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THE EXPERIENCE OF THE ADOLESCENT FOLLOWING KIDNEY TRANSPLANTATION: A GROUNDED THEORY

BY

TRACY RUTH SHABEN

A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of
Master of Nursing

Faculty of Nursing

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FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **The experience of the adolescent following kidney transplantation: A grounded theory** submitted by **Tracy Ruth Shaben** in partial fulfillment of the requirements for the degree of **Master of Nursing.**

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Date: August 20, 1992

DEDICATION

To my loving husband, for your patience, support, and constant encouragement. You have helped me to realize my dream. I dedicate this thesis to you.

ABSTRACT

The purpose of this study was to explore the adolescent's response to kidney transplantation and to provide a greater understanding of the chronic care experience from the adolescent's perspective. An inductive, qualitative research approach using grounded theory methods was utilized. Unstructured interviews with eight adolescent kidney transplant recipients provided information about the experience of having a kidney transplant.

A process emerged that these adolescents seem to undergo over time. The underlying core category appeared as Minimizing the Impact of Change following Kidney Transplantation. They strived to become normal and did not want to be different from others their own age. They also began to take on responsibility for themselves and others. Within this process, the adolescents went through five phases: Noticing the Changes, Concern over the Changes, Adjusting to the Changes, Integrating the Changes, and Moving Ahead to the Future. Changes in appearance, appetite, activity and energy levels, health status, medication and treatment regimens, relationships, and self-image were descriptive categories identified in each of the phases.

For these adolescents, the first year was the time of most dramatic adjustment. Changes in appearance, relationships, and self-image seemed to be most problematic. Various strategies were employed to cope with the concerns until adjustment to the changes took place and they were able to move on to other issues. The interaction of the adolescents' thinking about the consequences of their actions and the amount of perceived control they had, were key factors in adherence to medication or treatment regimens.

A number of implications were noted in this study including providing adolescents with health information as they seem particularly sensitized to taking care of their health, providing adolescents with opportunities to be involved in and make decisions affecting their health, and acknowledging the complexity and individuality of the various circumstances surrounding the adolescents' lives following kidney transplantation. Health care professionals can do much to minimize the impact of transplant-related change by providing adolescents with opportunities for successful adjustment.

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Statement of the Problem

The kidney transplant experience in adolescence is poorly understood. In fact, the adolescent's perspective has been generally disregarded by health care professionals. Yet, chronically ill adolescents and adolescents receiving long term medical care are increasing in numbers within our society due to medical and technological advances. Children, who previously would have died of kidney failure or would have faced a restricted life on dialysis, are now undergoing kidney transplantation and surviving into and beyond adolescence (Hobbs & Perrin, 1988; Pidgeon, 1989; Turk & Kerns, 1985).

However, survival does not mean cure. The kidney transplant patient is still considered to have a chronic condition because the treatment which is required to retain the transplanted organ is life-long. This treatment includes: taking immunosuppressive medications, continuing medical follow-up, and the constant uncertainty of graft rejection (Levi,1982; Locking-Cusolito, 1990).

The study of adolescents following kidney transplantation offers an opportunity to understand how adolescents with a chronic treatment condition deal with these changes. Most studies involving kidney-transplanted adolescents have used epidemiological measures to address transplant success. Transplantation success has been gauged by measures of graft survival rates, posttransplant growth rates, and kidney function tests (Flechner et al., 1985; Melzer, Leadbeater, Reisman, Jaffe, & Lieberman, 1989; Potter et al., 1986).

Psychosocial aspects have only recently been studied. Various approaches for these research inquiries have been used. For example, Fine, Korsch et al. (1970) studied children, between the ages of two and seventeen, after kidney transplantation. Emotional reactions related to the fear of rejection and the psychological problems of taking immunosuppressive medications were areas of specific concern found in this study. Lilly et al. (1971) focused on emotional problems posttransplantation. Descriptions of the behavioral and psychiatric problems were documented. Korsch et al. (1973) used semi-structured interviews, a variety of personality tests including the California Test of Personality, Piers-Harris Self-Esteem Scale, and medical problems noted upon clinical examination to find out about the long-term rehabilitation of children after kidney transplantation. Other researchers have continued studying pediatric clients in much the same manner (Beck, Fennell, & Yost, 1980; Bernstein, 1971; Drachman, Schlesinger, Shapira, & Druckker, 1989; Ettenger et al., 1991; Kahn, Herndon, & Ahmadian, 1971).

Quality of life, self-esteem, and independence measures have been used with children following kidney transplantation. These measures have included tests, questionnaires, and structured interviews (Gaedeke Norris, 1991; Weekes, 1991). Additionally, these studies have grouped all ages of kidney transplanted children together. Adolescents per se have not been a focus of study. Thus, little understanding of how the adolescent views his or her life within the situational context can be gleaned.

After a review of the current nursing, medicine, and psychology literature as well as reflection upon the author's own experience, current gaps in the understanding of the adolescent receiving long term medical care have been noted. If health care professionals do not know what the adolescent's experience is, what affects the way the adolescent lives, and how the adolescent manages, then how can appropriate care be provided to meet the adolescent's needs and expectations? Therefore, the research question developed to address the above problem was:

What is the adolescent's response to having a kidney transplant from the point of initial hospital discharge to the present day?

Purpose of the Study

The purpose of this study is to explore the adolescent's response to kidney transplantation. It is the investigator's hope that this study will provide a greater understanding of the chronic care experience from the adolescent's perspective following kidney transplantation. It is also hoped that hypotheses for further research questions in this area will be generated. Non-hospitalized adolescents are a suitable population in which nurses can begin to learn about life following kidney transplantation. These learning experiences may help to develop further the adolescent-nurse relationship and to provide appropriate nursing care for these individuals.

Chapter 2: LITERATURE REVIEW

A variety of areas of research are connected within the proposed research question. The impact of adolescent development on the experience of kidney transplantation is explored in this chapter. The issue of chronic illness and its relationship to the transplantation experience is discussed. Finally, relevant literature on the psychosocial aspects of kidney transplantation in children, specifically adolescents, is examined to provide the needed background for this study.

Adolescence

The current psychological and nursing literature defines adolescence in terms of biological maturation periods, chronological age, developmental stages, sociocultural conditions, and combinations of these views (Atwater, 1983; Coates, Petersen, & Perry, 1982; Lerner & Galambos, 1984; Rogers, 1985; van Hasselt & Hersen, 1987). One popular definition is that adolescence is a "process of achieving the attitudes and beliefs needed for effective participation in society" (Rogers, 1985, p.4). Another definition is that adolescence is "a transitional period between childhood and adulthood, with a biological beginning (puberty) and a social ending (the assumption of adult roles such as full-time employment or parenting)" (Coates et al., 1982, p.63-64). Little emphasis has been placed on the adolescent's perspective in the above definitions (Knowles, 1986; Rogers, 1985).

The adolescent is of specific interest to the investigator as this group has been characterized in the literature as being involved in a tumultuous period of change and growth (Blos, 1979; Erikson, 1968; van Hasselt & Hersen, 1987). More recent studies have challenged this assumption of "storm and stress" in adolescence (Bandura, 1980; Conger, 1973; Offer, 1969). Adolescence is a unique period, therefore it needs to be studied independently of other childhood time periods and separate from adulthood (Dragone, 1990).

Adolescence is a time where cognitive ability, social and emotional development, biological maturation, and moral reasoning undergo rapid changes. The adolescent displays a certain vulnerability requiring support and opportunities for experimentation until efforts at mastery are fulfilled (Petosa, 1989). Therefore, developmental aspects of adolescence are key to understanding the adolescent. Combining the changes associated with adolescence with a chronic condition, such as kidney transplantation, may set the stage for some of the greatest challenges that an individual will ever face (Tisza, Dorsett, & Morse, 1976; Zeltzer, Kellerman, Ellenberg, Dash, & Rigler, 1980).

<u>Cognitive Development</u>. The shift in cognitive development from concrete operations to more abstract thinking of formal operations occurs throughout adolescence and has an influence on decision-making (Piaget, 1967, 1978). Developmental theorists, such as Piaget (1967), Kohlberg (1958), and Elkind (1981), have generally agreed that adolescents have the capacity for moral and cognitive maturity around the age of 14 years. The majority of individuals are able to reach

this capacity of moral and cognitive maturity by 15 or 16 years of age, thereby refuting the belief that adolescents are incompetent to make informed decisions (Weithorn & Campbell, 1982). Tradition, based on feudal law and custom, has governed the age issue surrounding decision-making and consent. Age limits have not been based on scientific or rational developmental information. Decisions regarding age of consent have been related to the societal and economic contexts of the time (Annas, Glantz, & Katz, 1977). Today, one is considered to be an adult at eighteen years of age, yet this has not always been the case. Thus, changes in how society views the adolescent may affect the amount of input into decision-making these individuals may have. This has obvious implications for the treatment of adolescents involved in cases of decision-making and ultimately, in health care issues.

As cognitive development progresses, a sense of vulnerability, felt early on by the adolescent, results in egocentric thoughts with some irrational components including the "imaginary audience" where the adolescent is preoccupied with looks and behavior even if no one else is nearby; the "personal fable" where personal qualities are exaggerated in importance; the "time wars" where events, situations, and feelings are not synchronized to allow for a sense of direction in life; and "cognitive conceit" where the adolescent believes that he or she knows more than others do, is replaced by a more secure, internalized sense of self (Schave & Schave, 1989, pp.9-13). These examples of egocentrism coined by Elkind (1967) become integrated into the developing self along with the capacity for an understanding of others. It is these cognitive changes which are often seen as crucial to understanding behavior (Coates et al., 1982).

Social Development. Identity development occurs as all the above cognitive changes progress. In this process, family and peers are important. Peers form the major support network, although parental influence, support and styles of parenting affect the outcome of adolescent development. Baumrind's work (1968) on parenting styles with adolescents indicates that authoritative parenting seems to be most effective. With this style, parents set limits based on negotiation and discussions with their children so that expectations are clear. Other alternative parenting styles from permissiveness to authoritarianism seem to be less effective ways of dealing with adolescents. Parental alliance or the ability of parents to work together for emotional support plays a key role in the success of these years (Cohen, Cohler, & Weissman, 1984). Integration of individuality and conformity occurs as identity develops within adolescence (Schave & Schave, 1989).

Emotional Development. Adolescent emotional development has been characterized as a period of stormy relations, rebellion, and general unrest. This stereotype persists even with studies showing, that for the majority of adolescents, this is a smooth period of transition. Approximately 20 to 25% of all adolescents may experience this stereotypical description of storm and stress, while clearly the majority are able to cope quite well in this period (Coleman & Hendry, 1990; van Hasselt & Hersen, 1987).

Risk-taking behavior is another matter. Often, the adolescent feels invincible because there is little connection between his or her own behavior and for instance, poor health. Therefore, taking on adult behavior without understanding the consequences may result in some serious health risks to the adolescent. Examples of such behavior include smoking, dangerous driving, drug and alcohol use, poor eating habits, and indiscriminate sexual activity. Thus, this experimentation period may encourage risk-taking in many areas directly related to the health of the adolescent, for example, adhering to treatment regimens. Thus, "the first barrier to cross in health promotion" may be the understanding of these types of behaviors and providing ways for the adolescent to experiment without sacrificing health (Coates et al., 1982, p.8; Lerner & Galambos, 1984). Health cannot be separated from the person, and problems involving health matters are inextricably linked with the psychosocial context. Relationships with fellow peers and with adults (especially parents), communication, responsibility, and trust are important factors in positive outcomes for the adolescent. Therefore, health care efforts with all adolescents including the chronically ill and adolescents under chronic care must involve these factors (Blum, 1984; Lerner & Galambos, 1984).

Biological Maturation. Physiological changes and the adolescent's views of him or herself are also related to each other. The rapid changes associated with puberty are different from other times in the lifespan. The adolescent is fully aware of the physiological changes and must somehow respond to form an integrated sense of self. The physical self is influenced by the psychosocial context surrounding the adolescent. A broader perspective is required to take these factors into consideration. Body image (Salter, 1988), self-esteem (Coates et al., 1982; Miller, 1987), and relationships with others, especially peers (Mitchell, 1986), all affect how the adolescent views the world and makes decisions. Therefore, in treatment decisions where medications and surgery may produce further physiological changes, these factors are important issues to consider when dealing with the adolescent. Involvement by the adolescent in health care decisions may be one way to acknowledge the adolescent as a person (Lerner & Galambos, 1984).

Autonomy. Autonomy is defined as being independent, free, and self-directing. It is a process that begins in the toddler years and continues through to adulthood (Atwater, 1983). While independence or psychological autonomy has generally been regarded as crucial to the adolescent's development, the role of relationships and interdependence has been down played (Lerner & Galambos, 1984). Yet, family support and peer relationships play a large part in the development of the adolescent. Work by Gilligan (1982, 1988) and McDermott et al. (1984) have challenged the importance of independence and the justice ethic in the moral development theories proposed by authors such as Freud (1925), Piaget (1932), and Kohlberg (1958). In Kohlberg's theory, only male interviews were included in data analysis, as they most closely approximated the views held by society at the time and, thus, were most heavily valued (Schave & Schave, 1989). Yet, gender differences appear to play a role in the understanding of adolescent development. Two separate voices, according to Gilligan (1988), provide the basis for moral judgement. One is based on the justice ethic and the other is based on a relational/care ethic. The relationship and care focus are more likely to be described by women while independence and equality are more likely to be described by men. It may be necessary to rethink our understanding of the concept of autonomy and recognize both independence and relationship as important (Shaben, 1991). Adolescence seems to be where internalization of these ideas becomes integrated.

Research. Adolescent research has been directed by natural science approaches (van Hasselt & Hersen, 1987). Developmental theorists such as Erikson (1963) have delineated the stages that a person goes through during life. According to Erikson (1963), there are eight stages. In adolescence, the important developmental task is the formation of an identity (1968).

Piaget (1953, 1965) has used a variety of methods including naturalistic observation, clinical experimentation, and a combination of these two often called the "clinical method" (used in psychology and psychoanalysis) to develop his theory of intellectual development. He describes the stages of intellectual development from infancy to adolescence. Adolescence is a period where abstract thought becomes possible. The adolescent is able then to participate in and make decisions about him or herself and in relationships with others. There is a developing sense of being able to look beyond the present to the future.

Goethal and Klos in a monograph entitled *Experiencing Youth: First Person Accounts*, is an early example which directly addresses the adolescents' experiences (cited in van Hasselt & Hersen, 1987). As well, Doan and Morse (1985) have written a book intendad for adolescent girls based on their qualitative research. It describes from many girls' perspectives, the experiences of menarche. The emphasis here is on the experiences of adolescent girls undergoing a normal developmental process.

All of these research efforts have provided some insights into how a person develops normally, yet little has been done to examine the reality of the individual who is chronically ill or who may be subject to treatments of a long-term nature. More approaches must be focused on the "wholeness" of the adolescent, to understand the adolescent from his or her perspective, while acknowledging the context and circumstances surrounding this understanding. Research into the adolescent experience of an unexpected treatment process with a chronic care aspect still needs to be examined.

Chronic Illness

Seminal work by Strauss and Glaser on chronic illness and quality of life (1975), as well as studies such as Benoliel's study of childhood diabetes (1975), and Canam's study of cystic fibrosis (1987) have used qualitative approaches to examine chronic illness in hospitalized patients (Forsyth, Delaney, & Gresham, 1984). Corbin and Strauss (1990) discuss illness-related work and everyday life-work of non-hospitalized chronically ill adults. Traditionally, "disease and treatment processes" from the disease-oriented medical model have been outlined by health care professionals with a focus on pathology rather than the behavioral or psychological responses to the disease or treatment process. Chronic illness response as a field of study has only recently emerged. Qualitative research seems to be a more comprehensive approach for the individual and family in dealing with illness (Kleinman, 1988; Morse & Johnson, 1991).

Traditionally, the focus within the health care system has been on acutely ill, hospitalized patients most often using quantitative methods of research inquiry. In a system still oriented to "acute, episodic illness", the need for understanding the chronically ill adolescent's experience becomes increasingly important to facilitate a change in the research approaches and the perspectives of health care professionals and the health care system in general (Thorne & Robinson, 1989, p.153).

The only studies with non-hospitalized adolescents who have undergone treatment procedures for chronic illness (for example, transplantation) are those discussing quality of life issues or psychosocial sequelae of various disease or treatment conditions. Adolescents are not specifically studied but are included into groups of children or adults (Frauman, 1991; Zamberlan, 1988).

Frauman (1991) is investigating the social development and level of rehabilitation of a group of children following kidney transplantation. She is using an exploratory, descriptive design to identify factors which interfere in these social and rehabilitation activities.

In a doctoral dissertation by Zamberlan (1988), the quality of life of school-age children following liver transplantation was studied. A combination of qualitative and quantitative methods were used. The findings suggested a good quality of life for these children, although it was "difficult to differentiate the impact of chronic illness, the transplant experience, and the antirejection medication on self-concept and quality of life" (p.2).

Psychosocial Aspects of Kidney Transplantation with Adolescents

Kidney transplantation has been accepted today as the treatment option of choice for persons with end stage renal disease (ESRD) in all age groups. This treatment option was originally not viable for children with ESRD because of the technical problems associated with the small size of the child. However, with advances over the past 30 years, many of the original concerns with kidney transplantation in childhood have been overcome. It seems that as technological expertise has increased, more emphasis has been placed on the psychological and social aspects that affect the kidney transplanted child and the family as a whole.

Historical Background - The 1960s. Since 1954, kidney transplantation has been performed relatively successfully with adults (Thomson et al., 1989). Children were not considered suitable candidates for this treatment alternative until the early 1960s. Dialysis and kidney transplantation programs for children with ESRD began to appear throughout the United States in the mid 1960s. In the late 1960s, centers in other "developed" countries were established to provide hemodialysis and transplantation treatment options in the management of ESRD in children (Fine, Salusky, & Ettenger, 1987; Malekzadeh, Pennisi, Uittenbogaart, Korsch, Fine, & Main, 1976).

Success with kidney transplantation in children was believed to be comparable to the success of kidney transplantation in adults with ESRD (Boulton Jones, Cameron, Bewick, Ogg, Meadow, & Ellis, 1971; Gonzalez, Martin, West, Spitzer, & McEnery, 1970; Potter, Belzer, Rames, Holliday, Kountz, & Najarian, 1970). Treatment centers in the U.S. and Great Britain described transplant program outcomes mainly through the use of mortality rates, rejection rates, and growth rates. Physiological complications were reported most frequently, although there were brief discussions of the overall rehabilitation of children following transplantation. Occasionally, some of the psychosocial problems encountered were briefly addressed, but these problems were not systematically studied.

In 1964, Riley wrote an article for the *Journal of Pediatrics* that outlined his concerns regarding the use of transplantation in children with ESRD. These concerns stemmed from both the physical and psychological trauma that these children would experience. In response to these concerns, the Children's Hospital of Los Angeles established a kidney program in 1967 which involved transplantation for children. The emotional and social aspects of treatment were considered to be very important in the development of programs for both dialysis and transplantation options. The aim was to provide physiological and psychological care for these children using a multidisciplinary team approach (Korsch, Fine, Grushkin, & Negrete, 1971).

This focus on treatment of children with kidney problems led to the collection of a separate set of statistics for children with ESRD in 1968. It was only at this time that trends and problems unique to childhood following kidney transplantation were identified more easily (Zarinsky, 1975). It was not until the early 1970s that the psychosocial issues of treatment were truly scrutinized.

The early 1970s. The early 1970s was a period of development for dialysis and transplant programs for children with ESRD. A number of research studies were undertaken regarding the quality of the emotional reaction following kidney transplantation, both immediately after the operation and over longer periods of time. Bernstein (1971) studied the emotional adaptation of 36 children at three different time periods from immediately after hospital discharge to up to six years following transplantation. Psychiatric evaluations of subjects and questionnaires to adolescents and parents of younger children were used. Some adverse emotional reactions to the transplant were identified in four of the 36 subjects in this study (all of whom were adolescents). For all subjects, regardless of the time since transplantation, the fear of rejection was identified as a problem. It was suggested that emotional support for children following kidney transplantation be an early and continued type of support. This study described the reactions of children after transplantation through the use of case studies. However, there was inadequate information about what was included in the psychiatric evaluation, and the reliability and validity of the questionnaires were not discussed. This makes replication of the study very difficult.

In another study by Kahn, Herndon, and Ahmadian (1971), social and emotional adaptation was investigated in 14 children, 5 children following successful transplantation and 9 children following chronic hemodialysis (2 having had previously unsuccessful kidney transplants). Structured and unstructured interviews were conducted with children and their parents in the areas of "social life and peer relationships, mood and affect, activity level (games and sports), school performance, other behavior changes, children's feelings and fantasies regarding transplant and dialysis, and relationship of children with donors" (p.116). Children were also given a test of intelligence and a Draw-A-Person test. This was one of the earliest studies in which both qualitative and quantitative measures were used in an attempt to understand the emotional and social adaptation of children following kidney transplantation.

The results indicated that the majority of children had problems with social isolation, dependency on parents, and depressive tendencies. It was suggested that some of these problems could be avoided if they became areas of focus in the treatment program. Excellent descriptions of the social and emotional problems within this group of subjects were provided, although study results could not be generalized due to the small sample size. A tremendous time commitment was also required from all individuals which influenced participation rates. Additionally, the rationale for use of all of the interviews and scales was not clear. Nor was it evident how the seven areas for assessment were chosen. Despite these problems, this study pointed the way for future research in this subject area.

From a review of these treatment programs and studies in the early 1970s, it became quite obvious that there were marked emotional and social adjustments that had to be made by children following transplantation. Adolescent girls were found to be heavily affected by the physical changes associated with steroid use. Relations with siblings and with school mates were affected. The fear of rejection was always present and return to school was a problem for some. Rehabilitation, on the whole, was thought to be satisfactory despite some of the above problems. Thus, these early studies gave the first detailed psychosocial descriptions of their populations which could be used as the basis for future research efforts (Fine et al., 1970; Lilly et al., 1971; Najarian et al., 1971).

<u>The Mid to Late 1970s</u>. In the mid 1970s, research efforts continued in the area of emotional and social adjustment. Specifically, study was undertaken to predict the outcomes after kidney transplantation as well as to determine the most effective

intervention in terms of overall rehabilitation for these children. The first systematic study to use healthy children and chronically ill children as controls, and kidney transplanted children was undertaken by Korsch and associates (1973). Personality tests and semistructured interviews were administered to 35 children with kidney transplants. Personality test results of the children with kidney transplants were matched by age with a group of cystic fibrosis patients. Additionally, these children were matched for age, sex, ethnicity, and socioeconomic status with two control groups from a large data base compiled by Pless and associates for the Rochester Child Health Study of Chronically Ill Children (cited in Korsch et al., 1973). The semistructured parent interviews were adapted from those used in the Rochester Study, while a new interview schedule was created for use with the kidney transplanted children. Reliability and validity of the adapted interview and the newly created interview tools were not addressed. Efforts to control for extraneous variables were evident through the use of the matching technique, making this a seminal piece of work upon which many of the later studies were based.

