INFORMATION NEEDS, AS PERCEIVED BY PARENTS, REGARDING SYMPTOM MANAGEMENT OF THEIR ADOLESCENT FOLLOWING A KIDNEY TRANSPLANT

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STATEMENT BY AUTHOR

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ABSTRACT

The purpose of this study was to describe the perceived information needs of parents and the processes they used to obtain information to manage the care of their child or adolescent following a kidney transplant. The sample consisted of three mothers who were the primary caregivers of their adolescent who had undergone a kidney transplant within the last year. Descriptions of parents' perceived information deficits and the processes used to manage their adolescents' care were generated from the data using a grounded theory approach. Sharing the Challenge was identified as the emerging core category. Sharing the Challenge represented the processes by which mothers, transplant recipients, and the health care team supported their shared goal of optimizing the health status of the transplant recipient. The descriptions of Sharing the Challenge and the related supporting subcategories provide a framework for understanding the processes by which mothers and transplant recipients fulfill caregiving responsibilities following a kidney transplant.
CHAPTER I
INTRODUCTION

Parenting is a challenging role, with multiple demands on time, energy, and finances. Parenting a chronically ill child imposes additional demands and restrictions, further challenging parents (Deatrick & Knafl, 1990; Dracopoulos & Weatherly, 1983; Frankel, F., 1993; Turner-Henson, Holaday, & Swan, 1992). The family is the primary caregiver for a child with chronic illness, and ultimately responsible for managing their child's condition on a daily basis (Dracopoulos & Weatherly, Jerrett, 1994; Turner-Henson et al.). Consequently, parents of chronically ill children need information, education, and support to feel secure caring for their child at home (Weichler, 1990, 1993). Following a kidney transplant, transplant recipients have a chronic condition requiring complex and ongoing symptom management (Alexander, 1991; Kennedy, 1992). Parents of children and adolescents who have had a kidney transplant have concerns and information needs regarding symptom management of their child on a daily basis (Weichler, 1990, 1993). Optimal care of this population includes addressing the information needs of parents managing the care of a child or adolescent following a kidney transplant (Weichler, 1990, 1993). The research question for this study is: What are the perceived information needs of parents and subsequent processes to obtain and use information regarding symptom management of their child following a kidney transplant?

Statement of the Problem

Kidney transplantation is the treatment of choice for children with end-stage renal disease, although pediatric clients, birth to 19 years, are more likely than adults to suffer
failure of the transplanted kidney (Ettenger et al., 1991; Fine, Salusky, & Ettenger, 1987; Korsch, Fine, & Negrete, 1978; Morgenstern et al., 1994; Rovelli, Palmeri, & Vorsler, 1989). Continuous and daily symptom management of children following a kidney transplant can be complex, yet is essential to optimize and preserve functioning of a transplanted kidney. Parents of children who have had a kidney transplant have added responsibilities in their role as caregiver, therefore have many informational needs related to managing their child's care at home on a daily basis.

**Immunosuppressive Therapy**

Maintaining proper functioning of a transplanted kidney is an arduous and continuous process for pediatric recipients, their parents, and health care professionals (Alexander, 1991; Kennedy, 1992). Maintaining a functioning transplanted kidney requires that recipients take immunosuppressive medications every day of their lives, undergo frequent monitoring of their existing blood levels, and comply with prescribed doses and adjustments (Alexander, 1991; Kennedy, 1992). Current immunosuppressive drug therapy includes taking three separate drugs, Cyclosporin, Prednisone, and Imuran, at distinct and continually changing doses (Jarrell, Nakazato, Crane, & Magelli, 1992). Taking each drug as prescribed each day and never missing a dose is critical to preserve kidney function (Alexander; Kennedy). Any mistakes with prescribed drugs could allow the body to reject the kidney. Accordingly, it is also imperative for these patients to frequently undergo blood studies for evaluation of kidney function, subsequently visiting their physician for

Due to significant advances in transplantation technology in recent years, successful renal transplant is the optimal treatment for children with end-stage renal disease (Ettenger et al., 1991; USRDS, 1990). Yet pediatric transplant patients are more likely than adults to have dysfunction and failure of their transplanted kidney, significantly due to noncompliance with medications (Ettenger et al.; Fine et al., 1987; Rovelli et al., 1989; Morgenstern et al., 1994). Additional reasons exist to explain why pediatric transplant recipients are more likely to reject a renal transplant. Ettenger et al. report adequate blood levels of Cyclosporin, a crucial immunosuppressant, are more difficult to maintain in children due to their rapid metabolism. Because they are more "immunologically reactive," young children may have elevated requirements for potent immunosuppression to maintain a functioning graft (Ettenger et al., p. 137).

Noncompliance with immunosuppressive medication in pediatric transplant recipients is reported in ranges from 17% to 50% (Ettenger et al.; Fine et al.; Rovelli et al.; Morgenstern et al.). Ettenger et al. reported a pediatric population sample (N = 70) 50% noncompliant with taking prescribed medication. The adolescents in the sample were 64% noncompliant with taking prescribed medication. Consequently, 13% of this population lost their transplanted kidney due to medication noncompliance (Ettenger et al.). Administering prescribed immunosuppressive medications is essential to preserve functioning of a transplanted kidney, indicating the profound need of parents and
adolescents to be educated in the importance of adherence to prescribed immunosuppressive therapy.

Parents of renal transplant recipients must be informed of the implications of existing side effects of immunosuppressive therapy. Infection is the number one cause of death in children post renal transplant (Avner, Chavers, Sullivan, & Tejani, 1995). Immunosuppressive drugs counter the body's immune systems' work, therefore lowering the body's resistance to infection (Kennedy, 1992). Consequently, transplant recipients must always guard against exposure to infectious disease and be alert and responsive to early signs and symptoms of infection. Recipients of renal transplants are expected to take their temperature daily.

There are additional side effects to immunosuppressive medications with which parents and transplant recipients must contend. Prednisone therapy often requires diuretic and antihypertensive medications to counter its side effects of sodium and water retention and hypertension (Alexander, 1991; Kennedy, 1992). Transplant recipients with hypertension require that their blood pressure be monitored frequently at home. Prednisone can also cause diabetes mellitus, requiring the addition of insulin to therapies (Alexander; Kennedy). Managing diabetes includes a regime of diet therapy and subcutaneous insulin therapy, based on daily or twice daily blood sugar levels. The degree of functioning of a transplanted kidney is detected primarily by serum creatinine levels, making routine lab studies imperative (Alexander). Lab studies and physician appointments immediately post transplantation will be two to three times weekly for several weeks (P. Yorgin, personal communication, May 4, 1995). Frequency of lab
studies and physician visits will gradually decrease as parameters of kidney function stabilize. Preserving renal transplant function requires a commitment of time, besides motivation and energy, to be informed and responsive (Alexander, 1991).

Most transplanted kidneys, excepting an identical twin donor, will be rejected to some degree (Alexander, 1991; Kennedy, 1992). Rejection can occur within hours of the transplantation operation or any time, even years, after transplant. However, rejection is most commonly seen within the first six months (Alexander; Kennedy). Parents of the transplant recipient and, if relevant, the pediatric transplant recipient must continuously discern signs and symptoms of rejection. Clinical signs and symptoms providing evidence of renal transplant rejection include pain in the area of a transplanted kidney, swelling of hands and feet, fever, high blood pressure, sudden weight gain, decreased urine output, restlessness or anxiety, and proteinuria (Alexander; Kennedy). The recipient of a kidney transplant may experience some or none of these symptoms. Signs and symptoms of kidney rejection may be especially difficult to observe in young pediatric recipients.

The earlier a rejection episode is discovered, the better the chance of saving the kidney. If kidney function is stabilized, partial or complete recovery is possible (Alexander, 1991). If rejection is allowed to continue, the transplanted graft will be lost; the recipient will need dialysis and await a new kidney donor. A "lost" renal transplant is a loss for society and all who were involved in the initial donation, transplantation, and diligent maintenance prior to rejection. Kidney donor resources are limited and associated transplant costs significant.
**Pediatric Renal Transplant Costs, Incidence, Survival, and Rejection Rates**

The costs of initial transplantation according to a University Medical System Renal Transplant Center in southern Arizona are approximately $57,000 (A. Alday, personal communication, May 4, 1995). The costs to maintain a functioning transplanted kidney, primarily medication costs, are $5,000 to $10,000 annually (A. Alday, personal communication, May 4, 1995). Avner et al. (1995) reported median hospitalizations for pediatric renal transplantation to be 17 to 19 days. The study by Avner et al. reported data collected by the 1993 North American Pediatric Renal Transplant Cooperative Study (NAPRTCS). The 1993 NAPRTCS summarized data voluntarily contributed by 82 participating centers in the United States and Canada from January 1987 through January 1993. This study reported on 3,223 children and adolescents who received 2,819 renal transplants during that time. Avner et al. reported the incidence of rehospitalizations during the first five months post transplantation to be 59%, decreasing at six months and beyond. The most common reason reported for rehospitalization was for treatment of rejection (32.7%) (Avner et al.). Rejection episodes, on average, require 3-day hospitalizations, with costs of approximately $2,000 to $2,500 per day (Avner et al.; A. Alday, personal communication, May 4, 1995).

Nationally in 1988, there were 833 new cases of treated end-stage renal disease in pediatric patients (ages 0 to 19), who were insured under the Medicare system (USRDS, 1990). Nationally in 1992 and 1993 (see Table 1) the total number of new pediatric renal transplants was 752 and 785, respectively (Intermountain End-State Renal Disease [ESRD] Network Data, 1995). The majority (45% and 43% respectively) of these
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transplanted pediatric end-stage renal disease patients were 15 to 19 years of age (n = 339 and 335 respectively).

The Forum of End-stage Renal Disease Networks gathers and reports national statistics on geographic regions divided into 18 networks. Arizona is a member of the 15th network, along with the states of Colorado, Nevada, New Mexico, Utah, and Wyoming. As shown in Table 1, incidences of new pediatric end-stage renal disease transplant recipients in the 15th network for 1992 and 1993 were 38 and 44, respectively. Fifty percent (n = 22) of 1993 pediatric transplant recipients in the 15th network were ages 15 to 19. Arizona currently has three medical centers offering renal transplants to children with end-stage renal disease. Eight and 12 pediatric patients received transplants in Arizona in 1992 and 1993, respectively. A 13-year-old female was the first to receive a renal transplant in Pima County in late 1993. In 1994, two young pediatric end-stage renal disease patients received renal transplants in Pima County. By the end of April 1995, two additional patients in Pima County had received renal transplants. A continued improvement in survival of kidney transplants was reported by Avner et al. (1995). Living donor graft (LDG) survival rate was 90% at one year, 85% at two years, and 75% at five years post-transplant. Cadaver graft (CG) survival rates were 76%, 71%, and 62% at one, two, and five years post transplant, respectively. Avner et al. reported that general mortality post transplant continued to be low (LDG 4%, CG 6.8%), but remained high in young infants (age 0-1 year, 17%). Since 1991, greater than 50% of all pediatric renal transplants have been from living donors (Avner et al.).
In a 1993 report, Avner et al. (1995) defined a rejection episode as the decision to initiate specific antirejection therapy, and reported 3,169 episodes of rejection from 1,673 transplants. Overall, 52% of rejection episodes were completely reversed (returned to baseline serum creatinine), 41% were partially reversed (kidney function improved without return to baseline creatinine), and 6% ended in kidney failure or child's death (Avner et al., 1995). This study reported complete reversal declines with increasing number of rejections, from 60% with the first rejection episode to 32% when four or more episodes occurred (Avner et al., 1995).

