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THE UNIVERSITY OF ALBERTA

BONE MARROW TRANSPLANTATION:
THE EXPERIENCE
OF THE
ADOLESCENT DONOR

BY

© HENDERINA (RENA) VAN DER WAL

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE

OF.....................MASTERS IN NURSING.................

FACULTY OF.......NURSING.........

EDMONTON, ALBERTA

(SPRING) (1988)

ISBN 0-315-42724-8

THE UNIVERSITY OF ALBERTA

RELEASE FORM

NAME OF AUTHOR: HENDERINA (RENA) VAN DER WAL

TITLE OF THESIS: BONE MARROW TRANSPLANTATION:
THE EXPERIENCE OF THE
ADOLESCENT DONOR

DEGREE: MASTERS IN NURSING

YEAR THIS DEGREE GRANTED: 1988

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Bone Marrow Transplantation
The Experience of the
Adolescent Donor

submitted by Henderina (Rena) van der Wal

in partial fulfilment of the requirements for the degree of

Masters in Nursing

(Supervisor)

Marion Allen

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Date: January 28, 1988

DEDICATION

This thesis is dedicated to all the oncology children and bone marrow transplant patients who made a difference in my life and who inspired this research and to the bone marrow donors who participated in this project and who offered so generously of their time and of themselves.

A special thank you to my husband, Harry Bouwman, for his continued support and patience.

ABSTRACT

The purpose of this research was to provide a description of the long term experience of the sibling adolescent donor. Nine bone marrow donors were interviewed to determine what the transplant experience was like and what variables affected their responses to the experience.

Indepth open-ended interviews were conducted using an interview guide. All interviews were tape recorded and transcribed. Data were analyzed for recurring themes or categories using the grounded theory approach. Relationships between these categories were identified and hypotheses about these relationships were postulated. The literature was then searched for existing theories that were consistent with the postulated hypothesis.

Results indicated that donors were confronted with the realization that their sibling could die. This situation was emotionally difficult and donors wanted to act in some tangible way that would alter this predicament and make a difference in the life of their sibling. Their moral codes influenced the manner in which they attempted to affect this difference. The transplant experience resulted in simultaneous life changes which intensified their emotional distress. Unsuccessful efforts were likely to increase emotional distress and generate further attempts at intervention while successful efforts at intervention were more likely to decrease the emotional strain.

The findings of this study are not generalizable or replicable. However, the results provide a description of the long-term effects of donating and provide beginning data regarding variables and theories that can be used in subsequent research studies. Several questions are posed for future researchers. The findings provide general direction for nurses. Several preventative intervention strategies for the pretransplant, posttransplant, and predischarge phases of the experience are offered.

ACKNOWLEDGEMENT

This project has been funded in part by a grant from the Alberta Foundation for Nursing Research. This Foundation does not necessarily support the findings or ideas associated with this project.

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CHAPTER 1

Statement of the Problem

Introduction

Bone marrow transplantation (BMT) is rapidly becoming a therapeutic modality in the treatment of aplastic anemia and acute leukemia (see Appendix A). BMT is an intensive procedure that can result in significant early morbidity (O'Reilley, 1983; Sanders et al., 1985; Sondel, Trigg, Hong, Finlay, & Bozdeck, 1983).

Research on the psychological adjustment of adult donors of organ transplants indicates that they are at increased risk for psychological sequelae when the health status of the recipient is compromised. Donors reported a greater incidence of fatigue, muscle soreness, discomfort at the donation site, depression, anxiety, feeling unappreciated or ignored (Eisendrath, Guttman, & Murray, 1969), negative attitudes toward the transplant (Simmons, 1981), regret regarding donation, difficulties in relationships with donors (Simmons, 1983), and a need for psychotherapeutic measures (Hirvas, Enckell, Kuhlback, & Pasternak, 1976).

Similarly, researchers who studied the psychological adjustment of pediatric bone marrow transplant recipients anecdotally document that donors are at increased risk for psychological problems if the recipient has increased morbidity after the transplant or if the recipient dies. They reported that minor donors experienced feelings of responsibility for the outcome of the transplant (Brown & Kelly, 1976; Gardner, August, & Githers, 1977; Patenaude, Szymanski, & Rappeport, 1979), a low degree of personal sacrifice (Gardner et al., 1977), and feelings of anger at the unavailability of parents (Patenaude et al., 1979). Wolcott, Wellisch, Fawzy, and Landsverk (1986a) reported that adult recipients described little change in their relationships with donors posttransplant but speculated that the quality of the relationship may be sensitive to changes in the recipient's health and psychosocial status. In the literature, only one study documents the long term psychological adjustment of adult bone marrow donors whose recipients survived (Wolcott, Wellisch, Fawzy, & Landsverk, 1986b) and methodological issues limit the conclusions that can be drawn from the results. Studies of pediatric bone marrow donors were not found in the literature.

Nurses in the inpatient, outpatient, public health and home care settings potentially encounter the pediatric recipient and their family members. They require information about the minor donor experience to allow them effectively to assist families in planning early strategies to prevent possible negative consequences which may require future psychological interventions. This information is vital to nurses if they are to provide a holistic approach to the care of the patient and the family undergoing a BMT.

Although researchers postulate that BMT donors may experience psychological sequelae posttransplant, there is a paucity of research to support this statement. There is no information available to nurses to indicate what this experience is like for the pediatric donor, what factors influence this experience, what problems can occur as a result of donating, what perceptions these donors have of the experience several years posttransplant, and what interventions can influence a positive experience. Although research regarding appropriate intervention strategies is essential, such research must not presuppose knowledge of what the experience is like for the donor. Therefore, the proposed study will provide a first level of inquiry leading to a characterization of the experience of the minor donor.

Purpose

The purpose of this study was to provide a description and a theoretical analysis of the long term experience of the minor bone marrow donor. A lack of information about the donor's experience necessitated that the investigator obtain first level data which identified the perspective of the donor rather than verifying concepts derived from an a priori theoretical framework (Diers, 1979). The properties of the concepts that characterize this experience will be determined. Future studies can be developed with the objective of verifying and measuring the identified concepts of this theory (Filstead, 1979).

Definition of Terms

The following are the definitions of the terms used for this research project.

Bone marrow transplant: a treatment approach for various neoplastic and haematologic diseases designed to replace malignant, defective, or absent cells of the recipient's bone marrow with normal cells from the donor.

Bone marrow donor: histocompatible sibling whose normal marrow is harvested and subsequently infused into the recipient.

Minor donor: a BMT donor between the ages of 11 to 18 years.

Research Questions

1. How does the minor donor describe the experience of being a bone marrow donor?
2. What variables appear to affect the response or the experience of the minor donor?

NOTE: For the purpose of this paper, the pronoun 'she' will be used to indicate the singular instance of male and/or female individuals.

CHAPTER 2

Review of the Literature

The experience of the donor who donates bone marrow has received little attention in the literature. However, researchers have provided detailed descriptions of the perspectives of other organ donors. The accounts of kidney donors were examined because, like BMT donors, these donors also survive their procedure. Conflicting results, methodological limitations, and different aspects between kidney and bone marrow donation preclude the assumption that these two donor experiences are similar. The framework of gift exchange can capture some of the experience of donating but the unique variable of the graft rejecting the recipient remains unexplained. A paucity of systematic research in this new field of BMT necessitates a first level of inquiry to conceptualize this phenomenon.

This review of the literature is divided into three sections. The first section contains a description of the donor experience with organ transplantation. In the second section, the theoretical framework of gift giving or altruism is assessed regarding its relevance to the donor experience. The psychological impact of transplantation on the bone marrow donor is outlined in the final section.

Organ Transplantation

Only articles that related to kidney transplantation were reviewed since it is rare for the donor to survive the procedure in any other donation setting. Donors who participate in a heart or liver transplant are usually dead or dying. The literature which focuses on these donors has limited relevance for understanding the long term effects of the procedure on the surviving bone marrow donor. For the purpose of this review, organ transplantation and kidney transplantation are interchangeable terms. The literature in this section is divided into two parts. The first part includes articles written in the early period of transplantation and the second part includes articles written when organ transplantation was a more established procedure.

The researchers in the 1950s to the early 1970s concentrated on establishing the existence or nonexistence of negative responses to the donation of a kidney. The methodology used in these studies included case studies (Crammond, 1967; Eisendrath et al., 1969; Fellner & Marshall, 1968), data obtained from professional experience (Knight, 1980), and routine psychiatric evaluations (Basch, 1973; Fellner, 1971; Kemph, Bermann, & Coppolillo, 1969; Wilson, Stickel, Hayes, Harris, & Durham, 1968).

Several researchers attempted to substantiate their initial research findings by conducting further research (Eisendrath et al., 1969; Fellner & Marshall, 1968, 1970). Fellner and Marshall interviewed an additional six donors pre and posttransplant to clarify concepts identified earlier. Eisendrath et al. (1969) obtained their preliminary data by interviewing 25 donors and further substantiated these findings by sending a questionnaire to 65 unselected donors. These investigators did not indicate whether they had developed the questionnaire or whether content or construct validity of the instrument were established. One therefore is unable to assess whether the questionnaire actually elicited the data appropriate for the research question (Giovannetti, 1981; Polit & Hungler, 1983; Waltz & Bausell, 1981).

Potential researcher-induced distortions may account for the conflicting results that were reported by these investigators. Biases can result from academic training. Researchers with different theoretical backgrounds may focus on different aspects of the data (LeCompte & Goetz, 1982). Fellner and Marshall (1968, 1970), Knight (1980), Wilson et al. (1968), Basch (1973), Eisendrath et al. (1969), and Crammond (1967, 1971) were psychiatrists who obtained their data during an initial assessment interview and follow-up interviews. Several of these psychiatrists (Basch, 1973; Crammond, 1967, 1971; Crammond et al., 1968; Eisendrath et al., 1969; Knight, 1980) provided therapeutic interventions during the interview sessions or used the information obtained in the interviews to effect improved medical care. Neither Basch (1973) nor Knight (1980), however, claimed to be conducting research but were simply communicating clinical observations. Only Fellner and Marshall (1968, 1970) did not offer interventions during the interview sessions. They used open-ended questions and ensured confidentiality of data, thereby encouraging donors to freely relate their feelings and experiences.

Providing therapeutic interventions during the interview session could change the donor's knowledge base and thereby alter the type and amount of data the donor gives to subsequent questions. The interviewer could imply to the donor that their responses to the situation are incorrect or they may learn how the interviewer thinks (Field & Morse, 1985; Swanson, 1986). The researcher's social role as a psychiatrist may also influence the donors' perceptions of the kind of information that was appropriate (LeCompte & Goetz, 1982). Although interviews are a useful tool which can assist the researcher to understand the donors' experience and to learn about their perceptions of the phenomenon (Chenitz & Swanson, 1985), the interviewer must communicate to the donor that there are no correct answers and that no judgement will be made by the interviewer of the answers. The interviewer should not be a therapist and participants should be referred to other appropriate resources if follow-up is required (Field & Morse, 1985; Swanson, 1986). Results may, therefore, not be replicable unless subsequent researchers have the same social position and operate within the context of providing assessments and/or interventions during the interview (LeCompte & Goetz, 1982).

Conflicting results were reported by investigators. Most indicated that the majority of donors grew with the experience and developed a greater appreciation of life and of other people (Basch, 1973; Crammond, 1967, 1971; Crammond et al., 1968; Eisendrath et al., 1969; Kemph, 1965, 1967, 1970). However, researchers varied in their descriptions of both the amount and the degree of psychological sequelae. Crammond (1971) speculated that 25% of living donors would show signs of long-term harm. Although Kemph (1970) and Basch (1973) observed no severe, permanent psychological sequelae, depression was noted to occur frequently (Kemph, 1970) and dependence conflicts and ambivalence occurred especially in parental donors (Basch, 1973). In contrast, Fellner and Marshall (1968) documented only positive, meaningful, and integrative experiences. Wilson et al. (1968) also reported an absence of psychological sequelae.

Investigators were more consistent in their findings for the pretransplant period. They found that most donors believed they had no choice in making the decision to donate. Donors felt they could not refuse to participate. Most would do it again given the opportunity (Eisendrath et al., 1969). Donors seemed to be motivated by the golden rule (Wilson et al., 1973) or by a desire to save the life of the recipient (Fellner, 1970). They made an immediate, split second decision to donate and remained committed to this action (Fellner & Marshall, 1968, 1970; Kemph et al., 1969). Only Kemph et al. noted that donors had some misgivings preoperatively.

For the posttransplant period, donors responses included feelings of unappreciation, depression, and/or disinterest. Eisendrath et al. (1969), Kemph (1967), Basch (1973), and Crammond (1967) indicated that donors felt unappreciated and ignored posttransplant. They received less attention from parents and staff as interest again focused on the recipient. Donors mourned the loss of their organ and verbalized feelings of receiving little reward for a major sacrifice (Kemph, 1967; Basch, 1973). Sibling donors had more misgivings about donating than parents and they expressed hostility toward the recipient most openly (Kemph, 1970). Eisendrath et al. (1969) reported 13/65 cases of posttransplant depression and noted that negative comments increased when the transplant was unsuccessful. In contrast, Fellner and Marshall (1968) found that donors felt well rewarded for their sacrifice and experienced no lack of attention posttransplant.

Relationships between donors and recipients often changed as a result of the transplant. Crammond (1967) and Basch (1973) both observed that most relationships improved. However, problems that had existed pretransplant often were exacerbated posttransplant. Crammond (1967) noted that while donors had a need to overprotect the donated organ and overinvested time and attention in the recipient, recipients were clearly aware of their obligations toward the donor. He postulated that the manner in which the donor 'gives' the kidney influenced the response of the recipient to the gift and the degree of obligation and guilt.

In summary, the data obtained by psychiatrists who offered treatment during the interview sessions appeared to be different than that obtained by researchers who used open-ended interviews and offered no interventions. The former appeared to document more problems and more depression than other researchers. The differences in results and the methodological weaknesses limit the conclusions that can be drawn from these studies.

The studies in the late 1970s and 1980s are fewer in number but are more sophisticated in their methodology. Researchers reported positive attitudes and little regret in the majority of donors. Psychological sequelae were more likely to occur when the kidney transplant was unsuccessful.

Interviews and questionnaires were used to ascertain both the immediate and the long term effects of donating. Hirvas, Enckell, Kuhlback, and Pasternak (1976), Simmons, Klein, and Simmons (1977), and Higgerson and Bulechek (1982) conducted indepth interviews with kidney donors at various stages of the posttransplant experience. Hirvas et al. (1976) had a psychiatrist interview 23 donors pretransplant and 64 donors posttransplant. Follow-up interviews were done after one year. Both Simmons et al. (1977) and Higgerson and Bulechek (1982) conducted exploratory studies using an investigator developed questionnaire. Simmons et al. (1977) interviewed 14 families one year posttransplant while Higgerson and Bulechek (1982) interviewed 27 donors whose recipient continued to live with the transplanted organ. Simmons et al. (1977) developed the interview guide which was subsequently adapted and used by Higgerson and Bulechek (1982). Content validity was established by clinical experts who reviewed the revised guide.

A 63-item investigator-developed questionnaire was used by Smith et al. (1986) to conduct a multicentre study of 536 donors. Content validity of the questionnaire was established by several health care experts and a pilot study with 126 donors was done to detect gross inadequacies and to determine clarity. While the authors stated that statistical analyses were performed, they did not indicate which specific tests were used to evaluate the adequacy of the questionnaire. The questionnaire was revised and sent to the remaining donors.

Methodological triangulation occurred in studies done by Simmons et al. (1977) and Hirvas et al. (1976). They used different methods of data collection to depict more accurately the experience of the kidney donor (Mitchell, 1986). Qualitative information was enhanced with quantitative measures such as an investigator developed questionnaire which used self-esteem and depression/happiness items and scales from other well-known sources. They established internal consistency of the instrument by performing the coefficient alpha test. Two independent raters categorized the interview material. Questionnaires were given to donors pretransplant, several days posttransplant, 1 year posttransplant, and 5-9 years posttransplant (Simmons et al., 1977). Hirvas et al. (1976) augmented their interview data by performing Rorschach tests with each donor and studying each donor situation in detail at a case conference. An analysis was then made of the donor experience. They also interviewed 10 unilateral nephrectomy patients as a control group. The control group provided the baseline against which the effects of transplantation could be measured (Pagano, 1981; Polit & Hungler, 1983).

These researchers were more congruent in their results. Most donors reported positive attitudes and little regret (Bernstein & Simmons, 1974; Higgerson & Bulechek, 1982; Simmons et al., 1977; Simmons, 1981, 1983;

Smith et al., 1986). Psychological trauma was most evident in the study by Hirvas et al. (1976) who documented moderate to severe psychic trauma in 18% of kidney donors. They noted that donors were reluctant to discuss the experience to avoid boasting and to avoid provoking feelings of guilt in the recipient. However, as in the earlier studies, these donors were interviewed by a psychiatrist. After each interview, the case was discussed in a case conference. These researchers speculated that data from the tests, the interviews, and the case conferences indicated that the transplant was a painful sacrifice and a source of much anxiety. They found similar concepts in the data obtained from their control group of unilateral nephrectomy patients and speculated that similar trauma might be experienced by any person undergoing any major surgical procedure.

The level of trauma posttransplant was not correlated to the outcome of the transplant, but the risk of trauma increased when the recipient was a sibling (Hirvas et al., 1976). Simmons et al. (1977) also noted that parents expressed less ambivalence regarding the transplant than sibling donors. In contrast, however, Simmons et al. documented virtually no significant regret, although they did report increased regret, if the donation was unsuccessful.

Donors were noted to make an immediate decision to participate (Higgerson & Bulechek, 1982; Simmons, Klein, & Thornton, 1973; Smith et al., 1986). This decision was motivated by a desire to save the recipient (Bernstein & Simmons, 1974; Higgerson & Bulechek, 1982; Simmons et al., 1973). Although donors' preoperative concerns were documented (Bernstein & Simmons, 1974; Higgerson & Bulechek, 1982), most donors reaffirmed their decision to donate. This affirmation was not correlated to the success of the transplant (Smith et al., 1986).

Relationships between donors and recipients either remained the same or became close, with only a few relationships developing a further rift (Higgerson & Bulechek, 1982; Simmons et al., 1977; Smith et al., 1986). Bergan (1973), in a study which described the long term physiological effects after a nephrectomy, anecdotally described donors who became alcoholics, who blackmailed the recipient's family, who requested payment from the recipient, and who became hostile toward the transplant institution after the graft failed. However, little systematic research has been done with donors whose relationship with the recipient actually deteriorated posttransplant.