The analysis of the results by Korsch et al. (1973) indicated that there was no evidence of increased psychological disturbance when the treatment group was compared to the two control groups of children. However, some of the anxieties that were described by the treatment group included fear of rejection and body changes resulting from steroid induced side-effects. A suggestion noted on completion of the study was that assessments of psychological functioning prior to entering the treatment program may provide for optimal care of these children. This suggestion makes intuitive sense and now needs to be examined.

In an addendum to the article, the authors reported on a further sample of 55 patients using the same procedures. The results continued to support the findings reported in the initial study. The largest proportion of the treatment group of children were found to be within normal limits on the personality tests. The children with the lowest scores in each of the tests were noted to require therapeutic intervention. These children were also most likely to demonstrate noncompliance with the immunosuppressive therapy. These first tentative results led to the development of a study on noncompliance in 1978 (described later).

Quality of life was studied by Pozanski, Miller, Salguero, and Kelsh (1978) using semistructured interviews with 18 kidney transplanted children and adolescents. Successful transplantation seemed to have a positive influence on friendship development and dating encounters. Adolescents were affected more intensely than other children and some had problems with low self-esteem, depression, and lack of social opportunities. Quality of life was not well defined in this study, although the measures used to define the concept were based on objective or functional properties including peer relations, self-esteem, and daily activities. The results were descriptive in nature and continue to add to the knowledge base in this area of study. However, the study's small sample size does not allow for generalization to other populations.

Outside the United States, kidney transplant centers have documented similar results to American studies in relation to psychological and social adjustment with children and adolescents. Treatment program results from Australia and England in the late 1970s have demonstrated the negative effects of steroid usage, especially on adolescent body image and self-esteem. Small stature and the development of social relationships have remained problematic. School attendance and ability to work also have been affected (Chantler et al., 1980; Henning, Tomlinson, Rigden, Haycock, & Chantler, 1988).

Chantler et al. (1980) used descriptive methods to report their treatment program results. There was heavy emphasis placed on the physiological aspects of treatment while only general statements were included about psychosocial problems and rehabilitative efforts. Henning et al. (1988) administered a questionnaire asking about social and psychological problems to 31 children who had faced ESRD. Of these children, 26 had a functioning kidney transplant. The results were compared with the responses of a group of 17 children with juvenile diabetes. The results indicated that the diabetic children had "notably better education and employment records than those with ESRD" (p. 38). The effect of short stature and cushingoid appearance on social life were noted to be more prevalent with the transplanted children than with the comparison group of diabetics. Sexual problems were also noted more frequently with ESRD subjects than with the diabetic subjects. It was pointed out that the usefulness of the interventions for psychosocial problems seemed to be dependent on the family make-up and pre-illness personality traits, and not solely based on the transplantation or disease condition that was present.

The low participation rate of the diabetic comparison group was mentioned as a limitation to this study. It was also unclear how well matched these groups were. This is necessary to make even basic comparisons between the two groups of children. Therefore, redesigning this study to try to control for these threats to validity would make the study much stronger.

Throughout the 1970s, a frequently reported psychosocial problem of treatment was the negative response to steroid-induced body changes. The reaction to these changes was particularly intense in the adolescent population. Adolescent girls were noted to have stopped taking their immunosuppressive medications very early on in their treatment programs. It was hypothesized that the changes in body appearance resulted in decisions by the adolescents to discontinue their immunosuppressive medication (Kahn et al., 1971). Further studies have continued to report this phenomenon (Korsch, Fine, & Negrete, 1978).

Noncompliance, defined as failure to follow through with prescriptive treatments (Sackett & Haynes, 1976), was the subject of a study in 1978 by Korsch et al. Personality tests, IQ tests, and semistructured interviews (described in the previous study by Korsch et al., 1973) were used to assess rehabilitation and try to understand the possible determinants of noncompliant behavior in children. Of 202 kidney transplantations in 152 children, a total of 14 children demonstrated some failure to take their immunosuppressive drugs over a 10 year period. There were a number of differences between the compliant and noncompliant children including extreme scores on the

California Test of Personality, the Sarason's General Anxiety Scale, and the Piers-Harris Self-Esteem Scale, and there were differences in 9 of 15 family function test items. With adolescent subjects, it was more difficult to discriminate the compliant subjects from the noncompliant ones, so that additional items had to be included to allow for this separation. It was hypothesized that adolescents may be predisposed to noncompliance because of their developmental stage more than any other factor. The results suggested this hypothesis may well be true, that the stressful experience of transplantation on adolescent girls was responsible for "noncompliance", rather than any inherent emotional or social disturbance. Thus, developmental issues may play a part in the complex issue of noncompliance. However, no further attempts to research this topic were made until much later. Other transplant centers have reported comparable findings in relation to adolescent noncompliance (Litt & Cuskey, 1980; Malekzadeh et al., 1976).

Another psychosocial topic of interest during the 1970s was the reaction of the child to the transplanted organ (Malekzadeh et al., 1976; Zarinsky, 1975). There has not been a great deal of investigation with the child or adolescent, specifically, following transplantation, although fantasies about the transplanted organ and the donor have been reported by Korsch et al. (1971).

The 1970s were productive for the study of psychosocial adjustment in children and adolescents following kidney transplantation. Emotional and social adaptation were studied from a variety of angles, reactions to the transplanted organ were described, quality of life was defined using objective criteria, and the possible relationship between body image, self-esteem, and noncompliance following steroid administration were first raised. It is obvious that further research is needed to validate these initial findings. All of the studies in the 1970s were helpful, but most remain limited in their potential application. There were problems with small sample sizes, inadequate description of the reliability and validity of instruments, and inadequate explanation of the variables selected for study.

The Early 1980s. The early 1980s appeared to be a time period where few review or research articles were published regarding children and psychosocial issues following kidney transplantation. Of particular note to this time period, however, was a more thorough discussion of the relationship between chronic illness and transplantation. Levi (1982) stated that the child or the adolescent following kidney transplantation must continue to be regarded as having a chronic illness. This was an aspect of transplantation previously overlooked.

In adolescence, the effect of living with a chronic illness and the emotional stress surrounding the possibility of graft rejection become important issues. The adolescent faced with the constant uncertainty of kidney rejection seems to be especially vulnerable. This may be associated with the developmental process of fostering an integrated identity. If an integrated sense of self cannot be created, then this may lead to problems in psychological and emotional adaptation (Gradus & Ettenger, 1982; Levi, 1982; Zeltzer, Kellerman, Ellenberg, Dash, & Rigler, 1980). Therefore, combining the changes associated with adolescence and a chronic condition, such as kidney transplantation, may provide great challenges to these individuals (Tisza, Dorsett, & Morse, 1976).

The Mid to Late 1980s. Successful transplantation was a frequent topic of discussion in the mid 1980s. Treatment centers around the world described their subject populations in objective terms such as mortality and morbidity rates. For example, morbidity was measured by comparing the number of days in hospital before and after transplantation or hemodialysis, and by measuring serum hemoglobin levels, blood urea nitrogen concentrations, and creatinine clearances (Arbus et al., 1986; Broyer, 1984; Offner et al., 1988; Potter et al., 1986; So et al., 1986). While the above factors remain important areas for assessing transplant success, some authors began to suggest that facilitation of optimal growth was a necessary element in a successful transplant program. After almost two decades of discussion about low growth rates in children with ESRD and the potential harmful effects of short stature on body image and self-esteem, systematic study of this area began (Fine et al., 1987; Fine & Tejani, 1987).

Other issues, including the problem of noncompliance with adolescents following successful kidney transplant operations, continued to be reported throughout this time period. Efforts to explore the psychosocial dimensions involved in noncompliance were not undertaken except through dialogue in journals (Fine & Tejani, 1987; Offner et al., 1986). In a preliminary study of 15 transplanted children treated with cyclosporin, the majority of children developed major facial changes. These included "thickening of the nares, lips, and ears, puffiness of the cheeks, prominence of the supraorbital ridges, and mandibular prognathism" (p. 1405). It was felt that this may increase the risk of adolescent noncompliance, although studies have not yet been developed to address this topic area (Reznik, Durham, Lyons Jones, & Mendosa, 1987).

Other concerns noted in previous studies continued to be investigated. Rehabilitation, as measured by employment on a full-time basis and attendance at school, had been deemed to be quite successful in most of the ESRD treatment programs (Potter et al., 1986; Samuel et al., 1986). In a report of the experiences of a dialysis and transplantation program over a period of 14 years (Offner et al., 1988), 113 children between the ages of 2 and 16 were followed until December, 1985. In addition, interviews were conducted with 74 children and adolescents to determine their own perception of rehabilitation (full-time jobs, school attendance, and state of health). Most of the subjects stated that they had a good to excellent health state and attended school regularly. A team approach by health care professionals was suggested to provide as complete a rehabilitation program as possible for these individuals. Evaluation of these interventions has yet to be completed.

The research efforts of the late 1980s were strongly focused on functional impairment and social adjustment following kidney transplantation. A study by Melzer, Leadbeater, Reisman, Jaffe, and Lieberman (1989) identified an area of research with adolescents that they believed had been neglected, namely, the effect of the chronic illness, ESRD, on the development of a social network with others outside of the family system. Interviews and structured questionnaires were administered to 16 kidney transplanted adolescents who, on the average, were 1.5 years posttransplant. These adolescents were matched on age, sex, ethnicity, and family structure (intact or not intact) with a group of healthy adolescent control subjects. While this is a small sample, it provides initial data to suggest that support networks are smaller in the transplant group of adolescents with fewer persons from peer groups, especially members of the opposite sex, than the healthy group of adolescents. It was proposed that development of peer relationships be an aim of pediatric transplant treatment programs. It remains to be seen whether or not this will be a helpful intervention. Evaluation of these interventions is needed.

In many of the research and review articles of the late 1980s, authors utilized objective measures to evaluate the success of the transplant treatment programs. There was increased discussion of the problems of noncompliance and poor growth rates posttransplantation. Yet few organized studies were undertaken to deal with these issues. Description of the treatment outcomes of individual programs continued to be published. These study efforts serve to add to the knowledge base for future work in this area.

The 1990s. Psychosocial adjustment following kidney transplantation in children continues to be a focus of study in the

1990s. Measures of quality of life, self-esteem, and independence have been performed with the aid of tests, questionnaires, and structured interviews on children after kidney transplantation. While these methods continue to be used (Gaedeke Norris, 1991; Weekes, 1991), there are also increasing numbers of qualitative studies. For instance, Frauman (1991) is currently investigating the social development and level of rehabilitation of a group of children following renal transplantation using telephone interviews and administering the Vineland Adaptive Behavior Scale. She is hoping to identify factors that interfere in these areas using an exploratory, descriptive design.

Past studies have provided support for the beneficial effects of transplantation on the psychosocial well-being of children with ESRD as compared to the other treatment modalities (Brownbridge & Fielding, 1991). However, Reynolds, Garralda, Postlethwaite, and Goh's results (1991) do not support some of the findings from earlier work regarding kidney transplanted children's concerns about their appearance and growth. When parents of these children were asked, only 2 out of 29 sets of parents spoke about the problems of changed appearance and poor growth in their children. A possible problem with this study was to consider parents' responses as representative of the transplanted children's responses. The results might have been different had the children themselves been asked.

Noncompliance continues to be problematic in the 1990s. In one study, Ettenger et al. (1991) found that approximately 64% of adolescents with kidney transplants were found to be noncompliant with their antirejection-immunosuppressive medications. In other studies, the general rate of noncompliance is 25-35% for various age-groups involving a variety of individuals with different health problems (Conrad, 1985; Pidgeon, 1989; Sackett & Haynes, 1976).

Noncompliance with prescribed medications is not a new phenomenon. However, the alarming consequence to the kidney transplant recipient may be rejection of the transplanted organ (Hesse, Roth, Knuppertz, Wienand, & Lilien, 1990). Because a healthy kidney is so critical for this population, one wonders why a person would ever be noncompliant. While this is the traditional retort of health care professionals to noncompliant transplant patients, this approach must be reconsidered as these attitudes have not helped to shed light on this complex problem (Nekolaichuk, 1990). What seems to be needed is a more in-depth look at the adolescent's experience following kidney transplantation to enhance the experimental studies done to date (Blum, 1984; Korsch et al., 1978; Turk & Kerns, 1985).

Summary

In reviewing the literature, it is evident that the experiences of the non-hospitalized adolescent under long-term treatment care have not been well studied. Adolescents with kidney transplants have rarely been separated as a special population for study. More frequently, children and adolescents are grouped together (Zarinsky, 1975). Additionally, studies involving adults overlap into the adolescent period. Age ranges in many studies involving kidney patients are quite varied. Age ranges of 15 or 16 years to well into the 60 years are common. It seems that little differentiation has been made between adolescence and adulthood (Devins et al.,1990; Landes, Holman, & Maxwell, 1983; Simmons & Kamstra, 1980; Taber, Lee, & Slapak, 1982). Yet, the adolescent facing the rapid developmental changes unique to this time period may be susceptible to some specific psychosocial problems which may not be identified if large age groupings are used (Grushkin, Korsch, & Fine, 1973; Zarinsky, 1975).

Additionally, studies to date have been largely descriptive. The results have provided the necessary data to undertake more systematic studies with this population. Qualitative research studies may be helpful to determine the common themes that emerge from the kidney transplanted adolescents' experiences as explained by the adolescents themselves; then, quantitative studies can be devised to test these hypotheses.

A study of the experiences of the adolescent under long-term medical care following a kidney transplantation may increase our understanding of these adolescents to allow health care professionals and the health care system to respond appropriately to this population. A qualitative research approach was undertaken to further understand the adolescent's experience following kidney transplantation. In the next chapter, this approach is described in more detail.

Chapter 3: METHODS

A qualitative research approach using grounded theory was used to gain an understanding of the adolescent's experience following kidney transplantation. A process was developed from the interviews to describe the phases that the adolescent kidney transplant recipient progressed through over time following hospital discharge.

Grounded Theory

In grounded theory, the question that is asked is: "What is going on here?". Grounded theory methodology aims at understanding a basic social process (BSP) in a continuing search for commonalities over the lifespan within the human experience. For instance, a good example of this is life following kidney transplantation (Coleman & Hendry, 1990; Conrad, 1990; Field & Morse, 1985; Glaser, 1978). The goal is to explain, interpret, and predict basic patterns of phenomena (Chenitz & Swanson, 1986; Stern, 1980).

A BSP may be found as a "core category" involving two or more stages. These findings form the basis for developing further research hypotheses. These findings may also begin to describe substantive theory. Substantive theory may be generated within a specific area such as adolescent kidney transplantation or it may be generated in a general area such as adolescent chronic illness (Glaser, 1978; Stern, 1980). The data provide the direction to be followed. The investigator must "bracket" what is known from the literature and use only the data collected from the interviews in order to derive the basic patterns or processes (Morse & Johnson, 1991). Testing can then be carried out to validate and refine the current knowledge or understanding of the situation (Chenitz & Swanson, 1986; Glaser, 1978; Stern, 1980).

Grounded theory method utilizes symbolic interactionism as its guiding theoretical framework. Symbolic interactionism is derived from the work of Mead (cited in Rock, 1982). It is a process where people come to know and make sense of their world, interpret the meaning of happenings around them, and use symbols in relation to what is believed to exist. Human behavior within the contextual surrounding is key; therefore, to determine commonalities and understanding, research must be done in the natural setting and come from those experiencing the situation (Chenitz & Swanson, 1986).

Both inductive and deductive modes of inquiry were used in this grounded theory study. Of most significance, was the inductive generation of data using the constant comparative method of analysis (Glaser, 1978). Adolescents were interviewed about what it was like for them to be a kidney transplant recipient. From these experiences of living with a kidney transplant as told by the adolescents experiencing it, a description and understanding was derived, a theory was developed to incorporate these findings, and further hypotheses were generated. Thus, the findings were truly "grounded" in the reality as seen by these adolescents.

Sample

The initial sample was eight English speaking non-hospitalized individuals who were living with a kidney transplant during their adolescence. The sample was obtained through the renal transplant clinic in the pediatric nephrology department of a large metropolitan hospital in western Canada. The inclusion criteria were that the informant was:

-English speaking
-non-hospitalized at time of interview
-13 to 18 years of age
-currently experiencing life with a kidney transplant
-an expert informant (see below)
-willing to participate in audio-recorded interview sessions

The pediatric nephrology secretary or one of the renal transplant nurse clinicians asked the potential informants for permission to have the investigator come and explain the study. An attempt was made to find "expert" informants. These were individuals who had been through the experience, were willing to participate, were honest, insightful, and had time to tell their experiences (Morse & Johnson, 1991). This type of sample is called a theoretical sample. The informants were chosen specifically for their expertise and were not a random or demographic representation of all adolescent kidney transplant recipients (Lincoln & Guba, 1985). Adolescents aged 13 to 18 were included in this study. This age range was chosen to provide for enough informants while remaining within the age range commonly accepted for the adolescent period (Adelson, 1980; Blos, 1962).

Informants were interviewed between one and three times about their experiences (Table 1). When unusual findings or "negative cases" were identified, other cases were specifically sought out through secondary sampling. This was done to try to create as complete a picture as possible of the informants' experiences (Glaser, 1978). The data received from the interviews were continually analyzed and once no new categories or themes emerged, then data collection was seen to be complete.

Additionally, two English speaking individuals, over the age of 20 years, who had gone through the experience of kidney transplantation in adolescence, but who were now beyond adolescence, provided richness and depth to the data of the informants (see below & Table 1) (Glaser, 1978; Strauss & Corbin, 1990). This supplied insight and validation of the informants' experiences as the kidney transplant experience had been fairly recent and had been seen in its entirety.

Description of the Sample. The sample consisted of eight informants, three males and five females. Their ages ranged from 13 to 18 years (Table 1). Informants all had functioning kidney transplants, although the prior kidney disease diagnoses were different. Diagnoses included bilateral renal atrophy, focal segmental glomerulonephritis, medullary cystic disease, streptococcal infection, and other infection related causes of kidney failure including frequent urinary tract infections. Three informants were uncertain of the cause of their kidney disease requiring transplantation.

All informants attended school. Five informants were in the appropriate grade for their age. Three informants were behind in school either one or two years. Informants, with one exception, were 12 years or older at the time of transplant. One informant was eight years old. For two of the eight informants this transplant was not their first kidney transplant. One informant had had three kidney transplants and the other informant had had two transplants.

The time since transplantation varied ranging from 6 months to 6 years 5 months. One informant had had the transplant 6 months previously, three informants had had their transplants between 2 1/4 to 3 1/2 years before, while four informants had had their transplants for at least six years. Six of the informants had not been hospitalized within the last year. Two informants had been hospitalized for rejection episodes. Only one informant had a higher than normal creatinine level (130mmol/dl), although this was currently stable. With one exception, all informants were on cyclosporin and prednisone. A single informant was on cyclosporin only. Other medications some of informants were taking included: azathioprine (Imuran), diuretics, antihypertensives, and vitamins,

Validation interviews were done with two informants over the age of 20 years. These informants had had transplants in their adolescence. Both were currently employed. Both had stable creatinine levels and both had not been hospitalized in the past year as a result of kidney problems. Time since transplantation was greater than eight years for both informants. A renal transplant nurse, a nurse colleague, and a pediatric nephrologist were also included in the study. Demographic data were not included for these individuals as they were asked only to comment on how their professional experiences compared with those of the informants.

Table 1. Characteristics of primary and secondary informants and number of interviews

Informants	Age in years	Grade in school	Number of transplants	Number of interviews
Primary				
1	13	8	1	1
2	16	9	1	2
3	18	12	1	1
4	18	11	3	1
5	16	11	1	1
6	17	11	1	3
7	17	11	2	2
8	13	8	1	2
Secondary				
9	24	N/A	1	1
10	25	N/A	1	1
Other				
11	Nurse colleague			1
12	Renal transplant nurse clinician			1
134	Physician			1

Setting

Study participants were interviewed in a quiet setting of their choice. These sites included an office within the hospital complex, an office at a school, a parent's office, and a informant's home.

Interviews were audio-recorded in a quiet place free from interruption and distraction with only the investigator and the participant present.

Data Collection Procedures

The methods of data collection in this project included unstructured audio-recorded interviews, informant face sheets for biographical data, field notes of the investigator, and memos of the investigator. Most interviews lasted approximately one hour, although three interviews were one and one half hours long, and two interviews were two hours in length. This was typical of interviews in other research studies done with adolescents, as well as typical of what this population of adolescents was believed to be able to handle (Faux, Walsh, & Deatrick, 1988; Kikuchi & Molzahn, 1989).

In this type of qualitative research, "the experts" were the adolescents themselves. In other words, the adolescents defined the questions. Unstructured interviews were used to allow the informant to tell his or her story. Guiding questions were used quite extensively in the interviews and became more specific as the data collection progressed (Morse & Johnson, 1991) (see Appendix A for examples).

Demographical information was asked at the beginning of the interview as it was felt to be least threatening. This was followed by more private types of questions involving increasing disclosure. Informants were asked for a description of their kidney transplant experiences. To illustrate this approach, the initial statement might have been: "Tell me about what it has been like for you after you received a new kidney". Based on the substantive content of the response, the interviewer then proceeded with questions that elicited more detail about the experience. For example, some subsequent questions were: "What areas of your life have been affected following the transplant operation? What is different from other times in your life? This order allowed for the building of trust and a nonthreatening relationship (Faux et al., 1988).

Open-ended statements were used initially, although the adolescents expected more specific questions. Short responses and silence often greeted the investigator. While this was not unexpected, the investigator had to acknowledge inherent biases in the proceeding questions to elicit more detail about the experiences. This was particularly true of the first few interviews as informants may have been led in certain directions by the investigator and this may not necessarily have been the adolescent's choice of direction. However, this is an interactive process between the investigator and the informant. It was felt that the adolescent's story was truly reflected in the interviews. Trust and comfort did develop over the course of the interview. Therefore, the adolescent was actively involved and was able to direct the interviews as he or she saw fit. This was fully realized when the investigator made it explicitly clear at the beginning and at another point in each interview that this was the informant's story and that the investigator was not looking for any "right" answers.

The second set of interviews were used to clarify points made in the first set of interviews and were used to validate the emerging findings. Countersuggestion was used here to rephrase some of the statements or questions asked in the first interview. This helped to deal with possible problems where stories were not quite consistent each time they were related. A number of secondary sources were available including one informant's diary and one story by a friend of one of the adolescent kidney transplant recipients. These were coded and were valuable sources of information to substantiate the informants' responses from the interviews (Faux et al., 1988). Kidney transplantation experiences were sought specifically, and other sources were followed as the data emerged (Glaser, 1978). Issues of self-image, sexuality, and socialization were some examples that were followed during the interviews.

A pilot interview was conducted first with an adolescent who met the study criteria. This pilot was used to check the appropriateness of the interviewer's approach and to eliminate questions that may have been biased from the investigator's point of view. This interview was critiqued by the thesis supervisor for possible changes to the interviewing process. This interview was included in the data set for analysis.

The interview process consisted of an introduction to the study, signing of the consent form, the actual interview or interviews, clarification of the written transcript, and termination of the relationship. Measures to ensure a good interview included the development of a good rapport, trust, and freedom of expression in a non-judgmental relationship. The first questions related to demographic characteristics; these were followed by increasingly more personal questions. The first questions were used to make the informants feel more at ease. The questions became more complex as the interview progressed and as trust and comfort developed. Any points that needed clarification were followed up with a second and a third interview (Glaser, 1978).