**Parent's Role as Primary Caregiver**

To a great extent, the successful management of a child following a kidney transplant is dependent on the parents' competence to follow the prescribed care. Additionally, older children, particularly adolescents, begin to take responsibility for their health and health care decisions and are delegated portions of caregiving responsibilities (McCaleb & Edgil, 1994). Thus, successful management also depends in part on the transplant recipients' diligence of adhering to prescribed care (Fine et al., 1987; McCaleb & Edgil, Morgenstern et al., 1994; Rovelli et al., 1989). Following a kidney transplant, prescribed care includes strictly following medication prescriptions, obtaining lab studies, frequently visiting the physician, and following diet and activity instructions (Jarrell et al., 1992; Kennedy, 1992). Parents of a child who has had a kidney transplant must learn to be alert and responsive to the child's often subtle signs of rejection and infection. Parents must monitor their child's temperature, blood pressure, weight, urine output, and affect daily. Additionally, the family must actively avoid circumstances that expose a child who
has undergone a kidney transplant to colds and infections (Alexander, 1991; Jarrel et al., 1992; Kennedy, 1992). Following kidney transplantation, parents and if relevant, transplant recipients, have many added responsibilities and much to learn to optimize the transplant recipient's health status and the survival of the renal transplant.

Parents caring for a child at home following a kidney transplant describe their responsibilities as demanding, producing stress and fear (Dracopoulos & Weatherly, 1983; Weichler, 1990, 1993). Parents harbor fear of their child's death from both infection and rejection (Dracopoulos & Weatherly; Weichler). Weichler (1990, 1993) documented that following a child receiving a kidney or liver transplant, parents expressed they had many needs related to coping and feeling secure with the pending discharge of their child. According to Weichler's studies, informational needs were among the highest type of needs expressed by parents and were mostly related to medications, signs and symptoms of infection and rejection, and physical activity limitations. Parents of children post renal transplant require an array of education, information, and support to feel secure caring for their child at home (Weichler).

Significance of the Study

Maintaining renal transplant function and avoiding rejection require complex symptom management on a daily basis. Parents of pediatric transplant recipients face added parental responsibilities in a new caregiving role. Accordingly, parents require education and information and support in methods to optimally maintain their child's renal transplant and adjust to their new role. The ongoing informational needs of parents of
renal transplant recipients must be met to maximize the quality of care of these children on a daily basis, thus optimizing their renal transplant function and lowering their risks of rejection.

Noncompliance with medication administration is reported in the pediatric population as contributing to an increased likelihood of losing degrees of functioning or an entire renal transplant (Ettenger et al., 1991; Fine et al., 1987; Korsch et al., 1978; Morgenstern et al., 1994; Rovelli et al., 1989). Yet little has been reported in the literature regarding the significance of a parent's role in successfully managing their child's renal transplant. Few studies have addressed the information necessary to adequately support parents in their efforts to care for their child post renal transplant. Weichler (1990, 1993) reported that parents of children post renal and liver transplants ranked informational needs high and said that adequate, timely information contributed to their ability to cope and support their children. Therefore, to optimize pediatric renal recipients' outcomes, research is needed to explore the informational needs of parents concerning managing their child's care on a daily basis. Potential benefits of exploring parents' informational needs exist for both the parents and their children, health professionals and nursing practice, and society.

Parents experience stress and fear relative to the responsibilities of caring for their child post renal transplant (Dracopoulos & Weatherly, 1983; Weichler, 1990, 1993). Addressing potentially stressful events and supplying adequate and timely information have been reported as means to reduce stress and support parents caring for chronically ill children (Lynn, 1986; Weichler; Whyte, 1992). Therefore, to better help the families of
children with chronic conditions, health care professionals need to know more about what
information parents need (Frankel, 1993; Horner et al., 1987; Turner-Henson et al., 1992;
Weichler, 1990, 1993; Whyte, 1992). Exploring parents' perceptions of their informational
needs will serve to heighten health care professionals' awareness of their needs, thus
providing the groundwork necessary to develop educational and support programs to
satisfy their needs (Weichler; Whyte). Ultimately, satisfying the informational needs of
parents caring for a child post renal transplant attempts to lower levels of stress due to the
unknown, increase parental confidence in caring for their child post renal transplant, and
optimize the quality of care provided to their child on a daily basis.

Addressing the informational needs of parents managing the care of their child post
renal transplant potentially can improve parents' ability to care for their child, thereby
improving the quality of care they provide for their child on a daily basis (Bates &
renal transplant recipients' daily quality of care potentially lowers their incidences of illness
exacerbations and consequent treatments and hospitalizations and preserves renal
transplant function, subsequently lowering their risks of rejection (Fine et al., 1987).
Exploration of the informational needs of parents managing the care of their child post
renal transplant potentially improves the quality of care received by pediatric renal
transplant recipients.

Describing the ongoing informational needs of parents caring for a child following
a kidney transplant and the process (es) by which their needs are met can contribute to the
body of nursing knowledge upon which nursing interventions can be based. Accurate
assessment of parents' informational needs will help nurses to be better prepared to identify specific types of information needed and furnish educational programs that address these needs (Weichler, 1990, 1993). Assessing parents' informational needs has the potential to increase nurses' awareness of the processes by which parents and their children manage the condition (Whyte, 1992). Increasing awareness of parents' needs promotes partnerships between health care providers and parents. Partnerships promote increased assurances for health care providers that responsible care is given to a pediatric patient on a daily basis (Smith, 1994).

Assessing the informational needs of parents caring for a child post renal transplant will potentially provide the necessary interventions to inform and support parents, enabling parents to provide high quality of care to their child post renal transplant (Weichler, 1990, 1993). Facilitating parents' provision of high quality care to their child post renal transplant diminishes this population's risks of illness exacerbations and sequelae and potentially improves pediatric renal transplant recipient outcomes, while containing costs. Improving pediatric renal transplant recipient outcomes more effectively utilizes resources by conserving the limited resources of donated organs and public funds.

Statement of Purpose

Studies show that noncompliance with medication administration significantly contributes to rejection and loss of renal transplants in the pediatric population (Ettenger et al., 1991; Fine et al., 1987; Morgenstern et al., 1994; Rovelli et al., 1989). Preliminary studies report that parents of children post renal transplant have many informational needs due to the potential complications of their child's renal transplantation and their
adjustments into the role of caregiver (Weichler, 1990, 1993). To improve outcomes of pediatric renal transplantation, further exploration of the information needs experienced by their primary caretakers is required. The purpose of this study is to describe parents' perceptions of their informational needs regarding symptom management of their child following a kidney transplant and the processes to obtain and use information to manage the care of their child following a kidney transplant.

Summary

Renal transplantation is the preferred method to treat pediatric age groups with end-stage renal disease, although noncompliance with medications plagues its success (Ettenger et al., 1991; Fine et al., 1987; Morgenstern et al., 1994; Rovelli et al., 1989). The successful management of a pediatric renal transplant is dependent, in part, on the parents' competence to follow the prescribed care and if relevant, the transplant's willingness to adhere to prescribed care (Fine et al.; Jerrett, 1994). Prescribed care includes strict adherence to administering medications, obtaining blood studies, recognizing and properly managing symptoms of infection and rejection and routinely visiting the physician (Alexander, 1991; Kennedy, 1992). Parents of a child following a kidney transplant are challenged to manage the complexities of the transplant recipients' care at home. Subsequently, parents have many ongoing concerns and informational needs (Weichler, 1990, 1993). The ongoing informational needs of parents of renal transplant recipients and the process by which they meet those needs must be explored and ultimately addressed to maximize the quality of care of pediatric renal transplant recipients receive on a daily basis. Maximizing the daily quality of care of pediatric renal transplant optimizes
renal transplant function, potentially lowering the risks of rejection. The purpose of this study is to describe parents' perceptions of their informational needs regarding symptom management of their child following a kidney transplant and the processes employed by parents to obtain and use information to manage the care of their child following a kidney transplant.
CHAPTER II

CONCEPTUAL ORIENTATION AND REVIEW OF LITERATURE

As primary caretakers, parents of a child with chronic disease and conditions face the additional parental responsibilities of managing and monitoring the child's condition and related symptomatology at home. Health care providers customarily rely on their perception of the consumer's need in planning and developing health care systems (Horner, Rawlins, & Giles, 1987; Rawlins, Rawlins, & Horner, 1990). However, this approach may be inadequate for parents assuming responsibilities in the roles of primary decision maker, caregiver, and advocate for their child (Horner et al.; Rawlins et al.).

There is growing recognition that the best health care services for children with special needs are family-centered and must consider the social and community support system that relates to the family (Meerpol, 1991; Steele, 1993; Youngblut, Brenan, & Swegart, 1994). Thus, understanding the perceived need of family caregivers from their point of view becomes important to the nursing management of the chronically ill child and family. King (1981) suggested that because perceived needs are defined in part by personal, interpersonal, and social systems of the patient, elements of perception motivate or hinder achievement of health goals of families with chronically ill children. Accordingly, in developing plans and goals, nurses, patients, and families must corroborate perceptions.

Conceptual Orientation

The best way to discover the ongoing education, information, and support needs of parents of children post renal transplant and the process by which they obtain these is to ask the parents themselves (Horner et al., 1987; Rawlins et al., 1990; Steele, 1993).
Accordingly, this study uses the qualitative method of grounded theory. Characteristic of qualitative research is the idea that multiple realities exist and create meaning for individuals (Lincoln & Guba, 1985). Therefore, inquiry and study of a process must be directed to individuals who live them. Exploring chronically ill children's parents' perceptions of their ongoing information needs will offer views of processes by which they identify and learn to manage their child's condition and symptomatology.

Inherent in qualitative research is the inductive method of discovery, allowing for emergence of concepts and themes from the data (Streubert & Carpenter, 1995). Therefore, this study begins with a conceptual orientation, rather than a conceptual or theoretical framework. A conceptual orientation is a broad perspective of the conceptual area being studied, and is the basis of concept identification (Hinshaw, 1979).

Parents of children who have had a kidney transplant are challenged to manage the complexities of their child's care at home, yet little has been reported regarding the significance of the parental role in successfully managing their child following a kidney transplant. On review of the literature, three dominant concepts emerged in relation to parents of chronically ill children and form the conceptual orientation for this study: impact of chronic illness, parental information needs, and adaptation processes.

**Impact of Chronic Illness**

The impact of pediatric chronic illness on parents and family is profound, changing previously known parenting roles, family patterns, spousal relationships, and social interactions (Dracopoulous & Weatherly, 1983; Gold, Kirkpatrick, Fricker, & Zitelli, 1986; Whyte, 1992). Recurring health crises, time constraints, and lack of sufficient finances
contribute to parents' uncertainty of the future (Dracopolous & Weatherly, 1983; Turner-Henson et al., 1992; Whyte, 1992). Parents' greatest fear is the uncertainty of their child's survival (Cohen, 1993; Dracopolous & Weatherly; Gold et al., 1986; Whyte).