Several factors preclude the application of these results to a BMT donor population. Most interviewers used mainly interview data. Random selection of donors was not carried out by any of the researchers. These methods effectively allowed investigators to achieve an increased understanding and description of the phenomenon. They fulfilled their purpose by describing a new experience or event. However, the findings cannot be generalized to the population of kidney donors or to other populations and may not be replicable (Campbell & Stanley, 1966; Morse, 1986; Polit & Hungler, 1983). Therefore, further research is required to substantiate these results and to establish whether similar findings would be observed in other donor populations. While the findings of this project also will not be generalizable, they similarly will provide a conceptualization of the experience upon which other research can be based.

Lesko and Hawkins (1983) believed that the psychological perspective or issues outlined by kidney transplant donors could be applied to other settings. However, there are significant differences between BMT and kidney transplantation that preclude generalizing the above findings to the minor bone marrow donor. First, most kidney donors are adults who consent to donation. Minors are generally excluded from donation (Bernstein & Simmons, 1974; Knight, 1980). Second, unlike the kidney, bone marrow is regenerative tissue (Starkman, 1985) and harvesting of bone marrow involves a minor surgical procedure (Buckner et al., 1984; Bortin & Buckner, 1983). Minor siblings are frequently used as donors. As the procedure may be considered less serious to staff members and parents, the donation may also bring less praise for the donor (Wolcott et al., 1986b). Third, the bone marrow recipient usually has a life threatening disease for which there is no alternative cure. The use of cadaver bone marrow is not available (Mugishuma, Terasaki, & Sueyoski, 1985) and tissue typing requirements usually preclude the donation from parents and almost exclusively favour the sibling. Kidney or pancreas transplant recipients can return to dialysis or insulin if the procedure fails and have access to cadaveric transplants. Finally, graft versus host disease (GVHD) is another unique aspect of BMT. In this disease, the donor's immunologically competent bone marrow attacks the recipient's skin and internal organs to cause potential morbidity and mortality (Lesko & Hawkins, 1983; Wolcott et al., 1986b).

In summary, the organ transplant literature presents conflicting results about donor experiences which limit the conclusions that can be drawn. Methodological limitations and the unique aspects of BMT preclude the generalization of the results of studies of kidney transplant donors to the BMT donor population. These factors indicate a need for a factor-searching study regarding the impact of the transplant experience on the BMT donor.

Altruism

Several authors used a framework of gift exchange or altruism to conceptualize the experience of donating and accepting an organ (Abram, 1978; Fellner & Marshall, 1968; Fox & Swazey, 1978; Hardin, 1978; Knight, 1980). They refer to the organ as a 'gift' (Crammond, 1967; Simmons, 1981, 1983) or to donation as an 'exchange' (Freebury, 1974). These authors described kidney and not marrow donation.

Gift exchange is described as an act where something material, symbolic, and interpersonal is given. Societal norms guide this exchange by outlining the obligation to give, to receive, and to repay (Fox & Swazey, 1978; Hardin, 1978). The gift of an organ is unique because it can only be produced by humans and it involves the donor in the area of death and family relationships (Prottas, 1983). Accepting the gift places the recipient under social and moral pressure to eventually repay the donor with a gift of equivalent value. Failure to repay the gift produces social strain on all members involved in the gift exchange (Fox & Swazey, 1978).

Wilson (1978) differentiates two types of altruism: 'hard-core' and 'soft-core'. Hard-core altruists offer a gift with no verbalization or no unconscious desire for a reciprocal exchange. Soft-core altruists usually expect some return from the recipient or from society. This expectation may be either conscious or unconscious. Farley (1982) postulates that soft-core altruism is the primary source of motivation for donation in that the donor, often unconsciously, expects some return after the transplant. Reciprocation can take the form of increased recipient health or expressions of appreciation by the recipient and the family. He postulates that recipients of unsuccessful transplants do not reciprocate with increased health. Donors may then develop depression and/or somatic complaints in an attempt to elicit some reciprocal attention or return.

Evidence to support this theoretical framework of gift exchange has been documented by several studies on kidney transplantation. Researchers report that donors feel unappreciated and may be hostile to the recipient (Basch, 1973; Crammond, 1967; Eisendrath et al., 1969; Gulledge, Buszta, & Montague, 1983; Kemph et al., 1969), recipients feel they have taken advantage of the donor (Castelnuovo-Tedesco, 1978; Kemph et al., 1969; Lesko & Hawkins, 1983; Muslin, 1971; Tourkow, 1974), recipients feel they are unable to repay the obligation (Bernstein & Simmons, 1974; Crammond, 1967, 1971; Knight, 1980), and parents have a clearer moral obligation to donate to their children than siblings to their sibling (Hirvas et al., 1976; Knight, 1980; Simmons, 1981; Simmons et al., 1977). However, for the BMT donor, a unique variable remains unexplaine[illegible]y the framework. The donor's gift of bone marrow is not rejected by the recipient as in kidney transplantation, but the gift 'rejects' the recipient, can cause significant morbidity, and can contribute to mortality. In this study, the investigator determined the expectations of donors regarding their need for a reward or praise, ascertained the type of appreciation they received, and identified their feelings regarding the gratitude they received.

Bone Marrow Transplantation

The psychological effects of donating bone marrow have received little attention in the literature (Wolcott, 1986b). Several authors anecdotally reported findings of increased donor guilt when the recipient undergoes health complications (Brown & Kelly, 1976; Gardner et al., 1977; Patenaude et al., 1979; Wolcott et al., 1986a). The lack of systematic research into the experience of the BMT donor makes it a theoretically underdeveloped phenomenon.

Several authors (Brown & Kelly, 1976; Freud & Siegel, 1986; Gardner et al., 1977; Patenaude, 1979, 1982) described the psychological adaptation of pediatric bone marrow recipients. Gardner et al. (1977) studied seven pediatric recipients and their families. As previously noted in early research with kidney donors, these investigators also provided counselling services to the participants. The remaining authors (Brown & Kelly, 1976; Freud & Siegel, 1986; Patenaude, 1979, 1982) documented data obtained from their professional experience with pediatric BMT patients. Only negative aspects of the donor experience were generally outlined.

Donors verbalized ambivalence about donating. They wished they were not chosen but enjoyed the extra attention. Donors experienced guilt when GVHD and other complications occurred or when the transplant failed. Explanations from health professionals did little to relieve donor guilt (Patenaude et al., 1979). Donors felt responsible for the outcome of the BMT (Gardner et al., 1977) and were concerned that their marrow might fail the recipient (Brown & Kelly, 1976).

Parents expected donors and other siblings to accept extra responsibilities (Patenaude, 1979) and donors experienced a sense of abandonment during their parents' absence (Freud & Siegel, 1986; Patenaude, 1979). Some donors felt they had not received appropriate gratitude for their contribution (Freud & Siegel, 1986).

Though their study focused on the recipients, Gardner et al. (1977) documented psychopathology in donors ranging from very mild to severe although they did not state how many donors were affected with each label. They stated that donors require a supportive environment in order to develop a sense of pride regarding their contribution. They believed that donors required psychological evaluations pretransplant and therapeutic interventions throughout the experience. They also provided therapeutic interventions during their data collection phase which, as previously discussed, may change the donor's knowledge base and alter subsequent responses (Field & Morse, 1985; Swanson, 1986).

Only one study (Wolcott et al., 1986b) focused specifically on the psychological adjustment of the adult BMT donor. Findings indicate that these donors showed little emotional distress, a high self-esteem, and a high degree of current life satisfaction. The perceptions of the donors regarding the quality of the donor-recipient relationships were highly correlated with family approval status, mood state, social role functioning, and the recipient's self reported current health status. The researchers suggest that the degree of physical or psychosocial morbidity in BMT recipients may therefore negatively affect the psychological status of the donor. They speculated that 10-20% of donors experienced some 'negative consequences'.

The authors themselves stated that methodological weaknesses limit the conclusions that can be drawn from this study (Wolcott et al., 1986). They studied the long term psychosocial effects of donating on donors whose recipient survived. They used an investigator constructed questionnaire, a demographic questionnaire, a Profile of Mood States checklist, and the Simmons Scale which was used for kidney donors. The questionnaire was not validated by the authors. They stated that this limitation occurred because BMT was a new field and cited a lack of systematic research in this area. The assumptions of a questionnaire include the fact that all aspects of a phenomenon are known to the investigator and are included on the questionnaire (Leininger, 1985; Morse, 1986). While it is possible that the investigators have the experience and the knowledge in this area that will allow them to develop a good questionnaire without prior research to guide them, most investigators require a first level of inquiry or a preliminary study to guide them in an area which is theoretically underdeveloped (Douglas, 1976). In order to lay the groundwork for future studies concerning the BMT donor experience, this present study conceptualizes this experience.

Conclusions

BMT presents unique aspects to the donor experience as compared to the kidney donor. Most of the BMT research has involved minor recipients instead of donors. Although the framework of gift exchange may characterize the experience of the kidney donor, the unique aspect of GVHD in BMT necessitates further study in order to delineate the phenomenon of the BMT donor. In order to avoid a priori assumptions that could influence the study results, this study details the important aspects of the BMT donor experience from the perspective of the adolescent donor and conceptualizes the event, thereby providing the groundwork for future studies in this area.

CHAPTER 3

Methods

Design

The type of research problem or the level of inquiry of the research question determines the study design (Diers, 1979). A quantitative design is appropriate if a researcher starts with a previously developed theory and then designs ways to validate or invalidate this theory. The variables would be quantified or measured and the resultant numbers statistically analyzed. In contrast, a qualitative design is valuable when the researcher needs to describe the world of individuals undergoing an experience. The researcher does not begin with a theory but a theory can be developed to conceptualize the phenomenon under study (Leininger, 1985).

This study is a factor searching study (Diers, 1979). The method of data analysis is the grounded theory approach developed by Glaser and Strauss (1967) and outlined by Chenitz and Swanson (1986). The purpose of this qualitative research is to characterize the poorly understood phenomenon of the bone marrow donor's experience from the perspective of the person(s) undergoing the experience. There is no attempt to control for extraneous variables or to place experimental controls on the phenomena (Chenitz & Swanson, 1986; Field & Morse, 1985). The resultant theory is presented as a "theoretical discussion using the conceptual categories and their properties" (Glaser & Strauss, 1967). Although the results are not generalizable to a larger population and may not be replicable (LeCompte & Goetz, 1982; Morse, 1986), the purpose of the study is not to test a theory but to conceptualize this phenomenon and to develop a theory.

The Sample

As the purpose of this study was to understand and characterize a phenomenon and not to 'determine the distribution' of attributes or to 'test relationships between variables' (Morse, 1986, p. 2), a non-probability sampling procedure was used. Non-probability sampling assumes that all donors are not equally knowledgeable about the experience as some donors may lack perceptivity, be inarticulate in describing their experience, or have poor recall (Douglas, 1976; Morse, 1986). As the research product depends upon the quality of the understanding developed of the phenomenon, the investigator planned to select informants according to their expertise and their receptivity to participate in the study (Morse, 1986; Turner, 1981). Informants were to be selected who were articulate, knowledgeable, and receptive to the investigator (Morse, 1986).

In this transplant centre, patients came from other states and other countries. Although the number of potential adolescent donors was substantial, few were accessible by car; thereby limiting sample selection. Several donors were interviewed who were not articulate but who had knowledge of the experience.

The criteria for subject selection were as follows:

1. the donor was willing to participate in the study;
2. participant was able to speak and understand English;
3. the donation of bone marrow occurred at least 12 months prior to the interview; and
4. the donor was between 11 and 18 years of age.

Donors were interviewed at least 12 months after the actual donation in order to ascertain the long term effects of the experience. Morbidity related to the BMT maybe evident early in the transplant procedure. However, late complications can occur several months to several years posttransplantation, require long periods of observation, and leave residual disability (Sanders, in press; Sanders et al., 1987; Sullivan et al., 1984). Children who develop long term complications posttransplant may then live with a chronic illness. The Commission on Chronic Illness defined chronic illness as any impairment or deviation from normal that has one or more of the following characteristics: 1) is permanent; 2) leaves residual disability; 3) is caused by non-reversible pathological alteration; and 4) may be expected to require a long period of observation, supervision, or care (Mayo, 1956). In order to allow these potential late complications to occur and in order to allow families to experience the long term effects related to transplantation, donors were interviewed at least one year posttransplantation.

The age range of donors was limited because adolescents have different developmental attributes than preschool or school-aged children. Erikson (1968) and Inhelder and Piaget (1958) postulated that children undergo a continual process of development. Donors between the ages of 11 and 18 years will likely perceive the experience of donating differently than donors less than 11 years of age and those more than 18 years of age. Only donors, therefore, who were between 11 and 18 years of age were considered potential participants. Although adolescence typically is identified as the age between 13 and 18 years, Inhelder and Piaget state that developmental stages can be achieved at varying ages and this variation may be partially determined by the child's experience. Donors who were 11 years old would have experienced the transplant situation for at least a year, potentially advancing them to the same developmental stage as their older counterparts.

Initially, the criteria for subject selection included the stipulation that only donors whose recipients had a Karnofsky score (Karnofsky & Burchenal, 1949) of less than or equal to 80% (see Appendix B) and who were in remission would be considered as potential participants. Karnofsky developed a scale of performance that quantifies an individual's degree of morbidity by identifying the degree of interference the individual has in activities of daily living due to the side effects of the treatment. This criteria was originally included because findings reported in the literature (Wolcott et al., 1986) indicated that psychological sequelae may increase as the recipient's health status deteriorates and this observation warranted further investigation. However, the nurse expert was unable to identify any adolescent donors whose recipient met these criteria and who lived within the state. This criteria was therefore deleted.

The theoretical sampling method required that the investigator choose the participants according to the needs of the research and according to which individual could best enrich the investigator's understanding of the donor experience (Chenitz & Swanson, 1986; Field & Morse, 1985; Glaser & Strauss, 1967). In analyzing the data, it became clear that further information was required regarding donors who refused to donate, donors who developed psychological sequelae, and donors who requested payment in return for donating. The nurse expert could not identify any such adolescent donors. Three adult donors were then considered but one did not speak English, one was out of the country, and one refused to participate. These practical considerations limited the extent to which theoretical sampling methods could be implemented.

Data Collection

All subjects but one were transplanted in the same institution and were selected from this institution's computerized donor registry. One donor who was transplanted in another institution heard about the project and offered to participate. The bone marrow transplant facility was a large research centre which accepted patients from around the world. As the investigator had limited familiarity with the setting and the donor population, a nurse expert was selected by the nursing department of the institution to assist the investigator in the purposive selection of the sample.

In consultation with the nurse expert, potential candidates were identified. Initial contact was made by the nurse expert and the donor's willingness to take part in the study was established. The names of donors who agreed to participate were then given to the investigator. The parents of donors who lived at home were contacted and verbal consent was obtained to allow the investigator to discuss the project with the donor. Donors who lived away from the parental home were contacted directly. The purpose of the study was outlined, consent to participate was verified, and a meeting time and place were arranged.

Open-ended interviews were conducted using an interview guide (see Appendix C) which identified several general questions that the donors could be asked. However, the investigator attempted to follow up and explore concepts or ideas raised by donors during the interview and to avoid predetermining the topics for the interview (Swanson, 1986). This interviewing technique allowed participants to describe the experience from their perspective with minimal bias or direction from the investigator (Field & Morse, 1985; Swanson, 1986).

Most interviews were conducted in the donor's home. One out-of-state donor was interviewed over the telephone. The length of the interview was determined by the tolerance of the participant and the type and amount of information they were able to contribute. Interviews varied in length from 1 hour to 2 1/2 hours. All interviews were tape recorded and transcribed to ensure accurate, unbiased, and detailed accounts of the interaction (Diers, 1979; Leininger, 1985).

A total of nine donors was interviewed. The first three donors were interviewed on two separate occasions, approximately 2 months apart. The first interview was designed to explore new ground. The initial questions were more superficial in nature than those in later interviews. The second interviews provided donors with an opportunity to confirm the data contributed by subjects who were interviewed later and to verify the developing hypotheses, thereby providing increased depth to the data. The next four donors were asked both general questions and questions which focused on verifying the concepts and the relationships that were identified from the initial interviews. These donors had a chance to identify new concepts and to corroborate the information given by the earlier donors.

The goal of qualitative research is to ensure richness of data (Robertson & Boyle, 1984), credible understanding of the phenomenon (Sandelowski, 1986), and complete, precise and accurate data (Morse, 1986). The investigator cannot predetermine the sample size for the study. Rather, sample size is determined when the investigator is collecting no new information about the characteristics of the categories and when the investigator has an understanding of the situation (Field & Morse, 1985; Glaser, 1978; Glaser & Strauss, 1967; Morse, 1986). Donors of recipients who had died were describing similar experiences to donors of recipients who had survived. These donors were perceived by staff to have no major problems posttransplant and they all identified similar concepts relating to the donating experience. As no new data were being obtained and as practical considerations limited the extent under which theoretical sampling methods could be achieved, the data collection phase of the study was concluded with nine subjects.

Characteristics of the Sample

The ages of the donors at the time of transplant and the present health status of the recipients are summarized in Table 1.

Demographic Data

Table 1

Demographic Characteristics of BMT Donors

Donor	Sex	Time from Dx to BMT	Age at BMT	Only Match	Years Post BMT	Status of rec
001	F	6mos	17	Y	9	Alive
002	M	4mos	16	N	2	Alive
003	F	3mos	15	Y	3	Alive
004	M	11yrs	13	Y	8	Alive
005	F	2mos	14	N	16	Alive
006	M	6yrs	18	Y	12	Died
007	F	8yrs	13	Y	5	Alive
008	M	12mos	17	N	7	Died
009	F	12mos	12	Y	4	Died

At the time of the transplant, all donors lived in their parental home. The recipient resided in the same home in all cases except one in which the recipient had already left home but returned for a short period to receive care from the family. At present, three donors had moved out of their parental home while the remaining six donors continued to live in their parents' home. Three donors were in their final years of high school and two were attending college. These five donors also held part-time jobs. Two were employed in full-time jobs outside of the home. One of the two donors who were full-time homemakers maintained a part-time job outside the home.

Data Analysis

Data analysis began after the first interview was completed and continued throughout the data collection period. The method of analysis used was grounded theory (Chenitz & Swanson, 1986; Glaser & Strauss, 1967). All the interviews were tape recorded and the data were transcribed onto a computer disc. In order to document the context and the setting of the interviews, field notes were written to document the investigator's thoughts and experiences during the interviews. A description of the setting, a description of the actions of the interviewee, and the activities or interpretations that occurred during the interview were recorded. Repeat interviews were scheduled with three donors to allow the investigator to verify the data and to ensure that the researcher's interpretation of the data was the same as that of the interviewee (Field & Morse, 1985; Wax, 1971).