Field notes were documented within 24 hours of the interview. These notes described the situational context, the nonverbal behavior of the informant, various impressions that the investigator had after the interview, and additional question and/or suggestions for subsequent interviews. Memos were written describing the emerging themes and patterns and were initially developed on the actual transcripts. These were analyzed and expanded with each additional informant interview. They later became more formalized on separate pages and served as the basis for questions in the second and third interviews. These two types of notes helped to display personal impressions that were present. Initial findings were clarified and validated in this way.

Data collection was complete after no new categories or properties of categories became evident in the coding and analyzing of data. This is called theoretical saturation (Glaser, 1978). A total of eight primary informants and two secondary informants and fifteen interviews were needed to reach this point (Table 1).

Data Analysis Methods

Interviews were transcribed by an assistant and the tapes were checked for accuracy against the written transcripts by the investigator. Constant comparative analysis began after the first interview was transcribed. This is a method of deductive analysis using inductive data collection methods. The investigator was the primary coder for all of the data collected. The data generated the labels used. This is called open coding. This coding involved line by line sorting. Commonalities in themes were grouped. Field notes describing the contextual surroundings (anything influencing the analysis), and memos outlining any ideas or categories thought of during the interview or while coding were written down for later analysis. Both processes were carried out simultaneously.

Selective coding was used to compare concepts to new data emerging from subsequent interviews. Concepts were selected by how well they fit within the various relationships. This was coding at a more abstract level. This linkage of concepts at different levels to each other is called theoretical coding. Because of its abstract nature, the use of diagrams and models were used to illustrate more clearly the relationships between the various concepts (see Chapter 4) (Chenitz & Swanson, 1986; Glaser, 1978; Strauss & Corbin, 1990). One or two categories accounted for most of the variation in the analysis. Word descriptions from the informants were utilized as the codes themselves. These are called *in vivo codes*. They provided the study with terminology identified by the informants themselves.

Current literature was incorporated, as the analysis developed, to see how this knowledge "fit" with the emerging theory (see Chapter 5). Content experts including one renal transplant nurse clinician, one nurse investigator having completed similar research work with adolescents following kidney transplantation, and one pediatric nephrologist, were also asked to review the results of data analysis for fit with their particular professional experiences. This was an ongoing process even as the writing of the project neared completion so that the grounded theory explained, as well as supported, the existing literature and reality for these informants (Stern, 1980).

Reliability and Validity

Reliability and validity issues were addressed using the framework outlined by Lincoln and Guba (1986). The criteria of trustworthiness was used within a qualitative framework to address issues of rigor. These concepts parallel some of the concepts from empirical research, although additional aspects are involved because of the contextual nature of this methodology. The parallel concepts include credibility (for internal validity), transferability (for external validity), dependability (for reliability), and confirmability (for objectivity). Additionally, issues of authenticity (including fairness, ontological, educative, catalytic, and tactical authenticity) must also be addressed. Thus, true equivalency is not possible between the two perspectives.

Internal validity is called credibility (Lincoln & Guba, 1986). Issues of credibility in this study were handled by: (1) obtaining an appropriate sample using theoretical sampling, for example, interviewing adolescents who were currently experiencing kidney transplantation, (2) performing a pilot interview to check the investigator's interviewing abilities and to ensure the interview developed and was reflective of the study question, (3) having the investigator conduct all of the interviews to ensure consistency of approach, (4) having the investigator check all audiotaped recordings for accuracy against the written transcripts, (5) undertaking more interviews with some informants as new data emerged to see how this all went together within the experience, (6) actively searching for negative cases (those cases that were not explained by the tentative theory), (7) conducting interviews with individuals beyond adolescence to validate the experiences as these experiences have been seen in their entirety, and (8) discussing the findings with peers, colleagues, and the thesis committee, to test the working theory as it emerged.

Transferablity or external validity is addressed as the best approximation of the truth. During data collection, a variety of data sources, along with detailed field notes, were used to understand the specific contextual or historical factors that had an effect on the results. Also informant-investigator effects were noted in the field notes for later analysis. Differences in informants were noted on a demographic sheet or a "face sheet" (Appendix B) (Chenitz & Swanson, 1986; Glaser, 1978). Data collection was halted once no new properties of categories or categories, themselves, were obtained. This ensured a rich, descriptive account of the experience (Lincoln & Guba, 1986).

Reliability or representativeness is called dependability (Lincoln & Guba, 1986). Reliability was determined by the "adequacy of the data" (Morse & Johnson, 1991, p.9). It was important to be able to trace the path taken to determine the process that the investigator went through. The final written research report provided evidence of the data and the findings provided the end product derived from the interviews. Data saturation was extremely important here so that the path taken by the investigator could be followed by others.

Since the investigator alone coded and analyzed the data, there was not a problem with inter-coder agreement. A random selection of 10 pages was recoded by the investigator to assure consistency. There was 96% agreement on categorization of the units of analyses. The units of analyses were the common words derived from open coding in a line by line examination of the transcripts.

Field notes and memos were used to delineate the investigator's thoughts and helped to acknowledge the possible influence of bias that is evident in most, if not all, research attempts. The search for a BSP led to the development of a tentative theory found to "interpret, understand, and predict phenomena" within this study which now can be tested by other researchers in comparable settings and with other related problems (Chenitz & Swanson, 1986, p.13).

Authenticity of qualitative research involves treating the context, value-driven reality of the informants in an equitable manner. It also means trying to understand the informant's reality and to understand the construction of their world from this same view. Yet, it is not enough to understand another's reality. There is a requirement to act on the findings, for example, to put into practice the derived theory. Therefore, it is also necessary to make this a mutual process between the investigator and the informants. The telling of the informants' stories and constant inclusion of these informants in the development of the emerging theory were essential components of this research study (Lincoln & Guba, 1986).

Ethical Considerations

Ethical approval was obtained from the Faculty of Nursing Ethics Review Committee prior to initiation of the study. Institutional approval was also obtained from the large metropolitan hospital in western Canada where the pediatric nephrology outpatient clinic and kidney transplant clinic are situated.

Access to Informants. Informants were approached initially by the pediatric nephrology secretary or a renal transplant nurse clinician who initiated the request with the adolescent and least one of his or her parents. They asked for permission to have the investigator explain the study. An information sheet was distributed at this time (Appendix C). The investigator was then given the telephone number to contact the adolescent directly. Written informed consent was obtained from both the adolescent and one parent following an explanation of the study (Appendix D). Subsequently, secondary informants, additional informants who have experienced kidney transplantation in adolescence but are now beyond adolescence (as defined in this study), were approached by a renal transplant nurse clinician. The renal transplant nurse clinician initiated the request with the possible informant and asked for permission to have the investigator explain the study. The investigator was given the telephone number to contact the person directly if permission was granted. The same procedure for consent was followed with these individuals except parental consent was not needed for informants over the age of 18 years. Participation was voluntary at all times and informants were aware that they could withdraw from the study at anytime without penalty.

Confidentiality. Confidentiality of all personal information, including any written materials, audio-recorded tapes, and transcripts was guaranteed. All names and identifying information were erased. Informed consent forms were stored separately from the audiotapes, written material, and the transcripts. All material was kept in locked cupboards when not in use. Audiotapes, written material, and transcripts will be kept for seven years (University of Alberta Research Guidelines, 1992). Data collected during the study including stories, quotes, and ideas were free of identifying characteristics, and an attempt was made to maintain as much informant anonymity as possible. Informants were aware that the material may be used in teaching, in writing for publication, and possibly in secondary analysis, but that no names would be used. If secondary analysis seems appropriate, ethical approval would be sought for any new proposal (Brink & Wood, 1989).

Risks and Benefits. There was no monetary gain or other benefit to the informants in this study. However, this study provided an opportunity for the informant to help others understand the experience that was being addressed. The study involved a commitment of one to three interviews of approximately 1 - 1 1/2 hours each in length. The interviews were conducted in the informant's home and at other locations mutually agreed upon by the informant and interviewer to ensure a natural, comfortable environment free from interruption. All information was kept confidential and it was left up to the informant to decide whether or not to discuss the interviews with significant others including their parents.

The interview may have released unexpected emotions and/or have revealed confidences. In the event of moderate to severe distress, the adolescent would be referred to an appropriate person, such as the nephrology social worker or a psychologist by the investigator. Additionally, if it seemed that certain thoughts or behaviors might jeopardize the individual's health status, this information would have been passed on to the appropriate person by the investigator following a discussion of the matter with the adolescent. One informant requested to speak with a psychologist because of the difficulty this individual was having in dealing with socializing and with body image. No other concerns materialized, although the possibility did exist for more of these matters to take place.

Study results will be made available to the informants.

The informants were asked to fill out the lower portion of the consent form if they wished to be given a copy of the report. The investigator will forward results upon completion and acceptance of the research study by the committee members.

Chapter 4

FINDINGS

The findings from the interviews and the personal diaries of the sample of adolescent kidney transplant recipients are presented in this chapter. The data from the above sources revealed a process that these adolescents seem to undergo over time following kidney transplantation. The underlying core category appeared as Minimizing the Impact of Change following Kidney Transplantation. The adolescents went through phases of Noticing the Changes, Concern over the Changes, Adjusting to the Changes, Integrating the Changes, and Moving Ahead to the Future. Changes in appearance, appetite, activity and energy levels, health status, medication and treatment regimens, relationships, and self-image were descriptive categories identified in each of the phases (Table 2).

Overview

All of the informants talked about <u>noticing changes</u> to their appearance, their appetite, their activity and energy level, their overall health status, the medication and treatment regimen, how they related to other people, and how they saw themselves following the transplantation. <u>Concern over the changes</u> in some of the above areas gradually became the informants' focus, while other changes were not viewed with concern and as such did not present difficulties. Frequently physical changes were first noticed as a result of looking in the mirror. What the adolescents saw in the mirror and what they expected to see did not match. Other changes did not seem to have as large an impact as the physical changes did at this point. Adjustments to the noticed changes involved a number of different strategies, including cognitive, behavioral, and a combinations of both. The outward, noticeable changes were dealt with because of their immediate consequences. For example, other people could see these changes, thus, strategies were quickly implemented to deal with them. Internal, less noticeable changes had a dramatic effect on how easily the adolescents were able to integrate the experience of kidney transplantation into their life. Yet, these changes were not as easily dealt with. If strategies were not effective and the outcome did not meet the informants' expectations, then new strategies had to be tried until they produced the desired effect. Adjustments had to be made before the adolescents could integrate the changes from the experience of having a kidney transplant into their lives and before they could move on to thoughts and plans for the future.

Core Variable: Minimizing the Impact of Change following Kidney Transplantation

The core category, minimizing the impact of kidney transplant change, was closely linked to the categories of taking on responsibility and creating normalcy (wanting to be normal). Taking on responsibility was the process of moving towards becoming an adult. It included the efforts made by the adolescent to become involved in decisions and care impacting on their health and well-being. Creating normalcy was defined as the efforts made by the adolescent to be like other adolescents who do not have a chronic illness. It was a process which provided opportunities to move on with aspects of their life not tied to the transplant experience. One informant described it like this:

> *...Like if you're different from somebody else, you don't want to them let know because then they might look at you differently and think well, you can't do this and you can't do that so I'm not going to be friends with you. Or just little things like, other people might think that well, you can't do this because this happened...or they're like oh wow, like you know, and they're are-they're in awe that you had one [kidney transplant]. And... you feel like it's not a big deal. Like yeh, I had a kidney transplant...Different and I'm not different. I'm the same as you. A couple of scars on my body. That's the only difference (S6).*

These two categories, while being processes in their own right, were important parts of the adolescents' attempts to minimize the impact of changes resulting from the kidney transplant. As one informant noted: "I think that you want to be normal so-so bad and everything, but then you can only be normal because you just get...the added responsibility and stuff like that. You just slowly begin that process 'cause you know, you get older, you take on more responsibility" (S6).

The phases of the basic social process (BSP) and the categories involved in each phase are shown in Table 2. A description of the dynamic nature of the process of Minimizing the Impact of Change following Kidney Transplantation is outlined in Figure 1.

The process of Minimizing the Impact of Kidney Transplant-Related Changes is described over the next few pages. Examples from the eight informants' interviews are used throughout to highlight how the data were used to define the process as described. At the end of each quote a code number is given, designating an informant. Informants (S) with code numbers one, two, six, seven, and eight were female. Informants (S) numbered three, four and five were male. Secondary informant nine was female and ten was male.

The time immediately before and after the kidney transplant operation was not without its own set of events, but these were not the focus of this study. Constant comparisons given by the adolescents during the interviews provided valuable data about this time period that were not included in this study. However, it became evident quite quickly that there were some similarities in the experiences for these adolescents from the time following discharge after the transplant operation to the point in time of the interviews with the investigator.

The basic social psychological problem for these adolescents was the fear and uncertainty of trying to live a normal life with a chronic illness treatment, in this case, transplantation for end-stage kidney disease. The kidney transplant operation itself was both the trigger and the change.

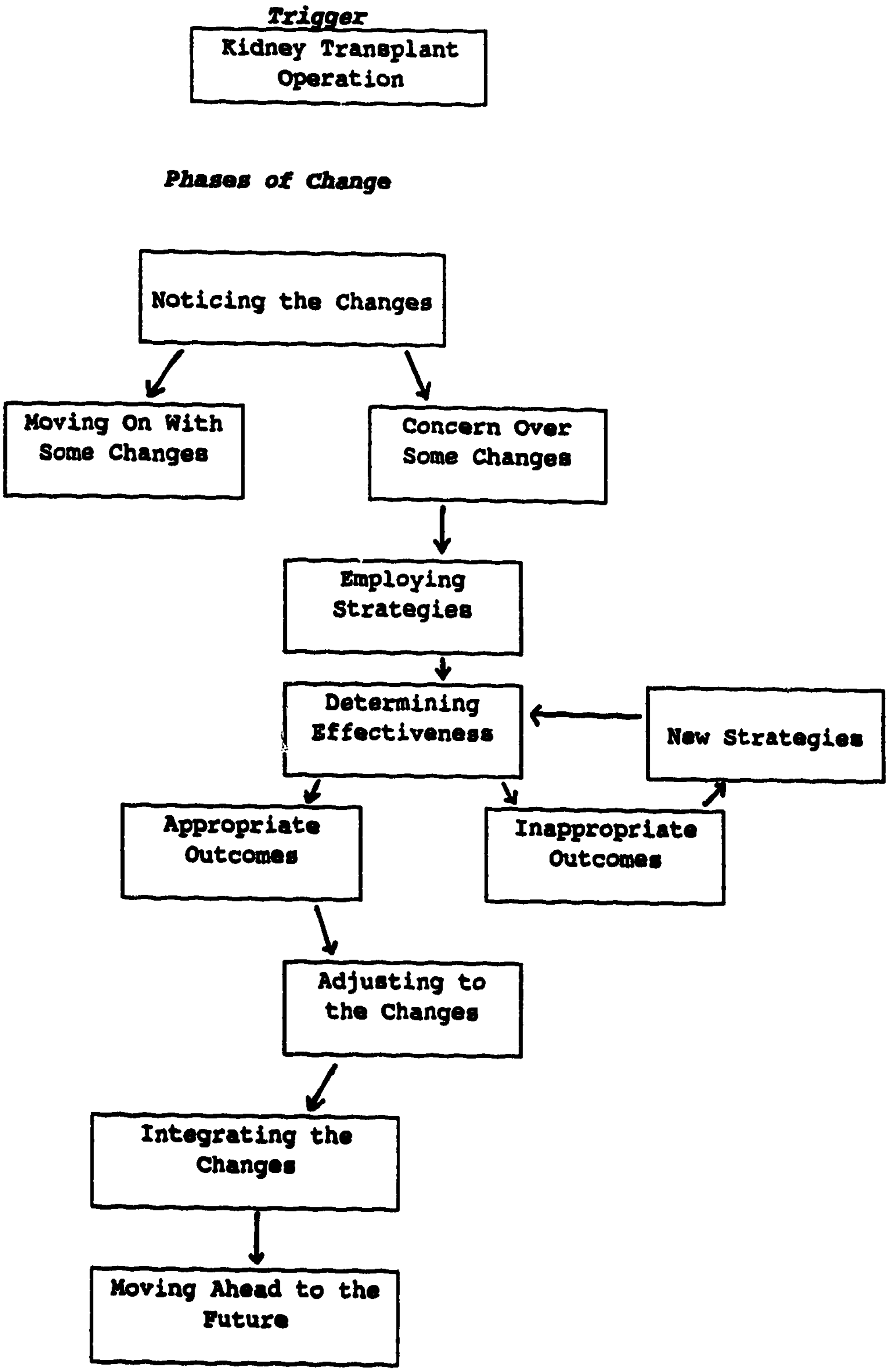
Table 2. *Phases of the Basic Social Process*

Phases of Change **(Row 1);** ***Category Descriptors*** **(Column 1)**

	Noticing the Changes	Concern over the Changes	Adjusting to the Changes	Integrating the Changes	Moving Ahead to the Future
Appearance	Facial puffiness, weight gain, hair growth	Unhappy, see self as fat, ugly, different	-BA-Diet, activity -CA-Denial, rationalize	Some able to become comfortable with the changes	Concern not related to transplant
Appetite	Increased appetite with cortico-steroids	Enjoying food, appetite unchanged	Appetite unchanged, eat less if gaining weight	Eating right foods in right amounts	Moderation of all foods
Activity & Energy Level	Increase in all activities and more energy to do them	No concerns here, continuing to be active	-BA-Avoids contact sports, -CA-Takes risks, less vulnerable	Minimizes activities depending upon energy levels	Activities a part of lifestyle
Health Status	Feels healthy, taking care of health	No concerns here, believe are not sick	Taking health for granted, normal	Consciously takes better care of health	Thinking of health in all aspects of life
Medicine & Treatment Regimens	Fewer medicines, fewer life interruptions	No concerns here, close supervision	-BA-Some develop routines, some make changes to their regimens	Some take it in stride, thoughts about rejection	Incorporate regimens into their lifestyle; problems discussed
Relation ships	Closer family & friends, interacts more with others,	Important not to be different, some over protection by family	-BA-Avoid others, or purposely seek out and deal with people	Good relation-ships with family and friends	Feels normal, takes on responsibility for self/others
Self-Image	Positive feelings, excitement, pleasure, and confidence	Does not like mirror image, low confidence,hard to socialize	Deals more easily with self if has close family and friends	For some a smooth transition,	Confident, career and family issues key, realistic outlook

Typical category descriptions **(Boxes)**
(BA=behavioral adjustment; CA= cognitive adjustment)

Figure 1. *The Process of Minimizing the Impact of Change following Kidney Transplantation*



Phase One: Noticing the Changes

This phase was where the consequences of the transplantation began to appear. Changes were noticed soon after the transplant operation and continued for some weeks after hospital discharge. They were external and internal changes affecting nearly every aspect of the adolescents' lives. Great emotional upheaval was felt by these informants and there was a period of absorbing all, taking in everything - seeing the transplant in all its reality. The emotions swung from regret to relief to excitement and joy.

Following the kidney transplant operation, most informants described intensely positive feelings of excitement and relief. Two informants had negative feelings early on in the post-transplant period. One informant described a feeling of regret immediately post-operatively perhaps due to the fact that the kidney did not function properly at the start and that there was a high level of pain following the surgery.

> *Well, like I said, the first day, the first three days really hurt a lot, for me...like I was in quite a bit of pain so I kept saying to my mother that I shouldn't have had this done. I would rather be in school right now and that I, this was the wrong thing to do...(S5).*

Once the kidney started to function and the pain decreased, the feelings of regret this informant had, were replaced by the same positive feelings of excitement and relief that the other informants had experienced:

> *Pretty much normal to what anyone else would be like if they*

> *weren't sick. Other than that, I mean I have to take a pill or two, but it doesn't bother me at all. Yeah, I'd say it's pretty much normal (S5).*

Another informant experienced acute depression when her kidney did not function immediately post-operatively. The expectations of eating and drinking as much as she wanted did not materialize. She was very disenchanted by these events: "...I was really grouchy 'cause...I didn't really have any appetite and I couldn't drink very much and I was not in a great mood...Um..it..felt like I couldn't do anything and [I was] just going through a total state of depression. It was..(sighs)..not very good" (S8). Three days later, the kidney started to function and this changed everything: "I didn't think any longer that maybe it was better the way it was before the transplant" (S8).

Most of the informants did not regret the transplant. One informant said: "Yeah, ... actually I never went through that stage [regret]...I went straight to this stage - the recovery, the relief, you know, excitement over and on. I can do more stuff like everybody else" (S6). Another informant compared her life from before the transplant to after:

> *No, I didn't regret it cause my family said if you'd regret it, it would be bad to regret because it's better than being on dialysis where I could hardly do anything, like nothing at all. Not go swimming, not do this, not do that without getting hurt. I was skinny so it was hard to dress me. And so I find it kind of better now cause I can do a lot of things, more things with*

> *my friends. I can dress easier. And I'm more active. I'm not as tired all the time. Not always wanting to sleep. I don't miss as much school with my, you know, doing dialysis in the morning. Being late for school and then coming in at 4 o'clock to do it so I couldn't do things with my friends for like hours and hours. Or going outside and enjoying things, you know. It was hard (S2).*

Changes in appearance, appetite, activity and energy level, health status, medication and treatment regimens, relationships, and self-image were also noticed by all the informants interviewed. In the following section each of these categories is more fully explored.

Appearance

Adolescents began to notice changes in the post-operative period. These included changes in appearance as a result of the side effects of the medications to prevent rejection of the transplanted organ. Facial puffiness, edema, weight gain, and increased hair growth were some of the first side-effects. These informants were on very high doses of corticosteriods in the early transplant period. This is a standard practice, necessary to avoid any acute rejection episodes. Other side-effects soon began to follow. For one informant gingival hyperplasia developed. There, however, was a gradual reduction in the dosages of corticosteroids over the next few months for all informants and with this medication decrease came a period where growth in height occurred. This growth spurt was a period of extreme hopefulness for these informants, that they would begin to develop normally. For one informant the initial changes were, for the most part, good:

> *I gained quite a bit of weight after that and I just, I don't know. I felt better. I felt healthier and more energetic and...it uh..probably from my prednisone that makes my cheeks kind of puffy...(S8).*

Changes in appearance were noticed almost immediately. In a matter of days, informants realized that changes were occurring:

> *Actually the side effects are pretty...I would say that you don't notice them after the first few months, you notice them right away. I noticed mine right away...the cyclosporin made me have high blood pressure, the prednisone-the puffiness. I had a lot more hair growth than I did before and just stuff like that. I noticed the side effects right away (S6).*

Initial comments by family and friends also served to remind and reinforce the realization that changes were indeed occurring. Other peoples' reactions were critical to how the informants saw these noticed changes. Friends and relatives were continually amazed at the changes in the informants appearance and abilities to live a more normal life:

> *Everyone was so used to me skinny that when they saw me, you know, a bit bigger or puffier or whatever, that it just amazed them. Like even my relatives; I don't think they..oh yeah, one cousin and uncle and aunt-they've seen me after and they find it, you know, pretty amazing how I've changed inside and stuff. Plus I grew a couple more inches after. I was never growing*

> *when I was skinny. I'm not growing right now. Like with the Prednisone, it's making me grow slowly...(S2).*

Another informant stated: "I guess some of them that knew me before and after. But not, they just think I look more healthier and always doing stuff with them" (S3).