Parental Information Needs

Information needs of parents caring for a child with a chronic illness or condition at home include factual materials about the child's condition, care, and future (Horner et al, 1987; Meerpol, 1991; Weichler, 1990, 1993). Families of children with chronic conditions also require information about available resources, programs, and social support (Horner et al.; Meerpol; Weichler). Parents of children with chronic conditions have ongoing medical and nonmedical information needs to maintain the health and well-being of the child and family.

Adaptation Processes

Providing for the needs of a child with a chronic condition at home requires parents, primary caregivers, and family to adapt to new roles and new skills over time (Deatrick & Knafl, 1990; Jerrett, 1994; Youngblut et al., 1994). The processes involved for parents to take on the responsibilities that will enable them to manage their child's daily chronic care include mobilizing family and social supports and acquiring information (Jerrett; Lynne, 1986; Rawlins, 1991; Youngblut et al.). As parents learn to manage their child's care, they become more confident as primary decision makers for the child's ongoing needs (Deaton, 1985; Jerrett; Youngblut et al.).
Review of the Literature

A preliminary literature review serves as a point of reference for the conduct of the study (Streubert & Carpenter, 1995). Literature is reviewed on the following: The impact of pediatric chronic illness, parental information needs, and parent and family adaptation.

Impact of Pediatric Chronic Illness on Parents and Family

Several recent studies provide evidence to support the profound impact pediatric chronic illness has on the family and the challenges facing parents managing their child's chronic condition at home (Cohen, 1993; Dracopoulos & Weatherly, 1983; Gold et al., 1986; Turner-Henson et al., 1992; Whyte, 1992). Two descriptive reports and two qualitative studies are included that explore and describe parents' experiences (Cohen; Dracopoulos & Weatherly; Gold et al.; Whyte).

Gold et al. (1986) collected data over a four year period from parents attending a support group for parents with children undergoing heart or liver transplants. The investigators learned of the many psychosocial issues common to this group. Chronological clustering of psychosocial issues of the transplant process as viewed by parents suggested three phases: preoperative, perioperative, and long-term postoperative. A central focus of the long-term postoperative phase was the long awaited return to home. Returning home required adaptation to a new parenting role, readjustments in their family structure, and continued uncertainties of the future. Uncertainties of the future included the fear of organ rejection and their child's death. Following a kidney transplant a child has a new condition called organ transplant and more energies must now be shifted to
normalization and reintegration of the child and primary caregiver into the family, and the family into society.

Dracopoulos and Weatherly (1983) are two mothers who described the experience of being primary caregivers for their child diagnosed with end-stage renal disease, unsuccessfully transplanted. Responsibility for managing and monitoring their child's compliance with prescribed treatment was a chronic burden. Time and energy were consumed with prescribed treatments, including dialysis three times per week for six to eight hours per day, negotiating the school system for frequent absences and makeup assignments, and attempts to allow their child to be "normal" and participate in social and sporting events. Other stressors described included constant changes in their child's appearance, personality, and energy levels due to their prescribed steroid therapy. Losses included their careers, their sense of accomplishment for financial contributions, and enough income to make ends meet. Their child's chronic illness was a chronic drain on their family finances, even with insurance. In addition, stressors resulted in chronic exhaustion and marital strain. Ultimately, their most difficult stressor was the fear of death of their chronically ill child. This report exemplifies the long term toils of the care of a child with a chronic condition.

Whyte (1992) reported an analysis of four case studies of families caring for a child with the chronic illness, cystic fibrosis. The focus of this study was the nursing contribution to the support of the family. An additional aim of this study was to report some aspects of the families' own accounts of their experience caring for a child with cystic fibrosis (CF). The data used for the case studies were collected over a 5-year period as an
ethnographic study. Additional qualitative approaches, including grounded theory and life history interviews were used by the investigator. At the end of the study life history interviews were conducted with each member of three of the families, and the mother of the fourth family.

Four research questions were reported in this study along with their induced concepts. The first question addressed the genetic implications of cystic fibrosis. The associated themes were an "assault to self image," "frustration of generativity," and "difficult decisions" (Whyte, 1992, pp. 320-321). The parents and family members found it exceptionally difficult to deal with the implications associated with a disease of genetic impairment.

A second question addressed how families respond to the life-threatening nature of CF. The associated themes were "suffering" and "facing the facts" (Whyte, 1992, pp. 321-322). Each parent mentioned fear. Family members used denial as a way to cope, focusing on their child's treatment instead of prognosis. Parents also reported they felt anger and blame, closely followed by guilt.

A third question addressed what events precipitate crisis in the lives of families caring for a child with CF, producing the themes of "the chronic burden of care" and "the state of crisis" (Whyte, 1992, p. 322). Children with CF require daily routines of physiotherapy to aide them with their thick secretions, taking up to one hour and possibly several times per day. Spousal discord often resulted from the constant bartering of caregiving responsibilities. Added to the chronic burden of care, were the stresses of ordinary family life. Financial burdens contributed to the cumulative burden for all families. Due to the
life-threatening nature of CF, episodes of crisis were not uncommon, but always a source of stress, which required considerable energy and emotional strength.

The last question addressed how caring for their child affected interaction patterns and the coping response of families? "Synchrony between partners" and "parents and children" are the themes reflecting families' need to communicate well and resolutely "travel together" through the experience (Whyte, 1992, p. 323). Whyte reported these families depended on a nurse for information, education, support, and a connection between the clinic and the home and between the home and the school.

Turner-Henson et al. (1992) used three questionnaires to examine parents' caring responsibilities for their chronically ill child, including both parenting and chronic illness caring behaviors. Structured interviews were conducted in subjects' homes by trained female interviewers. Data were collected in both Alabama (n = 158) and California (n = 209), with no statistically significant differences in findings attributed to demographic differences in population size, racial ethnicity, per capita income, education, and resources.

Findings reflect the experiences of 367 children and their parents, stratified by socioeconomic status, randomly drawn from a sampling frame of 937. Most of the caregivers were mothers or females, ages 20 to 55 years, who had assumed the mother role for the chronically ill child. Most of the sample was white (59%) or black (24%), with dual-parent households representing only 50% of the sample, single parent households 18.4%, extended family member households 31.7%. Over half of the caregivers were employed full-time outside the home. Children in the sample were ages 10 to 12 with chronic illnesses in 10 diagnostic categories.
Average daily treatment times for this sample totaled 42 minutes. Mothers for the majority of the sample (58.4%) assumed primary responsibility for daily medical treatments in the home. The chronically ill child was solely responsible for the treatment in only 19.7% of the sample, whereas fathers assumed minimal responsibility for the child's medical treatment (18%). In summary, this study confirmed that mothers, or acting mothers of chronically ill children, maintain primary responsibility for medical treatments and household chores, besides fulfilling the demands of employer expectations or the constraints faced by single parent families.

The qualitative approach of grounded theory was used by Cohen (1993) to conduct a secondary analysis of data from several sources to describe uncertainty as a multidimensional concept pervading the everyday life of families who have a child diagnosed with a life-threatening, chronic illness. The findings of this study are part of a more comprehensive, longitudinal, grounded theory study that explored parental behavior under conditions of emergent and sustained uncertainty (Cohen). Cohen analyzed longitudinal data from a study by Dr. Ida M. Martinson at the University of California, San Francisco, entitled "The Impact of Childhood Cancer on American Families," relevant literature on uncertainty, additional data from interviews of parents of 21 children, and published autobiographies of parents of children with the following life-threatening, chronic illnesses: cancer, hemophilia, congenital heart disease, cystic fibrosis, and Lowe's syndrome.

Cohen (1993) reported that after a child is diagnosed with a life-threatening chronic illness, multiple dimensions of uncertainty permeate every aspect of the family's
life, experienced as "existential, etiological, treatment, situational, biographical, social uncertainties" (p. 138). Each dimension of uncertainty is interactive with and under the influence of the other. With these uncertainties, families search for a new frame of reference to give meaning to their present circumstances.

Existential uncertainty refers to what is foremost in the mind of all parents following the diagnosis: what does the disease mean for their child's survival and quality of life? Parents are generally left with the stress of an uncertain prognosis for their child.

Etiological uncertainty is related to the need for parents to understand why the disease occurs and if it will occur again. The etiology of some genetic diseases is well established, however much may be unknown. Parents learning of a new diagnosis may be presented with both information overload and information deficit, making decisions about treatment difficult.

Under time urgency, treatment uncertainty was a source of significant stress. The unfamiliar environment of the hospital created situational uncertainty. Biographical uncertainty in this study addressed the contradictions parents felt in participating in the suffering of their child. Biographical uncertainty included conflicts in spousal and family relationships and the need to reevaluate family plans and goals to accommodate their new life, after the diagnosis. Social uncertainty occurred because chronic illnesses carry stigmas and some friends and co-workers were uncomfortable with their tragedies, which made previous and future social situations unpredictable. The diagnosis of a life-threatening, chronic illness changes the families' previously known order of life, replacing it with multiple dimensions of uncertainty.
In summary, the impact of pediatric chronic illness on parents and their families significantly infiltrates every aspect of daily life. Relationships between family members and with society change, requiring readjustments in the family structure and adaptation to new roles. Uncertainty and fear predominate thoughts of their future together. Everyday life contains normal stresses of parenting, compounded by recurring health crises and the chronic burdens of caregiving, associated losses, financial hardships, and time constraints. Females, usually mothers, assume the primary caregiver role for a child with chronic illness. Some mothers worked outside the home, besides providing caregiving responsibilities. Some mothers expressed the loss of no longer working outside the home due to caregiver responsibilities.

**Parental Information Needs**

The challenges facing parents caring for a chronically ill child result in parents requiring education and information concerning a myriad of aspects of their lives as a family and their child's illness (Horner et al., 1987; Weichler 1990, 1993). To assess the special concerns of parents caring for a chronically ill or disabled child, Horner et al. (1987) surveyed a convenience sample of parents \(N = 493\) in a Midwestern city. Their names were obtained through the State Crippled and Chronically Ill Children's Program, the local Head Start Program, and local parent support groups. A total of 164 parents returned mailed questionnaires developed by the authors to identify families' program, socioeconomic, and health care needs. More mothers (87%) than fathers (9%) responded to the questionnaire. Many chronic conditions were represented among the 164 children. Results indicated that parents wanted information in many areas. The greatest information
needs concerned planning for their child's future (55%), identifying appropriate community resources (49%), and understanding how the illness or disability affects their child's physical and emotional growth (45%). Additional informational needs included printed material about their child's condition (39%), advice on behavior management (38%), updates on their child's school progress (33%), and information on ways to encourage their child to appropriately interact with peers (32%). Information deficits concerning the child's health and wellness were consistently expressed by this sample. A limitation of this study includes that no reliability or validity of the instrument was reported.

As a new Clinical Nurse Specialist in an orthopedic outpatient department, Meerpol (1991) distributed a questionnaire to a convenience sample of 78 parents and their children attending one of the four speciality clinics to identify the needs for education and support. The distributed questionnaire was an adaptation of a questionnaire developed by Schade and Passo (1981) and further revised by Coffman (1983). The questionnaire gave these parents (N = 59) and their children the opportunity to identify their needs for education and support, report which of these had been discussed in clinic, and indicate preferences for methods of receiving information. The children ranged in age from 15 months to 21 years (M = 9.1). Information needs surrounding their child's condition included information related to diagnosis (78%), effects of the diagnosis on the child's development (73%), and ways to get answers between clinic visits (63%). More than half of the participants indicated additional information deficits about surgeries and medications, effects of their child's chronic condition on fertility, and ways to explain their child's condition to their families and friends and their child's school. Parents preferred to
receive information and support through individual meetings with professionals (73%), pamphlets (73%), and newsletters (61%). The responses indicated that parents required additional information about diagnosis and treatment in context of the development of the whole child.