The data were analyzed for categories that described aspects of the bone marrow donor's experience. Each category was given a label which characterized its data. The developing categories were examined for their fit with incoming data. The categories were considered 'saturated' when the qualities or characteristics of the categories were identified (Corbin, 1986; Field & Morse, 1985; Glaser, 1978; Stern, 1985; Turner, 1981). Subcategories or properties of the categories were identified which describe the conditions under which certain behaviours or acts occur and the consequences of these behaviours or acts. When new categories were no longer emerging from the data, the investigator reviewed the categories and postulated links between them and the conditions under which these links held. Hypotheses concerning these relationships were developed. All hypothesised relations were rechecked with the data and in subsequent interviews. This process was refined until a theory was postulated that described the phenomenon of bone marrow donor experience (Corbin, 1986; Glaser, 1978; Stern, 1985; Turner, 1981). The literature was then searched for existing theories that were consistent with the postulated hypotheses.

Ethical Considerations

Ethical clearance for the study was obtained from both the Fred Hutchinson Cancer Research Centre and the University of Alberta. All potential participants received their initial contact by a designated Fred Hutchinson Cancer Research Centre staff member to ascertain their willingness to participate. At the initial interview session, the investigator outlined the purpose of the study and answered any questions. The preliminary discussion included the fact that all information would be kept confidential.

The participants and the parents of minor participants were then given the appropriate consent form(s) (see Appendices D, E, and F). Written consents were obtained from all donors prior to the interview except for one donor who gave a telephone consent. The written consent form was read to this donor over the telephone and the nurse expert of the institution acted as witness to the subject's verbal consent. Two copies of the written consent form were subsequently sent to this donor and one copy was returned signed.

The investigator conducted the interviews in the donor's home environment. A professional at the Fred Hutchinson Cancer Research Centre had been designated as the referral person if participants required follow-up but it was not necessary to use this resource. If donors became upset during the interview, the investigator reminded them that they could stop the interview at any time. Some donors shed a few tears or developed tremors in their voice indicating emotional difficulty. However, these donors did not wish to discontinue the interview. They recovered their composure when supportive statements were made and they conveyed a desire to continue. At the end of the interview, several donors expressed appreciation for the opportunity to share their experience and to participate in a project that might make a difference in the lives of other donors.

CHAPTER 4

Results

Two prevalent issues thread through most of the data: a) donors needed to make a difference in the life of their family and b) donors found the transplant experience emotionally difficult. However, all were proud of their contribution and reaffirmed their decision to participate.

Their need to make a difference resulted from the fact that they were having an encounter with death. A member of their family was seriously ill and had no hope for a cure other than through a transplant procedure. Their sibling might die. Donors wanted this situation to be different. Therefore, they tried to 'help out' by acting in any manner that would change the outcome or the situation, thereby making a difference. This desire to 'help out' continued until the recipient was healthy or died.

Two factors contributed to donors' feeling that the experience was 'a big deal emotionally'. First, contemplating the potential death of their sibling was emotionally difficult. Second, while donors were attempting to effect a difference in the life of their family, both the illness and the transplant experience were making a difference in their own lives. They experienced changes in their relationships with their parents, friends, and recipient. As well, donors experienced a change in their life philosophy. Coping with the effects of these two factors was a 'big deal emotionally'. The physical part of donating appeared to be almost inconsequential compared to these emotional aspects.

In this chapter, a detailed description will be given of the donors' desire to make a difference in the life of their family. The emotional difficulties that donors encountered and the changes that occurred as a result of their transplant experiences will then be outlined. In summary, a model which depicts the donors' experience will be proposed.

Making a Difference

All donors described feelings of helplessness associated with having a sibling who has a life threatening disease. The sibling would die if 'something was not done'. Therefore, donors wanted to "do something" to "help out" and they wanted their action to be something tangible. By acting, they attempted to re-establish hope and to make a difference in both the life of the recipient and the life of their family.

The donor's need to 'help out' was evident in mainly two aspects of the transplant experience: pretransplant and posttransplant. Pretransplant, donors made an immediate decision to become a donor. By performing the physical act of donating, they provided an intervention which might make a difference in the life of the recipient and which gave them a feeling of control in a helpless situation. However, when they observed little physical change in the recipient posttransplant, they again felt a need to make a difference and to "help out". However, this time the appropriate interventions were more difficult to identify and they experienced a renewed sense of helplessness and lack of control. Donors felt envious of staff members who daily offered concrete care activities. This need to intervene on behalf of recipients ended when recipients either regained their health or died. All donors felt proud of their role in the transplant but this feeling was tempered by the health status or the attitude of the recipient.

This section begins with a description of the donor's encounter with death and continues with a discussion of the a) decision to donate, b) experience with the act of donating, c) desire to help in the posttransplant period, and d) consequences of acting in order to make a difference.

The Encounter with Death

All donors were aware that their sibling could die. All verbalized some understanding of the situation; if some intervention was not offered, their sibling would die. They reached this conclusion despite lacking a clear understanding of the disease process.

Donors encountered death in two ways. Firstly, they realized that, without their donation, their sibling would die. All stated that their reason for donating was to save the life of their sibling. Posttrans~~plant,~~ however, most donors believed that the recipient would not die because something was now being done for them. The tangible act of donating would affect the desired outcome of a normal life-span for their sibling.

> 'I didn't think during the transplant that the R (name of recipient) could die because here we were doing this thing and something was being done.'

Secondly, as a result of living in the transplant environment, donors saw other recipients die. Prior to the transplant experience, most had not experienced the death of someone they knew. Now, people they had met and had talked to were dying. Hearing about the death of someone whom they knew seemed to be an illustration and a reminder of the reality of the situation. Knowing that others died had more of an impact on donors than hearing staff discuss the potential risks of the procedure.

> 'I had never seen that before - seeing someone and then they're gone.'
>
> 'Suddenly people you talked to, spent time with, got close to, they're dying. You really start to realize that this could happen to R.'
>
> 'Until they started dying, I never really thought that R could die.'

The various reactions of donors to the death of others included their considering the possibility that the recipient could die, realizing that their sibling had a temporary deliverance from death, experiencing relief that it was not their sibling that had died, expressing guilt at feeling relieved, expressing no guilt at feeling relieved, and/or feeling sad for the loss of someone they knew.

> 'You don't want to see anybody die but if I had to choose between R and somebody else, I would have chosen R to live.'
>
> 'I was relieved that it wasn't R that was dying. That was a relief but I felt guilty because I was relieved it was them and that made me feel bad. I was sad because I liked them, glad because it was them and not R and guilty because I was relieved it was them.'

The cause of death remained prominent in the memory of the donors. They expressed concern regarding the health of their sibling whenever they observed symptoms similar to those related to the cause of death of that other patient.

> 'Another patient died because she had pneumonia so I was afraid that if R got sick, that it could turn into pneumonia.'
>
> 'If that happened to them, it could happen to R.'

In summary, donors lived for a period of time in a world that consisted of people who might die--both other patients and their own sibling. Although most donors had heard of the likelihood of death, they now began to encounter it, to see it happen. This encounter contributed to the emotional impact that all donors described as the most difficult aspect of the transplant experience. They expressed a desire to intervene with physical acts to avert this undesirable situation and to make a difference in the lives of their family members.

The Decision to Donate

Donors made an immediate decision to donate. Donors perceived the situation as an opportunity to make a difference in the quality of another person's life. This perception was consistent with their values regarding life. For the purpose of this paper, these values will be labelled 'moral code'. It was their moral code that directed them to realize an opportunity to 'make a difference' in the quality of another person's life. They felt they had no choice. Refusing to participate was not considered an option and they lacked understanding for individuals who refused to donate. Donors felt that they contributed in a tangible way by donating and all would donate again given the opportunity.

Although donors varied in the magnitude of their desire to be the donor, all were willing to be tested to determine if they were an appropriate match. All donors wanted the best matched bone marrow for their sibling. Most wanted to be the person that matched. Only two donors stated that it made no difference whether the donor was them or one of their siblings. All donors felt that donating was a physical or tangible act which could affect the outcome. It offered a sense of control and decreased feelings of helplessness.

> 'I had some control.. It was the first time that I felt I could do something. I had a chance to do something instead of being helpless.'

It appeared that individual siblings had their own guidelines as to what constituted a good match. They raised issues such as bigger was better, same sex donors were better, and individuals who were most available or least inconvenienced were better.

> 'I was a little bit macho too. I didn't want my sister or little brother to have to go through the thing.'
>
> 'I knew they'd take my bone marrow before they'd take my other brother's or sister's bone marrow because I'm bigger anyway.'
>
> 'I figured that I would be the one because I was the only one that didn't have a job or family so I would be the logical choice and it ended up to be true.'

On hearing that they were the best match, all donors made an immediate decision to donate. This decision was not made after carefully weighing the pros and cons nor was it made over several days. It was often made prior to a full understanding of what the procedure entailed. Most knew immediately that they would donate if they matched. They felt they had no choice in this situation.

> 'I didn't think I had any option in the matter. There was no decision to make. It was kind of automatic.'
>
> 'It never crossed my mind that I wasn't going to do it.'

This automatic 'decision' to donate appeared to originate from the moral codes held by the individual donors. In general, the prevailing belief was that if one is presented with an opportunity to 'make a difference' in the quality of life of any other individual, one has a responsibility to realize that potential. Donors saw life as being one's most valuable asset and applied the golden rule of 'do unto others as you would have them do unto you' to this situation.

> 'Life is more important than just a little bit of suffering.'
>
> 'If I had refused somebody else, then I wouldn't see any reason why they'd have to help me, really.'

Several donors also described other reasons for wanting to be a donor which included feelings of 'being able to do a great thing' and get a little attention as a result, and feelings of protectiveness for their remaining siblings. Some believed that, because they were older or male, they were more able to manage this procedure. Only one of the donors, however, related any awareness of the feelings of her other siblings when they were not chosen. She understood that her other siblings envied her.

Two donors had siblings who were equally matched and both of these donors considered themselves to have no choice in the decision to donate. Neither had any thoughts of abdicating their role in favour of the other matched sibling. They assumed that their bone marrow would offer recipients their best chance for a healthy life. Refusing to donate was considered an uncaring act.

Donors' moral code was operational in various aspects of the transplant experience. The moral code influenced their decision to donate and to view that donation as nothing special, their perceptions of persons who refused to donate, and their willingness to donate again in the future. Their moral code directed their thinking and prescribed the appropriate behaviours.

Most donors felt they had not done anything special in donating the bone marrow because their moral code had required this behaviour. They believed that other people would have similar moral codes and therefore would have done the same thing. This belief was reinforced by some of their friends who had told them that they too would have donated if they were in a similar position. Two donors did regard the donation as something special, but the recipients in both cases verbalized a sentiment that they could have survived the disease without the donors' int[illegible]ention.

[illegible]cause their moral code had directed their behaviour and because they assumed others would have similar moral codes, donors lacked understanding for any potential donor who would refuse to donate or who would request some form of reimbursement for donating. The issue was raised by one donor who had watched a television program about a cousin who had refused to donate. This same situation was then presented to all donors for their reaction. Only three other donors had heard of similar situations. However, all donors expressed disagreement and disappointment with such a decision. Some donors became quite forceful in stating their horror and disbelief at this occurrence.

Donors perceived the donation process to be a minor procedure which presented little risk. It involved an organ which had the capacity to regenerate. It was a minor inconvenience for donors compared to the opportunity to help their siblings by potentially saving their lives. This benefit, in the minds of the donors, far outweighed any minor risks.

Donors considered individuals who refused to donate to be selfish and inhumane. Several described them as murderers. They found such an act to be incongruent with their moral code of taking the opportunity to make a difference in an individual's life if one had this potential. Although they could not understand how an individual could refuse to donate to any person, it was more incomprehensible when it applied to a family member as this was also perceived to be a lack of caring.

> 'That's just as bad as murder because she didn't even give her cousin a chance'
>
> 'That's like coming out and saying, Let her die. That's like shooting somebody once and just letting her die.'
>
> 'I don't know how people can do that, even if it's not a relative. It just doesn't make sense to me personally. Why would you pass an opportunity to help someone out.'

The donors' moral code indicated that they actualize any opportunity which would offer any individual a chance at a better life. Therefore, for these donors, it would be worse if one refused to donate and the person died than if one did donate and the person died. In the latter situation, at least one had tried everything possible. The chance had been offered but the potential cure had not been realized. In the former situation, no attempt was made to offer the chance of survival. Therefore, one is left with the uncertainty of wondering if a difference could have been made. For all donors, this uncertainty would have been unbearable. They would have experienced feelings of guilt and remorse at not having actualized the potential to make a difference in a life threatening situation.

> 'You'd carry around that guilt for the rest of your life. It would be hard to live with'
>
> 'You'd be left with the guilt, wondering, could I have helped. To me, that would be almost unbearable.'

All donors found it difficult to come up with scenarios in which they felt it would be acceptable for an individual to refuse to donate. Some could not think of any such circumstances while others listed situations in which the donation procedure would pose a threat to the life of the donor, pose a threat to the life of the recipient, prolong the suffering of the recipient, or place severe emotional stress on the donor.

Willingness to donate again seemed to be influenced more by the donors' moral code than by their posttransplant experience or by the success of the transplant. All donors stated that they would donate again for either a relative or an unrelated person. They also verbalized a willingness to participate in a national donor pool.

> 'You do what you can to help. That's the way I was brought up. No matter if you know her or not.'
>
> 'The chance of saving anybody's life, as many times as it would take, as many times as I could, I would. I think the bone marrow, for saving someone's life, it was nothing.'

In summary, donors saw the physical act of donating to be a minor inconvenience when compared with the chance of saving the recipient's life. Their moral code appeared to guide their thinking and their behaviour. They undertook action which could affect a difference in the life of another individual. All donors reaffirmed their decision to donate and would donate again to an unrelated or a related donor.

Consequences of Deciding to Donate

Donors remembered feeling worried and scared after they had agreed to donate. There were two aspects to this fear: a) a fear of the actual procedure and/or b) a fear of hospitalization.

Fear of the procedure: When donors initially heard that they might be the donor, they wondered what the procedure would involve. Some imagined that it would require a surgical procedure similar to other organ transplants while others either asked questions immediately, were willing to do whatever was involved, or avoided thinking about the issue.

Upon hearing the words 'bone marrow transplant', most donors visualized what the procedure might entail. Donors imagined that the transplant involved a surgical procedure in which some bone was removed and subsequently reimplanted into the recipient. These ideas seemed to germinate from an association with heart and kidney transplants. Donors had seen TV news reports which described surgical interventions related to these procedures and they linked their upcoming transplant experience with these descriptions.

Donors who did not imagine what the procedure might entail described responses which included asking immediately what the procedure was like when they first heard the words, having no images because they had no idea of what to think, avoiding thoughts relating to the procedure in order to decrease their own anxiety, and lacking curiosity because they were satisfied that this procedure would help their sibling. Most donors did not know how or why their donation would help, only that it would.

> 'I thought it probably meant taking a bone of some sort. I didn't know where it came from. I imagined it would be somewhat debilitating for a while but again, I didn't know how. Transplant just sounded like a major thing. On TV, you always hear of heart and kidney transplants so that was the only way I could equate it. I really didn't know what bone marrow was.'

The donors who imagined debilitating surgery all described fear regarding the procedure. However, these donors did not withhold their consent despite their concerns. They agreed to donate before they knew any details of what to expect. They did express relief, however, when they were informed about what the transplant actually entailed.

> 'I really hoped I was the match. Yea, I worried about how it would affect me long term. I thought about that. But it was never a question in my mind of whether I would or wouldn't. If it was me, I was going to do it no matter what. When they explained the process to me, I was kind of relieved cause then it didn't sound like that big of a deal.'

All expressed satisfaction with the type and amount of information they were given about the donation event. Education was not only provided on an individual basis by the health care staff, but donors also collected additional information on their own. They watched other donors return from their procedures, read information panels in the lobby, talked to other donors about their experiences, and talked to nurses on the unit. In general, donors felt they had been well-informed and that they understood the upcoming events as much as they were able.

Fear of hospitalization: Donors described a fear of undertaking a new procedure on their own. However, they still wanted to donate. Their concerns were ameliorated by their trust and confidence in the medical staff and their strong desire to make a difference in the life of the recipient.

All donors described some fear of hospitalization.

This fear occurred after they received their donation information/education and was greater than their fear of the actual procedure. This apprehension did not appear to stem from any past experiences with hospitals but was related more to a fear of the unknown. Some donors actually enjoyed visiting their siblings or other patients on the unit and were comfortable with a hospital setting. However, the idea of their own hospitalization was frightening. For most donors, this was their first encounter with hospitalization and they related a vague feeling of uneasiness that they found difficult to characterize. Fearful experiences included being admitted to hospital, staying overnight, or going into the operating room. Common to these events was the fact that they were either new experiences which they had to go through by themselves or experiences of which they had little previous information.

> 'I wasn't scared going into hospital. I'd been in hospital before and my whole family was there. Just when I had to go off by myself, like without my parents with me.'
>
> 'You don't have a clue what it would be like and it was all brand new.'

While most donors viewed this new situation as 'scary', two donors identified an exciting aspect of this 'scary' situation. They described the experience as novel, unique, and different and therefore felt an exciting kind of nervousness.

> 'I think it was an exciting nervous. Something different, something new. You know how you get tense when you're doing something new. Kind of nervous because you're not exactly sure, hard to sleep the night before, that kind of a nervous because you're excited.'

Despite their concerns regarding hospitalization, donors did not wish to withdraw their participation.

> 'I was scared about going in but I was kind of happy that I could do this.'

Donors' fears were partially alleviated by their trust and confidence in the medical staff. Most did not understand how the transplant was helping the donor but they believed the physicians who said it would. They assumed that the donation procedure was safe because they believed that the medical staff would not have been asked them to perform the procedure if it was unsafe. This trust in the medical staff and their strong desire to save the recipient helped donors cope with their fears.

Donating

The actual donation procedure was described as being 'no big deal' despite the fact that all donors remember having pain. The pain lasted only for a few hours or a few days and it 'wasn't bad at all.' As a result, all donors advised new donors that they need not be concerned about the actual procedure. In general, they felt that the benefits to the recipient far outweighed the discomfort they themselves experienced from the donation.

Consequences of Donating. For donating, donors received rewards from three sources: verbal praise from friends and family, feelings of appreciation from the recipient, and increased self esteem. Appreciation was expressed in tangible or intangible ways and occurred regardless of the outcome of the transplant experience. Donors appeared satisfied with either tangible and/or intangible expressions of gratitude. Their moral code had determined their decision to donate and most believed that any rewards they received were a bonus for doing something they ought to have done in the first place.

Close friends and relatives were more likely aware of the donor's role and had an appreciation for the donor's contribution than classmates or teachers. Therefore, verbal rewards came mainly from close friends and family members. While few donors noted that classmates or teachers were kinder to them at school, most saw no difference in the way other students treated them. Classmates often had little understanding of the role of a bone marrow donor or of the bone marrow transplant procedure.