Therefore, soon after the transplant operation, the adolescents noticed changes to how they looked and were pleased by these changes. There was a dramatic change for these informants from being thin, gaunt, pale, jaundiced, and sickly looking to being rosy cheeked, rounded out, and healthy looking with a pink complexion. Changes in appearance were seen in a positive light.

Appetite

There was also a substantial increase in appetite for all informants. This was a sudden, yet wonderful change for these informants. For many months and, even many years, the appetite of the majority of informants had been small, almost nonexistent. Additionally, the informants were often on quite restricted diets in the pre-transplant period. Restrictions on the amount of fluids informants were able to have were most frequently talked about. For one informant, pretransplant restrictions included fluid restrictions, salt restrictions, and protein restrictions. In addition, high calorie additives were a standard part of her diet. This was how another informant described the restrictions while on dialysis: "I was always in the hospital. I was always getting puffy like every time; I couldn't drink hardly anything... and really restricted

...like from eating; I couldn't have chips, no salts, nothing. And..just not luxury at all" (S3).

After the kidney transplant, all of the informants expressed how great it was to be able to enjoy food again:

> *Yeah, I was glad I could eat again cause I-I didn't like just eating, you know, watching everybody eat and then me eating and saying I'm not hungry (S2).*

> *Yeah. Actually, I felt more like eating than...before [the transplant]. It's like, before, it was just like water, milk, juice and then that would be my particular breakfast...My body just started accepting food. I don't know how it, how that happened (S4).*

Therefore, this added to the pleasure of the changes noticed by these informants in this phase. Being able to eat foods that, for a long time, had not been allowed or of interest really brightened up the informants' lives

Activity/Energy Level

The adolescents were also able to be involved in more sports and they felt that they had more energy to do more activities. In fact, increased energy levels were taken full advantage of by these informants:

> *Over the last little while like since my kidney transplant...Oh gee! It's been in a word, great! (laughs)...I've always had a passion for swimming and water. I go swimming all the time...And um..I don't know. I'm just; last year was the first*

> *time I was in baseball...I'm just getting into more sports...And all of a sudden, I would have the energy to play these things and so I would try them and I would like them because I've never been able to do them before. And you know, it was just; I've been just more energetic. I can do stuff. Generally just do more stuff as in sports and like, I have more energy. Like even just walking. Like even just walking around town and walking to school (S6).*

> *Well, um, since I've been off dialysis I've had more freedom and I can- I have more energy so I can do what I want instead of just staying at home and sleeping, or something to that effect, just lounging around (S5).*

The early post-transplant period was an exciting time for many of the informants because they could get involved in more physical activities and had the energy do to so. The informants were able to participate in events that previously were not possible:

> *Ah, I can do things without, ah I don't know, just free and that. I can do things like, kind of, that we take for granted sometimes cause you're not on dialysis anymore and you kind of take for granted. You can go in the tub and you can go in the swimming pool. You can eat whatever you want without thinking (S7).*

Certain activities, however, were avoided that could cause injury directly to the kidney. Hockey, football, and other body contact sports were avoided. This was taken in stride and did not seem to be too much of a hardship compared to what the informants' lives had been like before the transplant.

Health Status

After the kidney transplant, many of the informants mentioned that they were taking better care of their health than they had in the past. One informant who had received a living-related kidney said: "...I told myself I'd take care a lot better" (S1). It was a chance to start over again with a healthy kidney. This was a period of hopefulness that everything would work out.

This was also a time where other aspects of health were almost taken for granted. The sick role was discarded by the informants, although thoughts of rejection were never too far away. Most informants, however, believed that rejection was not something that could happen to them.

Medications/Treatment Regimens

There were changes in medications and treatment regimens. One informant talked of the tremendous saving in time because she no longer had to undergo dialysis. For another informant, travel to the regional health center was much reduced and she would be able to stay at home for much longer periods of time. There were fewer medications that had to be taken after the kidney transplant compared to the period while on dialysis. In fact, the number of medications was reduced many times by half. This was mentioned by most of the informants. A good illustration of this was given by one informant:

Actually, there's less drugs, I'd say, on a kidney. Cause I'm

> *right now...I'm taking Adalat, Lasix, if I need it, and my Prednisone, my Imuran and Cyclosporin, Septra and Vitamin C. But it was like only seven types of drugs (S7).*

The medication regimens were interrupted only if an informant had a bout of rejection. This did occasionally occur. However, these times were short lived. The medications and treatment protocols were reduced compared to those in the pre-transplant period.

Relationships

Relationships with friends and family began to show subtle signs of changing in the immediate posttransplantation period after discharge from hospital. For example, the informants were included more in household chores. Siblings, as well as others, would fight more readily and interact more with the informants than before the transplant. Informants were seen as too fragile and sickly before the transplant by their siblings. However, after the transplant siblings recognized that informants had a lot more physical tolerance. In fact, some informants took advantage of this and tested their new found strength and endurance on their siblings and friends:

> *He [brother] never, ever picked on me [before the transplant] because I was so weak and fragile. Oh, did I ever love it,... like, as soon as after my transplant I got strong. I remember a time me and my friend [were] standing on top of her stairs, throwing shoes at my [brother] and her brother...(S6).*

One informant noted this difference since the transplant: "They figure they could beat up on me a little bit more" (S4). This informant also described other changes:

> *...I think of all the classes I missed and all the things I couldn't do [before the transplant]. But then after the transplant, they sort of started making chores and all that other kind of stuff that I missed out before (S4).*

On reflection, one informant talked about the changes in what the family did together after the kidney transplantation:

> *I think that my family planned more activities for like, the actual family, the four of us together. I think before, they kind of [thought she] can't do this and she doesn't have the energy to do that and so you know, we can do a lot of things like fishing. My dad loves fishing and I love fishing and stuff like. I think we do a lot more things with my family (S6).*

This informant also spoke about the new friends she made following the transplant:

> *I did get new friends because like, before I was in with the, how do you put it, nerds-type (laughs). Like, you know, you'd always see the more popular ones or the outgoing or sporty type ones, so I wasn't one of them so..My groups of friends changed because I was in with like, the quiet ones and sort of, who only did, who were totally into school work and you know, didn't have much of a social life. I always looked at those other, you know, more outgoing people and say, I want to be like that. And after my transplant, I kind a made more friends and you know, I got into that group and had a group of friends where you know, you'd go out and play this and do this, and baseball and just*

all types of things (S6).

There were few comments made by the informants of a negative nature. Generally, the informants were closer to their family and friends. Support was given in a variety of ways to these informants. Communities helped financially, friends and schoolmates sent letters of encouragement, and family and close friends visited and made themselves available to the informants.

Self-Image

Generally, the period immediately following hospital discharge was a very positive time. The changes had begun and there were many good feelings. Informants liked the way they looked and thus, they felt good about themselves. The adolescents described how much better they felt and they found that this was a time to rediscover themselves. One informant commented: "I just remember just after my transplant because I felt so good. I probably didn't want to remember before my transplant" (S6). So while noticing the more visible changes, the informants seemed to dwell very little on their self-image. For example, they were enjoying the pleasures of a voracious appetite, the tremendous selection of food, and the time free because dialysis was no longer required.

Phase Two: Concern over the Changes

This phase describes concerns over some of the changes that were happening in the post-transplant period. This phase typically started a few weeks to a month after hospital discharge. Not all areas as described in the previous section were of concern. The informants' feelings of excitement and pleasure about the kidney transplant changes gave way to concern especially with regards to external changes that could be noticed by other people. Thus, changes in appearance, relationships with others, and self-image were most worrisome here.

Appearance

Concern over changes in appearance gradually became the informant's focus often as a result of looking in the mirror. What the adolescent saw in the mirror or in photographs and what he or she expected to see there did not match:

> *...I ate and ate and ate. And it didn't hit me till about grade nine that I looked in the mirror. Like it took; like at least, I think it was two years. Before that, I didn't even care. I was just so glad that I could eat and I could, that you know, I would taste things. It just; it felt like I was eating things for the first time 'cause before nothing...tasted good. And all of a sudden, everything was-everything was good...[Then I realised] Oh no, I'm fat! (S6)*

This same informant vividly recounted her thoughts about her own appearance and how she wanted to look like her best friend:

> *I would just-I would look at other girls and I would look, oh they're so skinny. They're so skinny! And then I would look at the mirror. Well I wasn't overweight. I wasn't like, you know,*

> *fat or anything. I was just, you know, just a little bit bigger than you know, most. Like it's not like I was really, really fat. Like 127 is not that big. You know, like. And I was just looking at myself in the mirror and I would just see these huge thunder thighs! (Laughs) And I would look at my jeans and they're like a size 30 and a 29. And I'm going God! And then one of my best friends. Actually I think why; it was one of my best friends, she has a size 26 waist. And I would always; I would look at her clothes and they would be so tiny and I would look at mine and they're so big! (Laughs) (S6)*

She also described the reasons for her conclusions, at least in this particular instance, that it was important for her to make efforts to look good: "...because I wanted [sic] to look better than I did. Like I wanted [sic] to have guys notice me when I was walking down the street or in school I wanted to have [that], you know.." (S6). For another informant, it was important for her to strive to look like others:

> *I don't know. Most of all, it's peer pressure. You see all your friends nice and skinny and then you feel like the odd one. Sometimes, you like these nice jeans and they don't have them in your size and then you, you know, you're a little upset. Sometimes it's nice to just feel comfortable and not wear a belt or anything. You just want it to fit nice and perfect. Want to tuck in your shirt without it being tight. And stuff like that. There's a couple times too I've wanted to feel comfortable. And then it's too tight. Have to give them away or something (S2).*

Friends and relatives continued to comment on how wonderful the informant looked and yet the adolescent did not have this view at all. It was aptly told by this informant:

> *...like you-when you get out of the hospital, okay, as soon as you get out of the hospital and you go home and you start having people notice and say "oh you look so good. You look so good!" Well then you look in the mirror and you look at yourself and you go,"Well no I don't because look at these you know, like things." You just; because people are complimenting you, you just; you'll look at yourself more critically because people are you know, saying well you look so good, you look so good. And then I'll look in the mirror and go,"Well no, I'm getting fat. No, you know, I've got all this hair on my face and stuff like that"...Yeah, usually what [illegible] that like-other people will see something totally different than I do cause I see a really ugly person there and you know, physically a really ugly person and most people say,"You look so beautiful!" And no I don't! (Laughs) (S6)*

There were some individuals who would make fun of the changes in the appearance of a couple of the informants:

> *Well, when I was in grade four, five, they like make fun, some kids would make fun of me because my face would be big and that. Like, at the time of my transplant, I never even think of myself like that. I thought it was just, like that picture of me, when I, before I was sick and I never thought, when I looked in the mirror I thought I saw a skinny person. And I, then also, okay*

> *then you take a photograph or something and you realize.. You don't realize in the mirror, until you take a photograph...I kind of gained, I had gained weight cause I, cause when I got my kidney transplant, I wanted to eat lots and lots because there was like, they made me [eat] from August to September because they thought I had an eating disorder ... They thought it was psychological. I wasn't eating food. I just wasn't feeling good. I didn't feel hungry. They made me eat when I didn't feel hungry and I felt a barfing urge and that (S7).*

Concerns over height were also expressed. Many of these adolescents had a continuing problem of poor growth from the pre-transplant period. End-stage renal failure as a result of various types of kidney disease significantly affected the rate of growth for all informants. While this was a problem before the transplant, the concern continued into the post-transplant period. Often there was a growth spurt soon after transplant: "...when I never had the kidney, you know, I didn't-I barely grew at all. And then when I had my kidney transplant, I had a growth spurt right after that. And um..I've grown quite a bit since my kidney transplant but I've started to slow down now" (S8).. This, however, did not return the adolescent to "average" or "near average" height levels. Many of these informants were affected emotionally because of this poor growth:

> *...my shortness is a little concern here. But I don't know, research just has to improve. But,.some day, they'll have something...I've seen on television that they have this stretching. They break the leg joints and stuff like that and*

> *you stretch it. But I don't quite think I want to take that route (S4).*

> *...Like um, sometimes I really want to be taller than I am. A lot of people judge me by how tall I am and that kind of bugs me sometimes (S8).*

Appetite

Concern over appearance had some direct effects on what the adolescent decided to eat. Less fattening foods such as salads and vegetables, and fewer fried foods such as french fries and potato chips were eaten. This was not directly connected to a reduced appetite, although there was a gradual reduction in the amount of corticosteroids that were needed as the period of acute rejection faded. Informants' appetites, for the most part, remained relatively unchanged.

For some of the informants, side-effects of the medications such as high blood pressure were responsible for changes to the diet. Low salt diets and lower protein diets were part of a number of informants' meal plans. The quantity and enjoyment of the various foods was affected to some extent. Medication adjustments were made to try and reduce the side-effects. It was not always possible. Informants noted the changes and were unhappy about them:

> *...when I was skinny, I could eat chips and stuff like that and now I have to kind of watch my salt intake for high blood pressure and for the kidney function which I don't really like that much but I have to, you know, watch out for it cause salt*

> *is a killer (S2).*

Activity/Energy Level

Despite concerns about other changes occurring in the lives of these adolescents, they were still able to become involved in activities and they had high levels of energy. There were few concerns in this early period about lack of energy or ability to do activities. Informants continued to monitor their involvement in body contact sports. Some of the informants began to do more vigorous activities such as long distance bike riding, swimming, and horseback riding. Exercise was enjoyed by most of the informants.

Health Status

Generally, feelings of good health continued. If there were no complications in the immediate post-transplant period, then the concern over appearance seemed to emerge and become the center of attention. As one informant stated: "I'm not sick" (S8). She didn't want to be treated differently from anyone else. One secondary informant described the changes pretransplant to posttransplant like this:

> *I don't feel different anymore. Like I felt different before like being on dialysis and everything. When I was sick, I felt different cause I had to take all these pills and I had to be on a strict diet which I hated. And always often cheated on it. But it didn't help matters but anyways..but afterwards, I felt like you know, I can do anything now. I feel like a normal*

> *person. That's how I felt. Like you know, no restrictions. You know, just take these pills and but that's not a big deal...(S9).*

Some of the above categories such as appetite and activity were focused on by the informants. Staying healthy by eating right and consciously implementing exercise components into their daily routine were common.

Medication/Treatment Regimens

All of the informants followed medical treatments and regimens closely and in consultation with the physician. There was little concern here about these regimens for the adolescents during the first year. Routines were taken in stride. Close monitoring by health care professionals and supervision by parents with medication and treatment routines were [illegible]. These informants had fewer hospitalizations and fewer emergency trips to see the physician following kidney transplantation compared to pretransplantation. For most of the informants, medications and check-up appointments to see the transplant team slowly decreased over time. Life was not interrupted to nearly the same degree as before the transplant.

Relationships

Concern by informants over changes in their appearance affected their relationships with others as well. There was recognition by most of the informants that they did not want to be different from their peers. Thus, the changes following transplantation which could be noticed by others were of great concern to most of the informants. School work became less important for a couple of the informants after their health improved following transplantation. One informant noted: "I hardly do any schoolwork and [I'm] always out working, driving around, having a good time" (S3). It was so important for one of the informants to be like all her friends that her school classes began to suffer:

> *You know, I had been labelled as the type of person who always got good grades, always studied, never cut class, never got in trouble in class. And I just wanted to break out of that mold. I wanted to say, "No, I'm not like that, I'm like you". I wanted to be, I probably wanted to be more normal than what people perceived me to be. And so I got into the habit of skipping and not doing my homework and stuff like that. I think I felt like I fit in more (S6).*

Wanting to be like "others" certainly affected many aspects of these informants' lives.

Two of the informants talked about limits their parents placed on them that they did not feel were necessary. One informant described the reaction of her mother when she asked to ride out to an acreage with a friend. Her mother felt that this was not appropriate and was worried that something might happen to her daughter and the kidney transplant because of the exertion. The daughter however went ahead and rode her bicycle out with her friend to the farm and everything turned out fine. This overprotection by parents was also mentioned by another informant. This informant felt that now finally, after transplantation, he would be able to do things and his parents could worry less about him:

> *Parents don't have to worry about you all the time. Uh..just being able to do what you want to when you want to...medication you can take with you if you decide to go some place. But CAPD, only your parents knew how to do it so they had to be there with you. That's..just more freedom (S4).*

One of the secondary informants discussed the overprotectiveness of his mother, although she was this way with all of her children and thus the kidney transplant did not explain the behavior completely:

> *She just; she's over protective...I don't know if it's because of the transplant. I'm sure that it has a lot to do with it and she donated it. And the whole thing but I see her being overprotective with my brothers and with her granddaughter and so that's the way she is anyway...I have two brothers. One doesn't have a transplant and the other does...I don't know what it's like to be a parent...all those years of having to do whatever they had to do to keep me alive (S10).*

Self-Image

Responses by others to changes in appearance affected how these informants felt about themselves. Many of the informants could not bridge the gap between what others thought of their appearance and what they, themselves, saw. It also became evident that the experiences pre-transplant had major consequences post-transplant on the ability of informants to socialize with others and handle situations that did not always go as expected. There were other intervening variables that seemed to affect self-image and the movement to the next phase of adjusting to all of the changes. If informants were included in decisions, were not blamed for their particular symptoms in the early stages of kidney disease before a true prognosis was determined, and were treated as equals within the family, then these informants fared much better in terms of self-image than those where this was not the case.

Some of the informants had feelings of low confidence, low self-esteem, and some were unable to socialize with others. Internal feelings were extremely difficult to handle effectively, while the external changes in appearance could be dealt with:

> *Well, I've gained about 20 pounds since then and uh, well, cyclosporin increases your hair growth, so I'm a little bit hairier than I was before, but uh.. really, I wouldn't say anything that different,* other *than those two things ... Means I have to shave more, but uh, it's really, I mean, if that's about one of the only side effects, I can live with that. It's nothing major or anything (S5).*

For this same individual socializing and being comfortable around people was quite intimidating:

> *Yeah, because for about five years out of my life [while on dialysis], I mean I've had to stay in my room and do nothing, so I'm quite used to that now, I mean, I don't like to go out anymore than I have to. I don't like to be in public because I'm not comfortable anymore being in front of large groups of*

> *people and stuff. I stay in quite a bit (S5).*

Another informant spoke frequently about lacking confidence:

> *I feel like I'm inconfident [sic] and that I don't..(long pause) Ah..I'm not sure of myself, like I always double check stuff, just to be sure that I'm right. Like, even if with the alarm clock, I'll be sure I put it on right (S7).*

It was impossible for one informant to think about meeting other people until she was able to feel good internally:

> *H-mm..(laughs) I don't know. I can't go out until I feel good about myself. And like, if I feel good about my self, I'll feel good about others and be able to do things. I don't put people down or anything like that, I just..it's hard to explain (S7).*

Friends were able to point out the problem of low self-esteem in another informant. She explained to the investigator:

> *Um, [I'd] probably [change] a little bit about the way I look. And 'cause uh..my friends are always telling me I have really low self esteem and um..[they say] you know, I'm pretty and everything...I guess I don't see what they see (S8).*

This informant's strategy was to let it go and hope eventually things would be better: "Some days, I just don't like the way I am...I just wait and see what happens. The next day, I'll probably feel a little better about myself..." (S8).

Concern over appearance had a distinct impact on how these informants felt about themselves. Three female informants used the word "ugly" to describe themselves. Lack of confidence in some of the informants' abilities to socialize with others was distressing. They were able to verbalize their concern but did not know what to do about it.

Phase Three: Adjusting to the Changes

From this point on there appear to be some differences in the routes taken to reach integration of the transplant into one's lifestyle. Adjusting to the concerns over the transplant changes are dealt with in a variety of ways. The informants implemented cognitive strategies, behavioral strategies, and combinations of both. If one strategy was ineffective, then another strategy or strategies were tried. Many of the descriptive categories are interconnected by way of the strategy chosen.

Appearance

Adjustments to the noticed changes in appearance have included reducing food intake (dieting) and exercising. Informants were able to deal more effectively with some of the changes than with others. They were able to deal with the hair growth and the increased weight:

> *Um..(laughs) When I was, lets see, grade six, I remember I wanted to lose weight so I just exercised. I, I, it was better cause I wouldn't, I'd eat a normal meal and I'd just exercise it. I'd put music on and dance, and make-up dances and that (laugh). Cause I used to take jazz and thought it's neat doing dances ... I can tell, my face is feeling better. In a couple of years, I'll be back to my old self, my real face again (S7).*

Some strategies worked better for some than for others. A number of intervening variables were involved in success or failure of certain strategies:

> *And last year, I was looking at myself in the mirror going " I've got to lose some weight". (Laughs) And now, I just ...I've been eating right more. Like starting-stopping, cutting out junk foods and stuff like that. And I got down-(whispering)-I'm 114 [pounds] right now. I'm so proud of that. Oh, I'm so proud of that because what was she [the nurse] saying? The average weight for a person my height is between 110 and 115 [pounds] (S6).*

For others it was not so easy: "I've tried a lot of things but none of them has really has worked. Like, like a diet or something of salad and stuff like that but I don't know" (S4). Increasing the amount of exercise has helped in some other cases.

Appetite

Adjustments in eating habits had to be made as described above if weight gain became a problem. Appetite seemed unaffected. Generally the informants were taking relatively low doses of corticosteroids after the first year. For some of the adolescents their regimen was, as infrequent as, every second day.

Activity/Energy Level

Activities involved more risk-taking than before. Horse-jumping and more competitive sports were played as the warnings and the danger of rejection were becoming more remote. One informant would not give up her horse-jumping hobby even if it meant damaging her kidney. She did not want this to happen, but was unprepared to change the one thing she enjoyed most in life for the good of the kidney (Quote S8).

Energy levels were somewhat decreased as the informants participated in many activities and got less sleep then ever before. Physically they were well and as such took their bodies further than at any time previous. However, the side-effects of Prednisone were already being felt by a couple of the informants who were unable to be fully active:

> *Well..before [the transplant] I wouldn't really exert myself at all, I mean, I wouldn't walk any further than I had to. I'd usually get people to pick me up and take me places instead of walking to the bus stop or something, but now I prefer still not to walk further because of my knees and ankles, but if I have to I will, just 'cause I have the energy (S5).*

> *Um..I used to like do a lot of; I do a lot of sports like volleyball. I don't like basketball. I play softball and badminton, soccer, and stuff like that. But um..right now, my medication is starting to affect you know, my hips and they get sore sometimes when I run (S8).*

One informant remarked that he rarely went to bed before midnight and found it hard to get up for school at seven o'clock in the morning. Therefore, he was often quite tired in school.