Weichler (1990, 1993) reported studies identifying the information needs of parents with a child receiving a liver or a renal transplant. To identify information needs, Weichler (1990) used a descriptive, exploratory design and interview data from a convenience sample of eight mothers of children aged five through 16 years. The interview guide consisted of 13 open-ended questions, developed by the author, and pilot tested on one mother who met the criteria for study inclusion. Four of the 13 questions elicited the mother's perception of the child's illness, and the remaining nine questions elicited the mother's information needs related to liver transplantation, within the first month after their child's transplant. The mean length of time after transplantation was 2.5 weeks. The condition of all transplant recipients' was stable at the time of interviews. Interviews were tape-recorded, transcribed, and content analyzed, revealing five transplant stages (evaluation-waiting period, intraoperative phase, intensive care unit phase, postsurgical recovery phase, and discharge phase) and medical and nonmedical categories.

Weichler (1990) reported specific information needs and concerns during each phase of the transplant process. Across all categories, this sample needed more information about laboratory values, process of organ rejection, presence of infection, and ways of emotionally supporting their children. The consistent emotional response
expressed by this sample was fear. Parents feared the death of their child and feared the child's rejection of the transplanted organ.

Regarding the discharge phase, mothers were asked "What essential information is important for you to possess in order to care for your child after discharge from the hospital?" (p. 92). Parents expressed both medical and nonmedical information needs. Medical information needs were concerned with medications, signs and symptoms of infection and rejection, blood pressure parameters, childhood immunizations and diseases, and their child's future fertility. Nonmedical information needs included physical activity limitations, details in their discharge teaching book, follow-up procedures, obtaining lab values, diet, return to school, whether their child would now lead a "normal life," and how the family would reintegrate their lives.

This sample actively sought information, used information seeking as a way to cope, and identified available resources and support people as important, including parents who had already experienced the process. Seven of the eight mothers in this sample found a parent support group helpful. Four of the eight mothers in this sample identified the phase of preparing to go home as the time they needed information the most. Information deficits regarding physical care of the child and reestablishing a normal home environment were found. A limitation of this study, cited by the author, was the timing of interviews soon after the child's transplant surgery, which may have limited this sample's comprehension of the whole process, thus all possible information needs.

In a descriptive, exploratory study, Weichler (1993) asked about the information needs and concerns of primary caretakers of pediatric liver or renal transplant recipients.
A semistructured questionnaire consisting of 11 questions, developed by the investigator, was distributed to a convenience sample (N = 50) over a 2-year period. Questions concerning primary caretakers' needs were asked in relation to the following six phases of the transplant process identified by the author: preevaluation-waiting, intraoperative, intensive care unit, postsurgical recovery, discharge, and reintegration. Some questions were open-ended, others requested information to be ranked in order of importance. The reliability and validity of the tool had been established in two previous studies (Weichler, 1988; Weichler & Hakos, 1989).

Potential participants took the questionnaire home upon discharge, resulting in a return rate of 42% (n = 21) and a response time for returns of two to three months after leaving the hospital. Twenty respondents were mothers and one a father, 24 to 43 years old. The transplant recipients were ages 6 months to 16 years, (M = 7). Eleven of the children received liver transplants and 10 received kidney transplants.

The major concerns of this sample, across all phases, were: rejection, infection, normalization of the child and family unit, and reintegration into society. In the discharge phase, 80% of parents of children post renal transplant identified medications as the primary area they needed information, followed by the signs and symptoms of rejection and infection (60%). Parents of children post liver transplant ranked the need to know signs and symptoms of rejection and infection as the primary information needs (64%), followed by knowing the medications and how to administer them (54%). In the reintegration phase 30% of subjects stated they resumed a "normal" family life almost immediately following discharge; twenty percent stated they had not yet achieved a
"normal" family unit and "probably never would" (Weichler, 1993, p. 138). This sample identified two major problems during the reintegration phase, marital conflict and disciplinary problems due to "acting out" of the organ transplant recipients. Mothers generally stayed with the transplant recipient during hospitalization, sometimes two to three months, and averaging four weeks. Weichler (1993) reported all of the parents in this sample used information seeking as a means to cope and needed information the most before transplantation (preevaluation-waiting phase) and before assuming care for their child at home (discharge phase).

In summary, parents' necessity for information related to care for a chronically ill child is paramount and ongoing. Parents require specific medical information to fulfill the responsibilities of managing prescribed care at home. In addition to information needs related to the physical care of their child, parents require ongoing information about reestablishing their home environment, reintegration into society, and ways to promote their child's continued growth and development.

**Parent and Family Adaptation**

A third common theme reflected in the literature is the processes of adaptation required of the parents and family of a chronically ill child to adjust to the consequences of their child's chronic illness. Deatrick and Knafl (1990) explored the concept of "management behavior" to understand how families who have children with chronic illnesses make daily adjustments to adapt to the children's special needs through "goal, underlying conceptual dimension, implementor, and foci" (p. 16). Goal was defined as the result toward which the family's effort is directed related to maintaining the affected child's
health care. The underlying conceptual dimension was qualities or the organizing framework characterizing the management behaviors. The implementor component describes the person, usually the mother, responsible for carrying out the behaviors necessary to accommodate to the child's illness or disability. It is common for an affected child to become increasingly responsible for his/her own care, evolving as the implementor.

Deatrick and Knafl (1990) defined foci in terms of three broad areas for management behaviors: ill child, family, and social system. "Target behaviors" are the actual, observable behavioral accommodations family members use to manage on a daily basis (p. 17). The possibly complex symptom management and treatment of the ill child warrants behavioral accommodation in the ill child's activities of daily living, treatment regimens, and family relationships. Management behaviors on the family level for example, reallocation of resources, are those that have implications for the family unit and its members. Resource reallocation includes use of finances, time, and energy for physical and psychological care of the ill child versus the well family members. The chronically ill child often requires additional social systems to obtain treatment, information, and services. Management behaviors of the family are then targeted toward people and organizations outside the family, including schools, churches, and organized sports. Parents seek normalization for their chronically ill child, requiring negotiations with teachers, principals, coaches and other organizational leaders. Deatrick and Knafl (1990) explicated a conceptual framework to begin viewing the necessities of parental coping and adaptation in the care of chronically ill children and as primary caregivers to dependents.
Jerrett (1994) employed a phenomenological approach to investigate how parents of children with chronic juvenile arthritis experience their child's illness. Participants (N = 19) were parents, in two-parent families, of children with juvenile arthritis. Both mothers and fathers of the children were interviewed two to three times separately in the home. One father was not willing to be interviewed. Jerrett reported parents' "coming to know" the experience of caring for a child with juvenile arthritis as a learning process, based on the conviction that the family held responsibility for their child's daily care (p. 1050).

Common themes included the initial responses of "turmoil and confusion" and "struggling to know," and progression to "a different way of knowing" and "taking charge" (Jerrett, 1994, p. 1050). The illness (juvenile arthritis) altered parents' perception of their role and the difficulties involved in finding meaning in their new realities. Parents initially felt confused and unable to cope with what was happening to their child. They were expected to add painful and time consuming caregiving tasks (daily exercises involving painful stretches of the joints, distasteful medications, splints to be applied to arms, legs, and neck at night, and multiple trips to the physiotherapist and other health professionals) to parenting responsibilities. Parents expressed anger, sadness, feelings of helplessness, and said that words could not describe their devastation.

In their struggle to know their new parenting role, they expressed how a lack of information about the illness complicated their sense of feeling overwhelmed, and how they had obtained the information only after "a lot of perseverance" (Jerrett, 1994, p. 1053). This sample experienced their situation differently once they began to accept managing their child's illness on a daily basis, diligently controlling time to accommodate
their responsibilities. Eventually, caregiving activities became integrated into family life.

Some parents in this sample challenged medical authority as they developed expertise regarding their child's care. This subjects in this sample felt reassured to be a part of the decision-making process. Their growth of confidence increased their involvement, bringing some meaning to their ability to affect change and affirming their own way of knowing. In the context of learning, parents in this sample accepted a new parental role and reality and regained confidence and control as caregiving parents.

Youngblut, Brennan, and Swegart (1994) conducted an exploratory study of families recruited from a pediatric rehabilitation hospital, to describe typical decisions and problems families experienced on a day-to-day basis, their coping strategies, and family resources. Three scales were used to measure family strengths, family resources, and coping strategies used in dealing with the child's illness. A one hour interview was also conducted. Families were asked to identify two decisions they faced recently in the care of their child, to whom they go when they have a question about caring for the child, and major problems they face in caring for their child. For each problem identified, the interviewer asked to whom they go for support and where they get information for that problem. The interviewer also asked if they had other problems the family must deal with.

The convenience sample consisted of 10 families with a child discharged from the pediatric rehabilitation facility during the six months before the interview. Most families were two-adult families (n = 7). Three families were single mother homes. Children ranged in age from one to 18 years (M = 5.3, SD = 5.46). Five children had primarily neurologic conditions, including cerebral palsy, closed head injury, paralysis, and seizure
disorder. Four had primarily respiratory conditions. One child had chronic renal failure. Most of the sample required a wheelchair and daily medications (n = 7). Other required daily treatments included dialysis, respiratory treatments, and continual oxygen.

Recent medical decisions included consenting to surgery for the child, whether to go to the hospital, and whether the child should use a walker or wheelchair. Developmental decisions included allowing the child to play on the floor, the use of the high chair for feeding, revising the child's bedtime, and issues with schoolwork. Problems included: toilet training, problems with transportation, sleep/wake patterns, nutrition, and discipline. Health professionals were consulted about decisions concerning medical treatment options or changes in care due to the child's development. Informal sources of support were consulted about common child problems, such as toileting, sleep, nutrition, and discipline. This sample reported receiving adequate support services, and frequently used health care services including the family physician, physical and occupational therapists, caseworkers, and the school system. Families reported a moderate amount of strengths, including trust in each other, shared values and beliefs, few conflicts, ability to express their feelings, family pride, family loyalty, and the belief that things work out well for them, despite their tendency to worry about many things.

Strategies employed to cope were categorized as mobilizing family, acquiring social support, and seeking spiritual support, sharing difficulties with relatives, seeking information and advice from the family doctor, seeking professional counseling and help, and receiving gifts and favors from neighbors. Additional services desired included financial resources and alternate child care providers. This study provides details of the
many decisions caregivers could typically encounter and the methods employed by this sample to effectively adapt to continual needs with available resources. Youngblut et al. (1994) assert this study provides baseline data for continued research needed on ways to help integration of the family and to support the family's adaptation to providing for the child's needs in the home.

To identify factors influencing the coping efforts of mothers of acutely-ill hospitalized children, Lynn (1986) interviewed a convenience sample of 45 women, all white, whose children aged one to 24 months were hospitalized on a general pediatric unit. After the children had been hospitalized for at least two but no more than seven days, the consenting mothers were interviewed and trained in the magnitude estimation procedure. The subjects used a magnitude estimation procedure to evaluate 16 stressful stimuli from a previously developed tool by Schepp (1985), for each of the following concepts studied: Expectation of events, situational control, situational anxiety, and coping efforts.

