmented and only dealt with one particular problem, not the whole person.

It seems important to remember that as nurses we practice within a framework made up of personal and professional biases which influence our approach and our practice. It is often easier to stay within our own framework than to venture away from our comfort zone of knowledge and professional status, but professional and personal growth can only come by assuming some risk. Risk can be as simple as asking a question to which we think we already know the answer but by actively listening, we hear a far different response. The opportunity to listen to these participants, as they talked about their experiences of becoming islet cell allotransplant recipients, truly reaffirmed the importance of understanding the client's perspective framed within the context of their own lives.

The research can help nurses and other health care professionals be more aware of the impact that this experience has on the recipients and in recognizing this, be able to teach others about the experience. As well, it is hoped that health care professionals recognize the important roles they play in the client's lives, and how important support and encouragement can be at all stages of a person's life who is living with diabetes, chronic disease, or who is living with the changes that health problems bring into their lives.

Restrictions of This Study

In conducting an essentially retrospective study of experiences, there is a risk that the participants' memories of the events may be less vivid than they were at the time of the events. As time moves forward and new life events unfold, the clarity and related emotions of past experiences may have faded. Since the actual islet cell allotransplant experiences occurred at least one year before this study was conducted this may have influenced the richness of the data collected. However, after speaking to six informants, there was no new information shared and the same or similar comments were being made by each person. This allowed the research questions to be answered and so further interviews were not necessary.

The sample size can be viewed as a restriction of this study. The intent of this study however, was to discover the meaning of becoming an islet cell allotransplant recipient, not to measure the characteristics of a population (Field & Morse, 1985). The fact that the participants were representatives of two separate islet cell research programs and were cared for by two separate teams of professionals strengthens the reliability of these findings.

A final restriction of the study is that all the participants were in the young to middle adulthood range and so the findings may not apply to other age groups, specifically the older adult. Due to the investigational nature of the islet cell programs, some programs have not included participants with non-insulin dependent diabetes (NIDDM), and other programs are just beginning to transplant islet cells into persons with NIDDM, thus age was not a true limitation of this study at this time.

Suggestions for Future Research

In future research, a study that follows the islet cell recipients through the actual process as it takes place may identify even more information about the experience due to an enhanced recall of the situation and the outcomes. This could be done using a grounded theory approach which would enhance the understanding of this experience.

As identified in the findings chapter, a study which looks at the decision making process surrounding transplantation would help to identify key factors in how and why a particular decision is made. This would enable nurses and other health care professional to help potential recipients make the best decision for themselves, as well as support the decision based on an understanding of how that choice was made.

In relation to the context of living with IDDM, there are several issues that would be interesting to research to help gain a better understanding of how diabetes impacts the family. 1). Further studies related to living with a chronically ill parent and its affects on children could provide the means and understanding needed to help children and families cope. 2). The psychological effects of living with a chronic disease during a medical crisis could be examined from the perspective of the client, spouse, and family. This could help health care professionals effectively assist individuals and families to adjust and cope with increasing uncertainty and role changes. 3). It is also important given the role of support identified in this study, to examine the family dynamics when one member has a chronic disease, and how roles may change as the health condition of that member changes. 4). Findings from this study also identified the impact diabetes may have on spousal relationships. An in-depth examination of how spousal relationships and marriage are affected by living with a chronic disease can help to identify how health care professionals can ease the transition and acceptance of the chronic disease as well as identify the best sources of support and stress management. The issues of how chronic disease effects the family are many and would benefit from further study.

The final research suggestions are related to decisions about work. These issues were identified as important to participants in the findings and literature. The experience of reentering the workforce following a long illness would be interesting to investigate to help in identifying how the decision is made and what factors make this a positive experience. Another research question could examine the choice to remain out of work after reestablishing an acceptable level of health or well being.

It is important that further research continue so we can build a stronger knowledge base.

Additional Suggestions and Recommendations Related to the Program

The following findings are important but because they go beyond the focus of the research questions they are presented separately. These comments relate to suggestions and recommendations made by the participants regarding the islet cell allotransplant program. I believe that they are also important in helping the program(s) move forward.

1. Recommending it to Others

Most would recommend this transplant to others but they felt that anyone coming in to the program should know what the expectations are, be dedicated, and should having a very thorough understanding of the risks and potential benefits. They would suggest several meetings with someone from the research team before the transplant to ensure that the potential participant is well informed, clearly understands what they have been taught, and knows what will happen before and after the procedure. As "Z" stated:

> -You have to be a strong person. Mentally you have to really be a strong person and realize that this is a gift...you know you're given a gift and that gift is life.