Adjustments were made to incorporate activities that were not very different from adolescents without chronic illness at this point. Efforts were made to fit in with the crowd:

> *And I just...I do a lot of walking and stuff...I'm going swimming tonight. Like just you know active, more; a little bit more. Not too much more exercise because I do get a lot cause I swim and stuff and I'm going to be playing baseball and stuff like that, you know. But just more exercising (S6).*

Health Status

Over the first year, these adolescents were followed very closely by the health care team, for medical reasons. As their health stabilized and the risk of rejection lessened, these informants were followed less frequently. The adolescents generally talked about their feelings of being healthy and that they were back to normal. They saw themselves as no different from other teenagers anymore. One adolescent said: "...I think I; I'm about normal. I figure I'm just an ordinary, normal kid except that I take medications which just doesn't seem right" (S4). Another adolescent compared how she looked before to how she was now: "I looked pale, for one thing and...I got dizzy a lot and I couldn't run around a lot too. Now, um... [I am] pretty much normal" (S1).

One informant had a friend who did a school project on how it felt for this informant to have a kidney transplant. The informant's response was: " And I just; I just said ... `like anybody else' " (S8). This informant also gave her thoughts and advice regarding the treatment of individuals following kidney transplantation: "... I'm the same as everyone else. I feel the same as everyone else. There's no reason why I should be treated different or act different. I say, 'Please don't, you know, be so touchy and I'm a regular person like everybody else' " (S8).

Informants thought very little about physical health matters and thought about possible rejection of the kidney only in rare serious moments. One girl spoke about her method of being positive. She would pat her kidney every night and say "good kidney". This she felt warded away any bad spirits that might be lurking nearby (S7).

Medication/Treatment Regimens

For about half of the adolescents interviewed, the thought of not taking the anti-rejection medications and the prescribed treatments was inconceivable. Some had thoughts about not taking their medications but this was quickly dismissed upon reflection of the possible consequences which included, most importantly, rejection of the kidney. These informants did have worries about the long-term effects of the medications. However, they felt that the risks of not taking the medications outweighed the risks of taking them: "Oh, I uh..I've thought, you know, lots before. Why am I even bothering you know? I'm sure I'd be fine without it but you can't take your chances I guess" (S8). The thought of discontinuing her medications was impossible for another informant: "I can't, I can't think like that, because if I think like that, I think about dialysis..." (S7).

One informant seriously considered approaching the doctor to try and taper the medications because they were so inconvenient:

> *If I could change it I'd like to reduce my medication but..like I could do that myself but then someone's going to get back on it ... Like I said it's kind of time consuming. It seems like that few minutes to take them could be spent sleeping in or something like that or going to bed early ... I can't really see any difference ... 'cause I've taken it for so long that I can't tell that it's changed anything.*
>
> *[What would happen if you stopped taking them?]*
>
> *Well they say that they're-they're afraid of a rejection, and I haven't heard of anybody actually reducing their medication to zero but..so I don't know (S4).*

It was important that he received the lowest possible dosage and number of medications as possible. He was going to ask the physician the next visit.

Another informant asserted that he had no trouble taking the cations as ordered: "Nope. I mean I've been, I've known for seven or eight years that uh, I'd be on medications and stuff like that for the rest of my life so maybe I've more of an advantage of knowing about that but..like I say, taking a pill, if it's going to save your kidney or your life, it doesn't make a big difference at all to me" (S5).

There were three adolescents who had been or currently were reducing their immunosuppressive medications. For all of these individuals, the overriding feeling of good health and the physical side effects of the medications, mainly nausea, seemed to be the key factors for considering stopping or reducing their medications.

Hassles of fitting the medications into their lifestyle were of far less concern and the effect that medications had on their appearance were also surprisingly absent from the rationale these informants gave for decreasing or halting their medication intake. It was also evident that these informants did not think about the consequences of such actions. Rejection, to them, was an extremely remote possibility because they were feeling so well. The fact that the medication reductions also had few or no immediate repercussions reinforced their opinion that medications were not needed. These individuals eventually showed some signs of rejection which may have done some permanent damage to the transplanted kidney. At this point, the reality of rejection became real and all informants were convinced of the need for these medications and resumed taking them.

Control in decision-making and awareness of the consequences of actions seemed to play a large role in whether or not these informants chose to take or not take their medications. Figure 2 describes the possible paths that these informants took regarding medication and treatment decisions.

Compliance with treatments and other medications not related to immunosuppression were likewise dependent upon how critical these regimens were perceived to be by the informants. Blood pressure medications, and dietary restrictions were manipulated as the informants saw fit. Again, decisions were made with little understanding of the consequences of such action.

Thoughts about Consequences

Control over Decisions *(Responsibility and Independence)*		YES	NO
	YES	Takes medications (Easy Integration)	Does not take medications (Feels healthy)
	NO	Takes medications (Remains Questioning)	Does not take medications (Reacts to not having control)

Figure 2: *Medication Decision-making*

Relationships

Concern over the changes in the post-transplant period, related to relationships with others, had a couple of outlets. One strategy was to avoid others. Another strategy was to use denial and pretend that these changes were not actually occurring. Another approach was to begin to deal with these changes. One informant decided to take the initiative and just start socializing more and not worry about what others might think or say.

There was increasing involvement with friends and family usually by confiding and sharing the worries that they were experiencing:

> *...One thing for now, I'm a lot more open with my friends with what's going on with me and what's happened, ...before the*

> *transplant I only told my friends before I left for the transplant, that I was leaving ... for about three months or whenever and uh, now I talk about it more openly. But I mean, I don't think I would get up in front of my class and start talking about it but, in front of close friends I do (S5).*

All of the informants used one or more of these strategies of avoidance, denial, taking the initiative, and confiding and sharing at one time or another. A number of individuals dealt with their outward appearance but did not deal with their inner self. Few had much success with how they were feeling inside about themselves. This posed problems for some of the informants in finally integrating the changes into their life and moving on.

Self-Image

Adjusting to how informants felt about themselves was again easier for some than for others. Certain intervening variables were involved here as well. Having a close friend was important to how informants seemed to see themselves. A supportive family was also helpful. Early childhood experiences were also involved. For one informant, she remembers always being shy and having her family split up by divorce. This she felt did not help her to have a positive view of herself. Thus, pretransplant issues, developmental issues, and those related to the transplant itself seem to be involved in the development of an integrated self.

In this study, the phases of change involve adjusting to the appearance and relationship changes in order to develop a sense of self and move on to the future. The relationship between external appearance and internal feelings about the self that seemed to emerge from this study is shown in Figure 3 as a 2 x 2 table. Adjustments are made to incorporate changes in appearance from time to time. Setbacks are common, although a feedback loop is evident. Success, at times, for the adolescent in incorporating the various changes may be interspersed with more difficult times where nothing seems to go right and the adolescent feels very badly about him or her self. Thus for the adolescent, the development of a sense of self is crucial to moving on to the future.

External Appearance

		Positive	Negative
Internal Feelings About Self	Positive	Open, talkative, socializes easily	Confident, possibly tough, wants to be treated normally
	Negative	Shy, lonely, does not socialize easily	Closed, concealing, depressed, unrevealing with others

Figure 3. *Relationship between Appearance and Feelings About Self*

Thus the first year or two seemed to be the time of most intense change and where most adjustments to these changes occurred. One informant spoke about it this way:

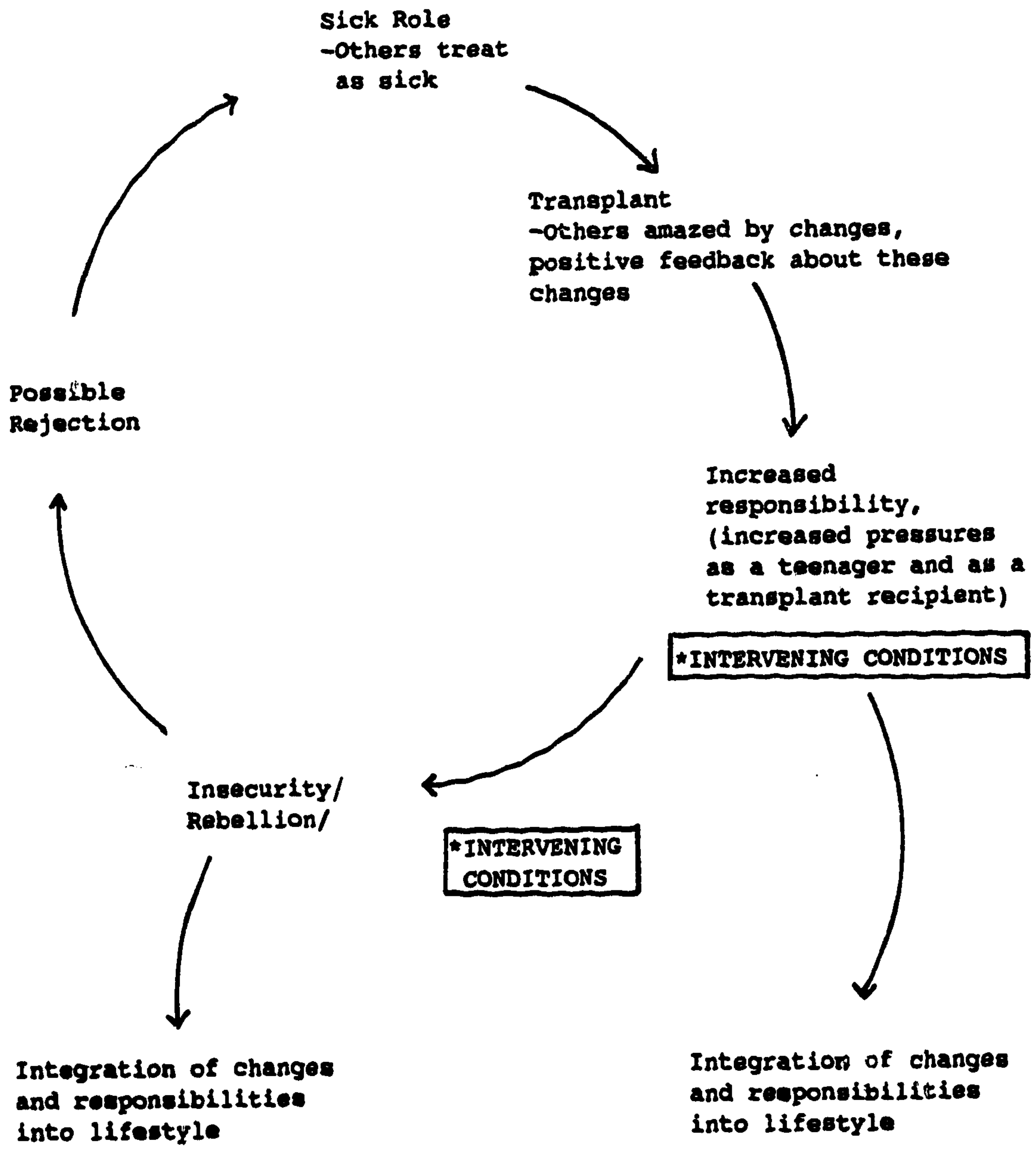
> *It'll start out-everything will be a hassle. Everything will be all worry and you won't know what is really going on at first. But after awhile, everything gets to be routine. And um..you just; you feel better afterwards (S8).*

A secondary informant was unable to remember events that had happened after the first year. This was because all of the problems, concerns, and intrusions into his life were dealt with in the first year. From that time on, adjustments were made and the kidney transplant changes were integrated into his lifestyle.

Phase Four: Integrating the Changes

Adjustments had to be made by these adolescents, in all seven descriptive categories of change, in order to move on and begin to think about the future, about career, about marriage, and about family matters (intimate and otherwise). The informants were at various stages of adjustment to and integration of the changes, yet all seemed to be moving towards integration. The possibility does exist that integration will not occur. Rejection and a return to the sick role is just one possible outcome. This was not found in this study, although it requires further examination. The evolving nature of this process of adjustment and integration of the kidney transplant experience into the adolescents life is depicted in Figure 3.

Figure 3. Evolving nature of the process of adjustment



Appearance

The informants were experiencing some difficulties in integrating the changes in appearance. Informants worried about the after effects of the kidney disease and the long-term side-effects of the medications. For most of informants, small stature was and continues to be problematic. Surgery and other medical alternatives have been considered by some of the informants to make some changes in their appearance. Other informants keep trying to rationalize that they are not responsible for their kidney disease and they deal with the problem in this way. A statement that summarizes very nicely what the majority of the groups' feelings were regarding their short stature is: "Like um, sometimes I really want to be taller than am I. A lot of people judge me by how tall I am and that kind of bugs me sometimes" (S8). Another informant takes her small stature in stride: "I mean, I'm not bothered at my height, other than that, it's hard to reach things, but I would like to be taller, because it's a lot harder trying to drive when you can only see about three centimeters over the wheel..but I'm fine at my height" (S5).

Appetite

Appetite remained unchanged. The informants were not concerned about this area and made the necessary changes early on in the adjustment period. This was a particularly easy change to make.

Activity and Energy Levels

Activities were incorporated easily into the adolescents' lives. Energy levels continued at a high level. Rest and activity were more evenly balanced in this time period. Informants were able to participate in most activities and there were very few restrictions.

Health Status

Continuing to take care of one's health was important and seemed to be included in one's responsibility following transplantation: "Well...my life has changed a lot. I have to think about a lot of things and keep trying to remember to take my medicine and try and get enough rest" (S1). For a number of informants, health was not taken for granted as much as in the first year or two. There was recognition that efforts had to be made to stay healthy. Again, at times devoted to serious thinking, informants discussed how they made pacts with their body to keep healthy, and focused on being positive. One family was very supportive of thinking positive and encouraged the informant whenever she was feeling low:

> *Sometimes, my second sister will give me a little bit of advice. If I'm in the hospital, depressed or something, she's said, "Have a good attitude. Sometimes it gets you out earlier." My dad sometimes says to try; like cause our brain is the most powerful part of our body. And we don't know how it works and only you can make it work. So if you say make the pain away, it might make the pain go away and stuff like that. Some people, when they get sick, it's cause they create that illusion in*

their mind (S2).

Other worries these informants had included thoughts about rejection and again being different from others. These thoughts were mentioned by most of the informants when they were asked about any worries they had regarding the whole kidney transplant experience. One informant answered: "...losing, losing my kidney. Um, what would it be like if I did have to go back on dialysis. Would people be different at school after that? And uh..this, you know, stuff like that" (S8). Another informant discusses her worries: "I've had a couple [of worries] like if I'm going be able to keep it [the kidney]. If I'm going to be able to take care of it. Those type of things. If I'm going to lose it" (S2).

Medication/Treatment Regimens

The period of testing and adjustment was followed by a quiet period. Medications were seen as necessary for continued health. The protocols were followed again. Questions about the medications and treatments were now more openly discussed with the family and health care professional. The adolescent felt more in control of the situation and was responsible for taking the medications. Changes were made in consultation.

Relationships

Informants have developed and improved close friendships. More enjoyment has been derived from family involvement. One of the secondary informants felt that their relationships were now deeper and more meaningful (S10). He had a few close friends with whom he shared his feelings and did a lot of activities. Very little time was spent thinking about the effect the transplant had on relationships. In fact, informants often avoided the informant. Informants felt normal and wanted to be treated like everyone else.

Overall, some adolescents have had a longer period of time playing or adjusting to changes, in order to finally put it all together and feel comfortable. But it seems like everybody finally does fit it in. Some have said that it's no big deal. After awhile, it's almost like people don't even talk about it with others. One of the secondary informants responded in this manner: "I do very rarely talk about it. I-I guess I almost try to avoid talking about it...deep down I don't want to be any different than anyone else" (S10). This same informant also spoke about the growth of his faith in God and in Christ. This relationship has been strengthened by the experience of having a kidney transplant. A favorite quote of this informant was Romans 8:28:

> *It says something to the effect of and we know that in all things, God works for the good for those who love him. Um..basically that through, for me, through suffering and pain, uh..while that first looks-looks bad, uh..God can use that for his glory...So, like my faith is growing...I can't say that it would not have; if this hadn't happened. But this is what happened and..just my relationship with Christ is that much closer (S10).*

Self-Image

Adjustment to one's self-image continued to be problematic for most of the informants. It remains to be seen whether or not in time all informants will be able to integrate the changes they are presently facing , so that the transplantation experience will not have a lingering impact on their future life. Both secondary informants have made the adjustments and would not change anything about the experience. For one secondary informant, the experience can no longer be separated from who he is:

> *(Laughs) Uh..well the whole thing is-is part of who I am. I can't really; I can't dismiss that. Um..and because I've gone through it, I think I can relate to a few more people than what-what the normal Joe Blow can. I guess (S10).*

Phase Five: Moving Ahead/Making Future plans

For some of the informants, then, integration of the transplant into their lifestyle has occurred or has begun to occur. Other issues relating to careers, marriage and family have begun to take precedence over the transplantation experience. One informant's response to the question, what future plans do you have for yourself, was: "(Short pause) Wife, kids, and career (S10).

Appearance

It seemed after the first couple of years that the emphasis in life for these adolescents turned to the future, with few thoughts about the past: "Well, I can't really tell the difference really now. Like all my past has sort of been erased. But if uh..like I have a lot stuff that's been kept up and newspaper clippings and all that. Like you still look back on it and think it over" (S4). A similar comment was made by another informant:

> *I ... remember just after my transplant because I felt so good. I probably didn't want to remember before my transplant. Yeah, I don't know. It was-I was run down and you know, I didn't feel so good and being on CAPD (continuous ambulatory peritoneal dialysis) was just the pits. I did not like it(sic) and I was very restricted in what I could do and I just did not like it at all (S6).*

One secondary informant described the cyclical nature of concerns over appearance. At some points these concerns were of higher priority than at other times. Various strategies were used to deal with the concerns and the crisis passed. It, however, did not carry as much importance as it did in the period of adolescence and more strategies were available because of the added experience over time to deal with these concerns (S9).

Appetite

Informants' appetites continued to remain stable. Changes in eating habits become necessary for other reasons than those of the transplant. Now, concerns over increasing weight revolved around the decrease in metabolic rate as a person gets older, not the side-effects of the immunosuppressive or corticosteroid medications.

Activity/Energy Levels

There was a focus on other activities than have to do with the transplant experience:

> *Well, like I said, if I get my license and I can drive around, that will change it. I'll probably do more and if I want to go somewhere I can, instead of just staying at home, I can just hop in the car and drive away, but uh, that's one way I could see it changing. I guess maybe in a year or two, when I graduate I want to go to university or to college so, then I'll totally be on my own, so it'll be a whole new experience (S5).*
>
> *I do less now (laughs)..I don't know. I'm just starting to realize that there's more to life than school, cause I'm just going, I'm going to remember some of it (S7).*

Plans for careers were discussed. Informants were applying to college, applying for jobs, and placing transplant worries and concerns behind them.

Health Status

Caring for health became high priorities. Rejection was still considered a possibility, but thoughts were focused on how to prevent this from occurring. Some of the informants did not like to discuss the topic because they believed positive thinking was necessary at all times in their efforts to take care of the kidney transplant. Informants believed that they took more notice of their health. They felt they had made conscious decisions to care for their health, while other adolescents without a chronic illness and/or treatment really did not appreciate their health and took it too much for granted. Thus the issue of caring for health has come full circle. Early on in the process caring for health was recognized, then it was taken more for granted, finally caring for health was again a conscious aspect of these adolescents' lives. One of the secondary informants described it like this:

> *I've always-I've always caught myself taking my health for granted. I don't think that's very healthy. So when I catch myself taking or doing for granted uh..I just try to check that (S10).*

Medication/Treatment Regimens

In this phase medications were taken as prescribed. However, there appeared to be times in the lives of the informants where the acceptability of certain side-effects or intrusions by these regimens into their lives became too much. Discussions with the health care professionals did or did not occur. For one secondary informant, he was currently considering not taking a medication whereas he had never considered this possibility before. Thus, changes in thinking occurred throughout the time following transplantation with medications.

Relationships

An increased sense of responsibility to others and feelings of being normal, just like everyone else, were pervasive thoughts described in this final stage. One informant stated: "Just, you know, the only thing that's there to remind me of it is scars and..everything else is just .. normal I guess" (S8). Another informant also stressed the normal part:

> *Pretty much normal to what anyone else would be like if they weren't sick. Other than that, I mean I have to take a pill or two, but it doesn't bother me at all. Yeah, I'd say it's pretty much normal. Other than that, I'm not physically active...(S5).*

One informant was currently discussing more permanent relationship arrangements. Sexuality issues were raised along with issues of having children. These were important issues for her at this time. She was moving ahead and planning for the future. The secondary informants were also dealing with these issues of intimate partnerships and deciding whether or not to have children. One informant had these thoughts about the future:

> *Um, how long is it going to last, right? Cause I think about it; my Dad-my Dad is going to be 61 next month. That means my kidney is 61 right, you know? (Laughs) That's what; I think about that right? And that kind of scares me so I try not to think about it too much right? Cause-they say it's a healthy kidney so..so and uh..in terms of like you know, future, like if I want to have children or anything, like you know, that scares me too cause my blood pressure will probably go up for sure, right? And you don't know. Dr. --- says, oh lots of women have had babies too. He says they have babies on peritoneal dialysis...So..(S9)*

These issues were still discussed within the context of informants having a kidney transplant.

Self-Image

For most of the informants when asked if having a kidney transplant had any effect on them as a teenager, a few informants felt it had only a small effect. One informant explained: "Just, I think, just more responsible I think cause you grew up faster having a transplant and always taking medications and stuff like that. I don't know" (S3). For one secondary informant, the physiological changes brought increased awareness of the changes to the to the teenager. In fact, a realistic outlook took over. This outlook was summarized very nicely:

> *I would...have to say that if the transplant is going to work, that person would have to grow up faster. Simply...you'd have to have an increased awareness of what's going on with you, with your body, and the responsibility of taking the meds. And realizing that if you don't take your meds, there are consequences. Some very big consequences. And normally, a normal teenager doesn't have to face that at that point in their lives (S10).*

For the secondary informants beyond adolescence, their struggles over changes in appearance and self-image were replaced by other issues related to family and career. These issues caused much heartache for one of the informants in the teen years:

> *And then I got home and looked in the mirror..and pictures were*

> *taken and I just noticed on a-on a picture, I was lying on a couch and I couldn't believe it was me. So that was..like I was; I'd gained like a lot of weight and I looked like Dumbo. You know, that wasn't..I don't know. That was hard...There was a big weight gain. I had a lot of trouble with acne. Apparently that's a side effect of Prednisone. So that was a tough first year afterwards till my medications came down. And I-I guess, the doctor thought for awhile that I was...anorexic cause I was losing weight...I was really watching what I was eating. I'd be eating salads and apples and stuff...Because it was such a change from what...I looked like...a month ago that I wanted to look like me... But I looked at myself in pictures and the mirror and that's not what I saw. I saw this fat guy (S10).*

Now this informant has a steady job, his own apartment, and is looking forward to marrying and having children.