One hypothesis tested was that the more parents anticipated or expected events as likely to occur during the child's hospitalization, the greater would be their control over the variables in the situation, leading initially to less situational anxiety and ultimately to less coping effort needed to adapt to the whole experience. It was also proposed that the more the parent expected or anticipated events, the less would be their situational anxiety, again resulting in less coping effort being needed.

As predicted, the more mothers anticipated or expected certain events, the less the situational anxiety and the lower coping effort was found to be. The parts of a hypothesis not supported in analysis were the links between anticipation of events and situational
control and situational control and situational anxiety. The extent of a mother's influence over variables in the child's situation (situational control) was not supported as related to any degree of situational anxiety. The results support that children whose parents can offer them attention, support, and comfort during hospitalization recover more rapidly. Coping and adaptation to the hospital experience are promoted by the provision of relevant information to parents. Parents can offer their hospitalized child support only when the parents have adapted to the hospital experience. Therefore, education to specifically address potentially stressful events is a very important nursing action (Lynn, 1986).

Rawlins (1991) conducted a qualitative study to develop a beginning substantive theory describing the needs perceived by caregivers and the processes by which caregivers can get needs met. In addition to grounded theory, Rawlins used family systems theory to view the family as an interdependent, dynamic group in which anything affecting one member would influence the whole family. Family caregivers were selected for interview by theoretical sampling. A purposive sample of seven families currently engaged in caregiving activities participated in the study. Data collection was accomplished through one-time, audiotape-recorded interviews with family caregiver groups in their own homes. Children and adults were interviewed together using a semistructured questionnaire. Recipients of caregiving included a wife with back pain, a developmentally delayed daughter, a husband disabled by an amputee, a husband with Alzheimer's, a young developmentally delayed grandson, a frail elderly mother, and a frail elderly aunt.

Three themes were identified from the data (help, hope, and happiness) and the interrelationships of the needs with processes used to meet the needs. Written face
validity was provided by five families, unanimously agreeing with the author's identification of the samples' needs and proposed relationships (Rawlins, 1991).

The first caregiver need identified was the need for help. Caregivers needed help with giving direct care to the dependent person in the home, help from health professionals, especially for ongoing information needs, and help from family members and friends for respite or relief from the continuous burden of caregiving. The second need, hope, was needed from God and other people. This sample drew strength and in part meaning of their role through hope. The third need, happiness, was reflected in terms suggesting unhappiness: "loss of life's pleasure" (Rawlins, 1991, p. 215).

The basic social process of "connecting" was identified as fundamental, characterized as finding viable, helpful resources to meet perceived holistic needs (Rawlins, 1991, p. 213). Subprocesses of "misconnecting" and "disconnecting" were identified as concurrent processes that were both functions and deterrents of the connecting process (Rawlins, p. 213). Misconnecting characterized resources or situations that were not helpful, and included health professionals who did not attend to the holistic aspects of the patient and the family. Disconnecting depicts the loss of certain resources and situations. Caregivers' self-sacrificing behaviors and the stigmas of some chronic illnesses often resulted in social isolation, loss of friendships, and loss of self-esteem.

The nature of decision making by parents of children with asthma was studied in an attempt to identify adaptive and maladaptive decision makers and to evaluate to the degree to which adaptiveness may predict outcomes in terms of quality of life and illness control (Deaton, 1985). Thirty parent-child dyads participated in the study. Most of the sample
were rated by their physicians as having asthma of average or below average severity. Interview data, using audiotaped structured interviews with each parent-child dyad, were collected on parental knowledge of asthma treatment, decisions regarding compliance, and predictions of their child's performance on various tasks. Ratings of the severity of the child's asthma from one (much less severe than most children with asthma) to five (much more severe) were made. The child's quality of life was rated on a 5-point scale and the parents' reported level of compliance with medications and with behavioral recommendations was also rated on a 5-point scale. Data were also gathered on the children's task performance, adaptiveness of compliance decisions (The Adaptiveness Rating Scale) and medical and quality of life outcomes. Based on the interview data, The Adaptiveness Rating Scale was used to rate patients' decisions about compliance including decisions to comply and not to comply. Parents completed a "Breathing Self-Report Postcard" which reported the child's breathing difficulties, asthma attacks, and medical regimen each day during three 1-week periods during the three months following the interview. Physician and medical charts were consulted for information on the number of phone calls and visits to the physician over a 9-month time span, the number and duration of hospitalizations during this period, the prescribed medical regimen, and ratings of asthma severity.

Results showed that parents varied in the adaptiveness of their compliance decisions. Greater adaptiveness was associated with better outcomes; degree of compliance was not. Parents tended to underutilize medications increasingly over time from diagnosis. There was a low moderate negative correlation between diagnosis and
degree of compliance with medications ($r = -0.32, p < .05$). Medications were less likely to be given as prescribed when physicians viewed the asthma as less severe. There was a moderate positive correlation between compliance and the physician's ratings of asthma severity ($r = 0.42, p < .05$). Compliance with medications and with behavioral recommendations were not significantly related to medical outcome variables of amount of hospitalization and rated quality of life. Medication compliance was correlated with parents' rated adaptiveness ($r = 0.50, p < .01$). Parents' rated adaptiveness was also moderately correlated with quality of life outcomes variables ($r = 0.42, p < .05$) indicating children of more adaptive parents tended to experience fewer restrictions in activities and negative effects due to asthma. Similarly, adaptiveness was negatively correlated to a moderate degree with number of school absences in the last year ($r = -0.38, p < .05$).

Compliance with regimen was unrelated to either the quality of life or illness control outcomes. Children of more accurately predictive parents required fewer medical interventions and parental adaptiveness predicted quality of life outcomes. Parents made conscious decisions not to comply with the prescribed medical regime based on information of the prescribed regime and on intimate knowledge of their child. Deaton asserted that this level of conscious decision by parents reflect their adaptiveness as the primary caregiver with the evolved competence to judge what may be best for their child and is superior to passive compliance.

In summary, families who have children with chronic illnesses, like primary caregivers for dependents, adjust to accommodate caregiving and related activities and support. Adaptation of individuals and the family involves a process over time. The
process has been described as learning, mobilizing family and social supports, acquiring
information, and the processes of connecting, misconnecting, and disconnecting. The
evolved ability to exercise degrees of control through conscientious decision making
promotes parents and primary caregivers feelings of confidence. Managing a dependent's
care or that of a child with a chronic condition requires the adaptation of individuals and
families to new roles and new realities.

Summary of Literature Reviewed

Pediatric chronic illness has a long term impact on parents and their families,
resulting in changes in family and societal relationships and requiring family structure and
role readjustments. The normal stresses of parenting are compounded by fear and
uncertainty for the future, recurring health crises, chronic burdens of caregiving, associated
losses, financial hardships, and time constraints. Mothers and other females primarily
assume the caregiver role for a child with a chronic illness, in addition to other
responsibilities.

Many studies support that the responsibilities and management of the care of a
child with a chronic condition at home are challenging for parents, creating ongoing,
education, information, and support needs (Gold et al., 1986; Horner et al., 1987; Jerrett,
1994; Meerpol, 1991; Rawlins et al., 1990; Turner-Henson et al., 1992; Weichler, 1990,
1993; Whyte 1992; Youngblut et al., 1994). Parents require both medical and nonmedical
information to manage their child's prescribed care. Information in the context of the
whole child facilitates promotion of the child's continued growth and development,
reestablishment of the home environment after hospitalization, and reintegration of the child and family into society.

Adaptation is a process required of families and primary caregivers to accommodate caregiving needs and integrate their new roles and reality. The process has been described as learning, mobilizing family and social supports, acquiring information, and the processes of connecting, misconnecting, and disconnecting. Confidence and increased caregiving expertise evolve with the processes of adaptation making dependent caregivers and parents of chronically ill children increasingly viable participants in the decision making of care and treatments.

Research Question

A literature review of parental responsibilities, management behaviors, and subsequent information required to care for a child with a chronic condition revealed a lack of research addressing the information needs of parents of post renal transplant children, specifically in the area of the process (es) by which parents attempt to obtain and utilize information. Therefore, the research question for this study is: What are the perceived information needs of parents and subsequent processes to obtain and use information regarding symptom management of their child following a kidney transplant?

Definition of Terms

Parent. Biological mother or father, legal guardian, or primary caregiver who assumes primary caregiving responsibilities and is accountable for the well-being of a child or adolescent.
Parental Information Needs. Any factual deficit expressed by a parent attempting to fulfill the responsibilities of the role.

Parental Perception. Representation of reality by a parent related to past experiences, concept of self, biological inheritance, educational background, and socioeconomic group (King, 1981).

Symptom Management. Following prescribed instructions, administering prescribed medications, monitoring the condition and care, utilizing information to detect signs suggesting health or illness, and reporting variances in health status.

Child or Adolescent Post Renal Transplant. A kidney transplant recipient between the ages of birth to 19 years, who was transplanted within the last year and resides with a parent.

Summary

In qualitative research a conceptual orientation is appropriate for providing a context for the research question. The conceptual orientation for this study consists of: the impact of childhood chronic illness on parents and the family, parental information needs, and adaptation processes. The review of literature contributes to the basis for the study. Literature was reviewed in the areas of chronic childhood illnesses, parental responsibilities regarding symptom management of childhood illnesses, and the processes of parent and family adaptation related to caring for a chronically ill child.

Several quantitative studies have measured parenting related to chronic illness caring behaviors, program, social, and health related information needs of parents of chronically ill children, family problems, strengths, resources, and coping, and the
relationships of parents' decisions to a child's quality of life and illness control. There have also been several qualitative studies, using grounded theory, ethnography, and phenomenology to describe parents' experiences in caregiving for a chronically ill child. However, an identified gap in the literature is the process by which parents of children post renal transplant attempt to obtain and utilize information needed to promote optimal function of the transplanted kidney and the well-being of the child and family.

The research question guiding this study is: What are the perceived information needs of parents and the subsequent process (es) to obtain and utilize information regarding symptom management of their child following a kidney transplant?
CHAPTER III

METHOD

Research Design

A descriptive research design, based on a qualitative approach and using the method of grounded theory, was used in this study to examine processes by which parents experience information deficits and obtain and use information regarding symptom management of their adolescent following a kidney transplant. Grounded theory explicates the basic social processes occurring within human interactions as derived from or grounded in empirical data (Strauss & Corbin, 1990). The grounded theory method involves an in-depth exploration of human interactions through extensive data collection and rigorous data analysis using constant comparative analysis. From these data, subsequent explanations or theory of the phenomena of individuals emerge (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin). Grounded theory is recognized as an effective method for investigating phenomena important to nursing and contributes to the development of middle-range theories in nursing (Chenitz & Swanson, 1986; Streubert & Carpenter, 1995).

Sample

A purposive sample (theoretical sampling) of the primary caregiving parent of a child or adolescent (ages birth to 19 years) who had undergone a kidney transplant within the last year was obtained for this study (Strauss & Corbin, 1990). Eligible parents were referred to the investigator by a pediatric nephrologist of a university-affiliated medical center.
Sample size was not decided at the beginning of the study. The reciprocal processes of data collection and data analysis and subsequent categorization of concepts for construct formation provide evidence from which to base sample size (Glaser & Strauss, 1967; Strauss & Corbin, 1990). A clear understanding of phenomena, not generalizability, is the goal of qualitative studies (Strauss & Corbin). Therefore, an in-depth qualitative study typically uses a small sample size (Strauss & Corbin). The standard for deciding when to stop collecting data from additional participants is when theoretical saturation for a category is achieved (Glaser & Strauss; Strauss & Corbin). Saturation means that no additional data are being found through continued means of exploration (Glaser & Strauss; Strauss & Corbin). The availability of informants within the time constraints of this study was limited, therefore saturation of the data cannot be confirmed. The third informant had previously experienced the same child undergo an organ transplant. Data from this interview confirmed previously developed categories, but also introduced varied information.