All donors also received some sense of appreciation from the recipient, expressed in tangible and/or intangible ways. Only two donors received any tangible evidence of the recipient's gratitude. One donor received a stuffed animal and another received an older model car.

> 'She introduces me to people she knows as the one who saved her life. At Christmas, she always buys a gift for me and right afterwards, she gave me a car. I could do no wrong, almost.'

The remaining 7 donors received only intangible rewards. They received no verbal expressions of gratitude nor did they receive any gifts. However, each donor firmly believes that the recipient is appreciative of the donor's role. This belief was also evident in the two donors whose recipients stated that they could have survived the disease without the donors' intervention.

Among those who did not receive tangible signs of appreciation, donors identified a feeling of gratitude from certain recipient behaviours, such as different tones of voice and a more caring and gentle approach. Two donors assumed that the recipient was grateful because they were cognizant of the fact that their siblings were sensitive and caring individuals.

> 'She was kind of different with me, kind of more caring, warm, and gentle. She used to talk to me in tones that she'd never used before.'

> 'She thinks quite a bit like me and I think she didn't just want to say thank you. Words just were not enough

> so I don't think she bothered saying thank you. But I knew.'

Only one donor expressed regret at not having received at least a hug and a thank you, which was all she wanted. However, the recipient in this case felt that the donor had an obligation to donate. Despite this disappointment, the donor firmly believed the recipient was grateful.

Few donors talked to the recipient at any great length about the donation procedure. Some donors stated that they had no need to discuss their role as a donor with the recipient while others stated that they did not know what to say. In fact, most donation-related conversations between the donor and the recipient were conducted in a joking manner only. The effect of keeping communication between recipients and donors on a joking, light vein appears to be partially in response to a desire on the part of the donors to down-play their role in saving the recipient's life. Donors seemed to take an active role in ensuring that the recipient would not feel a need to repay them.

> 'I knew how much it meant for me to do it but I never wanted her to think that she owed me anything or that I was doing her a favour. So I never brought it up other than joking occasionally. It wasn't appropriate. It was the right thing for me to do. It's nothing you have to say thank you for, I don't think.'

It was interesting to note, however, the response of two donors who were asked to place themselves in the role of the recipient who had just received bone marrow. They both felt that if they were recipients, they would strongly feel a need to repay the donor, although they were not sure how they could go about compensating the donor. However, as donors, they did not wish to be rewarded because in their mind it was something they wanted to do and it was actually 'no big deal physically'.

All donors were proud of their role in the transplant experience. Having an opportunity to make a difference in their family's life resulted in donors feeling important and valuable. Subsequent feelings of increased self esteem occurred regardless of the outcome of the transplant. They had done something important, tangible, and unique for a family member.

In summary, most donors appeared to be satisfied with the nonverbal communications of gratitude. Donors avoided conversations relating to the transplant that might make the recipient feel a need to repay them. In general, it seemed important that donors sense their recipients' appreciation of their efforts but the method in which recipients communicated this gratitude was not critical.

The Desire to Make a Difference Posttransplant

Donors expressed a continued need to assist the recipient in the posttransplant period. Donating had made a tangible contribution towards making a difference in the pretransplant period. After the donation, donors watched for signs of recovery to determine if their action actually made a difference for the recipient. If no immediate evidence of improvement was forthcoming or if the recipient developed health problems, donors again experienced concern for the recipient's health status. Some expressed feelings of guilt and felt responsible for the behaviour of their bone marrow in the recipient. Donors again experienced a need to help out in tangible ways to avert a potentially fatal or undesirable outcome.

Waiting period. Donors often had unrealistic expectations about how quickly the recipient would recover posttransplant and about what that recovery period might entail. For example, when they were told that the recipient had a 25% chance of survival, the donors believed the recipient was part of the 25% that survived and not part of the 75% that died. They expected the recipient to steadily recover after receiving the bone marrow and further, they expected the recovery would lay the groundwork for restoration of a normal family lifestyle. The donors would then have effectively made a difference in the lives of the recipient and the family.

When the desired effect was not forthcoming, donors felt frightened, scared, helpless, surprised, and/or impatient. These feelings were reinforced when they saw other patients become seriously ill, die whi[illegible]n the process of their recovery, or return 1-2 years posttransplant in less than excellent health. Donors had to incorporate this new information into their present framework of thinking and realign their expectations.

> 'You think you're going to go in and do the transplant and everything is going to be fine and you go home. And as you're there a bit of time, a lot of people die and you start to realize that this is really, really serious and you get scared. You realized the doctors didn't have control of things.'

All donors considered the recipient to be the owner of the new bone marrow. However, several donors still felt possessive about the bone marrow and assumed responsibility for the way it operated in the recipient. Three donors described no such feelings. One donor still felt some title to the bone marrow but accepted no responsibility for its behaviour in the recipient.

Donors who assumed responsibility for the behaviour of their marrow in the recipient believed that somehow it was not adequate. They realized that they could not change the way their marrow functioned and that they had no control over its behaviour in the recipient. Professionals and relatives also told them that they were not responsible. However, this knowledge and these reassurances did not change the way the donors felt. For one donor, a verbal reassurance actually reinforced her notion of responsibility because another person had verbalized the same thoughts, thereby providing affirmation for these feelings.

These donors expressed great interest in the daily health status of the recipient and felt guilty when the recipient experienced any health problems. The feeling of guilt seemed to be affected by the donor's understanding of the cause of the health problems. If they believed that the health problems of the recipient were related to the behaviour of the donated bone marrow, they described a feeling of 'my marrow shouldn't be doing that to her'. Often donors did not have a clear understanding of the cause of the health problem. Few understood the normal function of bone marrow, how their marrow would help the recipient, or the pathophysiological mechanisms involved in GVHD. Factual information did not implicate them as an offender. Donors assumed responsibility regardless of the health status of the recipient and often were unable to articulate why they felt responsible, only that they did.

> 'If something goes wrong, maybe it was something because of me. You try to think of something you could have done and there's not really anything I could have done to change it. Maybe if someone else had donated, it would have worked. It makes you think about it.'

> 'The hardest part was the waiting afterwards, to see if it was going to take. How compatible it really was.'

Donors who did not accept responsibility for the way their marrow functioned in the recipient expressed either relief or sadness about the health status of the recipient. They were more likely to feel disappointed because the recipient was ill and that was not a good situation for their sibling to be in, but they did not feel culpable.

> 'If it didn't work, it wasn't my fault. It was just the way things go. It wasn't anything that I was responsible for or had any control over. The doctors said that I was a match and that it should work and that was their best guess.'

While some donors who donated to recipients of identical sex verbalized feelings of responsibility for the way their marrow functioned in the recipient, donors who donated to a member of the opposite sex were more likely to express these feelings. The idea that male chromosomes lived in a female body or vice-versa remained a salient concept in the donors' mind. This difference was enhanced by comments from family members or staff members.

> 'I remember my mom telling me that R would always have female cells in his marrow because it would always be my marrow so I think that's kind of what cemented the feeling that it's still my marrow in him.'

> 'The doctor said they could tell if it's female or male and it's all female. My bone marrow made more bone marrow in him so I guess it's still my bone marrow.'

In summary, donors expected to see a rapid improvement in the health status of the recipient posttransplant. Instead, they observed the death of other patients and a lack of immediate change in their sibling. Some donors expressed feelings of guilt when the health status of the recipient deteriorated or did not improve because they had assumed responsibility for the way their marrow functioned in the recipients. As a result, donors became impatient and again expressed a need to perform some act in order to speed the healing process.

Tangible acts to make a difference posttransplant. Donors who did not observe an improvement in the health status of the recipient felt a need to perform concrete activities which could avert an undesired outcome. However, appropriate interventions were less clear and donors did not know how to contribute at this stage. Most offered psychological support measures in an attempt to improve the emotional state of the recipient. Donors who were able to fulfill their need to intervene expressed less regret at being discharged home than donors who believed they were still needed by the recipient or the family. At the end of the transplant experience, donors experienced some sense of loss for their role as indispensable helpers.

Throughout the transplant experience, donors verbalized a need to perform tangible, physical, helping acts. This need remained evident until donors observed a difference in their sibling. Donors who did not see an improvement in the health status of the recipient again felt helpless and experienced a loss of control. If the donation had not resulted in the desired difference, something tangible had to be done again to alter the present situation.

> 'You want to fix it and you want to fix it now. You don't want to wait and see. So until you see, you want to keep fixing it until you see that it has been fixed.'

Donors were often unsure as to what concrete actions they could take to effect a change in the recipient's condition. However, despite their uncertainty, donors did undertake various helping efforts. These efforts consisted mainly of psychological support measures which included activities such as providing distraction, presenting a positive, upbeat approach, and/or being available for support. Donors felt that these activities could positively affect the recipient's emotional state and thereby influence the recipient's health status. As well, these efforts increased their feelings of control and decreased their feelings of helplessness.

> 'There wasn't really any other way I could help besides just helping her not get down.'
>
> 'I felt it was my job to be the emotional strength. I felt I needed to be there, giving verbal support.'

However, if the donor identified helpful strategies that were incongruent with the needs of the recipient, the donor's attempts to help were met with a negative response; thereby aggravating the donor's feelings of helplessness.

> 'She wanted quiet things, being there, holding her hand. She didn't want to be talked to but I couldn't sit there and say nothing. My mother could but I couldn't. She more or less kicked me out of the room.'

Donors responded differently to going home posttransplant. Donors who had the opportunity to remain in the transplant environment until they no longer felt a need to provide tangible interventions or until they saw a difference had been made in the recipient's situation seemed to experience their discharge back home with less regret than donors who were not provided this experience. These donors communicated excitement at having the opportunity to return home to their friends. However, donors who went home while they still felt a need to 'fix' the situation expressed the sentiment that they were sent away at a time when they were still needed. These donors felt helpless and experienced a lack of control at home. They believed that they did not have an opportunity to do everything possible.

> 'I didn't want to leave. I felt more in control when I was there. I felt helpless being back home. I felt like there was something I could do just being there.' 'I felt I was doing something if I was there. I wasn't but I felt I was. There was no more I could do there than I could do here but it just felt like I could.'

The need to act or intervene seemed to end when either the patient was well or when the patient died. As long as the individual was alive, there was hope. When the recipient's health status improved, the difference had been made and there appeared to be no further need for intervention. When the recipient died, the hope was lost, the difference now could not be made, and there was again no further need for action. The opportunity to make a difference was gone.

> 'When she relapsed, it seemed like everything was over. It took all the hope away from her ever getting better.'

If the patient survived, this need could recur on certain occasions. One donor described a need to ensure that the recipient maintained a good quality of life and received opportunities to make up for time lost in hospital. For example, if a situation arose where a parent was being overprotective of the recipient, the donor expressed a desire [illegible] advocate on behalf of the recipient.

At the end of the transplant experience, most donors experienced some feeling of loss regarding the ending of their vital role as indispensable helpers. They had played a key role in this whole experience. At some point, they lost their status. This loss occurred either in the immediate postoperative period or at the time of discharge home when they were no longer needed close to the transplant environment. This feeling of loss appeared to be more evident in donors who did not complete their perceived responsibility to provide tangible interventions or who did not see the difference made in the health status of the recipient.

> 'You weren't important anymore or necessary. You're not useful anymore. You're just like everybody else.'
>
> 'I felt detached. You went from being needed to you're not needed anymore at all.'

In summary, donors expressed a need to make a difference in the life of the recipient. Although appropriate interventions were difficult to identify, it was important that donors fulfilled their desire to help prior to their return home. During their struggle to identify ways in which they could help, donors observed and envied others who were helping in a tangible manner.

Observing Others Make a Difference. Although donors felt a need to 'fix' the situation posttransplant, they often could not identify appropriate interventions. However, they observed the daily concrete helping behaviours of health care members. Their moral code, which stated that a difference ought to be made in the life of an individual if the opportunity arises, again influenced what they saw and what they valued. Donors saw that staff were able to make a difference both in their own experience on the unit and in the situation of the recipient and their other family members. They valued the staff's caring approach and incorporated this style of intervention into their own job settings.

All donors valued the role of the health care members, especially the nurses, on the transplant unit. They perceived that nurses were able to make a difference in the life of the recipient in a tangible fashion on a daily basis. They provided physical care, supportive measures, and initiatives to recipients to carry out their self-care activities. Nurses were knowledgeable, provided honest straight-forward information, and were willing to answer any questions. They had a cheery, friendly, caring approach and a sense of humour. Observing these behaviours in staff, donors envied nurses for their knowledge and their ability to offer concrete interventions that could affect the health of the recipient.

> 'They could get their hands in there and do something everyday where you couldn't'

> 'I just thought it was such a neat profession to be able to help on a day to day basis like that. They really made a difference in the stay there.'

After observing nurses and medical staff in their 'helping' role, 5 out of 9 donors considered making a career in some aspect of the medical profession. However, only one of these donors actually followed through on this intent. All donors were highly complementary in their comments regarding care given by the health care team but they expressed several reservations about entering this field as a career. They watched nurses work hard and experience daily psychological stresses. They noted a high turn-over in staff on the unit. Although they admired the nurses for their excellent contributions, they did not wish to encounter similar stressors on a regular basis. They decided, therefore, not to pursue their health career plans.

> 'It's just the heartbreak of what people go through. It's not even that people die, it's just what people go through. I saw staff become so depressed sometimes. I don't think I could handle it.'
>
> 'If anything, it discouraged me cause I saw what they go through. They get close to patients and they take a turn for the worse and that's hard. I admire them for their job but I don't think I'd want it.'

The experience affected how donors operated within their own careers. Donors valued the staff's caring approach to their work and their ability to make a difference in the lives of other people. Therefore, in their present job setting, they attempted to demonstrate a similar caring approach and tried to take the time with their clients and employees.

> 'I do a lot of problem solving. Although none of it is medical, I always try to show that I am genuinely concerned with helping the individual.'
>
> 'I try to take the extra time, just talking to people. I think that's real important.'

In summary, donors felt that they could make a difference in the posttransplant period. However, they had difficulty identifying tangible acts which would have been appropriate. They observed the activities of health care members and saw that they were able to concretely intervene on a daily basis. As a result, the tangible acts of caring and genuine concern seemed to be carried into their own chosen professions.

Consequences of Attempting to Make a Difference

All donors were proud of their role in attempting to make a difference in the lives of their family. However, this feeling was moderated if the health status of the recipient was compromised or if the recipient died. All donors reaffirmed their decision to donate regardless of the outcome of transplant.

Posttransplant, donors described feelings of increased self esteem regardless of the outcome of the transplant. Donors of recipients who survived felt proud that the recipient was alive. Donors whose recipient died valued the opportunity of having provided a chance for their recipient to survive. The whole experience of trying to make a difference and of feeling that one had offered hope in a hopeless situation positively affected donors' perception of themselves.

> 'I feel good about doing something no one else could do. Although I have sad memories, it's something that I'm proud that I d[illegible]ink everyone that's done it should be very [illegible]at they did it regardless of what the [illegible]ome was because it takes a lot of emotional strength. It's just being proud that you did it...It makes you as an individual feel better about yourself. I never had a bad self-image but it made me feel better.'

This positive perception was tempered by the health status of the recipient and/or the attitude of the recipient after the transplant. If the recipient experienced multiple problems posttransplant, displayed a depressed, unhappy approach to life, or died, some donors, especially those who assumed responsibility for the way their marrow functioned in the recipient, felt some reservation regarding the effectiveness of their actions or expressed some disappointment in the recipient's attitude. Although all donors remained proud of their role in having offered someone a chance for a normal life and all related feelings of increased self esteem, these factors tempered some responses.

> 'I feel good about it but it bothers me whether it was because of me that it didn't work. It takes away some of the good feeling.'
>
> 'She carries an attitude of, well, my sight is blurry but I'm alive and isn't that wonderful! I think if they moped around and were depressed and said I can't do this anymore, it would be different. Then I think I would be tempted to bring it to her attention. You're alive!'

In summary, all donors expressed a feeling of increased self esteem. This feeling may be tempered if the health status of the recipients was compromised or if the recipients' approach to their new life was generally not positive. However, donors remained proud of their role in the experience.

Summary

Donors realized that the death of their sibling could result unless an intervention occurred. They intervened by donating, thereby offering the recipient a chance for survival. This act of donating provided donors with a concrete activity and allowed them to feel some control in a helpless situation.

After having donated, donors watched for an improvement in the health status of their sibling. Instead, they saw little change and heard about other patients who died. As this predicament was not the endpoint they had tried to effect, they felt helpless and again attempted to perform tangible acts to alter the situation. This time, they provided supportive measures in order to improve the recipient's feelings of well-being, thereby potentially influencing the physical progress. The need to intervene on behalf of their ill sibling ended either with the death or the renewed health of the sibling. All donors were proud of their role in being able to act in a tangible manner and sometimes envied others whom they saw as having more opportunities to undertake such acts.

Being A Big Deal Emotionally

All donors indicated that the transplant experience was a 'big deal emotionally'. Although each donor described different events as emotionally stressful, the emotional distress stemmed from two aspects of the experience, namely their encounter with death or some aspect of the dying process and their adaptation to the changes in their everyday life. Donors realized that their sibling could die and they lived in an environment where others might die. This factor was emotionally difficult and therefore they wanted to make a difference in this situation. However, while they were engaged in intervention activities, changes were occurring in their lives and in the lives of their families. These changes were unexpected, required adaptation, and exacerbated their feelings that the experience was a 'big deal emotionally.'

'Being a Big Deal Emotionally'

Donors were coping with both the possible loss of their sibling and the loss of their familiar lifestyle. The emotions of the donor were affected by living with the tensions within the hospital environment, undergoing new experiences, and coping with parental stress. While all donors verbalized positive changes that occurred as a result of going through the transplant event, they remembered that the emotional aspects of the experience were the most difficult to manage.

Donors described various events or issues related to the illness experience as emotionally stressful: listening to the screams of the sibling during painful procedures, living with other people and/or parents who were under stress, waiting to see if the marrow would take, watching others on the unit die, watching the recipient endure illness, feeling helpless, seeing little children who are ill, and worrying about the recipient's health status. They related a sense of the unfairness of this situation, the horror and heartbreak of what they observed, and their concern and helplessness at watching their family member enduring pain, procedures, and illness. Common to all these events and issues is the donor coping with the stress that results from an illness in the family and from the possibility that a death could occur.

Coping with the many changes that resulted as a consequence of the illness was another component of the 'big deal emotionally.' Many donors described their experience as being 'different'. Their parents behaved differently, their friends responded differently, the recipient n[illegible]erent things, and they were expected to assume a different lifestyle with new responsibilities. Donors described a feeling of loss for their previously 'normal', familiar, and comfortable lifestyle.