In conclusion, the phases these informants used to minimize the impact of change following kidney transplantation included noticing the changes, concern over the changes, adjusting to the changes, integrating these changes into their lifestyle, and finally, starting to move ahead with other plans and dreams. Generally, the informants have taken the transplant experience in stride. A final quote by one of the informants eloquently describes the experience of life following kidney transplantation for her:

It's hard work. It's a lot of responsibility. It's almost like taking care of a puppy, you know. You have to think about what you do. You have to always make sure you take your medications on time. You..like, the doctor will not tell you oh, come for bloodwork every week. You kind of have to also, you know, use your, I guess, intuition or something. Like, you have to take responsibility. You have to take charge cause not everybody will take charge for you. Like, when I started, I sort of had a bit of help, you know. But then after that, I was on my own. They'll help you out at first, but then after awhile when you're doing good, you're on your own. So it's..kidney disease is a bad case but it's not as bad as cancer or heart cause you have two kidneys. You can live on one. Though it's still a bad, you know, thing-I'm not saying it's good. But uh..it's a lot of hard work. It's a lot of responsibility. I didn't think it would be that hard of a responsibility. Always making sure I take my medication. Always making sure I did this and that, you know. Being nagged all the time. And having to go through bloodwork each week or having to go see the doctor all the time. Having to go through a lot..(S2).

Chapter 5

DISCUSSION

In this chapter the findings of the study are discussed in relation to the literature on kidney transplantation, adolescent development, and chronic illness. Also, the limitations of this research study, suggestions for further research, and implications for nursing are presented.

Discussion of the Findings to the Relevant Literature

The eight primary adolescent informants and the two secondary adult informants provided a wealth of information about the experience of having a kidney transplant, from the time of discharge to the time of the interviews. This discussion concentrates on several of the key findings of this research study. A process of minimizing the impact of change following kidney transplantation was the core category around which everything else revolved. These informants were striving to become normal and did not want to be different from others their own age. These informants also began to take on responsibility for themselves and others. The changes these informants faced, the concerns, adjustments, and ways of dealing with these changes, and their ability to move on to the future provided a picture of the experience following kidney transplantation for these individuals.

Phases of the Process

The process of *minimizing the impact of change following kidney transplantation* has been described in the previous chapter. This process and the five phases involved in the process have not been linked together before. They, however, encompass much of the previous work that has been done to date with adolescent transplant recipients and add further to the knowledge about this group (Bernstein, 1971; Gold et al., 1986; Korsch et al., 1971). A portion of the work on psychosocial implications and social maturation of adolescents with chronic illness also have some similarities to the process of adjustment to kidney transplantation (Abramson, Ash, & Nash, 1979; Orr et al., 1984; Pless & Pinkerton, 1975).

This process of minimizing the impact of change following kidney transplantation has been supported by a number of other published studies, some going as far back as 20 years ago. Korsch, Fine, Grushkin, and Negrete (1971) provided a beginning pictorial description of the experiences of children and their families during hemodialysis and transplantation. They described their treatment program at Children's Hospital of Los Angeles. Particularly useful was their diagram depicting what the child and the family's emotional and social adjustment were following kidney transplantation.

In this study, findings were similar to those of Korsch et al. (1971). For instance, two informants were disappointed in the posttransplantation period when there was no urine output immediately postoperatively. This feeling of disappointment also surfaced if there were minor bouts of rejection early on in the postoperative period. Korsch et al. (1971) noted these results as well.

The use of steroids was mentioned as a problem especially for adolescent girls. Korsch et al. (1971) listed weight gain, excessive appetite, acne, and a cushingoid appearance as problematic. Changes in appearance were also very hard to take. The 1971 study briefly alluded to the emotions and actions brought about by these changes including: disgust, despair, shame, withdrawal, and questions of whether the transplant was worth it. These emotions and actions were not well developed in terms of the timing and context for their appearance. The same changes in appearance were noted to be problematic in this study as in the 1971 study. The emotions cited in the 1971 study were also evident in some of the informants of this study. The negative emotions related to changes in appearance were most noticeable after the initial euphoria of the transplant operation had subsided (usually after hospital discharge). The phase generated in this study which deals with these emotions was labelled *concern over the changes*. These concerns arose mainly in relation to the external changes in appearance. These were often changes noticed by others, and/or changes that were hard to adjust to easily.

The period of recovery, as a final stage, in the study by Korsch et al. (1971), was not fully explored because the treatment program in Los Angeles had only been in place for about four years. Concerns about parental overprotection and relationship changes were documented. This was discussed by some of the informants in this study as well. However, greater detail of the recovery period has been provided by this study. An understanding of the impact that the changes have on adolescents adds to the knowledge that we have for these informants.

In another early study, Dorothy Bernstein (1971) outlined the emotional and adaptational responses of 36 kidney transplanted children at three time periods: the early period (hospital discharge to 3 months posttransplant), the middle period (4 to 11 months posttransplant), and the late period (1 to almost 7 years posttransplant). Descriptions were sought over time about the concerns that these children, adolescents, and parents had. The findings are similar in many respects to those of this study. Difficulties were encountered as a result of changes in appearance, relationships, and self-image. However, *noticing the changes* and the positive feelings associated with this phase were not well delineated. There was some mention of "secondary gain" (p. 1193), that is, becoming a celebrity because of the transplant, but few other positive outcomes were discussed. It is possible that in the early studies of transplantation with children, there were problems that do not currently exist; the posttransplant phase seems to be much smoother and less problematic now. Thus, more positive feelings are able to be expressed. It would be interesting to see if this phase of *noticing the change* as a positive time can be substantiated.

The "early period" described by Bernstein (1971) is closely mirrored by the data from this study regarding the phase of *concern over the changes*. Bernstein's "middle period" resembles the phase of *adjusting to the changes*. Strategies have been implemented so that the family and the child are managing the transplant realistically, although never easily. During the "late period", similarities to this study can again be found. Constant fears of rejection and uncertainty about the future remain, even though efforts are made to move on. If adjustments are successful, then the transplant is integrated more easily and the adolescent can begin to think about careers and future plans. Bernstein does not talk about the future, but rather the data suggest that problems such as fear and uncertainty were most predominant. This, again, may be indicative of how early Bernstein's study was in relation to the knowledge about transplantation. In this study, some adolescents did talk about future plans for career, intimate relationships, and feeling healthy. Thus, the data collected from this study has continued to expand on the previous descriptive work to understand the kidney transplantation experience over time.

A more recent study by Gold et al. (1986) describes three stages that families seem to undergo following liver and heart transplantation. Descriptions of the psychosocial issues raised by parents were used to develop these particular stages. These include the preoperative, perioperative, and long-term postoperative stages. Issues raised in the long-term postoperative stage were the adjustments relating to return to home including role adaptation of the parent, fears of rejection and possible death of the child, and adjustments regarding family relationships. Other long term issues were uncertainty about what the future would hold and financial matters.

Some of the psychosocial issues arising from the study by Gold et al. (1986) were identified by the informants in this study. This was true even though parental perceptions were the focus of Gold's study. Financial issues were not raised in this study, although this was a concern in the study by Gold and colleagues. This probably relates to the differences in Canadian and American health care systems. Direct financial costs are not the responsibility of the family members themselves in Canada. The costs are assumed by provincial medicare budgets. Issues of parental overprotection, family relationship changes, and balancing of lifestyle changes were evident in this study as well as that of Gold's study.

Weichler (1990) expanded on the work of Gold et al. (1986) by addressing the informational needs of mothers of children who have had liver transplants. A further delineation of the stages the families of children receiving organ transplantation go through was described in this article. Five phases were discussed. Informational needs of the mothers were assessed at each of these phases. While this may be useful for the overall success of any transplant program, it was also necessary to describe the informational needs of those individuals actually experiencing the transplantation itself, as well as the needs of other family members. Mothers of adolescent children expressed concerns related to future reproductive capacity of their children. Information was required more urgently at different points in time for different persons. This is important to take into consideration. Flexibility and continued assessment of individual needs is an ongoing process.

In 1991, a Master's thesis was completed by Pyke-Grimm. Pyke-Grimm adapted a conceptual model by developmental theorist J.P. Hill

(1980). This qualitative, exploratory descriptive study was conducted to find out about the influence of development on the adolescent experience following transplantation. Many of the findings from this current study are similar to that of Pyke-Grimm. Especially evident were the similarities about identity concerns that adolescents had regarding their body image. Peer relations, however, were not noted to be problematic in the 1991 study. This result differs from this current study. Many of the adolescents in this study had difficulty socializing and developing friendships. The reasons for this are unclear and need more investigation. Both studies have noted the positive and negative effects of development on the adolescent following kidney transplantation and have provided needed data in this area.

There have been a number of other models developed in relation to adolescents with chronic illness. Pless and Pinkerton developed a model of adjustment for adolescents with chronic illness (1975). This model has some similarities to the model developed to minimize the impact of transplant-related change. The response to noticed changes involves the employment of coping strategies, with intervening variables such as peer involvement, family dynamics, and previous use of coping strategies playing a role in the outcome of the strategies for successful *integration of the changes* and *moving on to the future*. It is hypothesized in the Pless and Pinkerton model, that the family and personal pre-morbid profile has a great impact on the response to illness. This relationship is also a variable discussed in this study, although the exact nature and dynamic of this relationship still needs to be explicated.

Orr et al. (1984) discussed the psychosocial implications of chronic illness in adolescence following their study of 144 young adults and adolescents diagnosed earlier in life with a chronic illness. An attempt was made to try to identify relationships between chronic illness and psychosocial well-being. A number of psychological tests and indexes were used to assess psychosocial functioning, including the California Psychological Inventory (CPI) and personal interviews using a structured questionnaire about social and family relationships. Comparisons were made between the earlier data collected in the Rochester Child Health Survey of 1968 and the 1976 study. A model depicting the complex relationship between chronic illness and psychosocial functioning was formed. The findings indicated that overall the informants functioned quite well psychosocially, although adolescents with chronic illness rated their health lower than those without illness. This, the authors suggested, may be linked to how these individuals feel about themselves. This finding seems to be supported by this research study. The informants' psychosocial state often reflected their current health state (Reynolds et al., 1991). Vulnerable areas for the informants in the study by Orr et al. (1984) included planning for the future, relationships with peers, especially those of the opposite sex, and assuming more independence, for example, by possessing a driver's license and planning for career and school. These same areas were affected in this study. Peer relations including dating were affected. Future planning was not easy if the adolescents were struggling with their feelings about their health as this also affected their psychosocial adjustment. Abramson and others (1986) also discuss the implications of social maturity with chronically ill adolescents. They have devised a model of social maturation that links self-esteem to future plans depending on the success or failure of family and peer relationships. This model seems to be relevant in this study. Some of the informants talked about how the lack of socialization with peers and some family members and the negative effect it had on the feelings about had about themselves. One informant was uncomfortable outside the home because most of the childhood had been spent in the house, thus isolation was evident. The informants, in these situations, had hopes for the future of gaining confidence to socialize with others. They did not, as yet, have the skills to meet this challenge. Although Abramson et al.(1979) describe their model in a linear form, the results from this study seem to indicate a more complex and circuitous route with steps taken forward at times and steps taken backward at other times.

Descriptive Categories of the Process

The descriptive categories underlying each phase can be supported by previous studies. Changes were noticed in seven key areas. These descriptive categories included: appearance, appetite, activity and energy levels, health status, medicine and treatment regimens, relationships, and self-image. Over the past 30 years, there has been an increasing focus on the psychosocial factors of informants involved in ESRD treatment programs and research studies to determine successful long-term outcomes.

Grushkin, Korsch, and Fine (1973) describe the major factors needed for psychological rehabilitation in the adolescent. These include: "growth, physical appearance, weight gain, diet, sexual development, educational, and vocational consideration and search for identity" (p.61). These findings quite closely mirror the categories arising from this study.

Appearance. Appearance is critical to how the adolescent is able to move on to the future with respect to career and intimate relationships. Pubertal and growth concerns are not only issues here (Chantler et al., 1980). Other external appearance changes are a concern for adolescents including acne, excess hair growth, and rapid weight gain (Grushkin et al., 1973). Zamberlan (1988), in a study of school-age children following liver transplantation, documented the problems these children had with a changed appearance, although their physical abilities had improved. This again is consistent with the findings from this study. Van der Vliet et al. (1989) employed the techniques of picture drawing and story telling to determine the feelings of children on dialysis and after transplantation. Results corresponded closely with some of the findings in this study. Informants expressed similar feelings of being "ugly" in each of these studies, as well as wanting to be normal. More contextual information surrounding these feelings was elicited from this current study to help gain more insight into the adolescents thoughts and feelings.

Sexual development problems have been cited in a few previous treatment program reviews and/or studies with adolescent kidney transplant recipients (Chantler et al., 1980; Grushkin et al., 1973). The majority of studies do not provide information on this topic (Offner et al., 1988). This was not an area that was discussed by informants in this study. It is uncertain whether it was not an issue for these informants or whether they did not discuss concerns of a sexual nature. Perhaps they felt too embarrassed to discuss this area with the researcher (Flaming, 1992).

Other less visible physiological problems, for instance, hypertension have been the informant of discussion by a number of authors (Chantler et al., 1980; Gartner et al., 1984; Koch & Muthny, 1990; Lilly et al., 1971; Najarian et al., 1971; & Offner et al., 1988;). The full effects of hypertension on the long-term prognosis of the kidney transplant graft have yet to be fully understood. In this study, informants were aware of whether or not they were hypertensive. At least two informants did not take their blood pressure medications as ordered. The consequences of not taking these medications were not fully realized by these informants. The time-consuming nature of taking medications and the disturbing side-effects such as dizziness and other visual disturbances were factors in the lack of adherence with the regimen of these two informants. They felt normal and did not understand the long-term impact of hypertension on their body including their kidneys. More investigation of the outcomes of these decisions by adolescents on graft success are needed.

Children involved in various end-stage renal disease treatment programs have described the effects of immunosuppressive medication on appearance. Adolescents, especially girls, seem to be most affected (Bernstein, 1971; Chantler et al., 1980; Fine et al., 1970; Henning et al., 1988; Hesse et al., 1990; Korsch, Fine et al., 1971; Korsch, Negrete, et al., 1973; Lilly et al., 1971; Najarian et al., 1971 & Simmons, 1985).

Only one study by Reynolds et al. (1991) provided conflicting evidence of the concerns about appearance. Parents in this study were asked to rate the concerns they had. Using this approach, few reports of problems with appearance were noted. The authors do discuss that the children and the adolescents, themselves, may need to be asked to accurately gauge the importance of these issues. Cyclosporin induced changes in physical appearance have been examined by Resnik et al. (1987). These changes in appearances from cyclosporin have an impact on the adolescent, just as the corticosteroids have. All the adolescents in this study spoke about the changes in appearance that they noticed and all were concerned over these changes.

The adolescents in this study provided more contextual data surrounding these issues. Some changes that were more easily dealt with were taken in stride. For example, increased facial hair growth that could be waxed off was less problematic than the "moon face" and/or the rapid weight gain characteristic of corticosteroid usage. Adjustments were made using a variety of cognitive and behavioral strategies. This was especially true for the first year after transplant. Authors in a number of studies have documented similar findings. They have documented that major adjustments take place most frequently in the first year posttransplant as compared to subsequent years (Bernstein, 1971; Chantler et al., 1980; Korsch et al., 1973).

Appetite. Appetite has been mentioned in a small number of studies in relation to the effect of corticosteroid-induced overeating (Fine et al., 1970; So et al., 1986). More description of changes with the adolescents' appetite over time was garnered in this study. Generally, appetite was fairly constant for these informants over time. Adjusting the amount of food eaten was necessary. However, if weight gain became a problem, then the influence of the medications on appetite became more apparent. For the most part, appetite was not a concern.

Activity/Energy Levels. Activity and energy levels have been studied previously (Korsch et al., 1973; Reynolds et al., 1991). Consistent findings among studies reveal an increased ability to become involved in more activities and there was a feeling of increased energy which informants were aware of and took advantage of to do things. Comparable results exist within the liver transplant literature (Gartner et al., 1984; Zitelli et al., 1988).

In this study, contact sports were avoided initially, but as time went, on there was an increasing sense of health and well-being . More vigorous activities were enjoyed. Some risks were taken. The rationale for taking certain risks was not well described previously. For one participant, horseback riding and equestrian jumping signified normality and, as such, she was willing to risk possible damage to her kidney from a saddle horn injury or from a fall. Issues of wanting to be normal seemed to underlie much of the adolescents' motivation for why they do what they do. In a number of previous studies. adolescents were seen to be willing to take risks; these risks seem to be related to the medication regimens, specifically the immunosuppressive medications. (Korsch et al., 1978; Litt & Cuskey, 1980).

In relation to involvement in activities, there were some definite descriptions by informants in this study describing their abilities and efforts to take care of their health. Getting exercise and eating right were examples that some of the informants used to explain this process. In the literature, to some extent, there is a discussion about the feelings of health and not wanting to be different from others (Henning et al., 1988; Mcanarney, 1985; Miller, 1987).

Health Status. Caring for health and the seeming interest by adolescents in these issues has not been noted before in the literature. In fact, the lack of interest in health matters and the high risk-taking behavior of adolescents seems to stand in opposition to the findings of this study (Coates et al., 1982; Mitchell, 1986). Adolescents following kidney transplantation are a population ideally suited to health promotion efforts as they are sensitized to the value of health and of life itself (Petosa, 1989). It seems as if there is a willingness by the adolescents in this study to participate in health promotion and disease prevention efforts.

Medication/Treatment Regimens. The medication and treatment regimens form a substantial part of the transplant experience. Frequent medical follow-up and monitoring of medications becomes a part of the routine for individuals after transplantation of any kind. For most of the informants the numbers of medications decreased and they felt a sense of relief in the first year or two because few problems had arisen with their medications or treatments. The literature provides little information about the timing for problems arising with medications or treatment regimens. This study helps to fill the gap in knowledge about timing and contextual factors that influence decisions to take or not take medications/treatments.

Noncompliance with immunosuppressive medication was noted in the earlier study by Grushkin et al. (1973). The regimented nature and timing of the medications and the inability to explore the thoughts and feelings that these individuals had regarding their kidney transplant experience were two of the reasons given by these adolescents for not taking their medications. Subsequent studies have described the high rates of noncompliance (Beck et al., 1980; Ettenger et al., 1991; Korsch et al., 1978; Litt & Cuskey, 1980; Malekzadeh et al., 1976). Corresponding descriptions have been documented in other adolescent populations (Dolgin et al., 1986; Zeltzer, 1980). The context and conditions for taking risks were not clearly defined. Issues arising from these previous studies included: self-image, family relationships, and independence. For example, the females' resentment of body and facial changes, enforced dependence on others, reaction to the "price" exacted by the living-related donor for kidney donation, socialization and communication problems, family support, and pre-transplant emotional stability may influence adherence to medication regimens (Korsch et al., 1978; Litt & Cuskey, 1980).

In this study, any thought of discontinuing the medication regimens occurred initially because of nausea-related side-effects. There was a physical inability to keep down the medication. As there were no immediate consequences to the discontinuation, the adolescents then, felt that the medication was no longer really necessary. Many of these informants initially took the medications in a liquid form and found the taste and smell intolerable. They, then, could not retake the cyclosporin or decided it was not really necessary and stopped taking it. They only did this if they felt healthy. Their motivation was the desire to be normal, like others their own age. For some of the adolescents in this study, the medications were thought to be a "hassle".

However, this in itself was not the only factor involved in the decision to discontinue the medications. The interaction of the thoughts to consequences and feelings of control that adolescents seemed to describe, regarding whether or not they adhered to the medication or treatment regimens, seemed to be an important relationship. Other researchers have made this link between motivation, actual behavior (performance), and commitment to a course of action depending upon the experience of control, choice, and self-determination that the individual had. If choices were given and there was a perception of increased control, then individuals were more likely to be motivated and carry through with their therapy

(Adelman, Kaser-Boyd, & Taylor, 1984; Deci, 1980; Perlmuter & Monty, 1979). It is apparent that there is a complex set of relationships that are involved in decisions to take medications. More recent studies examining medication compliance have also documented this complexity (Conrad, 1985; Nekolaichuk, 1990). There is general agreement that adolescents do have the capacity to make treatment decisions. Research provides support for the inclusion of adolescents in decision-making about issues affecting them (Grisso & Verling, 1978; Inhelder & Piaget, 1958; Lewis, 1981; Weithorn & Campbell, 1982). A better understanding of these variables involved in decisions by adolescents to take medications is necessary.

Relationships. In previous research studies, family support and interaction between family and friends have been noted to play an important role in the psychosocial development of adolescents. Some of the descriptions and factors influencing the relationships have been noted before in previous studies, including: short stature, obesity, drug side-effects, time since transplant, prior communication patterns and family cohesiveness (Henning et al., 1988; Kahn et al., 1971; Korsch et al., 1973).

Poor social adaptation has been reported in a number of areas such as inability to achieve lasting relationships with the opposite sex and dependence on other people (Henning et al., 1988; Fine, Malekzadeh, et al., 1978). Korsch and Negrete (1984) discuss some of the factors involved in the movement towards poorer outcomes for adolescents. Factors such as low family support, noncohesive family structure, high risk pre-illness personality traits including high anxiety and poor self-esteem, a complex medical course, poor community connections, low financial status, and kidney failure beginning in adolescence all seem to influence the outcome. Although most studies have reported relatively normal social and emotional adjustment in kidney transplanted recipients, this must be qualified if any of the above factors came into play. Even compared to the alternate treatments for kidney disease (hemodialysis and peritoneal dialysis), the normal population, and even those populations with other types of chronic illness including diabetes, kidney transplantation recipients have adjusted quite well psychosocially (Fine & Grushkin, 1973; Korsch & Negrete, 1984; Melzer et al., 1989). In this study similar findings were noted. Some of the informants were able to continue to develop close family and peer relations as they had done in the past, while those individuals who had difficulty with peer and family relationships continued to have much the same difficulties in the posttransplant period.

School attendance and job opportunities among the informants in this study were comparable to results cited in other studies. All of the adolescents had returned to school and many had after school jobs. The two secondary informants had full time jobs (Gartner et al., 1984; Najarian et al., 1971; Reynolds et al., 1991). Reynolds et al. (1991) and Zitelli et al. (1988) reported that minor behavior problems were often noted in school reports and some parents continue to notice behavioral immaturity after transplantation . These findings were not specifically noted in this study, although parental interviews may have discerned information about these areas of school performance and cognitive functioning better than self-reports by the adolescents themselves. Adjustment, for most of the adolescents in this study, was well under way by the end of the first year. For some informants, however, this adjustment period was longer, continuing beyond the time of this study.

Koch and Muthny (1990) discuss that in adults, family and interpersonal relationships were not affected very much by transplantation. These findings differ from studies with adolescents (Melzer et al., 1989). Family and relations with others are very important. Peer relations are extremely important, though little evaluative research has been done to substantiate these statements. Results of the study by Melzer and colleagues indicated that there were fewer social networks in adolescents with ESRD as compared to a group of normal adolescents. Poor peer relations place the adolescent at risk for difficult times in the future (Bierman, 1987; Kahn et al., 1971). In this study, some of the informants had difficulty with peers and some certainly had reduced social networks, relying heavily on family relationships with little external exposure. At least one informant did not have a close friend to rely upon. This particular informant was also having the most difficulty with personal self-esteem and identity.

Parental overprotection has been described in some of the studies done to date (Gold et al., 1986; Zitelli et al., 1988). This did not seem to be a big issue in this study. One possible reason for this may have been that most of the informants were interviewed after the first year when the majority of adjustments occur. Their recollection of details may have been less accurate than if they had been studied at the time these adjustments were taking place.