The following criteria were used to admit parents for this study: English speaking and primary caregiving parent of a child or adolescent who had a kidney transplant within the last year, was residing at home, and between the ages of birth to 19 years old. Parent participants had assumed primary responsibility for managing the care of the child (transplant recipient) following the kidney transplant and agreed to participate in the study.

Setting

Eligible parents of transplant recipients were referred to the investigator by a pediatric nephrologist from a university medical center pediatric outpatient clinic. The
university medical center served as the only pediatric renal transplant facility in the southern part of a southwestern state. Interviews were conducted in a setting of the subject's choice. Settings were the parents' home, a classroom available in a College of Nursing following a physician's appointment, and a meeting room available in the hospital following a physician's appointment.

Protection of Human Subjects

Human subjects approval from the Human Subjects Committee and the University of Arizona College of Nursing Ethical Review Subcommittee of the Research Committee was received (Appendix A). A letter of approval for accessing informants was also received from the attending pediatric nephrologist of the contact medical institution (Appendix B).

Protection of human subjects was addressed through obtaining written informed consent from each participant (Appendix C). Verbal explanation of the study began with the initial contact at a regularly scheduled appointment at the pediatric outpatient clinic or phone contact by the investigator. At the first interview meeting verbal explanation of the study was reiterated and reinforced by a written disclaimer (Appendix C) explaining the purpose of the study, the known risks and benefits, freedom of inquiry to receive answers to relevant questions any time during the study, freedom to withdraw without ill will or risk to one's care, and methods to assure confidentiality. Subjects interested in participating in the study signed the disclaimer and completed a demographic data form (Appendix D).
Confidentiality of the data was assured by assigning code numbers to each interview to be used throughout the analysis process. No names were used by the interviewer during taping of interviews. If the participant used names, the names were deleted in transcription of the interviews. Participants were verbally reassured of anonymity after the initial interview. Confidentiality was maintained during analysis of the study and in reporting the research findings. Participants were allowed to decline answering any question any time and allowed to withdraw from the study any time, without the family or child's continued care being affected.

It was recognized by the investigator that a potential risk for participants in this study might be the exposure of emotions while recounting their experiences related to the study. The investigator showed participants respect and allowed adequate time for participants to express their related emotions.

Data Collection Methods

Initial contact of eligible subjects was made either by a phone call from the investigator or at a regularly scheduled nephrology clinic visit. When initial contact was made at a nephrology clinic visit, the pediatric nephrologist introduced the investigator and the study. Otherwise, the investigator introduced herself, requested the eligible parent to participate in the study, and provided detailed verbal explanation of the study's purpose, risks, benefits, and methods of inquiry. A mutually convenient date and time was secured for the initial interview after interested parents confirmed their desire to participate.

Data collection began with eligible participants according to criteria and after informed consent was obtained (Appendix C). Participants were requested to complete
the demographic data form (Appendix D). Upon completion of the demographic data form, verbal permission was requested to turn on the audio taperecorder. Participants were asked not to identify themselves by name during audiotaping. A semistructured interview, of approximately 30-45 minutes, was conducted based on the interview guide (Appendix E). Following the interview, the audiotapes were transcribed verbatim except for names that were deleted, rechecked for accuracy of the transcription, corrected, then erased.

After data analysis was completed the researcher contacted each participant by telephone, discussed the results of analysis, and asked the informants to confirm the results and provide further feedback. This process of using "member checks" assured validation of the data (Guba & Lincoln, 1989, p. 238). Details of how member checks were conducted are presented under the section labeled Credibility. The results of member checks are discussed in Chapter 5 at the end of Discussion of Findings.

Instruments

The investigator was an active instrument in this grounded theory study. The personal experiences of the investigator influenced and enhanced understanding and interpretation of the problem studied (Strauss & Corbin, 1990). The researcher bracketed preconceived ideas related to the area of interest to avoid bias (Strauss & Corbin). Bracketing was done at the beginning of the data collection process and continuing throughout data collection. Bracketing was accomplished by recording and verbalizing the researcher's preconceived thoughts to committee members concerning the informational
needs of parents following a child's kidney transplant. Additionally, the researcher consciously strived to remain open to the directions the data provided throughout the study.

Participant data was obtained from the demographic data form (Appendix D) and through data generating questions taken from the interview guide (Appendix E) during semistructured interviews. In grounded theory, the interview guide serves only to focus inquiry according to the investigator's area of interest (Strauss & Corbin, 1990). Additional data generating questions or prompts were used based on participants' responses. Data generating questions become more specific with subsequent interviews of additional participants as data analyses explicated concepts and categories warranting deeper exploration by the investigator (Glaser & Strauss, 1967; Strauss & Corbin, 1990).

The principal two-part data generating question for this study was: As the parent and primary caregiver of a child following a kidney transplant, what are your information needs and what process(es) do you use to meet informational needs regarding symptom management of your child since the kidney transplant?

Data Analysis

The grounded theory research method involved five interactive steps: data collection, concept formation, concept development, concept modification and integration, and production of the research report (Chenitz & Swanson, 1986; Strauss & Corbin, 1990; Streubert & Carpenter, 1995). Specific research techniques of data analysis have been defined for the steps involved in grounded research and were followed for this study.
The grounded theory method mandates the researcher collect, code, and analyze data from the beginning of the study and simultaneously throughout the study (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Concept formation resulted from three levels of coding data collected: open coding, axial coding, and selective coding (Strauss & Corbin). Open coding involved examining the data obtained by interview, line by line, to identify processes and conceptualize the human behavior patterns. Level I, or open coding, entailed taking apart sentences and paragraphs and labeling each discreet incident or idea with a name representing what is going on in the data (Strauss & Corbin) (Appendix F). Open coding was accomplished by asking the following questions of the data: What is this? What does it represent? (Strauss & Corbin, 1990). The following is an example of analysis using open coding of data taken from an interview:

**Excerpt of Raw Data**

"I would watch it for about a day or two and if I seen [sic] that it's not going down or it stays up, I would give the doctor a call."

**Open Coding**

watching  monitoring  reporting

Coding of each labeled incident, called substantive codes, were compared to each new identified incident and similar phenomenon were given the same name (Strauss & Corbin, 1990). As many substantive codes as possible were identified from each sentence and incidences of transcribed data to ensure a thorough examination of the data. All open coded data were compared to one another, condensed, and assigned to clusters or categories according to where they appeared to fit (Strauss & Corbin) (Appendix G). Phenomena categorized together were given a conceptual name more abstract than that
given to the concepts grouped under it (Strauss & Corbin, 1990). Categories were initially
developed in terms of their properties, which could then be dimensionalized. Properties
were the characteristics or attributes of the category and the dimensions represented
locations of the property along a continuum (Strauss & Corbin). Relationships of the
categories and subcategories were formed by the developed properties and dimensions.
The following is an example of data developed in terms of properties and dimensions and
conceptually related with similar concepts to form a category:

<table>
<thead>
<tr>
<th>Excerpt of Raw Data</th>
<th>Open Coding</th>
<th>Properties</th>
<th>Dimensions</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;I would watch it [blood pressure] for about a day or two and if I seen [sic] that it's not going down or it stays up, I would give the doctor a call. That's what they have us do, is call him and let him know.&quot;</td>
<td>monitoring</td>
<td>duration</td>
<td>day or two . . . until next physician visit</td>
</tr>
<tr>
<td></td>
<td></td>
<td>monitoring</td>
<td>hi . . . lo</td>
</tr>
<tr>
<td></td>
<td></td>
<td>reporting</td>
<td>telephone call . . . visit</td>
</tr>
<tr>
<td>Following prescribed instructions</td>
<td></td>
<td>reporting</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>method</td>
<td></td>
</tr>
</tbody>
</table>

Theoretical Note: (I 1, p. 2, lines 59-63) Symptom Management
The mother of the transplant recipient watches, monitors, reports, follows prescribed
instructions. Mother has learned desired parameters for blood pressures, knows what to
do, who to call when B/P elevated. Mother makes judgement when to notify physician
regarding B/P elevation.
Watching is a component of monitoring, so will label both monitoring.
Monitoring, Following Prescribed Instructions, and Reporting are all components of
Symptom Management, so will be on the lookout for other examples of symptom
management.

Theoretical notes were begun during open coding. Theoretical notes record some of the
thoughts and questions going through the analyst's mind during coding (Chenitz &
Swanson, 1986; Strauss & Corbin, 1990). Additionally, theoretical notes hypothesized the
conditional relationships being formed of the phenomenon (Appendix G). Hypotheses of
the forming conditional relationships are the beginning of level II or axial coding (Strauss
Open coding and axial coding are two distinct analytic processes, but progression of analysis involves using both modes simultaneously (Strauss & Corbin).

Level II coding, or axial coding, involved the constant comparative method to construct categories beyond properties and dimensions and link categories to subcategories (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Continued construction of categories and connecting categories and subcategories through axial coding was accomplished by specifying a category according to a paradigm model (Strauss & Corbin, 1990). The paradigm model showed category linkages to subcategories in terms of the causal condition, the phenomenon, context, intervening conditions, action/interactional strategies, and consequences (Strauss & Corbin, 1990) (Appendix G). The process of axial coding the data accomplished the continued hypothetical relating of subcategories to categories, verifying those hypotheses against actual data, continued identification for properties of categories and subcategories and dimensional locations of data indicative of them, and the beginning exploration of variation in the phenomena (Strauss & Corbin). A primary purpose for the grounded theory method is to explicate the similarities and differences among and within categories (Strauss & Corbin).

The goal of grounded theory is to explicate the "core variable" in operation as the basis of the social process studied (Glaser & Strauss, 1967; Strauss & Corbin, 1990). The concept of core variable refers to a category that explains most of the variations in the human behaviors studied (Glaser & Strauss; Strauss & Corbin). The core variable was derived from the data through constant comparative analysis, reduction, and integration (Strauss & Corbin).
Level III, or selective coding, was the final step of identifying and developing the core category (Appendix H). Selective coding involved several interactive, nonlinear steps: explicating the story line or core category, relating subcategories around the core category using the paradigm model, denoting categorical relationships dimensional, and validating those relationships against data (Strauss & Corbin, 1990). The core category was identified from asking what is going on in the data, in relationship to the focus of the study, and identified as the problem for participants. In addition, the core category represented the initiation of explicating a basic social process by asking what processes were utilized by the participants to deal with the problem (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Explicating the core category or story line was accomplished by asking the following questions: What explains the major action in the situation under study? In all interviews, what seems to be the main storyline, pattern or theme? What category do all other categories seem to be leading up to or pointing to? After the core variable emerged, the researcher used the steps of concept modification and integration to move the investigation from a descriptive level to a theoretical level (Glaser & Strauss, 1967). The major categories were reviewed to determine the properties and dimensions of the core category (Strauss & Corbin, 1990). Then, all other major categories were related to the core category by means of the paradigm model, that is, causal condition, strategies, and consequences, to provide an analytic version of the story. Categories were also grouped along the dimensional ranges of their properties according to identified patterns (Strauss & Corbin). All identified relationships were constantly validated against the data, insuring the identified and conceptualized relationships were grounded in the data.
Trustworthiness

The goal of rigor in qualitative research is to accurately represent the experiences of those studied (Guba & Lincoln, 1989). Trustworthiness in qualitative research refers to the extent the experience of the study participants is accurately represented by the investigator's interpretation of the data (Guba & Lincoln). Trustworthiness of this study was supported by evidence of four criteria: credibility, transferability, dependability, and confirmability (Guba & Lincoln).