Donors identified issues as emotionally difficult based on their observations, experiences, and perceptions. If recipients were vocal in expressing their distress during painful procedures, a sense of horror at what they must endure was expressed. However, if recipients did not vocalize their distress, donors expressed limited awareness that these procedures could be painful. Similarly, donors who did not experience the transplant unit discussed issues related to the loss of contact with family members or the changing relationships with friends at school while donors who lived on the transplant unit described issues related to the tensions and the heartbreak of events that occurred on the unit.

> 'When R would have her bone marrow, it wasn't bad because I never knew it hurt her until I heard another donor screaming'

> 'Not being able to see everybody in my family like I was used to. I was confused and I couldn't understand. I felt neglected.'

Despite the fact that donors had different circumstances that were emotionally stressful, all donors stated that the emotional pain was the most difficult aspect of the transplant experience.

> 'The emotional, well that hurts inside and lasts longer than the physical pain which lasts maybe two days. You feel it when you talk about it. It will probably last for the rest of your life. What sticks out in my mind is the emotion, the feeling was just so strong, extremely sad, a bunch of mixed up feelings. You're mad that it's happening, sad, and afraid.'

> 'You had a lot of emotions. You had to face a lot of new things and you didn't quite always know how to react or behave. It was new in that we were dealing with such a serious situation, the possibility of death and such sickness.'

> 'It wasn't so much the physical pain as the mental pain afterwards that was the hard part.'

In summary, all donors stated that emotionally the transplant was a 'big deal'. The experience was difficult because they were facing a possibility that their sibling could die. They were also in an environment in which they experienced multiple changes and in which others were ill and had the potential to die. As a result, donors expressed a desire to take tangible actions that could cha[illegible]is situation back to a desirable experience.

Experiencing Things Becoming Different

The initial reaction of donors was their desire to make a difference. However, while th[illegible]e struggling to make a difference in concrete ways, th[illegible] illness and transplant experiences were themselves making a difference in the lives of these donors. As a result, donors experienced several major changes in their lives. Donors did want certain things to be different. They wished that the health status of their ill sibling would revert to a disease free state so that the family could resume their previous lifestyle pattern. However, they also experienced changes in their a) relationships with parents, b) relationships with the recipient, c) philosophy of life, and d) relationships with friends which they had not anticipated or desired. These alterations in their pattern of life were described as being difficult and contributed to the feeling that this whole experience was a 'big deal emotionally'.

Changes in the Relationships with Parents. The whole family was having an encounter with death. One of their members, a child, had the potential to die. Donors, therefore, observed that their parents were under extreme emotional stress. Parents spent more time with the ill recipient and donors were expected to assume more responsibility for tasks at home and for their own behaviour. As a result, three major changes occurred. First, donors assumed more responsibilities and became more independent. Subsequently, donors needed their parents less for physical needs but continued to require emotional support. Donors who perceived that their parents cared about them, as well as the recipient, were less likely to feel neglected because of the decreased access to their parents. Second, donors obtained an ability to view the situation from the perspective of another person. Therefore, most were able to understand their parents' need to spend time with the recipient and the recipient's need for their parents. Third, all donors described a different relationship with their parents in the posttransplant period. While donors needed their parents for emotional support, few actually used their parents for this support because they assumed some responsibility for decreasing their parents' stress or for at least protecting them from additional stress. Therefore, some parents and donors developed a friendship between them which replaced the previous parent/child relationship.

Parents were observed to be under emotional stress.

Donors described situations when their parents cried, were angry, were worried, and were hurting. Donors gauged the seriousness of the situation by the response of their parents. The situation was especially serious when fathers, whom donors had never seen cry, burst into tears.

> 'It's like you saw their raw insides, no fronts, nothing. That's mainly how you grasped the gravity of the situation, by your parent's reaction.'

Because of their concern for the ill child, parents spent more time with the recipient and less time with the remaining siblings. Parents might work extra jobs to cover financial obligations and/or spend time with the ill sibling in the hospital. One parent often remained with the recipient overnight. When their parents were not home, donors spent time with relatives, neighbours, or friends.

Because parents were around less, donors assumed new responsibilities. They became more independent in managing their own self care. In most families, both parents had worked outside the home pretransplant. Therefore, most donors were accustomed to a certain level of independence but their workload increased and they were no longer able to depend on their parents to carry the major burden of these chores. New responsibilities included cooking meals, doing laundry, doing other household chores, caring for younger siblings, and/or being responsible for one's own behaviour.

In retrospect, all donors stated that they were proud of and enjoyed their new independence. However, at the time the change occurred, donors responded differently. Several did not want the extra responsibility. This was especially true when it prevented them from participating in other activities. Only one donor saw this situation as an opportunity to demonstrate to her parents her level of maturity and her ability to manage. In general, this encounter with independence was different and therefore required adjustments.

Donors also assumed greater independence in managing their own behaviour. Parents were not readily accessible for advice, discipline, and guidance. Therefore donors began to define their own guidelines, make their own decisions, and assume responsibility for their own behaviour.

> 'I set my own limits. If I didn't do my work at school, I would stay home and work instead of going out. This is what I get for messing up. You don't get to play. It was different.'

One could postulate that because donors had less access to their parents, they would develop more independence and therefore would have less need of the parenting role. However, this hypothesis was not supported by the data. Donors needed their parents less for the physical aspects of life but needed them more for emotional support. The need for emotional support was evident in posttransplant donor-parent relationships. Donors appeared to be more understanding of their parents spending time with the ill siblings if they perceived that their parents still cared about them. This caring was evident when parents made the effort to take time out for them, were available to listen to their concerns, took time to keep their lives as 'normal' as possible, and/or provided regular opportunities for donors to feel like a part of the family group.

Four donors described situations where they missed at least one of the above listed caring measures. For example, some donors felt alienated from the family unit when they returned home because they missed the contact and no longer felt part of the family unit. Of these donors, those who felt cared for were less likely to feel neglected on their return home than those who missed the caring feeling.

> 'The major attention was on R for obvious reasons. However, they did take time for us. They set aside time.'
>
> 'I'd be by myself a lot. I was the only one home. I was in school and they were down there. I felt like they forgot about me. I thought they didn't care.'

Donors also developed a capacity to view a situation from another person's perspective. This new ability was helpful in identifying either their recipient's or their parents' point of view. Although donors could not recollect when or how they had gained this new skill, they saw it as a turning point in their lives.

> 'I think what really changed me a lot, and I never used to do this before, is that I started to figure out, what if I was in their shoes. And that's what makes me understand people a lot more now.'
>
> 'I think that was one of the first times that you realized what other people were feeling. You think, it's mom, sure, but that's her child so that's got to hurt..'

This skill granted donors a vantage point from which they could observe the situation. They gained insight into what the experience was like for the recipient and began to understand their need for a parent. Therefore, some donors believed that their parents should spend more time with the recipient and did not feel neglected. Others initially experienced feelings of neglect but over time were able to understand their parent's decision to spend more time with the ill sibling.

> 'If I was R, I would want my mom there too'.
>
> 'When I thought about R being there by herself, that wasn't really nice. She was scared and didn't like being alone. I didn't mind them spending a lot of time over there.'

The ability to view a situation from their parent's perspective gave donors an understanding of the stress their parents were under and their parents' responses to this stress. They saw their parents less as parents and more as individuals or friends who were undergoing a stressful experience. They began to need their parents in different ways and parents began to act less as parents and more as friends.

> 'Actually we got closer because she wasn't taking care of me and telling me what to do or watching out for me. She was more of a friend who was worried about her child.'

It was ironic that although donors needed their parents more for emotional support, few donors felt they could turn to their parents for this support. Donors had gained a clearer understanding of their parents' distress. They saw their parents dealing with a life and death issue. They believed that their parents had enough problems to manage and therefore they refrained from adding to their parents' stress. As well, their own problems seemed inconsequential when compared with the life and death issues of the recipient. Some donors actually felt guilty that they even had certain feelings or concerns.

> 'I never let them know that anything was wrong. I just thought it was kind of minor compared to what R was going through.'

> 'I knew how much they were concerned about the R, so I tried not to cause them any more stress.'

Donors therefore, assumed some responsibility for ensuring that they either decreased the stress on their parents or at least protected them from being exposed to any additional stress. They again acted in a tangible manner. Donors reassured their parents, provided distraction measures, assumed extra responsibility, managed their problems alone, avoided troublesome situations at home and at school, and behaved in a manner that would not attract their parents' time and concern.

> 'You try and support them. You behave yourself and try not give them any more problems. You give them a hug and make sure you don't misbehave so they'd have to take time out to tell you to stop it.'
>
> 'I didn't share my feelings with my parents. I felt like I had to be the emotional strength for them, someone they could lean on and who was going to say it was going to be ok.'
>
> 'I talked about other things beside R and tried to get their mind off her for a bit. I didn't like it when they were hurting.'

In families where the recipient died, donors often continued to support their parents. Parents experienced grief and tension after the death of the child. In this setting, donors encountered limited access to their parents, not because of parental absence but because parents were emotionally distressed. Donors again acted to avoid adding to their distress. Actions included avoiding talking about the recipient and the transplant experience, thereby protecting their parents from reactivation of painful memories.

In summary, donors gained an independence in that they were more able to provide for their own physical needs and were more capable of monitoring their own behaviour. However, donors did not need their parents less. They now needed them more for emotional support rather than physical support. Therefore, it seemed important that donors perceived that their parents cared about them throughout the transplant experience.

Donors also developed the ability to see their parents' perspective of the experience. They saw their parents more as individuals undergoing a stressful experience instead of as caretakers. All donors achieved an increased independence from and a new appreciation for their parents regardless of whether or not their relationship improved. A change in the relationship seemed to occur for all donors with at least one parent. Although this change was not positive in all circumstances, relationships generally became closer.

<u>Changing Relationships with Recipient</u>. Realizing that the recipient could die, some donors experienced feelings

of guilt relating to their past relationships with the sibling. As a result, some made concrete efforts to develop a closer bond. However, a similar desire for closeness was required on the part of the recipient before a bond could develop. In relationships that did become closer, donors believed that recipients were motivated by a feeling of appreciation for the donor's contribution. All relationships with recipients did not become closer after the transplant experience. One relationship actually developed a further rift.

Several factors appeared to motivate donors to try to establish a closer relationship with the recipient. First, certain donors, on realizing that the recipient could die, expressed a desire to develop a closer bond. Some donors expressed guilt regarding their past relationships with the recipient and made a concrete effort to establish a feeling of closeness. These donors believed it was important to be 'close' to the siblings when they died.

> 'I was really trying to get to know her better and trying to get closer.'

Second, for some donors, the potential death of the ill siblings generated thoughts regarding what life would be like without them. This thinking appeared to foster a feeling of value or appreciation for the relationship. These factors motivated an attempt to develop a closer relationship while the opportunity still presented itself.

> 'What's life going to be like when she's gone. I couldn't imagine life without her. I didn't like that.'

Donors alone appeared unable to establish a closer relationship. It seemed equally important that the recipient also convey a feeling of wanting to become closer. The motivating factor for the recipients was their desire to convey a feeling of appreciation or gratitude to the donor for the life-saving bone marrow.

> 'When she got sick, I thought she might die and I didn't like that. I felt bad because she was so sick so I didn't want to be mean to her. I know she was thankful I could donate it. We got closer.'
>
> 'It was a fear of losing her on my part and for her, I think it was appreciation. It was a bit of both of them.'

One could postulate that a closer relationship could only develop if both the donor and the recipient were motivated. Further research is required to determine whether this hypothesis holds true for a larger population. Third, some donors felt closeness in the relationship several years posttransplant. This closeness was attributed to the fact that both individuals had matured and were more aware of each other's needs.

> 'I think it changed because we got older. We do a lot of things together. Relationships change with age.

> We know what the other likes to do and when to stay away from each other.'

Finally, the amount of interests these siblings had in common seemed to be a factor. If they had similar interests and participated in similar events or activities, they seemed more likely to become closer than if they had divergent interests.

> 'I felt that every time I saw her, I felt good about what I did but I didn't feel closer to her or further from her. I probably felt better about myself cause I had done something good but our relationship didn't really change. We really didn't do a whole lot of things together. We had different interests and different friends.'

In summary, some donors attempted to develop a closer relationship with the recipient because they realized their sibling could die. It seemed important that one have a close relationship when a sibling dies. Closer relationships could develop only when the recipient was also motivated to establish a closer bond. In general however, most relationships appeared to remain unchanged posttransplant.

<u>Change in Philosophy of Life</u>. As a result of undergoing the transplant experience, donors lost a sense of innocence, became aware of their own mortality, gained an appreciation for life and family members, and developed

a new philosophy of life. Donors described these changes as the positive aspects of the experience.

As a consequence of living with others who had the potential to die, donors related a sense of losing their innocence. Trouble had always happened to everyone else and had never struck their family. After watching their sibling become seriously ill and observing others die, donors lost this innocence. The initial response to this loss was a feeling of anger but over time, they began to examine issues such as the potential mortality of their own sibling and of all living individuals. As a consequence, they developed a greater appreciation for family members and friends.

> 'It makes you feel differently about other members of your family. It could happen to them. You learn to enjoy the time you have now.'
>
> 'You are going to die.' You always think it's the other guy but someday it's going to be you.'

A question arises about the implications of this finding for donors. If they begin to appreciate their family members more because of their encounter with death, what is the emotional impact on the donor if the family does not become closer as a result of the experience? This situation was observed in one family where grieving for the recipient seemed to have caused a distance between the siblings and their parents. This issue may be more relevant for families in which the recipient dies. If the recipient lives, one feels a sense of having made a difference. But if the recipient dies, one may need to feel a closeness to the remaining family members. Further research is required to determine if this issue is prevalent in a larger population of donors.

> 'I wish it could go back to the way it was. I think everyone is closer in the sense that they worry more about each other but further apart in the sense that you now know it can happen, something like that can happen.'

Most donors experienced a change in their attitude toward life and people after having experienced the transplant environment. These changes were described as the positive aspects of the experience and included the development of such attributes as: an appreciation for health, a clearer understanding of others, an appreciation for life, a decreased fear of death, a perspective on life, an empathy for ill individuals, a sensitivity for others, and a purpose for living. This evolvement of a new philosophy of life did not occur as a result of the act of donating but was a consequence of the total transplant experience which included both the physical and especially the emotional aspects.

> 'Much more appreciation for life. A lot less fear of death. We learned that we could weather something

> like that. You learn your coping skills. It puts things in your life in perspective.'

In summary, donors were proud of the changes that occurred. They felt they had gained a more realistic perspective on life and an appreciation for their family members and friends. Although they did not wish anyone endure a similar experience, many felt that people would benefit from a similar sensitization or understanding. O donor stated in retrospect, 'I should thank my sister.'

Changing Relationships with Friends. Most donors noticed the change in themselves when they compared themselves to their friends. Donors had experienced several changes prior to their return to school. They h encountered death, dealt with emotional stressors, and endeavored to make a difference in the life of their family. They experienced changes in their relationships and their outlook on life. On returning to school, dono noticed no similar differences in either their friends o their teachers. Classmates lacked an understanding of th experience.

> 'I noticed a lot of difference in my friends but it wasn't in them, it was in me. They didn't understa because I had changed so much.'

> 'I don't know if it was as much them changing as it was me. It gave me a boost. I'd been somewhere the hadn't. I'd seen things they would never see. They

wouldn't understand what I was seeing.'

Donors felt they gained a better perspective on life. They verbalized frustration with the approaches taken by their friends regarding life issues. Problems that were major for their friends were inconsequential for donors because donors compared them to what they had observed during their transplant experience. This negatively affected some friendships, resulted in the loss of some friendships, and effected the formation of a few new relationships.

> 'If they saw what I saw, they would realize their problems aren't so bad.'
>
> 'You would think the trauma of moving to a new high school--it seemed so inconsequential after what we'd been through. This wasn't life and death.'
>
> 'I felt that I was more enriched. I had a better understanding and better sympathy for those that were sick, a better appreciation of life. I felt I had one up on everybody. I felt I had a better perspective on things.'

This difference was less noticeable if friends had an understanding of the experience or shared a similar approach to life issues. These factors seemed to be evident in situations described by two donors who did not note any change in themselves as compared to their friends despite the fact that they both had described changes in their life philosophies. However, in contrast to the other donors, they stated that their friends had similar perspectives toward the problems of life and therefore their friendships remained unchanged.

A lack of increased independence and an unaltered life philosophy described by one donor raises a question regarding the possible difference between this donor and the remaining 8 donors. On analysis, this donor did not verbalize any recollections regarding the development of an ability to view the situation from another person's perspective. This ability was acquired after but not during the transplant experience. This donor appeared unable to take one concept and abstract it onto another situation. For example, the donor was given a tour of the research facility where technicians were performing experiments with bone marrow transplants on the dogs and monkeys. However, the experience of the animals was not connected or related to that of the recipient.

> 'I thought it was neat just looking at the animals, not really registering that they were going through the same thing that R and others were going through two floors down.'

This donor went through the transplant experience in the early adolescent years. However, another donor of similar age experienced a level of independence and an alteration in life philosophy which matched that of the other donors. One could therefore postulate that younger adolescents may perceive their situation differently than their older counterparts and these perceptions may be related to their level of cognitive development. The next step then would be to identify how school-aged children saw this experience. Do they view the situation with similar abilities and in a similar manner to the adolescent or is their experience different? This topic could be the focus of another research project.