"X" added:

> -Well one important thing, I think is that they don't think it's a cure at this point, that it's a quick fix, that they realize what they might be getting into, if it's the testing that they don't like they might be getting into more testing. I just talked to a fellow and his wife not that long ago, but ah, there is the possibility that the islets contribute to the kidney rejection. Ah, the possibility is there, I like to think that it doesn't make much difference. I did a literature review, and all I found was three articles that specifically for my situation one said it might, one said that no it doesn't and the other one said they don't know. So, that was no help to me what so ever. But, that they know that it's not a

> cure at this point in time, that it involves a lot of diligent testing that you still kind of stick to your CDA business, That, ah, you might even end up being more stringent than if you didn't have the islets, and I think it's a bit of a commitment too...I think it only fair that you take part by giving them the results and the numbers and you know if there's, if you're up to public speaking or talking to other people about it that, not that anybody has ever made me feel obligated but I just kind of think that is something you can do in return, so it's not an easy way out by any means, and it might not work. You know, be prepared for that sort of thing too. People might have to consider the more successful the transplant the more commitment there is. And I think the more numbers they get, then in turn that helps with hopefully the success in the future.

Along with enthusiastically recommending this procedure to others, "T" feels that the program should look at transplanting those people who do not already have complications. "I would really like to see them do some clinical trials with diabetics that don't have kidney failure...I think that would be really pushing it a little bit, but I think that's where it needs to go, because it would be nice to not have the complications to be able to get islet cell treatment if you like, and then maybe save all the complications that are involved with diabetes".

2. Inclusion Criteria

Although there were no stringent recommendations about who should be included there was great concern about recipients wasting the transplant.

> -...put me on a waiting list but I'll be damned if the hundred people before me on that waiting list are people that don't deserve it, that aren't willing to take care of it, that aren't willing to do what they have to do to take care of it, and they're going to waste it...why should you be wasting something I could use? (Z)
>
> -I'd hate to see them waste it on someone who's a waster and noncompliant and, you know, not taking the anti-rejection drugs and, you know, loose them through poor behavior. (X)

There were suggestions that participants needed to be dedicated and committed, and one person even suggested psychological profiles be done on all potential recipients, which one of the programs is already going.

> -it's research being done and they have to do just as much to control or help the research out, you can't just sit back and have it just work for you....You have to show an interest in your diabetes, you have to show an interest in life in general, you have to show that you are going to follow the regime...if they need you to be there, you have to be there. (Z)

3. Protocol

Although most had few problems with the protocol, there were several who suggested that it be more detailed and provide guidelines of what to expect and what had to be done and when. Three people felt that the protocol was not clear and that this added to their feelings of uncertainty.

> -Try giving a clear picture of what's expected as far as it goes for blood tests and which ones are needed for them (islet program) particularly, what they're watching for, and how often it needs to be done. (T)
>
> -I think maybe talking over that contract and making you feel a little at ease about explaining it a bit better. I think for the layman it's a little bit intimidating. (Q)

4. General Changes to the Islet Program

There were few suggestions on how to change the islet program specifically but one person suggested fewer Sustacal® tests as he feared they damaged the islet cells. Two participants also wanted to know before hand if they were eligible for islet cells and whether they would get them, but they were only told the day of surgery. It was suggested that new participants should know that the islet cell allotransplant could only be made available at the last minute as it was dependent on harvesting a pancreas and subsequently the islet cells. Otherwise, the participants were pleased with the overall program.

5. Feedback and Obtaining Information

Several participants identified a lack of communication regarding their ongoing status. One person stated that she would have stayed on immunosuppression even when her renal transplant rejected had she been made aware that her islet cells were still functioning. There was a desire to have test results shared more quickly and consistently without having to ask and one person suggested mailing copies to the patient.

Feedback and information about the program in general and what was happening was also identified as lacking. Participants wanted to be kept informed about what was new, how many transplants had been done, what the status of each participant was, and where the program was headed. Some were very disappointed that they have been left out of what has happened over the years.

> - I figured the researchers would have a little more respect for the people putting them in the front of medical research. I'm not asking for anything, I'm not asking for no gold cross or no gold star or nothing, all I'm asking for is for them to come forward and say sit down with us and say look this is where we're going this is where we've been, this is what we've done, this is what you've helped do and we haven't gotten any of that. I don't know nothing about it (were the program is at). I read in the paper oh yeah, well thanks to the first of the, you know diabetic islet cell transplant back in March of 89, I'm a little blurb there but I don't hear anything from the doctors, and that's really too bad, I'm really disappointed in them. (Z)

6. Support, Follow-up, and Putting it All Together

As mentioned in the thesis, these people believed that support from a health professional and particularly a nurse would be of great benefit in helping them get through this experience and pulling all the information together.