In this study, relationships was found to be continually developing over time. This study provided more information with regards to some of the contextual and intervening variables involved in the process of evolving relationships in order for successful integration of the kidney transplant into the life of these informants. Relationships evolved as adjustments were made to the changes. Closer, more intimate relationships often developed. A recent qualitative study described the life of adult liver transplant recipients (Meeberg, 1992). In this study, relationships between the transplant recipient,family members, and friends, seemed to evolve over time. They, as well, became deeper and more meaningful.

Self-Image. Grushkin et al. (1973) noted that self-esteem was also susceptible to damage in some adolescents. For adolescents in today's society, the standards for physical beauty have created unrealistic expectations for the body (Williamson, 1987). The female must be attractive, slender, and tall. The male must be tall, handsome, and muscular. Failure results in feelings of lowered self-esteem. Therefore, not only do normal adolescents face goals that are hard to attain, but adolescents with a chronic illness must face these challenges as well as the challenges posed by the side-effects of medications and the disease process itself. Failure is akin to loss of personal worth (Williamson, 1987; Zarinsky, 1975).

In this study, if the adolescent could not adjust to the external and internal changes of normal development and transplantation,then the adolescent's self-image suffered greatly. In Coopersmith's study of self-esteem (cited in Miller, 1987), it was found that self-esteem was closely related to adjustment and behavior. If this is true, the process of minimizing the impact of transplant-related change may be this adjustment that Coopersmith was talking about. Therefore, the ease with which adolescents move through this process may be indicative of their level of self-esteem. Perhaps self-esteem could be used in assessment as one of a number of indicators of adequate or inadequate adjustment. Interventions could be implemented to help individuals move more smoothly through this whole process in order to maximize the building of one's self esteem. While self-esteem may be important to assess, there remains a complex relationship between adjustment and self-esteem that is not easily measured (Bastien & Adelman, 1984).

Developmental issues, such as responsibility and gaining an identity, were discussed by Grushkin et al. (1973) and Tisza et al. (1976). These efforts to reach the appropriate developmental stage and attain mastery are critical to moving on to the future. Similarly, in this study, taking on responsibility and wanting to be normal were key to the process of minimizing the impact of transplant change. There were definite developmental undertones in the research findings of this study. The phases of change were similar to those encountered in becoming an adult. The transplant operation was the trigger for a number of unexpected changes in this period of adolescence. The resultant movement towards increased responsibility and independence signalled the appropriate movement towards adulthood (Tizsa et al., 1976).

The formation of identity, according to Rainey (1982), involves achieving autonomy (independence), developing a comfortable body image and sense of self-esteem, adjusting to pubertal maturation and relationships with others, and preparing for future career and family goals. There was agreement found in this study for all of the above categories necessary for the formation of an identity. However, the identity formation involved not only the normal development of an adolescent, but that of an adolescent with a kidney transplant. The relationship between external appearance and internal feelings about the self that seemed to emerge from this study are particularly pertinent here (See Figure 3). For the adolescent with a kidney transplant, the development of a sense of self was crucial to moving on to the future. For the secondary informants, the concerns about the self-image were of lesser importance after this period of adolescence.

Various strategies have been implemented by these adolescents to adjust to the changes placed before them. Beck, Nethercut, and colleagues (1986) discuss the use of positive coping strategies by adolescents with ESRD in light of visible handicaps and/or visible side-effects of medication and treatment procedures. Beck and his colleagues compared the adolescents with ESRD to other chronically ill adolescents in terms of self-concept scores and found that the adolescents with ESRD faired very well. Coping strategies such as taking their appearance in stride and noting the time since transplant were common. Adolescents whose transplants were quite a while ago had higher self-esteem, although worries about rejection became more prominent as time went on. There were some definite similarities between the strategies reported by the adolescents in this study and the findings of the study by Beck and Nethercut et al. (1986). Various strategies were utilized by the adolescents in this study to cope with all of the adjustments to their changes in appearance and relationships until they were better able to deal with them at a later date. These included active strategies to change their diet and activities. They also avoided others and stayed at home when they were not feeling good about themselves or felt they could not socialize easily with others. Other strategies, the adolescents used, involved getting on with life by facing the challenges head on. Almost all of the informants at one time or another gave excuses for why they could not do certain activities or get involved with others. This rationalization was quite effective for the majority of these informants.

Coping strategies that have often been used by other adolescents to deal with changes in their life include denial, displacement, reaction formation, regression, rationalization, and depersonalization (Platzer, 1987). Common strategies to allow for adjustment by the informants in this study included denial and rationalization. Denial was used with issues about death and disability. This is consistent with the literature (Beard, 1969; Tisza et al., 1976). Downplaying of the seriousness of events or circumstances may be used by adolescents to cope with the stress of the treatments or medication side-effects (Zeltzer et al., 1980). Again the resiliency of these informants to cope with the stress and strain of the transplant was remarkable (Korsch & Negrete, 1984). Generally, the informants were coping well and moving on towards the future.

The impact of growth and development on the process of adjustment following kidney transplantation is evident throughout. Cognitive and behavioral changes have had an impact on these adolescents in this study. The movement towards future planning and taking on responsibility are a result of significant cognitive events in the normal pattern of childhood development (Grisso & Verling, 1978; Piaget, 1967).

Limitations of the Research Study

There were a number of limitations noted in this study. These included a small sample size, a more directed interview style, a short retrospective data collection period, and uncertain effects on the informants as a result of the researcher's gender.

The grounded theory method was chosen for this study. This method may be criticized for its small sample size and its inability to generalize beyond the population studied. However, this method was appropriately used to study the phenomenon of interest to the researcher. Concepts have been derived and relationships regarding the experience of eight adolescents following kidney transplantation have been exposed which are theoretically generalizable beyond these eight informants (See Glaser, 1978; Corbin & Strauss, 1990 for more detail).

Theoretical generalizability allows the theory derived from the findings to be tested using other populations. The individual results may not always be found but the conceptual categories provide a more abstract picture of the experiences discussed here. As the findings in this study have been taken to the conceptual, abstract level these categories are theoretically generalizable. Thus, this study has provided new conceptual information relevant to other adolescent kidney transplant recipients.

Another limitation became evident during the interviews with the adolescents in this study. The interviews were more directed than desired for this type of study. The researcher's own interests may have been a source of bias influencing the direction of the questions asked in relation to certain issues. What were meant to be guiding questions only, were often used systematically to meet the silent, waiting looks of the informants. Even following the guidelines set out by other authors such as Faux et al. (1988), the researcher had continually to remind the adolescents that their story was important and that there were no right answers. Informants were less talkative, generally, than was even anticipated. It seemed that these informants were used to being asked questions and they found it difficult to just tell their story without prompting. Therefore, more questions were asked than originally intended. This may have had an effect on the information received from the adolescent in the interview, although the direction of the effect was uncertain. It has been suggested by some authors that these types of informants, specifically adolescents, lack the cognitive and/or social maturity needed for interviews of this nature (Dulit, 1972; Hamburg, 1984). However, other authors believe cognitive maturity is functional in early adolescence (Weithorn & Campbell, 1982). The difficulty with the interview may also have been due to a general discomfort with the interview process even though efforts were made to try to reduce this uneasiness See Chapter 3 for further details.

This study was also limited because the data were collected from adolescents over a short period of time. Between one and three interviews were arranged with these adolescents to have them tell their story. Remembering incidents in the past was a possible threat to the validity of the information collected from these informants. The difficulties with this approach has been noted previously (Weekes, 1991). This, however did not seem to be a big problem. Validation from other sources, such as parents and health care professionals, were found to substantiate the stories these adolescents told. Additionally, this approach was felt to be the most time and cost effective way of getting at the desired information, while still being able to bring the reality of these adolescents' experiences to the forefront. There was recognition of the possible problems that may be involved with this approach. Diaries would have been useful to capture the moments as they occurred, but this source was available from only one informant.

It is uncertain what effect the researcher's gender had on informants' responses. The effect of gender may have limited the amount of information informants were willing to disclose. In gender specific research, about the experience of puberty with adolescent males, Flaming (1992) delineated a process of minimizing the embarrassment of changes occurring in normal growth and development. The researcher, who was male, had difficulty with the depth and richness of the interviews even though informants consented to participate in the study and chose face to face interviews. Denholm and Chabassol (1988) discuss that even being an adult interviewer may affect disclosure of embarrassing events by adolescents.

Suggestions for Further Research

Kidney transplantation is a chronic care treatment modality. It is only through continued research that we may learn how best to provide care for children and adolescents and to attempt to understand what these individuals really experience following kidney transplantation. There are many directions that can and should be taken to further the understanding of the psychosocial aspects of treatment in children and adolescents following kidney transplantation.

Studies to date have been largely descriptive. For example, program success rates have often been cited. Particularly, graft survival has been well researched. Some studies have used quantitative methodology, but describe only very small segments of a very large area of study. These descriptive and experimental results have provided the necessary data to undertake more systematic studies with this population.

Kidney transplant recipients in this study were selected on the basis of a functioning graft. These recipients are only a portion of the total number of adolescents who have been transplanted. It now needs to be determined how adolescents, who have rejected their kidney, feel and have progressed through the experience following the kidney transplant operation. Longitudinal studies, following adolescents from the pre-transplant period to long after the transplant, are needed to truly gain an understanding of the complex interrelationships briefly discussed in this study and in the previous work done to date with adolescent kidney transplant recipients. Various qualitative and quantitative designs should be performed in order to understand the effect of the informant's pre-treatment psychosocial status on posttransplant psychosocial adjustment over time.

Different informants were interviewed at various points in this research study to develop the five phases of minimizing the impact of transplant-related change described in Chapter 4. It would be helpful to provide prospective longitudinal studies to support this work following the *same* informants over long periods of time. While the data collected from this study has continued to expand on the previous descriptive work to understand the kidney transplantation experience over time, now this process needs to be validated.

It would also be interesting to compare these informants with a similar population of adolescents currently with other types of chronic illness or with healthy adolescents problem to see if any differences exist-in number of concerns or in the intensity of emotion experienced between groups. This would be of special interest with the concerns over self-image and changes in appearance. What findings can be explained by adolescent development alone? What areas are similar or dissimilar with regards to areas of concerns for the different population groups? The impact of development on the chronic illness experience has also been noted. Zamberlan (1988) discussed the difficulty of trying to separate these components from each other. Studies that attempt to consider these components may be useful to understand more about the adolescent with a chronic illness.

It is important to also describe the informational needs of those individuals actually experiencing the transplantation itself, as well as the needs of other family members (Weichler, 1990). Mothers of adolescent children following liver transplantation expressed concerns related to future reproductive capacity of their children. Information was required more urgently at different points in time for different persons. This is important to take into consideration. Flexibility and continued assessment of individual needs is an ongoing process. This needs to be validated with the informants themselves and with other populations. Further studies of this nature need to be developed to include all those involved in the transplant experience, not only the mothers.

It is important to evaluate the effect of strategies used by the adolescents in this study to deal with the various changes in the seven descriptive categories. Evaluative research in this area is almost nonexistent. Many authors describe interventions but few have tested the interventions for their effectiveness. Treatment programs to date have described effective methods of maintaining graft survival, but the psychosocial interventions by health care professionals in dealing with adolescent kidney transplant recipients now need to be evaluated. The immediate postoperative physical sequelae have traditionally been the focus of research studies, now we need to focus on studies with of a long-term nature.

For example, concern over height has been expressed by adolescents in most of the studies to date. Many of these adolescents have had continuing problems with poor growth from the pre-transplant period. End-stage renal failure as a result of various types of kidney disease has significantly affected the rate of growth for all informants who have not had their growth spurt modified in adolescence. Many of these informants seem to be affected emotionally because of this. The adjustment process needs to be examined further. Also it is important to work with these individuals to inform them about the patterns of growth that can be expected and help these adolescents to deal realistically with their circumstances. Until new ways to stimulate growth and minimize drug therapy are found that ultimately affects growth potential, strategies to cope with these challenges must continue.

Antirejection medications by the adolescents were followed some of the time and not at other times. Different factors played a role in the decisions made here. One factor was the nausea from the immunosuppressive medication due to the bad taste, especially in the liquid form. Perhaps different pill dosages or new forms of the drugs could be found and made available to try to reduce the effects of nausea. This may be one way of reducing the incidence of noncompliance in children and adolescents. Treatments and other medications not related to immunosuppressions were likewise followed or not depending upon how critical these items were seen by the informants. This needs further investigation especially for very long term outcomes now that acute rejection has been curtailed quite well and is much less of an issue. Other medications impacting on one's quality of life in the long-term have become more important.

Blood pressure medications, and dietary restrictions were manipulated as the informants saw fit in this study. Some decisions were made with little understanding of the consequences of such action. This area needs further investigation to fully understand the relationships described here between thoughts to consequences and control over decisions.

Adjustment to one's self-image continued to be problematic for most of the informants. It needs to be determined whether or not, in time, adjustments will be made by all informants to integrate the changes into their life. Informants were interviewed at various points in these phases so it was not possible to determine all possible routes that these adolescents may take to reach this phase. It is uncertain if all informants will reach integration and move on to make future plans. Both secondary informants have managed to incorporate and move on to the future. It would be helpful to provide longitudinal studies to support this work.

Resiliency of informants when faced with chronic illness has been noted in the literature (Korsch & Negrete, 1984). Research might be useful to look at the concept of resiliency in light of the fourth phase described in this study. The fourth phase deals with the integration of transplant-related changes into the informant's life. What are the conditions needed for resiliency? Is resiliency a necessary condition for integration? What is the relationship between resiliency and integration?

Caring for health became a high priority for many of the informants in this study. No longer was health taken for granted. Efforts were made by these adolescents, in all seven descriptive categories, to achieve a better state of health. Eating right and exercising were considered to be very important ways of staying healthy. While not all of the adolescents have reached this phase of integration, most have made choices in some of the descriptive categories to become more healthy. This is an important area for further investigation. Much of the research to date on adolescents describes their activities as risk-taking, not health taking (Coates et al., 1982. This may have a number of significant implications for dealing with adolescents and involving adolescents in health promotion programs. There may be opportunities to involve adolescents in these areas as there appears to be a willingness to care for health.

Implications for Nursing

There are a number of implications for nursing arising from this research study. This study provides more detail into the circular, feedback loop that seems to be involved in decisions regarding medication/treatment regimens and caring for health. This may have an impact on how we approach adolescents with information. They seem particularly sensitized to taking care of their health following a dramatic treatment such as kidney transplantation. While efforts are not always successful, adolescents could be provided with opportunities and education regarding more effective ways to care for their own health.

The interaction of thoughts to consequences and feelings of control that adolescents described earlier, in Figure 2, seems to be important in whether or not they adhere to the medication and/or treatment regimens. This has particular relevance for how we approach adolescents. Health care professionals must be aware of this complexity. They need to treat each adolescent on an individual basis depending on the specific factors or intervening conditions involved in the particular circumstances.

In some circumstances in this study, medication and treatment decisions were made by informants without understanding the consequences of their actions. Blood pressure medications, and dietary restrictions were manipulated as the informants saw fit, even when immunosuppressive medications were followed appropriately. There seems to be room for efforts by health care professionals to become involved in this area through discussion on a one to one basis with every adolescent following kidney transplantation. The various phases these informants seemed to go through may provide some clues as to the timing necessary in providing information offered by health care professionals. Other strategies that might be useful would be peer group discussions so that others can learn from those who have experienced certain of these phases already.

Vulnerable areas for the informants in the study by Orr et al. (1984) included planning for the future, relationships with peers, especially those of the opposite sex, and assuming more independence for example by possessing a driver's license and career and school planning. These same areas were affected in this study. Peer relations including dating were affected. Many of the informants had little contact with others of the opposite sex. Future planning was not easy if adolescents were struggling with negative feelings about their self-image and were isolated from peers. Psychosocial adjustment was affected and the adolescent could not move on to think about the future. Health care professionals need to help adolescents move on with their lives. Serious consideration of these aspects, involved in the phases over time, needs to be integrated in any program developed for adolescents following kidney transplantation. Developing strategies to allow adolescents to move on to other issues are important efforts that can be developed jointly between health care professionals and adolescents.

Inclusion in decisions is an important part of moving through adolescence to adulthood. Encouraging activities that allow control, increased responsibility, and normalcy within the context of the individual situation is extremely important. Health care professionals can do much to provide adolescents with opportunities for success.

Summary

This research study has described in detail the experiences of eight adolescent kidney transplant recipients and two adult secondary informants. A process of Minimizing the Impact of Change following Kidney Transplantation has been developed. This process involves five phases containing seven descriptive categories. A discussion of the findings in relation to the literature, the limitations of this approach, and suggestions for further research have been provided. The adolescent faces many changes following transplantation, yet adjustment occurs over a period of time. The most intense adjustment period appears to be the first year. However, with time other equally important issues have arisen that impact on the adjustment patterns of these individuals. Suggestions and implications for nursing have also been noted. For all informants, kidney transplantation is the preferred method of treatment for ESRD. The adolescents feel normal and less different from others than with any other treatment modality. If another transplant became necessary, these adolescents would choose to have another kidney transplant operation.

REFERENCES

Abramson, M., Ash, M.J., & Nash, W.R. (1979). Handicapped adolescents: A time for reflection. Adolescence, 14, 557-565.

Adelman, H.S., Kaser-Boyd, N., & Taylor, L. (1984). Children's participation in consent for psychotherapy and their subsequent response to treatment. Journal of Clinical Child Psychology, 13, 170-178.

Adelson, J. (1980). Handbook of adolescent psychology. New York: John Wiley & Sons.

Annas, G.J., Glantz, L.H., & Katz, B.F. (1977). Informed consent to human experimentation: The subject's dilemma. Cambridge, Massachusetts: Ballinger.

Arbus, G.S., Geary, D.F., McLorie, G.A., Major, M.L., Berdock, S.E., Freedman, L., & Baumal, R. (1986). Pediatric renal transplants: A Canadian perspective. Kidney International, 30, 31-34.

Atwater, E. (1983). Adolescence. Englewood Cliffs, N. J.: Prentice-Hall, Inc.

Bandura, A. (1980). The stormy decade: Fact or fiction? In R. Muuss (Ed.), Adolescent behavior and society. New York: Random House.

Bastien, R.T., & Adelman, H.S. (1984). Noncompulsory versus legally mandated placement, perceived choice, and response to treatment among adolescents. Journal of Consulting and Clinical Psychology, 52, 171-179.

Baumrind, D. (1968) Authoritarian versus authoritative parents' control. Adolescence, 3, 255-72.

Beard, B.H. (1969). Fear of death and fear of life: The dilemma in chronic renal failure, hemodialysis, and renal transplantation. Archives of General Psychiatry, 21, 373-380.

Beck, A.L., Nethercut, G.E., Crittenden, M.R., & Hewins, J. (1986). Visibility of handicap, self-concept, and social maturity among young adult survivors of end-stage renal disease. Developmental and Behavioral Pediatrics, 7, 93-96.

Beck, D.E., Fennell, R.S., Yost, R.L., Robinson, J.D., Geary, D., & Richards, G.A. (1980). Evaluation of an educational program on compliance with medication regimens in pediatric patients with renal transplantation. Journal of Pediatrics, 96, 1094-1097.

Benoliel, J.Q. (1975). Childhood diabetes: The commonplace in living becomes uncommon. In A.L. Strauss & B. Glaser (Eds.), Chronic illness and the quality of life. St. Louis: Mosby.

Bernstein, D.M. (1971). After transplantation-the child's amotional reactions. American Journal of Psychiatry, 127, 109-113.

Bierman, K.L. (1987). The clinical significance and assessment of poor peer relations: Peer neglect versus peer rejection. Developmental and Behavioral Pediatrics, 8, 233-240.

Blos, P. (1962). On adolescence. New York: Free Press.

Blum, R.W. (Ed.). (1984). Chronic illness and disabilities in childhood and adolescence. London: Grune & Statton, Inc.

Boulton Jones, J.M., Cameron, J.S., Bewick, M., Ogg, C.S., Meadow, S.R., & Ellis, F.G. (1971). Treatment of terminal renal failure in children by home dialysis and transplantation. Archives of Disease in Childhood, 46, 457-464.

Brink, P.J. & Wood, M.J. (1989). Advanced design in nursing research. Newbury Park: Sage Publications.

Brownbridge, G., & Fielding, D.M. (1991). Psychosocial adjustment to end-stage renal failure: Comparing haemodialysis, continuous ambulatory peritoneal dialysis and transplantation. Pediatric Nephrology, 5, 612-616.

Broyer, M. (1984). Kidney transplantation in children: Results of 383 grafts performed at Enfants Malades Hospital from 1973 to 1984. Advanced Nephrology, 16, 307-334.

Canam, C. (1986). Coping with chronic illness in families. Nursing Papers, 11, 46-51.

Chantler, C., Carter, J.E., Bewick, M., Counahan, R., Cameron, J.S., Ogg, C.S., Williams, D.G., & Winder, E. (1980). 10 years' experience with regular haemodialysis and renal transplantation. Archives of Disease in Childhood, 55, 435-445.

Chenitz, W.C., & Swanson, J.M. (1986). From practice to grounded theory: Qualitative research in nursing. Menlo Park, CA: Addison-Wesley Publishing Co.

Coates, T.J., Petersen, A.C., & Perry, C. (1982). Promoting adolescent health: A dialogue on research and practice. New York: Academic Press.

Cohen, R., Cohler, B., & Weissman, S. (1984). Parenthood: A psychodynamic perspective. New York: Guilford Press.

Coleman, J.C., & Hendry, L. (1990). The nature of adolescence (2nd ed.). London: Routledge.

Conger, J.J. (1973). Adolescence and youth: Psychological Development in a changing world. New York: Harper and Row.

Conrad, P. (1985). The meaning of medications: Another look at compliance. Social Science & Medicine, 20, 1,29-37.

Conrad, P. (1990). Qualitative research on chronic illness: A commentary on methods and conceptual development. Social Science & Medicine, 30, 1257-1263.

Corbin, J.M., & Strauss, A. (1990). Managing chronic illness at home: Three lines of work. In P. Conrad & R. Kern (eds.), The sociology of health and illness: Critical perspectives. (3rd ed.). New York: St. Martin's Press.

Deci, E.L. (1980). The psychology of self-determination. Lexington, MA.: Lexington Press.

Denholm, C., & Chabassol, D. (1988). Adolescents' self-disclosure of potentially embarrassing events. Psychological Reports, 60, 45-46.

Devins, G.M., Mann, J., Mandin, H., Paul, L.C., Hons, R.B., Burgess, E.D., Taub, K., Schorr, S., Letourneau, P.K., & Buckle, S. (1990). Psychosocial predictors of survival in end-stage renal disease. The Journal of Nervous and Mental Disease, 178, 127-133.

Doan, H.M., & Morse, J.M. (1985). Every girl. Toronto: Stoddart Publishing Co., Ltd.

Dolgin, M.J., Katz, E.R., Doctors, S.R., & Siegel, S.E. (1986). Caregivers' perceptions of medical compliance in adolescents with cancer. Journal of Adolescent Health Care, 7, 22-27.