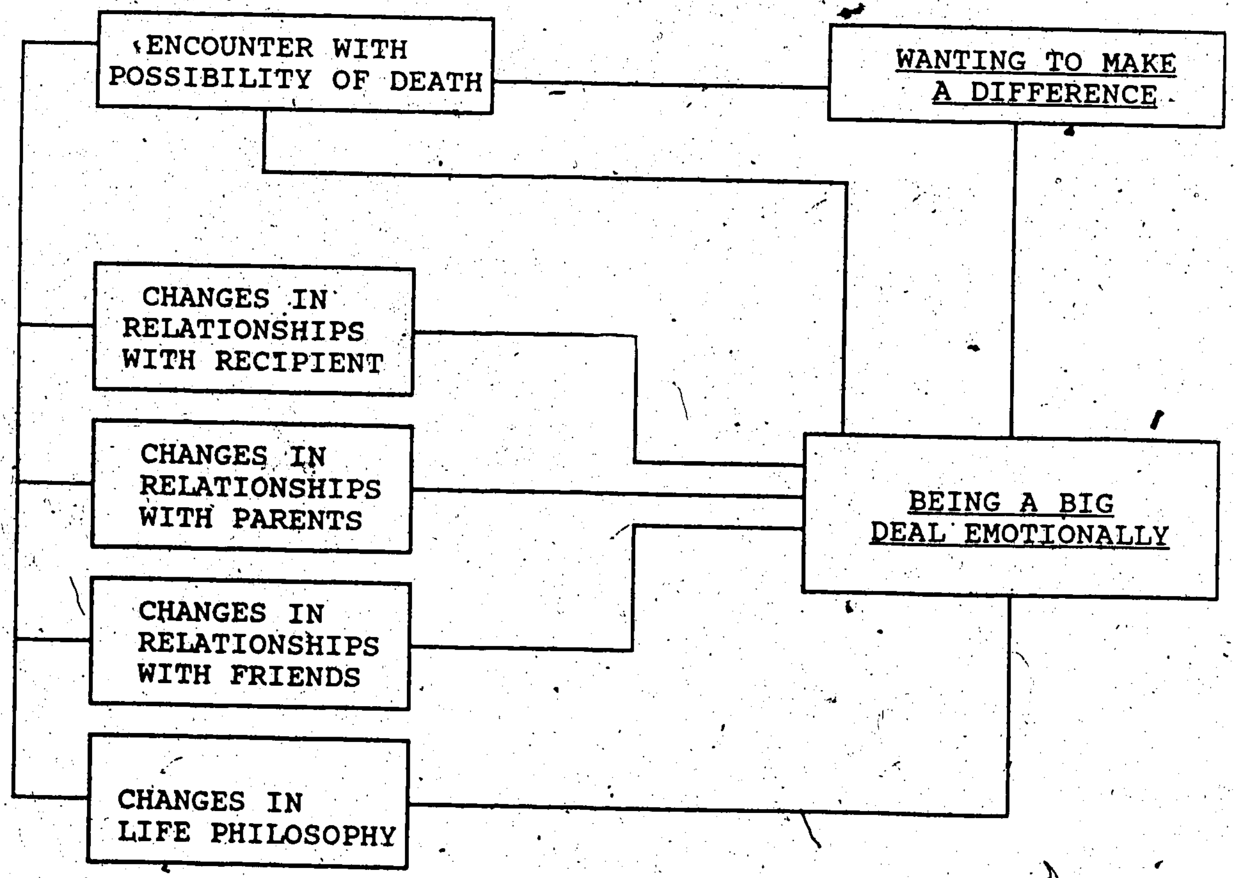
Summary

The findings of this study indicate that donors were confronted with the fact that their sibling could die. This situation was emotionally difficult and donors wanted to perform some tangible intervention which would alter this predicament. Donors' moral codes influenced the manner in which they attempted to affect a difference. The success of their actions affected their emotional state. Simultaneous changes which occurred in their life as a result of undergoing the transplant experience intensified their emotional stress. A model depicting this experience is presented in Figure 2, followed by a description of the key concepts and their relationships.

The encounter with the possibility of death was the mechanism which triggered donors' participation in the transplant procedure, their desire to make a difference, the changes in their relationships with others, the changes their life philosophy, and their feelings of emotional stress. This life-threatening encounter took the form of disease processes such as aplastic anemia or various types of leukemia in either remission or relapse. Most donors had little information regarding their sibling's disease process but all clearly detailed the impact, the potential consequences, and the subsequent repercussions of this event on their lives.

Figure 2

<u>A Model for the Donor Experience</u>



While the encounter with death was the key element which triggered the multiple consequences, it was the aftermath of the encounter that was most prominent or meaningful to donors. Principal concepts included their desire to make a difference and the feeling that the experience was a 'big deal emotionally'.

Their desire to make a difference was evident in both the pretransplant and posttransplant experience. The actions they undertook, however, were different. Pretransplant actions consisted mainly of donating, while posttransplant interventions included various types of psychosocial support measures that were more intangible in nature and more difficult for donors to identify. Donors who were unable to complete or fulfill their need to make a difference experienced emotional distress.

The strength of their desire to make a difference was influenced by their moral codes or norms. The norms determined the criteria that donors used to make their decisions, identify appropriate interventions, predict reactions of others, anticipate their own feelings of self-worth, and formulate their opinions of the behaviours of others in similar situations.

The feeling that the transplant experience was a 'big deal emotionally' resulted from donors experiencing an encounter with death and multiple changes in their lives. They observed their parents in emotional distress and noted the effect of this parental stress on their family lifestyle. Donors sought a return to their previous comfortable, ordered, and stress-free family lifestyle. Therefore, they endeavored to undertake tangible acts which would make a difference in the life of their family and restore a sense of 'normalcy'. Successful efforts resulted in decreased emotional strain while unsuccessful ventures increased the likelihood of emotional distress and further attempts at intervention. Distress was verbalized by donors who were unable to identify appropriate activities and/or who were denied the opportunity to act.

Chapter 5

Discussion of Results and Implications

The purpose of this research has been to provide a description of the long term experience of the sibling adolescent donor. Donors were interviewed to determine what the transplant experience was like and what variables affected their responses or their experiences. In analyzing the data, the two key concepts of 'wanting to make a difference' in the life of their family and coping with the emotional impact of the transplant experience became evident. These concepts related to the decision-making process, the consequences of agreeing to donate, the donation, the continued desire to make a difference posttransplant, and the emotional difficulty that resulted from things becoming different. Several of these aspects will be compared to the experience of kidney donors, siblings of children with cancer, and other bone marrow donors as presently described by other researchers in the literature. As well, data will be examined for similarities with theories relating to adolescence and altruistic behaviours. Areas for future research will be discussed throughout the text of this chapter. Finally, an overview will be given of the limitations of this study and of the implications of the findings for nursing practice.

Making a Difference

The finding that donors strongly desired to make a difference can better be understood in the context of Mitchell's (1977, 1979) theory of adolescent psychology. He postulated that there is an early, a middle, and a late phase of growth in adolescence. The early phase is characterized by individuals who are strongly dependent upon the reactions of others for their sense of identity and for their feelings of personal significance. They have a need to belong and to be accepted by their peers. However, their family remains the most important social and emotional factor in their lives. Egocentrism is more evident in this stage and abates when adolescents acquire the ability to view the situation from the other person's viewpoint. They are forming their identity or their concepts of themselves by interacting in their environment. They examine their own thinking processes while taking into consideration their expectations of themselves and those of significant others and society. Middle adolescents gain the ability to engage in abstract and analytical thinking and they become less egocentric. Peers become an important social factor and may threaten the family's role as the centre of their emotional life. In late adolescence, individuals become less dependent on the reactions of others. They begin to see themselves in terms of their own ability to manage life's experiences.

Mitchell's theory is congruent with the observations made in this study. Donors' need for emotional support from their parents despite their developing increased independence provides evidence for the fact that their family was the centre of their emotional life. Only one early adolescent donor did not acquire the ability to view issues from the other person's perspective during the experience and also described a limited ability to engage in abstract thinking. The remaining donors obtained these skills and developed a positive concept of themselves, a new philosophy of life, and an increased independence from the reactions and beliefs of their peers.

These changes that occurred as a result of wanting to make the difference parallel the four key traits which Mitchell identifies as affecting a person's maturation from the early to the late phases of adolescence. First, these adolescents needed to identify some aspect of themselves that was unique and special. They achieved this uniqueness by contributing in some relevant fashion, such as donating, to significant events in the lives of people to whom they feel close. This contribution was valued by significant others and by themselves. The resultant feelings of self-importance provided them with a confidence to explore other life issues and to feel that they could be different and gave them a reserve of psychological strength.

Second, donors offered some significant contribution in their family as a step toward establishing competence in handling adult roles. Their feelings of self-esteem increased and their ability to make a significant contribution improved. Third, the future was visualized as having the potential to actualize their visions or aspirations. All donors believed that the recipient would survive as a result of their contribution. Finally, Mitchell postulates that all humans behave in such a manner as to provide a net effect of making a difference. He states that being unable to make a difference is the 'closest thing to nonexistence man can experience' (1977, p. 16; 1979, p. 115). Similarly, donors ultimately wished to contribute in certain activities that would make a significant difference. Therefore, the ultimate honour one can pay to donors is to indicate that their existence has made a significant difference in one's life.

In summary, Mitchell's theory provides a framework which allows one to more clearly identify how the psychology of adolescence affects the donor's transplant experience. The actualization of their desire to make a difference could potentially save the life of the recipient and reestablish the family lifestyle but also could contribute to the donors' sense of self-importance and establish their competency in managing adult roles. Further research with adult BMT donors could determine whether adult donors also identify this desire to make a difference and whether this desire is a more salient issue for adolescent donors.

Decision-Making Process

Although all donors agreed to donate, most did not feel they made a conscious decision to participate. None of the donors deliberated the pros and cons of the procedure. All made an immediate decision to donate. Similar findings were noted by kidney donor researchers (Fellner & Marshall, 1968; Simmons et al., 1971). This process shows close fit with the moral decision-making model outlined by Swartz (1970; Howard & Swartz, 1981) which postulates that donors' moral codes provided the criteria against which they instinctively or consciously evaluated their alternatives and their decisions. It should be noted that in this study the term 'moral code' is used in a manner similar to Swartz's use of the term. It is acknowledged that this term may have other meanings.

Donors' decisions to donate were motivated by a desire to save the life of the recipient, to avoid feelings of guilt, and to make a difference in the life of both the recipient and the family. Similar motivations were documented for adolescent kidney donors (Bernstein & Simmons, 1974) and for adult kidney donors (Higgerson & Bulechek, 1982; Wilson et al., 1968). These motives are consistent with the clearly stated personal norms of BMT donors that prescribed an obligation to realize the opportunity to make a difference in the life of another person. Swartz (1970; Howard & Swartz, 1981) postulates that whenever individuals are in a situation where the welfare of a certain person is dependent on their actions, these individuals face a moral decision. Consistent with Swartz's moral decision model, BMT donors were aware that their sibling had a need and donors were aware of the consequences of their refusal to participate. If they did not donate, their sibling would die and they would have feelings of unresolvable guilt and remorse. If they did donate, they could potentially save the life of their sibling. Donors were identified by medical staff as being the best or often the only potential donor. Therefore, they clearly perceived that if they did not actualize this potential, the negative consequences would be a result of their inaction.

Similar to the steps outlined in Swartz's model, donors identified actions that could meet the recipient's need and they recognized that they could carry out these actions. They assessed the situation to identify if they were morally responsible for carrying out these actions based on their internalized values, thereby constructing a personal norm in each situation. Swartz stated that internalized values are different for each person and the closer these values are to the proposed action, the stronger the desire to comply. BMT donors foresaw feelings of self-satisfaction if they carried out the action and self-depreciation if they were inactive. Social norms which predict the reactions of others to the anticipated action, were also considered. The moral and nonmoral costs and benefits of acting were weighed, leading to a decision. Swartz theorized that if conflict resulted instead of a decision, defensive actions such as denial of the need, the effective action, personal ability, or responsibility may either weaken or strengthen feelings of obligation and allow a decision regarding the course of action.

Swartz hypothesized that this process of thinking about consequences, responsibilities, and norms may not always be a conscious effort. Certain factors can be considered without deliberate thought while other aspects may be painstakingly contemplated. Most donors in this study decided immediately that if their marrow best matched the recipient's marrow, they would donate. A few donors verbalized no express desire to personally be the donor, but they wanted the best matched donor for their sibling. If they were the best matched candidate, they would donate. All decisions were made prior to any information provided by medical staff.

The process of making an immediate choice without any deliberation is similar to the style of decision-making found in research done with kidney donors (Fellner & Marshall, 1968; 1970; Simmons et al., 1973; Eisendrath et al., 1969; Smith et al., 1986; Higgerson & Bulechek, 1986). Most kidney donors made instant decisions using the moral decision-making model. Although no member of this study refused to donate, Simmons et al. (1973) and Fellner and Marshall (1968) both documented instances of kidney donors refusing instantaneously when they heard of the need. Simmons et al. (1973) described two other decision-making models used by kidney donors. Donors who used the rational model engaged in a period of careful deliberation of the costs and gains of the procedure before agreeing to participate. Donors who used the postponement model postponed the decision and co-operated with the selection process until it became difficult to withdraw. While all donors in this study used the moral decision-making model, a subsequent study of BMT donors that has a larger sample size and that includes both non-donors or siblings who refused to participate and donors may identify whether the majority of BMT donors use Swartz's decision-making model and whether a minority of donors and non-donors use the defensive strategies to alter their feelings of obligation or responsibility.

Researchers who studied kidney donors documented that some donors felt pressured by family members to either participate or not participate in the transplant procedure. This situation was evident especially in potential donors who were interviewed after they refused to donate (Simmons, Hickey, Kjellstrand, & Simmons, 1971). Some friends or family members actually tried to prevent them from donating

(Fellner & Marshall, 1968; Simmons et al., 1971).

There appears to be less input from family members in the case of the BMT donors. All donors stated that they were identified by the medical staff after undergoing tissue typing and they denied receiving any family pressure to donate. There were no reports of anyone attempting to dissuade them from donating. To the contrary, donors received only positive comments about donating. Adolescent kidney donors also reported no pressure from family members. They noted that their parents actually protected them by hesitating to ask about donating or by initially opposing the donation until convinced by adolescent candidates (Bernstein & Simmons, 1974). However, this finding can be accounted for by noting some differences between kidney and BMT transplants. BMT donors perceived that the costs to them of helping their sibling were less than those of a kidney donor. They suffered no loss of an organ since the transplanted organ regenerated. Therefore, unlike the kidney donor, their donation did not preclude them from donating to other family members in the future if the need arose. They identified little potential for postoperative complications. The procedure involved only a two night hospital stay and they endured a short recovery period of a few days instead of several weeks. Therefore, all donors stated that the risks to them were minor compared to those of other organ donors and compared to the opportunity to save a life. However, most kidney donors also felt that the risks were well worth the opportunity it offered the recipient and most reaffirmed their decision to donate (Eisendrath et al., 1969; Fellner, 1971; Fellner & Marshall, 1968, 1970; Smith et al. 1986). While kidney donors could only donate once, BMT donors can donate several times and all stated that they would donate again to either a related or an unrelated donor as often as they could. These findings appeared unrelated to the success of the transplant procedure.

The data used to support the conclusion that some donors felt pressured to donate may be equally well explained by Swartz's moral decision-making model (Swartz, 1970; Swartz & Howard, 1981). Higgerson and Bulechek (1982) documented that 15% of their donors felt pressure to donate. They described a situation where donors felt that their families would have viewed them as cold and uncaring if they had not donated. Similar sentiments were verbalized by three of the BMT donors. While this sentiment affected their decision, it was not perceived by BMT donors as family pressure and it appeared to make the decision easier. Their desire to make a difference in the life of their family and in the life of the recipient and their moral norms of actualizing the potential of making a difference in the life of another person were influential factors in making the decision. Donors had ascribed personal responsibility to themselves for undertaking this action and for the consequences. They noted that not only would their family not respect them if they did not participate but they themselves also would be unable to live with the guilt of refusing. This thought process is congruent with the decision-making process presented in Swartz's model.

Swartz (1970; Howard & Swartz, 1981) postulates that personal norms may be different for each person, thereby leading to different decisions. The researchers of kidney donors documented that adult sibling donors were the best donors genetically but they were also the most unclear about their obligation to donate (Higgerson & Bulechek, 1982; Hirvas et al., 1976; Kemph, 1967, 1970; Simmons et al., 1971; Wilson et al., 1968). Adult siblings struggled with an uncertainty that arose from a lack of clear-cut norms regarding their obligation to their birth family and their obligation to their marital family. Parental sacrifice seemed to be a clearer expectation of societal norms than sibling sacrifice. It was less clear whether the siblings' duty was primarily for their wife or husband and children or for their brother or sister. Kemph (1970) noted that sibling donors expressed hostility more openly toward the recipient compared to other donors. Similarly, Hirvas (1976) predicted an increased risk of trauma for the sibling organ donor and Simmons et al. (1973) documented that these role-conflicts did result in some prospective donors refusing donation.

In contrast, the BMT donors in this study were all single and had no other family obligations. They described no conflicts regarding their moral responsibility. The risks were seen to be minimal. Donors could donate on several occasions because marrow regenerates and therefore this procedure did not preclude donors from donating to other family members if the need ever arose in the future. Therefore, it could be postulated that conflicting obligations to family members are not seen as a salient consideration for BMT donors. However, Briggs, Piliavin, Lorentzen, and Becker (1986) studied 489 apheresis or single cell blood donors to determine their willingness to donate bone marrow to an unrelated person. They noted a 33% difference between single men and married women in willingness to contemplate donating. Single men did not differ from single women but married fathers were more willing to volunteer than married mothers. Married individuals were not significantly different than unmarried people in their willingness to participate. The researchers speculate that mothers in particular may still worry that something could happen to them and as a result there would be no one to care for their children. A study of adult BMT donors which includes married and single individuals of both sexes is needed to determine whether perceived family responsibility and the perceived risks of the procedure affect a donor's willingness to participate.

In summary, the moral decision-making model (Swartz, 1970; Swartz & Howard, 1981) appears to be congruent with the decision-making process described by the BMT donors in this study. Donors made immediate decisions that were often viewed as being no choice decisions. Their internalized values prescribed for donors a sense of obligation to make a difference in the life of another if the opportunity arose. Although this finding is similar to the findings of researchers studying kidney donors, BMT donors were unique in that they viewed the marrow donation procedure as being easier than donating a kidney because it did not require a major surgical procedure and because the bone marrow regenerated. The small sample size, although effective in eliciting the experience of donating, is not effective in determining the proportion of donors that use other decision-making strategies. A follow-up study building on this baseline information would help to determine whether the majority of bone marrow donors would use the decision-making process outlined in Swartz's model.

<u>Consequences of Agreeing to Donate</u>

Donors who agreed to donate described feelings of being scared or worried. Their concerns related to a fear of hospitalization and/or a fear of the actual procedure and included a fear of the unknown and of undergoing a new procedure in a strange environment without unrestricted access to their parents. Both kidney and BMT donors described fears that included a fear of the operation (Bernstein & Simmons, 1974; Eisendrath et al., 1969; Higgerson & Bulechek, 1982; Kemph, 1967), fantasies of bodily disfigurement (Kemph, 1967), a fear of pain (Kemph, 1970), an apprehension of the hospital setting, a concern for the success of the transplant, and a concern for the life of the recipient (Eisendrath et al., 1969). Descriptions of what donors imagined the procedure entailed were not detailed in any of these reports, thereby precluding a comparison between the fantasies visualized by kidney and BMT donors. Kidney donors, however, outlined several different fears which included a concern regarding poor health following surgery (Bernstein & Simmons, 1974; Higgerson & Bulechek, 1982) and a concern that the kidney might be rejected (Bernstein & Simmons, 1974). Although BMT donors may have expressed some concern for their health before they understood what the procedure entailed, no donor reported any such fears after being informed. While most donors were concerned about the success of the transplant, fears of marrow rejection were not verbalized. The fact that kidney recipients can reject donors' organs while BMT recipients contend with the marrow's rejection of their own body tissue may account for this difference.