> -If it works they (islet cells) turns your whole life around, and you need to be able to deal with how your life is going to change. (Z)

"Z" also went on to say that having someone working closely with him through the experience of having an islet cell allotransplant is important. He believes having someone follow the patient would help them understand what's going on, and he, along with two other participants believed that a nurse or nurse clinician would be an asset to the islet cell team as a support for the patients. "X" suggested that maybe it should be mandatory for the patient and family to be involved with a social worker or health care professional on an ongoing basis while they tried to deal with the crisis of renal failure, dialysis, waiting for a transplant, and adjusting to the transplant.

Due to the complexity of the diabetes, living with complications, and the islet cell research, the participants felt it was difficult to put all the information together. They felt disjointed and were often unclear about what was happening in relation to their health.

> -I think if we had one group, because everything is related when it comes to your diabetes, your kidneys, your eyes, um, gangrene of the feet. All the different problems, you know, with all the parts that happen with diabetes, why should we have to go to twelve different specialists? (Z)

"T" also supported these ideas. She states:

> -Sometimes you get feeling disjointed because you're just seeing different guys that don't put an emphasis on this or, you know, the kidney guy's really concerned about the kidney, not too concerned

> about the islets...so it would be nice to sort of get a feeling that you were looked after all together instead of separate.

7. Media Involvement, Public Awareness

Most of the participants felt that there has not been enough exposure for the program and wanted to see more information in the media.

> -...we should know about it, a lot more people should know about it. (Z)
>
> -I think that I would like more media attention brought to it so that people know that it is a viable or workable idea...let people know the great need for it. (Q)

They wanted to boost public awareness of the program and hoped that this may increase funding and support to help the program more ahead more quickly.

8. Agencies Need to Work Together

Three of the participants believed that the agencies that support research and/or promote public awareness of a particular problem need to join forces to help in the fight against diabetes. The participants identified how important it is for the diabetes related organizations to work with the kidney related agencies, and so on, to channel efforts towards better treatment and cure for these diseases. The participants saw these agencies as nonsupportive towards each other.

9. Meet Other Recipients

All of the participants wanted to meet the other participants and socially meet with the physicians to celebrate the achievements and share experiences. This was very important to all of them.

Although there were not many suggestions, the recipients clearly identified the areas that needed to be examined and evaluated to improve the programs and in doing so, improve the success of the program outcomes.

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Appendix A

Interview Guide

I would like you to think back to when you first heard about islet cell allotransplants and tell me in detail about your thoughts, feelings and other aspects of your experience:

The following are some probing questions which may prompt the participants if they are unsure of what to say or how to start:

-tell me how long you have had diabetes and what it was like before your islet cell allotransplant.

-when were you approached about becoming an islet cell allotransplant recipient and how did you decide to participate?

-Did you reconsider your decision at any time?

-What was your experience as you waited for the transplant?

-How long did you need to wait?

-What were your hopes, fears and expectations through the process of becoming an islet cell allotransplant recipient?

-Having been through the experience, would you recommend this to others? Would you do it again?

-Has your life changed? -physical changes -emotional changes
-social changes -thoughts about the future

-If you would do it again, how would you change the system or process to improve the experience?

These questions will be used to encourage the discussion and to ensure that as many pertinent aspects of this topic are covered.

AppendixB

Letter of Introduction

Project Title: Becoming an Islet Cell Transplant Recipient

Researcher: Debbie Blais Telephone: (403) 487-8018

My name is Debbie Blais and I am a registered nurse and a masters in nursing student at the University of Alberta, who is interested in finding out what it is like to become an **islet cell allotransplant recipient** and how this experience may have affected your life. Dr. Warnock is aware of this study and his office has mailed this letter without me knowing your identity. What you have to share is very important and I would not be able to get this information anywhere else.

If you wish to participate in this study, or if you would like further information in the form of an information letter or tape, please contact:
Dr. Warnock at 492-7411 or
Dr. Marion Allen at 492-6764 or
myself (Debbie Blais) at 487-8018.
Any of us listed above would be happy to include you in this study or discuss any questions or concerns you may have about this study. **If you are not interested in participating in this study please contact Dr. Warnock's secretary (at 492-7411) by <u>February 10, 1996,</u> to ensure that your name and telephone number are not released to me. After the above date Dr. Warnock's office will assume that it is okay with you to have the researcher (Debbie Blais) contact you and <u>will release your name and telephone number to me.</u>**

Thank you for your time and consideration,

Debbie Blais R.N.