Drachman, R., Schlesinger, M., Shapira, H., & Druckker, A. (1989). The immune status of uraemic children/adolescents with chronic renal failure and renal replacement therapy. Pediatric Nephrology, 3, 305-308.

Dragone, M.A. (1990). Perspectives of chronically ill adolescents and parents on health care needs. Pediatric Nursing, 16, 1, 45-50.

Dulit, E. (1972). Adolescent thinking a la Piaget: The formal stage. Journal of Youth and Adolescence, 1, 281-301.

Dutton, M. (1987). Transplantation. Nursing (London), 3, 641-644.

Elkind, D. (1967). Egocentrism in adolescence. Child Development, 38, 1025-1034.

Elkind, D. (1981). The hurried child. Reading, MA: Addison-Wesley.

Erikson, E. (1963). Childhood and society. New York: Norton.

Erikson, E. (1968). Identity: Youth and crisis. New York: Norton.

Ettenger, R.B., Rosenthal, J.T., Marik, J.L., Malekzadeh, M., Forsythe, S.B., Kainl, E.S., Salusky, I.B., & Fine, R.N. (1991). Improved cadaveric renal transplantation in children. Pediatric Nephrology, 5, 137-142.

Faux, S.A., Walsh, M., & Deatrick, J.A. (1988). Intensive interviewing with children and adolescents. Western Journal of Nursing Research, 10, 180-194.

Field, P.A., & Morse, J.M. (1985). Nursing research: The application of qualitative approaches. Rockville, Maryland: Aspen Publishers Co.

Fine, R.N., Korsch, B.M., Stiles, Q., Riddell, H., Edelbrock, H.H., Brennan, L.P., Grushkin, C.M., & Lieberman, E. (1970). Renal homotransplantation in children. Journal of Pediatrics, 76, 347-357.

Fine, R.N., Malekzadeh, M.H., Pennisi, A.J., et al. (1978). Long-term results of renal transplantation in children. Pediatrics, 61, 641-650.

Fine, R.N., Salusky, I.B., & Ettenger, R.B. (1987). The therapeutic approach to the infant, child, and adolescent, with end-stage renal disease. Pediatric Clinics of North America, 34, 789-801.

Fine, R.N., & Tejani, A. (1987). Renal transplantation in children. Nephron, 47, 81-86.

Flaming, D.P. (1992). The experience of physical maturational changes in male adolescents. Unpublished master's thesis. University of Alberta, Edmonton, Canada.

Flechner, S.M., Conley, S.B., Van Buren, C.T., Rose, G., Kerman, R., Kahan, B.D. (1985). Impact of ciclosporine [sic] on renal function and growth in pediatric renal transplant recipients. Transplant Proceedings, 17, 1284-1288.

Forsyth, G.L., Delaney, K.D., & Gresham, M.L. (1984). Vying for a winning position: Management style of the chronically ill. _Research in Nursing and Health_, _7_, 181-188.

Frauman, A.C. (1991). Physical and psychosocial sequelae of renal transplantation (ANNA National Symposium Abstract). _ANNA_, _18_, 2, 159.

Freud, S. (1925). Some psychiatrical consequences of the anatomical distinction between sexes. (XIX). _The standard edition of the complete psychological works of Sigmund Freud_. London, Hogarth Press.

Frey, G.M. (1990). Stressors in renal transplant recipients at six weeks after transplant. _ANNA_, _17_,443-450.

Gaedeke Norris, M.K. (1991). Applying Orem's theory to the long-term care of adolescent transplant recipients. _ANNA_, _18_, 1, 45-53.

Gartner, J.C., Zitelli, B.J., Malatack, J.J., Shaw, B.W., Iwatsuki, S., & Starzl, T.E. (1984). Orthotopic liver transplanattion in children: Two-year experience with 47 patients. _Pediatrics_, _74_, 140-145.

Gilligan, C. (1982). _In a different voice: Psychological theory and women's development_. Cambridge, MA: Harvard University Press.

Gilligan, C. (1988). _Mapping the moral domain_. Cambridge, MA: Harvard University Press.

Glaser, B.G. (1978). _Theoretical sensitivity_. Newbury Park, CA: Sage Publications.

Gold, L.M., Kirkpatrick, B.S., Fricker, F.J., & Zitelli, B.J. (1986). Psychosocial issues in pediatric organ transplantation: The parents' perspective, *Pediatrics*, *77*, 738-744.

Gonzalez, L.L., Martin, L., West, C.D., Spitzer, R., & McEnery, P. (1970). Renal homotransplantation in children. *Archives of Surgery*, *101*, 232-240.

Goodinson, S.M. (1987). Chronic renal failure: A personal account of life before and after transplantation. *Nursing (London)*, *3*, 646-650.

Gradus, D., & Ettenger, R.B. (1982). Renal transplantation in children. *Pediatric Clinics of North America*, *29*, 1013-1038.

Grisso, T., & Verling, L. (1978). Minors' consent to treatment: A developmental perspective. *Professional Psychology*, *9*, 412-427.

Grushkin, C.M., Korsch, B.M., & Fine, R.N. (1973). The outlook for adolescents with chronic renal failure. *Pediatric Clinics of North America*, *20*, 953-963.

Hamburg, B. (1974). Early adolescence: A specific and stressful stage of the life cycle. In G. Coello & D. Hamburg (Eds.), *Coping and adaptation* (pp.101-124). New York: Basic Books.

Henning, P., Tomlinson, L., Rigden, S.P.A., Haycock, G.B., & Chantler, C. (1988). Long term outcome of treatment of end stage renal failure. *Archives of Disease in Childhood*, *63*, 35-40.

Hesse, U.J., Roth, B., Knuppertz, G., Wienand, P., & Lilien, T.V. (1990). Control of patient compliance in outpatient steroid treatment of nephrologic disease and renal transplant recipients. *Transplantation Proceedings*, *22*, 1405-1406.

Hill, J.P. (1980). Understanding early adolescence: A framework. Carboro, N.C.: Center for Early Adolescence.

Hobbs, N., & Perrin, J.M. (Eds.). (1988). Issues in the care of children with chronic illness. San Francisco, CA: Jossey Bass Publishers.

Inhelder, B., & Piaget, J. (1958). The growth of logical thinking from childhood to adolescence. New York: Basic Books.

Kahn, A.U., Herndon, C.N., & Ahmadian, S.Y. (1971). Social and emotional adaptation of children with transplant kidneys and chronic hemodialysis. American Journal of Psychiatry, 127, 114-118.

Kikuchi, J. & Molzahn, A. (1989). Children and adolescents of parents with renal failure on dialysis: Their reported quality of life. Unpublished research study. University of Alberta, Edmonton, Alberta.

Kleinman, A. (1988). The illness narratives: Suffering, healing and the human condition. New York: Basic Books.

Knowles, R.T. (1986). Human development and human possibility: Erikson in the light of Heidegger. Lanham, Maryland: University Press of America.

Koch, U., & Muthny, F.A. (1990). Quality of life in patients with end-stage renal disease in relation to the method of treatment. Psychotherapy Psychsomatics, 54, 161-171.

Kohlberg, L. (1958). The development of modes of moral thinking and choice in the years ten to sixteen. Unpublished doctoral dissertation, University of Chicago.

Korsch, B.M., Fine, R.N., Grushkin, C.M., & Negrete, V.F. (1971). Experiences with children and their families during extended hemodialysis and kidney transplantation. Pediatric Clinics of North America, 18, 625-637.

Korsch, B., Fine, R., & Negrete, V. (1978). Noncompliance in children with renal transplants. Pediatrics, 51, 6, 872-876.

Korsch, B.M., & Negrete, V. (1984). Psychosocial adaptation of children with ESRD: Factors affecting rehabilitation. In R.N. Fine & A.B. Grushkin (Eds.), End stage renal disease in children. Toronto: W.B. Saunders Company.

Korsch, B.M., Negrete, V.F., Gardner, J.E., Weinstock, C.L., Mercer, A., Grushkin, C.M., & Fine, R.N. (1973). Kidney transplantation in children: Psychosocial follow-up study on child and family. Journal of Pediatrics, 83, 399-408.

Landes, L.E., Holman, J.M., & Maxwell, J.G. (1983). Rehabilitation of the end-stage renal disease patient through transplantation. Dialysis and Transplantation, 12, 580-583.

Lerner, R.M. & Galambos, N.L. (1984). Experiencing adolescents: A source book for parents, teachers, and teens. New York: Garland Publishing Ltd.

Levi, M. (1982). The psychological dilemmas confronting the adolescent transplant patient. Nephrology Nurse, 4, 6, 42-45.

Lewis, C.C. (1981). How adolescents approach decisions: Changes over grades seven to twelve and policy implications. *Child Development*, *52*, 538-544.

Lilly, J.R., Giles, G., Hurwitz, R., Schroter, G., Takagi, H., Gray, S., Penn, I., Halgrimson, C., & Starzl, T. (1971). Renal homotransplantation in pediatric patients. *Pediatrics*, *47*, 548-557.

Lincoln, Y.S., & Guba, E.G. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. In D. D. Williams (Ed.), *Naturalistic evaluation*. San Francisco: Jossey-Bass Inc.

Litt, I.F., & Cuskey, W.R. (1980). Compliance with medical regimens during adolescence. *Pediatric Clinics of North America*, *27*, 3-15.

Locking-Cusolito, H. (1990). Renal transplant and uncertainty. *Canadian Nurse*, *86*, 27-28.

Malekzadeh, M., Pennisi, A.J., Uittenbogaart, C.H., Korsch, B.M., Fine, R.N., & Main, M. E. (1976). Current issues in pediatric renal transplantation. *Pediatric Clinics of North America*, *23*, 857-872.

Mcanarney, E.R. (1985). Social maturation: A challenge for handicapped and chronically ill adolescents. *Journal of Adolescent Health Care*, *6 (2)*, 90-101.

McDermott, J., Robillard, A., Char, W., Hsu, J., Tseng, W., & Ashton, G. (1984). Reexamining the concept of adolescence: Differences between adolescent boys and girls in the context of their families. *Annual Progress in Child Psychiatry and Development*, *15*, 155-165.

Meeberg, G.A. (1992). Living with a liver transplant. Unpublished Master's Thesis, University of Alberta, Edmonton, Canada.

Melzer, S.M., Leadbeater, B., Reisman, L., Jaffe, L.R., & Lieberman, K.V. (1989). Characteristics of social networks in adolescents with end-stage renal disease treated with renal transplantation. Journal of Adolescent Health Care, 10, 308-312.

Miller, S.A. (1987). Promoting self-esteem in the hospitalized adolescent: Clinical interventions. Issues in Comprehensive Pediatric Nursing, 10, 187-194.

Mitchell, J.J. (1986). The nature of adolescence. Calgary, AB: Detselig Enterprises Ltd.

Morse, J.M., & Johnson, J.L. (1991). The illness experience: Dimensions of suffering. Newbury Park, CA: Sage Publications, Inc.

Najarian, J.S., Simmons, R.L., Tallent, M. B., Kjellstrand, C.M., Buselmeier, T.J., Vernier, R.L., & Michael, A.F. (1971). Renal transplantation in infants and children. Annals of Surgery, 174, 583-600.

Nekolaichuk, C.L. (1990). Learning to live with uncertainty: The role of hope and medication compliance in chronic illness. Unpublished Master's Thesis, University of Alberta, Edmonton, Canada.

Offer, D. (1969). The psychological world of the teenager. New York: Basic Books.

Offner, G., Aschendorff, C., Hoyer, P.F., Krohn, H.P., Ehrich, J.H.H., Pichlmayr, R., & Brodehl, J. (1988). End stage renal failure: 14 years' experience of dialysis and renal transplantation. Archives of Disease in Childhood, 63, 120-126.

Orr, D.P., Weller, S.C., Satterwhite, B., & Pless, I.B. (1984). Psychosocial implications of chronic illness in adolescence. Journal of Pediatrics, 104, 152-157.

Perlmuter, L.C., & Monty, R.A. (Eds.). (1979). Choice and perceived control. Hillsdale, NJ.: Lawrence Erlbaum Assoc.

Petosa, R. (1989). Adolescent wellness: Implications for effective health education programs. Health Values, 13, 5, 14-20.

Piaget, J. (1932). The moral judgement of the child. New York: Free Press.

Piaget, J. (1953). The origin of intelligence in the child. London: Routledge & Kegan Paul Ltd.

Piaget, J. (1965). The child's conception of the world. Totowa, NJ: Littlefield, Adams & Co.

Piaget, J. (1967). Six psychological studies. New York: Random House.

Piaget, J. (1978). Intellectual development of the adolescent. In A. Esman (Ed.), The psychology of adolescence: Essential readings. New York: International Universities Press.

Pidgeon, V. (1989). Compliance with chronic illness regimens: School-aged children and adolescents. Journal of Pediatric Nursing, 4, 1, 36-47.

Plätzer, H. (1987). Body image (Part 2). Helping patients to cope with changes-a problem for nurses. Intensive Care Nursing, 3, 125-132.

Pless, I.B., & Pinkerton, P. (1975). Chronic childhood disorder: Promoting patterns of adjustment. Chicago: Year Book Medical Publishers.

Potter, D., Belzer, F.O., Rames, L., Holliday, M.A., Kountz, S.L., & Najarian, J.S. (1970). The treatment of chronic uremia in childhood 1. Transplantation. Pediatrics, 45, 432-443.

Potter, D., Feduska, N., Belzer, J., Garovoy, M., Hopper, S., Duca, R., & Salvatierra, O. (1986). Twenty years of renal transplantation in children. Pediatrics, 77, 465-470.

Pozanski, E.O., Miller, E., Salguero, C., & Kelsh, R.C. (1978). Quality of life for long-term survivors of end-stage renal disease. Journal of the American Medical Association, 239, 2343-2347.

Pyke-Grimm, K.A. (1991). Perceptions and concerns of adolescent renal transplant recipients: A descriptive study. Unpublished Master's thesis, University of California, Los Angeles.

Reynolds, J.M., Garralda, M.E., Postlethwaite, R.J., & Goh, D. (1991). Changes in psychosocial adjustment after renal transplantation. Archives of Disease in Childhood, 66, 508-513.

Reznik, V.M., Durham, B.L., Lyons Jones, K., & Mendoza, S.A. (1987). Changes in facial appearance during cyclosporin treatment. Lancet, 1, 1405-1407.

Riley, C.M. (1964). Thoughts about kidney transplantation in children. Journal of Pediatrics, 65, 797.

Rock, P. (1982). Symbolic interaction. In R.B. Smith & P.K. Manning (Eds.), Handbook of social science methods, Vol.2: Qualitative methods (pp.33-47). Cambridge, MA.: Ballinger.

Rogers, D. (1985). Adolescents and youth (5th ed.). Englewood Cliffs, New Jersey: Prentice-Hall Inc.

Sackett, D.L., & Haynes, R.B. (1976). Compliance with therapeutic regimens. Baltimore: John Hopkins University Press.

Salter, M. (1988). Altered body image: The nurse's role. New York: John Wiley & Sons.

Schave, D., & Schave, B. (1989). Early adolescence and the search for self: A developmental perspective. New York: Praeger Publishers.

Shaben, T.R. (1991). Autonomy: A concept analysis. Edmonton, Alberta: Unpublished paper.

Simmons, R.G. (1985). Social and psychological posttransplant adjustment. In N.G. Kutner, D.D. Cardenas, & J.D. Bower (Eds.), Rehabilitation and the uremic renal disease patient (pp. 85-97). New Jersey: Spectrum Publication Inc.

Simmons, R.G., & Kamstra, L. (1980). Long-term rehabilitation of transplant patients. Proceedings of the Dialysis Transplant Forum, 43-46.

So, S.K.S., Mauer, S.M., Nevins, T.E., Fryd, D. S., Sutherland, D. E. R., Ascher, N. L., Simmons, R. L., & Najarian, J. S. (1986). Current results in pediatric renal transplantation at the University of Minnesota. Kidney International, 30, 25-30.

Stern, P.N. (1980). Grounded theory methodology: Its uses and processes. Image, 12, 1, 20-23.

Strauss, A., & Corbin, J. (1990). Basics of qualitative research: Grounded theory procedures and techniques. Newbury Park, California: Sage Publications.

Strauss, A.L., & Glaser, B.G. (1975). Chronic illness and the quality of life. St. Louis: C.V. Mosby Co.

Taber, S.M., Lee, H.A., & Slapak, M. (1982). A rehabilitation assessment of renal transplantees (Based on United Kingdom experience). Nephrology Nurse, 9-14.

Thomson, N.M., Scott, D.F., Cesnik, B., Hooke, D., Wood, C., Marshall, V., & Atkins, R.C. (1989). Morbidity, mortality, and quality of life in long-term survivors of an integrated dialysis/renal transplant programme. Tranpslantation Proceedings, 21, 2184-2185.

Thorne, S.E., & Robinson, C.A. (1989). Guarded alliance: Health care relationships in chronic illness. Image, 21, 3, 153-157.

Tisza, V. B., Dorsett, P., & Morse, J. (1976). Psychological implications of renal transplantation. Journal of the American Academy of Child Psychiatry, 15, 4, 709-720.

Turk, D.C., & Kerns, R.D. (Eds.). (1985). Health, illness, and families: A life-span perspective. New York: John Wiley & Sons.

Van der Vlist, E., Wolff, E.D., Nanta, J., & Van de Ven, A.P.M.W. (1989). Psycho-social experiences of children on dialysis and other renal transplantation illustrated by picture drawing. International Journal of Adolescent Medicine and Health, 4, 45-50.

van Hasselt, V.B., & Hersen, M. (1987). Handbook of adolescent psychology. New York: Pergamon Press.

Weekes, D.P. (1991). Application of the life-span developmental perspective to nursing research with adolescents. Journal of Pediatric Nursing,6,1, 38-48.

Weichler, N.K. (1990). Informational needs of mothers of children who have had liver transplants. Journal of Pediatric Nursing, 5, 88-96.

Weithorn, L.A., & Campbell, S.B. (1982). The competency of children and adolescents to make informed treatment decisions. Child Development, 53, 16, 1589-1598.

Williamson, M.L. (1987). The nursing diagnosis of body image disturbance in adolescents dissatisfied with their physical characteristics. Holistic Nursing Practice, 1, 52-59.

Zamberlan, K.E.W. (1988). Quality of life in school-age children following liver transplantation. Unpublished doctoral dissertation. University of Pittsburgh.

Zarinsky, I. (1975). Psychological problems of kidney transplanted adolescents. Adolescence, 10, 101-109.

Zeltzer, L.K. (1980). The adolescent with cancer. In J. Kellerman (Ed.), Psychological aspects of childhood cancer (pp. 70-99). Springfield, CT: Thomas Publisher.

Zeltzer, L., Kellerman, J., Ellenberg, L., Dash, J., & Rigler, D. (1980). Psychologic effects of illness in adolescence. II. Impact of illness in adolescents-crucial issues and coping styles. Journal of Pediatrics, 97, 1, 132-138.

Zitelli, B.J., Miller, J.W., Gartner, J.C., Malatack, J.J., Urbach, A.H., Belle, S.H., Williams, L., Kirkpatrick, B., & Starzl, T.E. (1988). Changes in life-style after liver transplantation. Pediatrics, 82, 173-180.

Appendix A: Examples of Questions for Interviews

Research Question:
What is the experience of the adolescent following kidney transplantation?

For the teenager:
Tell me about what it is like for you as a teenager having a kidney transplant.

How have things gone so far? (How have you been since your transplant?)

Tell me your story about living with a new kidney after getting out of the hospital to now.

What is different from other times in your life?

What successes have you had since the kidney transplant?

What difficulties have you had since the kidney transplant?

If you could change anything about your life, what would you change? (Zamberlan, 1988).

For the older informant:
What was it like for you to have a kidney transplant during adolescence?

What was different from other times in your life?

What successes did you have in those years as a teenager with a kidney transplant?

What difficulties did you have in those years as a teenager with a kidney transplant?

Appendix B: Informant Face Sheet

Informant: No. of Interview:

Date of Interview:

Age: Sex:

Grade: Appropriate grade in school: Yes No Years behind:

Ethnic/Cultural background:

Renal diagnosis prior to transplantation:

Age first diagnosed:

Date of transplant:

Age at time of transplant: Time since transplantation:

Number of kidney transplants:

Treatment/Medication - Daily Regimen:

Number of Hospitalizations, if any,since transplantation:

Number of Hospitalizations, if any, in last year:

For what reason:

Present Health Status:

Present Graft Function (ie. creatinine levels):

Other:

Appendix C: Information Sheet

Thank you for agreeing to let me phone you about my study. My name is Tracy Shaben. I am a nurse and a graduate student in the Faculty of Nursing. I am interviewing teens who have a new kidney. I want to know what it is like to have a kidney transplant. I am interested in knowing what has happened from the time of getting out of hospital with the new kidney until now. If you want to talk to me after you hear more about the study, I will meet and talk with you in person. If I phone and you decide not to take part in the study this will be O.K. too. If you have any further questions, please call me at 434-3864.

Appendix D: Consent Form

Title of the Research Project: What is it like to have a new kidney?

Researcher:	Supervisor:
Tracy R. Shaben, BScN	Anita Molzahn, RN, PhD
Graduate Student	Associate Professor
Faculty of Nursing	Faculty of Nursing
University of Alberta	University of Alberta
Edmonton, Alberta	Edmonton, Alberta
Telephone: 434-3864	492-6279

I know that tape-recorded interviews will be done lasting about 1 hour. One to three interviews may be needed. I may decide to show the researcher my diary or any other story I have written about what it is like to have a new kidney. If I decide to let the researcher copy my stories I know that I will get my own work back once a copy is made of it. Interviews and some of the stories will be typed. Names or places that I may talk about during the interview or in the stories will not be used at any time. My name will also not be used. Tapes and stories will always be kept in a locked cupboard. They will be stored in a different place from this consent form.

It is not a problem if I decide to leave the study. I will tell the researcher if I do not want to continue with the study. At any time the interview may be stopped if I wish it, otherwise there will be no risks to me. Being in this study will not change the care I get in the outpatient clinic in any way.

Telling the researcher about what it is like after getting a new kidney may bring out feelings that I did not know I had. If I am having a lot of trouble dealing with my feelings the researcher will give me the name of a person I can go to for help.

If I am under 18 years of age, my parents must give consent for me to be in this study. It will be up to me to decide what to tell others about the interview, including my parents. The researcher will not talk about what was said in the interview with my parents. However, if it seems that any of my ideas or actions may harm my health, the researcher will talk to me about these things. After this talk, I know that the researcher will pass on my name and what we spoke about to an appropriate person

The story I give may be used to teach others and may be used in reports. The findings will be used to help others learn more about what goes on with people like me who get new kidneys. It may also help nurses give better care in the future.

If I have any questions I can contact Tracy Shaben at 434-3864. A copy of this consent form will be given to me. I can get results of the study by filling in the tear off portion below this consent and giving this to the researcher.
I agree to be involved in this study.

Signature of Participant______________________

I have read the form and agree to my child being involved in this study.

Signature of Parent ______________________

I have explained the study to both the child and the parent.

Signature of Researcher______________________ Date:

Cut

If you are interested in receiving information about the results of this study, please fill this form out and return to the researcher.

Name:________________________________

Address:____

____