Similar to the donors in this study

appeared to be well-informed about the procedure (Eisendrath et al., 1969; Smith et al., 1986). They verbalized confidence in the medical staff (Fellner & Marshall, 1969). Wilson et al. (1968) and Eisendrath et al. (1969) noted that although donors had misgivings or were not necessarily enthusiastic about donating, they still intended to proceed.

An attempt was made to determine whether similar fears or concerns would be evident in any adolescent admitted to hospital for a similar procedure. In one study, unilateral nephrectomy patients and kidney donors were found to experience similar trauma (Hirvas et al., 1976). Making comparisons, however, between this sample of BMT donors and 'normal' adolescents was difficult due to a lack of reported descriptions of the 'normal' adolescents' experiences. Thompson (1985), in his review of the literature dealing with the effect of hospitalization on children, also indicated that little research had been done to determine the adolescent's response to hospitalization. Most reported research focuses on younger children's responses. Often the purpose of studies related to adolescents' hospitalization focused on determining the adolescents' attitudes and opinions to the hospital experience or to identify their conceptions of health and illness. Therefore, further study is required to determine are similar to those of other adolescent patients facing minor surgery or whether donors' unique circumstances cause them to have different concerns and fears.

Donating

BMT donors in this study perceived donating to be a relatively minor procedure. The actual act of donating was portrayed as being 'no big deal physically.' Donors experienced pain for only a few hours to a few days. For kidney donors, however, researchers reported conflicting results regarding the level of trauma experienced as a result of donating. Most researchers noted that most kidney donors, who undergo a more extensive surgical procedure, describe the experience as painful but forgettable (Eisendrath et al., 1969; Fellner & Marshall, 1968). Donors believed that donating was not harmful to their health (Smith, et al., 1986).

In contrast, a few researchers (Hirvas et al., 1976; Kemph, 1970) reported that kidney donors experience a painful sacrifice which has the potential of becoming a source of anxiety. Kemph (1970) observed that donors mourned the loss of their organ, occasionally developing mild to moderate depression. Hirvas et al. (1976) noted that donors were reluctant to talk about the transplant because they wished to avoid being perceived as boasting, wished to avoid feelings of guilt or obligation on the part of the recipient, and/or felt they had nothing to say.

Both researchers interpreted their interview data to postulate that this posttransplant depression and this avoidance of the subject occurs because donors lost attention posttransplant in favour of the recipient and/or because they lost an organ. They concluded that these losses were a source of anxiety resulting from the painful experience of donating.

Neither postdonation depression nor reticence to speak with the investigator was reported by others (Fellner & Marshall, 1968; Higgerson & Bulechek, 1982; Smith et al., 1986). Similarly, several donors in this study expressed appreciation for the opportunity to talk. However, these donors stated that they generally did not discuss the transplant with others because of reasons similar to those given by Hirvas et al. (1976). Unlike donors in that study, BMT donors did not feel they had lost an organ. Only a few donors experienced a loss of attention that lead to feelings of neglect; most expressed an understanding of this loss and with time, all developed some insight into the reasons for this loss: Their decision to avoid the subject seemed to be guided by their moral norms which indicated that no obligation ought to be felt on the part of the recipient. Donors also implied that other people often lacked an understanding of the procedure and of the associated emotions and experiences. Donors did find it helpful to talk to other BMT donors who were perceived to have an understanding of the situation.

The Consequences of Donating. The theory of gift exchange or altruism has been used by some researchers in kidney transplantation to conceptualize the donation phenomenon (Crammond, 1967; Eisendrath et al., 1969; Fox & Swazey, 1974). However, this theory does not appear to provide an adequate description of the bone marrow donor experience. The decision to give the gift was guided by the donor's norms and reciprocation of the gift was often considered inappropriate. Most recipients did not offer tangible repayment of the gift. According to Fox and Swazey (1974) and Farley (1982), this situation should result in social strain on the members involved. This strain was not reported by donors in this study. Similar findings were observed by Simmons et al. (1977) who stated that although problems can occur, they rarely do occur. In this study, donors' personal norms of actualizing the potential to make a difference in the life of a family member appeared to regulate their decision to donate and their expectations of reimbursement for their contribution.

Both kidney and BMT donors received some praise for their participation in the transplant experience from friends, family members, and recipients. It was difficult to compare the types of rewards received by kidney donors with those received by donors in this study because kidney donor researchers (Bernstein & Simmons, 1974; Fellner &

Marshall, 1968; Simmons, 1981) did not detail how this gratitude was expressed or communicated. Simmons (1981) documented that donors who received more explicit expressions of gratitude from their family and recipient were more likely to perceive themselves as better people after the transplant. Further details were not given as to what specific rewards were helpful.

Norms guided donors in making their decisions to donate but also appeared to regulate what rewards they ought to expect. Most donors in this study did not receive verbal or tangible expressions of gratitude from the recipient. Yet, all donors knew the recipient was grateful and all donors described feelings of having matured and of developing into better people. These feelings could be explained partially by the fact that the donors' actions were motivated by their personal norms of 'wanting to make a difference'. These norms were used as a standard by which they evaluated their own behaviour as being positive or negative (Swartz & Howard, 1981). The fact that they actualized this potential made them all proud. Consequently, even though donors did not receive tangible appreciation from the recipients, they still believed and were proud that they had taken correct action. In addition, donors received gestures of gratitude from their friends and/or parents. Although donors received no tangible evidence of gratitude from recipients, they believed that the recipients were grateful because donors received nonverbal cues from recipients and because donors felt that they understood the internalized values of recipients which would prescribe for them a sense of appreciation toward the donor. They also perceived the continued life of their sibling as compensation and they valued their newly acquired coping skills. Receiving these different types of rewards appeared to mediate their need for concrete gestures of gratitude from the recipient, although such efforts would have been appreciated.

Several observations made by Muslin (1971) in his study of recipients of renal transplantation are congruent with observations made by donors in this study regarding the response of their recipients toward the donation of bone marrow. Muslin observed an effort by kidney recipients to deny or repress the donated organ and to demonstrate concern for the donors' health. Two BMT donors in this study similarly received comments from their recipients that they could have survived the disease without their donor's donation. Both donors indicated that the recipients' denial of the donors' contribution was likely the recipients' way of coping with their inability to communicate their gratitude to the donors. However, unlike Muslin's subjects, most BMT recipients verbalized no concern for the donors' health. This may reflect the perceptions of people that marrow donation is a minor procedure that presents few health risks.

Simmons et al. (1977) expanded on the concept of gift exchange by discussing the norms of kidney donors that related to helping others within a family. They compared business relationships, where obtaining the object is the goal, to family relationships, where the goal is continuation of the family relationship. They postulate that individuals would feel betrayed or used if they felt that the goal was to acquire the bone marrow while they themselves were not valued. Similarly, if the donor requests payment for the bone marrow, the object becomes the goal instead of the relationship. The normative standards of gift exchange within family is that a gift be given without thinking of personal gain. Once personal gain becomes the goal, the individual loses the respect of others and forfeits rewards given for sacrifices based on love. While donors are expected to donate without thoughts of personal gain, the gift ought to be reciprocated either with gifts in kind or with expressions of gratitude. If the donor considers personal gain or gives with reluctance, the need for reciprocation seems to be decreased.

This theory may be used to portray certain aspects of the BMT donors' experience but does not appear to capture all elements. The question remains as to why donors received a sense of gratitude from recipients when no tangible gifts or no verbal expressions of gratitude were exchanged. Some donors received nonverbal cues which were interpreted as gestures of appreciation but a few donors received no tangible or intangible rewards but still assumed the recipients were grateful. Although there were some initial feelings of disappointment, donors articulated an understanding of their perceptions of the recipients' viewpoint. Realizing that the concept of 'wanting to make a difference' was an aspect of their personal norms would account for donors' assumptions regarding an appropriate reward and the gratitude of the recipient.

In summary, the theory of altruism does not appear to provide an adequate explanation for the bone marrow donor experience. Donors appeared to be guided by their personal norms in their expectations for gratitude rather than by social expectations of gift exchange.

As well as receiving rewards for donating, some donors experienced another consequence of donating. Most donors believed that the way their marrow performed in the recipient was their responsibility. Even though donors verbalized the facts that they had no control over the bone marrow and that they could not change the way it behaved, these donors felt guilty when the recipient became ill. Similar findings were also anecdotally reported by researchers who studied BMT recipients (Brown & Kelly, 1976; Freund & Siegel, 1986; Gardner et al., 1977; Patenaude et al., 1979) and by researchers who studied adult BMT donors (Wolcott et al., 1986b), but were not documented by researchers of kidney donors. Instead, their discussion revolved around the recipients' feelings of guilt and indebtedness (Crammond, 1971; Kemph, 1970; Simmons et al., 1977) and the donors' feelings related to organ rejection or sacrificing in vain (Simmons, 1981). Dissatisfaction with donating occurred mostly when the kidney was rejected or the transplant was unsuccessful (Bernstein & Simmons, 1974; Eisendrath et al., 1969; Hirvas et al. 1976; Simmons, 1981, 1983; Simmons et al., 1977).

Some kidney donors experienced an emotional and a physical investment in the recipient (Crammond, 1967, 1968). They felt protective about the care of their donated organ and were inclined to overprotect the patient. These donors became concerned about the viability of the organ if the recipient behaved in a way that the donor did not approve. Only one donor in this study verbalized similar sentiments: the recipient refused to comply with medical care by refusing medications and by being uncooperative with treatment regimes; this donor experienced feelings of anger and frustration due to the recipient's lack of effort to care for the new marrow. Subsequent research studies are needed to determine whether this feeling of responsibility for the behaviour of the donated organ is unique to BMT donors and/or whether donors' feelings of protectiveness for their organ are related to their feelings of responsibility or to their feelings of closeness with the recipient.

Desire to Make a Difference Posttransplant

Donors' expectations concerning the recipient's recovery progress postdonation may be largely influenced by their parents' attitudes and perceptions, regardless of factual information provided by medical staff. Even though parents of kidney donors were given facts regarding prognosis and treatment complications, they usually entered the unit believing that their children would overcome all odds (Gold, Kirkpatrick, Fricker, & Zitelli, 1986). Similar feelings of hope were noted in parents of BMT patients (Brown & Kelly, 1976; Freund & Siegel, 1986; Patenaude et al., 1979).

After observing little effect from their initial attempt at intervention, namely donating, donors noted that they received decreased attention from their parents and from medical staff because interest had shifted to the recipient. Similarly, some kidney donors are reported to have experienced a sense of abandonment or a feeling that the attention they received pretransplant had been transferred to the recipient posttransplant. The donors' contribution was complete and recovery was underway. However, the recipient continued to require careful monitoring (Crammond, 1971; Eisendrath et al., 1969; Smith et al., 1986). One researcher reported that some donors felt that they received little attention or reward compared to the sacrifice they had made (Kemph, 1965, 1967).

Similar to findings in this study, other researchers reported that kidney donors experienced no such feelings of abandonment (Higgerson & Bulechek, 1982; Fellner & Marshall, 1968, 1970). Fellner and Marshall (1968, 1970) documented that in the immediate postoperative period, donors received attention from friends, relatives, and media personnel for a month or two. However, these donors did verbalize some disappointment when the attention decreased and they ceased to be celebrities. Bernstein and Simmons (1974) found that after a year, most adolescent donors continued to receive explicit gratitude from their family and the recipient. Crammond (1967) noted that while some donors did experience a loss of attention, most donors felt no need for continued active support.

The posttransplant experience of the BMT donors in this study also does not appear to be captured by statements postulating that feelings of abandonment are a result of decreased attention and loss of celebrity status. Only two donors described feelings of neglect. Most donors believed that the recipient ought to receive the extra attention because they empathized with the recipient's situation. For these BMT donors, factors such as the feeling that their parents cared for them as well as the recipient, the chance to participate in the family unit experience, the opportunity to satisfy their need to help out, and their moral norms influenced the impact of the decreased parental attention.

Several donors clearly articulated their need and their appreciation for the genuine, caring approach offered by staff. Donors stated that these staff members were a potential resource when their parents were unavailable. Donors felt cared for by the health care professionals, especially nurses. They found that nurses were interested in their welfare, contributed to the effort of 'helping' the recipient, included them as part of the care team, and were available for their support if necessary. However, few donors ever used this perceived resource and they were unable to articulate why they did not avail themselves of this source of support. In contrast, Simmons et al. (1977) noted that nurses had little time to give kidney donors praise and attention. Kemph (1965) also found that staff were more interested in ensuring the success of the graft in the recipient than in the ongoing progress of the donor. These different donor experiences may simply reflect the various philosophies of care delivery found in the various transplant facilities.

Being A Big Deal Emotionally

Several changes occurred in donors' lives as a result of encountering the stress associated with the transplant experience. These changes were not planned or expected and therefore were difficult emotionally. Changes related to relationships within families and attitudes toward life issues were also experienced by kidney transplant donors and siblings of chronically ill children. Several changes can better be understood in light of the theory of adolescent development.

Families with a health problem encountered alterations in the quality and quantity of both intra and extrafamilial communication. McKeever (1983), in a review of the literature on siblings of chronically ill children, noted findings similar to those found in this study. Siblings and donors rarely discussed issues related to the disease in order to protect their parents. They experienced a different family environment due to parental anxiety, preoccupation, and absence. Some experienced role strain when they assumed more responsibility for household chores. Although McKeever found several interesting themes in her review, she could not identify a theory which described the sibling relationship during chronic illness.

The experience of transplant donors is similar to that observed in siblings of chronically ill children. However, researchers who studied siblings of chronically ill patients (Cairns, Clark, Smith & Lansky, 1979; Grogan, Koocher, Foster & O'Malley, 1977; Harder & Bowditch, 1982; Iles, 1979; Spinetta & Deasy-Spinetta, 1981) reported different observations regarding the impact of their experiences. Cairns et al. (1979) indicated that school-aged siblings experienced severe stress in the form of isolation from parents, neglect in favour of the ill child, and anxiety regarding their own health. They noted that these siblings were normal except for the fact that they were under an enormous amount of stress. Similarly, Taylor (1980) noted that school-aged siblings reported an overall negative impact of the illness, with few positive affects being listed. Negative aspects included feelings of inadequacy related to a lack of feedback from parents and feelings of guilt related to egocentric desires. Spinetta and Deasy-Spinetta (1981) reported that the emotional needs of siblings were met at a level significantly less than that of either parents or patients.

In contrast, but similar to the findings of this study, Harder and Bowditch (1982) and Iles (1979) reported evidence of both positive and negative results. Siblings perceived that the quality and quantity of relationships with parents were decreased and expressed a desire to return to life as it was before the illness (Iles, 1979). They verbalized an understanding of the ill child's need for increased time and attention (Harder and Bowditch, 1982). They experienced a desire to contribute and a sense of helplessness at being unable to identify appropriate intervention methods (Iles, 1979). Both researchers documented siblings' feelings of increased responsibil and increased empathy for others and for the ill sibling.

Donors in this study also vividly described the tremendous emotional stress they sustained during the experience. However, all described an increased sense of self-esteem, independence, empathy, and maturity. Although statements of positive effects were noted in all donors, their overall feelings about the experience were affected by the success of the transplant and/or the subsequent health status of the recipient. Positive perspectives were more evident in donors whose siblings had survived with only minor complications than in donors whose siblings had died or had survived with significant emotional or physical problems. In general, most donors were positive in their comments, with no donor relating an overall negative outlook.

Coping with issues relating to the loss of their sibling and to the transplant experience may account for the decreased positive perceptions of donors whose recipient had died. Such factors included donors' feelings of responsibility for the way their marrow performed in the recipient, parental feelings of grief related to the loss of their child, personal feelings of grief and loss for their sibling, and donors' feelings of helplessness at being unable to fulfill their need to help. One donor who did not accept responsibility for the way her marrow loss for her sibling seemed to have a more positive perspective than the two donors who accepted responsibility and who continued to work through issues related to the loss of their sibling. It could be postulated that donors who have resolved the issues related to these factors are more likely to have a positive perspective than donors who continue to cope with unresolved issues. This hypothesis will need to be tested using a larger sample of donors of both surviving and deceased recipients.

Most donors in this study remembered the experience as being emotionally traumatic but did not feel neglected or abandoned. Siblings of children who survived cancer also did not remember feeling abandoned by their parents nor did they remember the treatment period as being traumatic (Grogan et al., 1977). Some donors in this study were able to contrast their transplant experience to their previous hospital encounters because their recipients had received several years of treatment for their cancer prior to undergoing a BMT. These donors also did not remember the first treatment phase as being particularly memorable. They had been involved in school and other activities and were distant participants. In contrast, they described the transplant experience as being more traumatic and more serious. It could be postulated that the degree of involvement of the sibling in the hospital experience may affect the level of emotional trauma experienced.

Donors described different levels of understanding regarding the decreased attention they received from their parents. Few understood immediately, most understood after observing the recipient and their parents cope with the transplant procedure, and some understood after or toward the end of the experience. These differences may better be understood in light of theories of adolescent development.

Adolescent thinking differs radically from that of younger children. Adolescents acquire new cognitive competencies. They gain an ability to analyze their own thinking, examine existing beliefs, construct theories, generate new viewpoints, engage in abstract thinking, and reflect on their own mental and personality traits. They can think about what is real and what is possible (Kagan, 1972; Inhelder & Piaget, 1958). Consistent with Piaget's theory, donors moved from a stage of egocentrism where they attributed unlimited power to their own thoughts to a stage of decentering where an objective approach allowed them to differentiate and coordinate different points of view. Piaget postulated that these skills could be enhanced or retarded by cultural and educational conditions and by social interaction. Therefore, the age at which donors were able to assume these adult-like thinking processes depended on social factors (Inhelder & Piaget, 1958) such as a transplant experience.

Using their newly developed skills, Elkind (1971) states that adolescents, unlike younger children, are now able to place themselves in another individual's shoes and view a situation from that perspective. Donors gained this ability but were unable to identify how they achieved this skill. Elkind postulates that this ability arises from the need of adolescents to understand how others are reacting to them. Donors found that this new skill assisted them to understand and manage their experience.

In summary, adolescent donors may have some characteristics that are different from child and adult donors. Their newly acquired cognitive skills could provide them with coping skills that are unavailable to younger donors. Their desire to make a difference, their need to contribute, and their wish to establish competency in adult roles may influence their perceptions of the experience. A subsequent study which would compare the perceptions of school-aged, adolescent, and adult donors could determine what aspects of the donation phenomenon are unique to adolescent donors.

Only limited comparisons can be made between the experience of kidney and BMT donors regarding the types of relationships that developed between donors and recipients posttransplant. In contrast to the kidney donors, unsuccessful marrow transplant patients usually die. Therefore, there can not be a discussion about relationships in this circumstance.