Credibility

Consistent use of the grounded theory method and bracketing helped to ensure credibility or confidence in the truth of the data (Guba & Lincoln, 1989). Credibility of the findings was supported by prolonged engagement with the subject matter and member checks (Guba & Lincoln).

Member checks were conducted with each consenting participant after findings were formulated into an analytic description of the story. Member checks involved a brief meeting by telephone with each consenting member to explain and discuss the findings by the investigator. The core category and each supporting subcategory identified by the investigator were first introduced to each participant in a summary. Then the core category and subcategories were each explained in greater detail with supporting data bits from the interviews. The relationships of the core category to the subcategories were also presented and discussed. Each informant was asked at several points during the discussion if the investigator's interpretations of the data were reflective of their perceptions of the experience. Informants were also asked at several points during the discussion if any
portions of the information should be added or discarded. Participants were asked to what extent the investigator's interpretation of the data accurately represented the process by which they as parents manage informational needs related to caring for their child following a kidney transplant. The results of member checks are discussed in Chapter 5 at the end of the Discussion of Findings.

**Transferability**

The transferability of qualitative research refers to the extent to which the findings from the data can be transferred to other settings or groups (Guba & Lincoln, 1989). The primary responsibility of the researcher to establish transferability is to provide sufficient descriptive data in the research report so that consumers can evaluate the applicability of the data to other contexts (Guba & Lincoln, 1989). Therefore a detailed description of the sample, the setting, data collection methods, instruments, examples of data bits, methods of data analysis and a detailed description of the findings are provided.

**Dependability**

The dependability of qualitative data refers to the stability of data over time and over conditions (Guba & Lincoln, 1989). The findings are dependable if another researcher can follow the progression of events in the data collection and analysis process and arrive at comparable conclusions. The dependability of the data in this study was assessed through ongoing scrutiny by the thesis chair of the data and relevant supporting documents with the emerging categories and themes identified by the researcher. The thesis chair performed open coding of segments of the first two interviews, including identification of properties and dimensions of the data, then compared and contrasted these
interpretations with the investigators' interpretations. The thesis chair was routinely consulted concerning the clustering of concepts into subcategories and subcategories into categories and the fittingness of conceptual labels. The development of each progressive level of coding was documented. The analytic process of decisions and judgements made by the investigator was documented in theoretical notes. The thesis chair tracked the progression of coding and the decisions and judgements of the investigator throughout the study.

Confirmability

The confirmability of data in qualitative research refers to the objectivity of the data (Guba & Lincoln, 1989). An audit trail was established that specifically documented decisions and steps taken during data collection and analyses that lead to the concluding themes. Each level of coding was documented, decisions about combining and relating subcategories and categories were routinely discussed and corroborated, and the explicated story line was examined and substantiated by the thesis chair. Routinely and throughout the study the thesis chair corroborated the appropriateness of decisions and concluding themes based on documentation of the data and progression of events.

Summary

A descriptive research design using the method of grounded theory examined the processes by which parents experience information deficits and obtain and use information regarding symptom management of a child following a kidney transplant. Parents of children who have had a kidney transplant, eligible for participation in the study, were referred by a pediatric nephrologist from a university-affiliated pediatric outpatient clinic.
Human subjects approval for the research was obtained. Informed consent was secured from each eligible participant before interviews were begun. Data collection was accomplished by obtaining demographic data and through semistructured interviews with consenting parent participants.

The interacting steps unique to grounded theory were simultaneously applied to explicate the operating core variable for the sample. Data analyses progressed from substantive to theoretical through the processes of open coding, axial coding, and selective coding. Sorted theoretical memos of coding were the basis for the research report, substantiated by the supporting and characteristic examples of data.

Trustworthiness of the study was assured by the consistent use of the grounded theory method, bracketing preconceived ideas, prolonged engagement with the subject matter, and strategies to assure credibility, transferability, dependability, and confirmability.
CHAPTER IV

RESULTS

A description of the sample and results using constant comparative analysis of the data are presented in Chapter IV. A description of characteristics of informants who provided the data for analysis is presented, including demographic data on the informants and the transplant recipients. An introduction to the core category as it evolved in relationship to the major subcategories is presented. Descriptions of the supporting subcategories in terms of their identified properties and dimensions and their relationships to one another and the core category follow. The core category is then described in terms of properties and dimensions identified from the data.

Description of Sample

The sample for this study consisted of three mothers who considered themselves the primary caregiving parent of their child following a kidney transplant. Demographic data of the informants and transplant recipients is presented in Table 2. The transplant recipients of this sample were all adolescents and will be called adolescents versus children for the remainder of the report. A diagnosis of disease causing chronic renal failure and the need for a kidney transplant, Alport's Syndrome and Glomerulonephritis, was made for two of the transplant recipients. The cause of chronic renal failure disease in one transplant recipient remained unknown. One transplant recipient had also had a heart transplant nine years previous to the kidney transplant. All transplant recipients received kidneys from living-related-donors.
Table 2

Demographic Profile of Informants and Transplant Recipients

<table>
<thead>
<tr>
<th></th>
<th>Informant # 1</th>
<th>Informant # 2</th>
<th>Informant # 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>33</td>
<td>42</td>
<td>37</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td>Married</td>
<td>Divorced</td>
<td>Married</td>
</tr>
<tr>
<td><strong>Years of Education Completed</strong></td>
<td>12</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td><strong>Number of Persons Living in Home</strong></td>
<td>6</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td><strong>Annual Income</strong></td>
<td>$20,000-$30,000</td>
<td>$20,000-$30,000</td>
<td>$20,000-$30,000</td>
</tr>
<tr>
<td></td>
<td>Transplant Recipient # 1</td>
<td>Transplant Recipient # 2</td>
<td>Transplant Recipient # 3</td>
</tr>
<tr>
<td><strong>Age in Years</strong></td>
<td>15.5</td>
<td>13</td>
<td>16</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>Male</td>
<td>Male</td>
<td>Male</td>
</tr>
<tr>
<td><strong>Years of Education Completed</strong></td>
<td>9</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td><strong>Number of Months Post Transplant</strong></td>
<td>6</td>
<td>11</td>
<td>5</td>
</tr>
<tr>
<td><strong>Number of Daily Medications</strong></td>
<td>8</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td><strong>Frequency of Physician Visits</strong></td>
<td>every 3 weeks</td>
<td>every 3 months</td>
<td>every 6 weeks</td>
</tr>
<tr>
<td><strong>Number of Hospitalizations Since Transplant</strong></td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>
The sample size was limited by the availability of informants within the time constraints of this study. In order to protect anonymity of each informant, pseudonyms will not be used in conjunction with direct quotes from the interviews. Directly quoted data bits are used to illustrate and support identified categories and subcategories. Quoted data bits are equitably taken from each interview.

Overview of Core Category and Subcategories

The core category evolved in relationship to the major subcategories. The evolution of the subcategories in support of the core category is presented linearly, although many parts of the process happened simultaneously (see Table 3). Presenting the subcategories linearly is an attempt to simplify the descriptions of the complex intertwinnings of the subcategories to each other and the core category.

The core category is called Sharing the Challenge. Sharing the Challenge represents the process of how a mother and her child, who has undergone a kidney transplant, share the responsibilities of caregiving with the health care team following the kidney transplant. Sharing the challenge of caregiving responsibilities among the patient and their primary caregiver and the health care team was an effort to support their shared goal of promoting the circumstances that allow the transplant recipient to reach and maintain their optimal level of wellness following the kidney transplant. A closely integrated, almost inherent subcategory of Sharing the Challenge is Accepting Responsibility. Accepting Responsibility represents the mothers' and transplant recipients' commitment to maintaining the optimal level of functioning of the transplanted kidney. Accepting Responsibility is evidenced by the acceptance of caregiving responsibilities required to support the general health of the
Table 3

Overview of Core Category and Related Subcategories

---

**Core Category:** SHARING THE CHALLENGE

**Subcategory:** Accepting Responsibility

<table>
<thead>
<tr>
<th>Causal Condition:</th>
<th>Strategy:</th>
<th>Consequences:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Threat of Kidney Rejection</td>
<td>Caregiving</td>
<td>Reassurance</td>
</tr>
<tr>
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**Subcategories:**

- Symptom Management
  - Delegating
  - Following Prescribed Instructions
  - Monitoring
  - Reporting
  - Information Seeking
  - Weathering
transplant recipient following the transplant. The health care team participates in accepting responsibility by assuming the role of professionals who provide guidelines and follow-up care to support the health of the transplant recipient.

The supporting subcategories of Sharing the Challenge are presented in the following sequence as related to the core category: the causal condition, strategies, and consequences. The subcategory identified as the causal condition was the threat of possible kidney rejection causing the response of Fearing Kidney Rejection. Mothers were aware that the human body's natural immune response is to reject a transplanted organ. They were also aware that the possibility of the threat of rejection extended throughout the life of the transplant recipient or the duration of functioning of the transplanted kidney. The risks of organ rejection, thus fearing kidney rejection, were highest immediately following the transplant, especially for the first year, decreasing over time.

The central subcategory identified in response to the threat of rejection was Caregiving. Caregiving encompassed the methods by which responsibilities were shared and delegated between the health care team managing the transplant recipients' medical care and mothers of the transplant recipients, providing caregiving at home. In turn, mothers of the transplant recipients shared and delegated caregiving responsibilities at home with their child, the transplant recipient. The subcategory, Caregiving, was identified to have the following subcategories: Delegating, Learning, Symptom Management, Information Seeking, and Weathering. Burden of Care and Reassurance were the subcategories identified as consequential to Sharing the Challenge. Reassurance reflects confidence of the involved members of Sharing the Challenge that the most was being done for the transplant
recipient to preserve kidney function and protect the transplant recipients against the threat of kidney rejection. Reassurance developed as a result of the united caregiving efforts of mothers and transplant recipients with the health care team. The Burden of Care was consequential to mothers accepting responsibilities for the transplant recipient following the kidney transplant and the consistent threat of rejection.

Accepting Responsibility

Accepting Responsibility reflects primarily the mothers' and transplant recipients', but also the spouse and other family members' and the health care team's, commitment to maintaining the optimal level of functioning of the transplanted kidney. The extent of Accepting Responsibility was evidenced by their response to each challenge they met while promoting the transplant recipient's health following a kidney transplant. Accepting Responsibility by the health care team was implied in their role by their ready availability, provisions of instructions, explanations, and support, provisions of routine monitoring through physician appointments, and increased monitoring and testing with evidence of possible problems. Accepting Responsibility by the transplant recipients, mothers, and other family members included all the extra caregiving responsibilities they provided and struggles they endured to support the health of the transplant recipient. A quality of Accepting Responsibility by these mothers was expressed as a sense of duty, without dilemma. One mother stated, "After the transplant, basically I think you know you have to do this for your kid and the well being of your kid." Another mother stated, "I just figured this [caregiving] is something I have to do, so I did."
A property of Accepting Responsibility, intensity, was high as evidenced by the following statement by a mother expressing the guilt both she and the transplant recipient assumed immediately after learning of an elevated blood creatinine level. "We kept thinking, trying to figure out, what did we do wrong?" The mother stated the transplant recipient said, "I didn't drink enough water."