Appendix B1

Information Letter

Project Title: **Becoming an Islet Cell Transplant Recipient**

Researcher: **Debbie Blais Telephone: (403) 487-8018**

Dear

This is the information letter that you have requested outlining the research project that I (Debbie Blais)wish to do with you. I am interested in finding out what it is like to become an islet cell allotransplant recipient and how this experience may have affected your life. Dr. Warnock is aware of this study and his office has mailed this letter to you. What you have to share is important and I would not be able to get this information anywhere else.

In order for you to take part in this study, you must have received your transplant at least two months ago. If you decide to take part in this study, you will be interviewed at least once and possibly up to three times. The interviews will be one to one and a half hours long and will be taped. The interviews will be at a time and place that is mutually convenient for us. If you prefer, you may also be interviewed over the telephone.
You will be asked to share your experience of becoming an islet cell allotransplant recipient. I would like you to discuss the process, feelings and actions that brought you to this point in your life. I will also ask you a little about your health history.

Only I will know who you are. The tapes will be heard and typed by a secretary but your name will not be identified on the typed copy. My committee may read the typed copy. The tapes, typed copies, your name, address, phone number and consent forms will be kept in a locked cabinet. The consent forms will be kept separately from the tapes and typed interviews. All tapes must be kept for seven years but will be destroyed after that time elapses. The typed interviews may be kept and used for another study in the future if I receive approval from the appropriate ethical review committee. Some of your words may be used but your name will not appear in the final report.

If you choose to take part in this study you may stop the interview, refuse to answer questions or withdraw from the study at any time. Whatever you decide will not affect the care you receive from Dr. Warnock or the rest of your health care team. Although you may not benefit directly from this study, your shared experiences may help other islet cell allotransplant recipients, nurses, and doctors caring for those patients.

Because I may not know your name or telephone number until you agree to be in the study, I must ask you to call me if you have any concerns or questions (please call collect if you must call long distance). If you wish to be in the study please call me (487-8018) or return the form below in the enclosed self addressed stamped envelope.

Thank you for your time.

Debbie Blais R.N.

I am interested in talking to you about this study.

Name_______________________________________

Telephone #__________________________________

Convenient time to call___________________________

Appendix C.

Informed Consent Form

Project Title: **Becoming An Islet Cell Transplant Recipient**

Researcher:	Thesis Supervisor:
Debbie Blais	Dr. Marion Allen
BScN MN Candidate	Professor of Nursing
Faculty of Nursing	Faculty of Nursing
University of Alberta	University of Alberta
(403)487-8018	(403)492-6411

Purpose: To gain a deeper understanding of the process of becoming an islet cell allotransplant recipient and how that has affected your life

Procedure: You will be asked to take part in one to three interviews. The interviews will be in person or on the telephone. The researcher will tape record the interview and each will take approximately one to one and one half hours. These interviews will be conducted at a time and place convenient for both of us. The tapes will only be heard by the researcher and the typist. The thesis committee may read the typed interviews. This information will then be analyzed along with other interviews to complete the study.

Participation: There will be no harm to you if you take part in this study, nor will you benefit from this study. Results from this study may help nurses educate other patients, provide support to these patients and give the nurses and doctors a better understanding of the patients' experiences all of which may help improve the care that nurses and doctors give to patients.

You do not have to be in this study if you do not wish to be. If you take part in this study, you may drop out any time by telling the researcher. You may stop the interview at any point. You only need to answer those questions you wish to. The care you get from your doctors and nurses will not be affected if you take part in or drop out of the study.

Your name will not appear in the study. Only a code name will appear on the typed interviews. The researcher will erase your name from the transcripts. All records, interviews and notes will be kept in a locked cabinet for seven years as required by the university. They may be used for another study in the future, if the researcher receives approval from the appropriate ethical review committee.

The information and findings of this study may be published or presented at conferences. Short excepts from the interviews may be used to support the findings but your name or any material that may identify you will not be used. If you have questions or concerns about this study at any time you can call the researcher or her supervisor at the number(s) above.

Consent: I ________________________________(print name) understand the above research procedures as they have been described. All questions have been answered to my satisfaction. In addition I know I may contact the researcher or her supervisor if I have questions now or in the future. I have been informed of the alternatives to participating in this study. I understand the possible benefits and risks of joining the study.

I have been assured that the records related to this study will be kept private. I understand that I am free to withdraw any time. I further understand that if I do not take part in the study or withdraw at any time, my medical and nursing care will not be affected. I understand that if any knowledge from the study becomes available that could influence my decision to continue in this study, I will be promptly informed. I have been given a copy of this form to keep.

________________________ ________________

Signature of Participant Date

________________________ ________________

Signature of Researcher Date

If you wish to receive a summary of the study when it is finished, please complete the next section:

Name: ____________________________

Address: ____________________________

____

____