Kidney donors often developed closer relationships with their recipients. Only a small percentage of these relationships became more difficult (Higgerson & Bulechek, 1986; Kemph, 1969, 1970; Simmons, 1981; Simmons et al., 1977). However, donors of unsuccessful transplants were more likely than donors of successful transplants to have difficulty in their relationships and were less likely to have a special closeness with the recipient (Simmons, 1983).

Similar to findings of this study, Wolcott et al. (1986b) noted that most adult BMT donors reported little change in their relationships. The current quality of their relationships appeared to be influenced by the degree of esteem given to the donor by the family unit and by the recipient's health status and level of social functioning. While these factors also influenced the relationships of donors in this study, additional issues included a desire to be 'close' to the 'dying' sibling, a desire to appease guilt regarding their past relationships, their maturity level, the amount of similar interests, and an equal desire on the part of the recipient for a closer relationship. Donors came to realize that everyone was immortal and they gained an appreciation for their families, their friends, and their recipient. Most donors verbalized closer relationships within their families but relationships with recipients often did not change.

Researchers who studied kidney or BMT donors generally report that donors benefit from donating. Although Kemph (1970) reported some severe psychological impairment in kidney donors and Hirvas et al. (1976) documented mild to severe psychic trauma in over 30% of their donors, other researchers did not record similar findings. Only one donor in this study reported any significant psychological distress as a result of the transplant. She experienced several episodes of anxiety attacks after the recipient's death but these rapidly dissipated after the donor shared these experiences with a health care professional. These episodes appeared to be related to the loss of the sibling rather than to the trauma of the transplant experience. Researchers in kidney transplantation documented that donors whose donation resulted in an unsuccessful transplant verbalized increased regret, negative comments, and physical and depressive symptoms (Bernstein & Simmons, 1974; Eisendrath et al., 1969; Simmons, 1981, 1983). Wolcott et al. (1986b) reported that although most BMT donors did well from a psychosocial standpoint, 10-20% of donors may have some adverse psychological sequelae. However, Wolcott et al. studied only donors whose recipients survived and they speculated that this statistic could increase when applied to donors of recipients who did not survive.

In general, donors reported positive changes as a result of undergoing the transplant experience. Kidney transplant donors experienced an increased enjoyment of life, (Crammond, 1968), an understanding and tolerance of others (Crammond, 1968; Eisendrath et al., 1969), a maturity or sense of responsibility (Crammond, 1968; Fellner & Marshall, 1968), a sense of increased self esteem (Bernstein & Simmons, 1974; Higgerson & Bulechek, 1982; Kamstra-Hennen, Beebe, Stumm, & Simmons, 1981; Simmons, 1981, 1983; Simmons, et al., 1977), and a sense of meaning or purpose in life (Fellner & Marshall, 1968; Higgerson & Bulechek, 1982). They were proud that they had done something great by donating (Eisendrath et al., 1969; Fellner & Marshall, 1968; Higgerson & Bulechek, 1982) and they enjoyed seeing the recipient feeling well posttransplant (Kemph, 1969). In general, the changes that resulted were beneficial, positive, and worthwhile.

Similarly, adult BMT donors reported a positive self-esteem and a high degree of satisfaction with current life activities (Wolcott et al, 1986b). Donors in this study gained a greater appreciation for family members, a greater appreciation of their health and life, a better perspective on life, an empathy for ill individuals, and a purpose for living. All donors were proud of these changes and most donors described them as being the positive aspects of the experience.

Limitations of the Study

The purpose of this study was to provide a description and a theoretical analysis of the experience of the bone marrow donor. No attempt has been made to test a theory or concept. There was little previous information in the literature about this experience from which to create a conceptual framework or from which to identify variables that could be used in a quantitative design. Therefore, the donors' experience was described and the variables which affected the responses of donors were identified.

Several methodological issues limit the conclusions that can be drawn from the data. A non-probability sample was used to obtain an understanding and a description of the experience. Therefore, these findings cannot be generalized to the population of all BMT donors and may not be replicable, although this was not the purpose of the study. A subsequent study which is based on the findings of this study and which uses quantitative methods can provide further verification of the representativeness of the data (Morse, 1986).

The design of the study was retrospective in order to determine the long term effects of donating on the donor. However, this method does not provide a clear picture regarding the actual transplant experience. The events that occurred since the transplant period and the process of maturation both have influenced donors' perceptions of the past events (Stanley & Campbell, 1966). However, the study's approach was useful in determining the donors' current status and current perceptions.

Donors' perceptions of staff behaviour and staff support may be influenced by the institution's philosophy of care and by the specific types of postdonation services. However, as far as the investigator could determine, there were no special programs at this institution which were designed specifically for the donor.

The theoretical sampling technique (Chenitz & Swanson, 1986; Glaser & Strauss, 1967) stipulates that the investigator choose the participants according to the needs of the research and according to which individuals can best enrich the investigator's understanding of the experience. However, practical considerations did limit the selection of donors. The expert staff member had difficulty obtaining individuals who donated reluctantly or who developed obvious problems posttransplant. Although this study allows some insight into certain aspects of the experience that could result in psychological sequelae, further efforts should be made in subsequent studies to include donors who refused to donate, who developed significant psychosocial problems posttransplant, who requested payment for donating, who live with a recipient who has health problems posttransplant, and who had difficulty making the decision to donate.

In summary, the findings of this study contributes to the current knowledge base about the BMT donor experience. However, methodological issues limit the generalizability and replicability of the study, the understanding of the actual transplant experience, and the conclusions that can be made about non-donors and donors who develop psychological sequelae. However, it does provide a description of the long-term effects of donating and provides beginning data regarding variables and theories that can be used in subsequent research studies.

Implications for Nursing

Several authors have described the emotional strain that the bone marrow transplant procedure has on family members and the patient (Gardner et al., 1977; Patenaude et al., 1979; Wolcott et al., 1986a). While these authors anecdotally described psychological sequelae observed in bone marrow donors, there was little information to guide nurses toward early preventative strategies. Interviews were conducted to determine the donor experience, to provide nurses with baseline data for further study, and to equip nurses with concrete information upon which to plan effective intervention strategies. Although the results of qualitative studies seldom give adequate information for determining appropriate intervention strategies, data from this study provide a general direction.

The findings of this study indicate that although there are many similarities between the experience of kidney organ donors and BMT donors, there are also some unique aspects to BMT donors. Bone marrow donors do not view the donation as a major sacrifice. The procedure is perceived to be minor compared to the emotional aspects of having a sibling experience extensive treatment regimes and become critically ill. In this latter respect, their comments are similar to those verbalized by siblings of chronically ill children. However, donors found that coping with the intensive nature of the transplant procedure was more emotionally difficult than living with the chronic aspects of the illness.

BMT donors clearly articulated the fact that the emotional aspects of the whole experience were more traumatic than the actual donation. Intervention strategies could be aimed at preventing or decreasing the experiences that contributed to their distress. Health professionals could ensure that donors enter the transplant experience with realistic expectations. Preoperative teaching and education regarding the donation procedure could include information about the expected prognosis and length of stay, the anticipated course of recovery, and the potential reactions of parents toward an ill sibling. Donors could be advised of their possible reactions to observing others die on the unit, to watching the fluctuating health status of their sibling, and to observing other parents and their own parents under stress. They could be taught that reactions may include feelings of abandonment or neglect, feelings of responsibility for the way their marrow functions in the recipient, and feelings of helplessness after donating. Providing donors with tangible, concrete tasks that they can perform to assist the recipient could potentially decrease the donor's feelings of helplessness posttransplant. Nurses can assure donors that they are willing to listen and to provide information.

All adolescent donors may not wish to talk about or discuss their experience. Most donors did not have a need to talk about their feelings with other donors or with other families. They frequently avoided talking about the experience in order to escape the worry and the tension. The tension related to the stress experience 'was always there' and they required some periods of relief.

Donors found a caring approach from health professionals to be helpful. This approach included being available to listen; demonstrating interest in them as well as the recipient; providing quality care to the recipients; being willing to give honest, straightforward answers to their questions; and making them feel like they were part of the helping team. This need for a caring approach was more important than providing an outlet for their feelings.

of donors could occur pretransplant. Nurses could assist parents to develop potential intervention strategies that would prevent feelings of abandonment on the part of the donor. A care planning session with both parents and the donor might be an appropriate strategy to raise the awareness of both parties to the potential needs of the other during the posttransplant period. Most donors preferred to talk to their parents regarding their concerns. However, they often did not approach their parents with their problems because they wished to protect their parents from further stressors or because their problems are perceived by them to be of little consequence, especially compared to those of the recipient. Intervention strategies should be developed with this restriction in mind. Family members could develop a scheme whereby either party could indicate a need for a subsequent session in the posttransplant period.

A discharge planning session with donors and their families may be helpful prior to their return home. At this time, nurses could assess whether donors were ready to return home or whether they had not yet completed their need to help. Education could include issues such as potential changes in friends at school, changes in the amount of responsibility at home, and feelings of wanting to be with the family group. Donors and nurses, along with donors could communicate the needs that arise as a result of their readjustment to the home setting. Referrals to community agencies may be appropriate.

In summary, nurses need to work closely with donors and their parents in the pretransplant, posttransplant, and predischarge phases of the experience. Providing preventative intervention strategies that would allow donors clear avenues of communication for their concerns and promoting a caring approach may assist donors in managing the emotional stressors of the experience.

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Appendix A

Overview of Bone Marrow Transplantation

Bone marrow transplantation is the treatment of choice for children with aplastic anemia, acute leukemia, and several genetic disorders. At present, bone marrow transplants are almost exclusively reserved for patients who have an HLA (human lymphocyte antigen) identical sibling donor. HLA identical donors can be found for 35-40% of patients (Kadota & Smithson, 1984; O'Reilly, 1983; Sanders et al., 1985; Sanders et al., 1986; Sondel et al., 1983). Although mismatched family bone marrow transplants are becoming an alternate form of treatment, this procedure is usually available only in large treatment centres such as the Fred Hutchinson Cancer Research Centre and is considered an experimental treatment modality (Powles et al., 1986). The use of bone marrow from cadaver donors is still undergoing laboratory study (Mugishuma et al., 1985).

The recipient with acute leukemia is treated with sufficient immunosuppressive and chemotherapeutic agents to ablate the recipient's capacity to reject the graft and to eradicate residual disease (O'Reilly, 1983; Sanders et al., 1985). The actual transplant procedure involves anesthetizing the donor and performing multiple aspirations from the iliac crest of the donor. The bone marrow is pooled, filtered, and then administered into the recipient via an intravenous transfusion (Stewart, Thomas, Somerville, & Stewart, 1985). In a study of 3,290 donors, the reported complication rate was 0.27% with no deaths or permanent sequelae. Potential complications for the donor include the risk of general anesthetic, potential blood loss, potential infection at the operative site, and potential pain at the operative site (Bortin & Buckner, 1983; Buchner et al., 1984).

The major risks to the recipient include graft versus host disease (GVHD), infection, graft rejection, and leukemic relapse. GVHD is a pathologic process where the T lymphocytes included in the donor's marrow recognize the recipient's tissue as foreign and destroy the recipient's skin and internal organs (O'Reilly, 1983). This is unique from organ transplantation where the recipient T-lymphocytes recognize the donor's organ as foreign and destroy the donor organ. Acute GVHD develops in 30-70% of patients and may be the direct cause of death in 20-40% of patients. Chronic GVHD develops 6-18 months post transplant in 15-40% of long term survivors. Chronic GVHD can be a single or multi-organ disease. It can result in minimal to severe morbidity and may be the indirect cause of death (Sullivan & Parkman, 1983). Immunosuppressive agents are used to treat GVHD. Of the patients with leukemia that survive the transplant procedure, approximately half will relapse with their original disease

(Sanders et al., 1985). Few patients have demonstrated that the relapse of their disease has occurred in the cells of donor origin (Witherspoon, Schuback, Neuman, Martin, & Thomas, 1985).

Appendix B

Karnofsky Scores

100%	Normal, no symptoms or signs of active disease
90%	able to carry on normal activity, minor signs or symptoms of active disease
80%	normal activity with effort
70%	unable to do active work, cares for self
60%	requires occasional assistance
50%	requires considerable assistance and frequent medical care
40%	disabled, needs special care
30%	hospitalized, death not imminent
20%	hospitalized, critical condition
10%	moribund
0%	dead (Karnofsky & Burchenal, 1949)

Appendix C

Interview Guide

Donor Background Information

No.: ______________________

Date: ______________________

1. Date of Birth: ______________________
2. Sex: __________
3. Date of Diagnosis of the Recipient: ______________________
4. Date of BMT: ______________________
5. Donor Match: Perfect _____
   Mismatch _____
6. Were there other potential donors?
7. Are you presently living in the same home as the recipient?
8. Current health status of the recipient:

   As perceived by the donor:

   As perceived by the medical staff or chart:

Interview Guide

Donor:

1. What was it like to live in your family *before* the bone marrow donation
   Probes: your relationship with your parents
   your relationship with the recipient
   your relationship with your other siblings (if any)

2. Describe how the decision was made for you to be a bone marrow donor

3. Describe what things you thought about or considered while making the decision to donate your bone marrow

4. What kind of information did you receive or did you seek out regarding the donation process

5. What did you expect the actual procedure of donating your marrow would be like

6. What was it actually like? how did it differ from your expectations

7. What was it like to live in your family in the *first months* after the bone marrow donation
   Probes: your relationship with your parents
   your relationship with the recipient
   your relationship with your other siblings (if any).

8. Since the donation, the recipient has had some health problems. What caused them? How long will they last? What, if anything, can you do about it?

9. Who do you think the bone marrow belongs to now
   Probes: to you; to the recipient

10. What aspects of this experience did you consider to be the positive aspects of donation

11. What aspects of this experience have concerned you the most

12. What is it like *now* to live in your family
    Probes: your relationship with your parents
    your relationship with the recipient
    your relationship with

13. What aspects of this experience have you been able to have some influence over or some control over

14. Has this experience affected any aspects of your life
    Probes: physical health, emotional health, school work, participation in activities, career choices, relationships with friends

15. If you had to make the decision to donate again, what have you learned about the experience that would help you make that decision

16. What have you learned about the experience that might help other individuals who live with or who work with a donor

Appendix D

FRED HUTCHINSON CANCER RESEARCH CENTER

Consent Form (Parent)

<u>Project Title</u>: Bone Marrow Transplantation: The Experience of the Donor

<u>Investigator</u>: Rena van der Wal, BSN, RN, MN Candidate
University of Alberta, Faculty of Nursing
Phone number:
or c/o Jolene Kelleher:

<u>Purpose of the Study</u>: The purpose of this research study is to describe and understand the experience of donors when the recipient develops significant health problems after a bone marrow transplant. It is anticipated that the results of this study will provide nurses with a better understanding of the experience of the bone marrow donor. Although there may be no direct benefit to the participants of this study, there may be changes in the care given to the donors following the completion of this study.

<u>Consent</u>: This is to certify that I, ____________________ hereby agree to have my child ____________________ participate in the above named research project. I understand that I give permission for my child to be interviewed and for these interviews to be tape-recorded. I understand that one or two interviews will be scheduled. I understand that the tapes will be destroyed after they are transcribed. The transcriptions will be kept for three years in a locked cabinet and then destroyed. All transcripts will have a code number only and will contain no reference to family name. I understand that the results of the study may be published but my child's name will not be associated with the research.

I understand that my child is free to refuse to answer any specific questions in the interview. I also understand that my child is free to withdraw his/her consent and terminate his/her participation at any time without penalty. I further understand that the content of the interview will be held in confidence by the investigator. If my child finds the subject matter upsetting at any time, the investigator will provide supportive measures. I have been given an opportunity to ask whatever questions I desire, all such questions have been answered to my satisfaction, and I have received a copy of this consent form.

Signature:____________________/____________________
Relationship to the donor:________________ Date:____________
Witness:____________________ Investigator____________________

Appendix E

FRED HUTCHINSON CANCER RESEARCH CENTE[illegible]
Consent Form (Minor Donor)

<u>Project Title</u>: Bone Marrow Transplantation: The Experience of the Donor

<u>Investigator</u>: Rena van der Wal, BSN, RN, MN Candidate,
University of Alberta, Faculty of Nursing
Phone Number:
or c/o Jolene Kelleher:

<u>Purpose of the Study</u>: The reason for doing this research study is to give nurses a better understanding of what it is like to be a donor for a bone marrow transplant. Although this study will probably not help you, it is hoped that other donors can receive better care as a result of the findings of this study.

<u>Consent</u>: I, ______________________________, hereby agree to be a part of the above research project. I understand that:

1. there will be one or two interviews that will each last about one hour
2. I will not have to talk about any subject I do not want to discuss
3. Everything I say will be kept confidential by Ms. van der Wal
4. I can stop the interview or stop my participation in this research project at any time I want to with no consequences
5. My name will not appear on any report that is published from this study
6. If I get upset at any time during the interview, Ms. van der Wal will spend time with me until I feel better

I have had a chance to ask whatever questions I want of Ms. van der Wal. All my questions have been answered and I have received a copy of this consent form.

Date: ______________________________

Signature: ______________________________

Relationship to Recipient: ______________________________

Witness: ______________________________

Investigator: ______________________________

Appendix F

FRED HUTCHINSON CANCER RESEARCH CENTER

Consent Form (Adult Donor)

Project Title: Bone Marrow Transplantation:
The Experience of the Donor

Investigator: Rena van der Wal, BSN, RN, MN Candidate
University of Alberta, Faculty of Nursing
Phone number:
or c/o Jolene Kelleher:

Purpose of the Study: The purpose of this research study is to describe and understand the experience of donors when the recipient develops significant health problems after a bone marrow transplant. It is anticipated that the results of this study will provide nurses with a better understanding of the experience of the bone marrow donor. Although there may be no direct benefit to the participants of this study, there may be changes in the care given to the donors following the completion of this study.

Consent: This is to certify that I, ____________________ hereby agree to participate in the above named research project. I understand that I give permission to be interviewed and for these interviews to be tape-recorded. I understand that one or two interviews will be scheduled. I understand that the tapes will be destroyed after they are transcribed. The transcriptions will be kept for three years in a locked cabinet and then destroyed. All transcripts will have a code number only and will contain no reference to family name. I understand that the results of the study may be published but my name will not be associated with the research.

I understand that I am free to refuse to answer any specific questions in the interview. I also understand that I am free to withdraw my consent and terminate my participation at any time without penalty. I further understand that the content of the interview will be held in confidence by the investigator. If I find the subject matter upsetting at any time, the investigator will provide supportive measures. I have been given an opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction. I have received a copy of this consent form.

Signature:____________________ Date____________________

Relationship to the Recipient____________________

Witness____________________ Investigator____________________