Mothers accepted the most responsibility for providing care for a transplant recipient at home. Yet the entire family was affected as the responsibilities of caregiving were fulfilled. Mothers stated fathers arranged to get off work and join them for physician appointments. Mothers spoke of discussing problematic issues with family members. When mothers spoke of the problems related to finances, health insurance, and transportation, it is assumed that all family members were somewhat affected. Transplant recipients accepted responsibility for their caregiving requirements to some extent, primarily involving symptom management. One mother stated, "He does it [monitors blood pressure] basically. . . . We [sic] got a couple of years left and he's going to be at college. He's got to learn. He's basically been responsible for himself." Specific properties and dimensions of delegated symptom management responsibilities to transplant responsibilities will be discussed under the subcategory Symptom Management.

Fearing Kidney Rejection

The threat of rejection was the causal condition for Sharing the Challenge. Mothers and transplant recipients learned from the health care team that the physiologic response of the human body receiving a transplanted organ was to attempt to rid the body of the foreign intrusion and reject the transplanted organ. Mothers' and transplant recipients' response to
the threat of rejection is reflected in the subcategory, Fearing Kidney Rejection. Fearing Kidney Rejection was caused primarily by a real or potential threat of rejection. Some degree of kidney rejection was expected, and feared, any time following the kidney transplant, but especially during the first year. One mother stated she reminded her son, "For as long as your kidney lasts you, we still will go up and down. . . . There are a few times when you may start going into rejection . . . . And like [doctor] said, the first year is when it's, you know, they watch it even closer." Another mother stated, "There's always, you always expect something [rejection] to happen."

Mothers were told by the physician that the risks of potential rejection of the transplanted kidney were higher in the early stages following the transplant. Frequent monitoring of kidney function by the health care team early in the transplant stage may suggest that the health care team also feared the threat of rejection more intensely, early in the transplant phase. Monitoring by the health care team was less frequent and varied later, suggesting the health care team may have regarded the threat of rejection to be less. The intensity of mothers' fear of kidney rejection was highest immediately following transplant. When recalling her thoughts regarding the transplant recipient's discharge from the hospital, one mother stated, "... I think I was more afraid of seeing signs of rejection."

Mothers learned signs of rejection were similar to flu symptoms. When the transplant recipient exhibited flu symptoms for the first time following the kidney transplant, mothers' fear of potential rejection increased. One mother stated, "And he got one bout with the flu, . . . . and I thought oh, my gosh, . . . . he's going to start going through rejection." As another mother expressed it, "When you first go through transplant it's scary
because anytime they get sick, you automatically think what is going on? Are we rejecting?"

There was evidence to support that as the amount of time following the transplant increased, the mothers' confidence in their child's kidney function increased, and the mother's intensity of fear of potential rejection lowered. A mother stated the following when faced with a potential rejection episode, five months following her son's kidney transplant, "It [potential of kidney rejection] caught us off guard, because he had been doing so well." Being "off guard" suggests this mothers' fear of kidney rejection had lowered over time.

Evidence also supported that the intensity of Fearing Kidney Rejection heightened intermittently, such as when mothers and transplant recipients awaited for routine blood creatinine results. Fearing Kidney Rejection seemed to covary with frequency of measuring blood creatinine levels. Mothers and transplant recipients were informed and keenly aware that the degree of kidney functioning, therefore degree of rejection, was gauged by measuring the blood creatinine level. Mothers and transplant recipients experienced high levels of anxiety waiting to find out the blood creatinine results at each physician visit, based on their high intensity of fear of potential rejection. One mother said she experienced the following when waiting for the blood creatinine results at a routine physician visit, "Oh my gosh, I can't wait, what do you think it's gonna be [son]? . . . I would always be nervous and he'd be nervous and get all tense and stuff . . . ."

After the immediate stage following a transplant when mothers were alerted by the health care team that the transplant recipient's blood creatinine level was elevated and
exhibiting an upward trend, the mother's initial response was increased intensity of fear of kidney rejection. One mother stated, "I was afraid that they would tell me that's what it was, that he was rejecting, and that's fatal. It's scary." Another mother stated, "That was my first instinct . . . oh, my gosh, he's going to totally reject this."

For some mothers, coping with the fear of their child rejecting their transplanted kidney was a struggle not to panic. An exception was a mother who stated she believed that early rejection could be successfully controlled by medications. In this case, the kidney transplant recipient had undergone a previous organ transplant without rejecting the transplanted organ, which increased the confidence of the mother that kidney rejection would not be a problem. The intensity of fear of kidney rejection for this mother varied between being low or nonexistent to being significant. At one point she stated, "We've never had to deal with rejection. He never rejected the heart. They have so many drugs now. Rejection's no big deal." However, the same mother also stated "I'm aware of it [kidney rejection]. . . . If there's ever anything, a change in him, I would immediately look to see if that's [kidney rejection] possible first."

Caregiving

Caregiving was identified as a broad subcategory encompassing strategies for Sharing the Challenge with the health care team and in response to the threat of rejection. Subcategories of Caregiving emerged which detail the methods for sharing with the health care team the requirements of caring for the transplant recipient and dealing with the threat of rejection. The subcategories of Caregiving identified are: Learning, Symptom Management, Information Seeking, and Weathering.
Learning

Learning is a subcategory of Caregiving, requisite to fulfilling the role of primary caregiving mother, especially in the initial stages following a child's kidney transplant. Informing and subsequent Learning was an integral part of Sharing the Challenge of caregiving responsibilities among the health care team, primary caregiving mothers, transplant recipients, and other family members. The information mothers and transplant recipients learned about their caregiving responsibilities was in large part dependent on what they were taught and informed by the health care team, although mothers also sought information from other sources. Their learning was secondarily dependent on their efforts in self-education. One mother said,

Well, the only thing that I really needed to know good [sic] was taking blood pressures because I wasn't familiarized for that [sic], you know, I had to learn on my own. My sister-in-law was the one that more or less taught me.

The health care team depended on mothers and transplant recipients Learning information about the patient (transplant recipient) at physician visits and more urgent information between routine physician visits. One mother explained,

I would watch it [elevated blood pressures] for about a day or two and if I seen [sic] that it's not going down or it stays up, I would give the doctor a call. That's what they have us do, is call him and let him know.

Providing caregiving for a child following a kidney transplant generally required Learning by mothers and transplant recipients in order to understand a great deal of new information. One exception was a mother who had previously learned similar information
because her child had experienced a previous organ transplant. Mothers were interested in Learning what it was like to experience a kidney transplant and what to expect after a transplant, before the transplant occurred. The preferred methods of being informed varied from written information to Learning from others who had experienced an organ transplant. One mother expressed that when Learning new information, it was important that she have written information that she could read and refer to when she had a question. She stated, "I would like to have it written down on paper. You know, something I can have as a file." Another mother stated that she had received written literature, but her Learning was mostly from speaking to others who had experienced having a child go through an organ transplant, such as in a support group. This mother also emphasized the informing value for her son in witnessing a rejection episode of a friend who had undergone a kidney transplant, before her son's own transplant.

The extent of being informed and Learning discovered in this study varied between sufficient and insufficient. The timing of being informed and Learning influenced the perceived extent of sufficiency. As previously stated, one mother described Learning on her own how to take the transplant recipient's blood pressure. After the transplant's discharge, she relied on her sister-in-law nurse to teach her. Another mother stated she sufficiently learned how to take a blood pressure before the transplant recipient was discharged from the hospital. Mothers' extent of knowledge about the symptoms of rejection varied between sufficient and insufficient. One mother stated, "Basically what I needed to know, and I still need to know, is what to look for in case I see that something's going wrong." Another mother stated that the physician and nurse explained everything about the signs of rejection.
several times, and she knew a great deal of it before the transplant. Mothers knew medication classifications, dosages, and some side effects, evidence they had been informed and had learned. Transplant recipients were for the most part in charge of taking their own medications, also evidence they had learned to some extent about medications.

The perceived complexity of information learned varied, dependent on the degree of familiarity. One mother, unfamiliar with taking a blood pressure, described it as difficult to do. Two other mothers with previous and similar caregiving responsibilities did not state that taking a blood pressure was difficult. Learning and acquiring additional information was continuous. Mothers expressed ongoing informational needs. Situations presented routinely in which mothers were uncertain how to respond or what they should do. One mother explained the dilemma when her son contracted a cold,

There was one incident where he had a cold and I wasn't sure what kind of medication I could get just over the counter for it, so I was like [son], you know, we have to find out first.

Mothers expressed the importance of continuing to educate themselves and the value of asking questions.

**Symptom Management**

Symptom management emerged as one of the primary methods and responsibilities of the primary caregiver and transplant recipient to fulfill their role in Sharing the Challenge with the health care team. The health care team relied on the mother as the primary caregiver to do symptom management at home, between physician assessments. Symptom Management is a label used in a broad sense to encompass not only what was done in
response to a variance in condition or health status, but what was routinely done to promote preservation of the transplanted kidney, be informed of the health condition of the transplant recipient, and in turn, inform the health care team. Symptom Management is a learned process including following prescribed instructions, monitoring the transplant recipient's condition and care, using information to detect signs suggesting health or illness, and reporting information as needed. The subcategories of Symptom Management are: Delegating, Following Prescribed Instructions, Monitoring, and Reporting. The subcategories of Symptom Management are discussed here in terms of the salient properties and dimensions.

**Delegating.**

The extent to which mothers engaged in Delegating symptom management responsibilities to the transplant recipient depended on their developmental stage and willingness of the transplant recipient, previous experience with the responsibilities, general inclinations of the mother, and the perceived benefit. All transplant recipients in this study were in charge to some extent of taking their own medications following recovery from the transplant. The mother of the youngest transplant recipient of the study stated,

He gets his medications . . . . Sometimes I'll open them up for him, and sometimes he'll do that, he loves to be in charge of that, so basically he does that. I just stand and watch, and make sure he has, he takes them all. And the same at night.

The oldest transplant recipient, who had also previously experienced an organ transplant, had been delegated most of the responsibilities of his care. The mother stated, "He does it [general care] . . . . We got [sic] a couple of years left and he's going to be at
college. He's got to learn. He's basically been responsible for himself." In addition, this mother also stated, "He can usually tell physically if his blood pressure's high or low. If he gets feeling weird, he'll know and he'll take his blood pressure to see if that's causing it."

The other two mothers increasingly relied on the transplant recipient to learn daily symptom management requirements such as maintaining hydration and reporting to them any problems, such as not feeling well or having a decreased urine output. But these mothers were more actively involved in reminding and monitoring the transplant recipients by checking that symptom management tasks were done on time, correctly, and routinely.

**Following prescribed instructions.**

Mothers relied on the health care team to provide instructions for Symptom Management at home. Concomitantly the health care team was reliant on mothers and transplant recipients for Following Prescribed Instructions. The extent of Following Prescribed Instructions was dependent on the perceived seriousness of the consequences of not following instructions and the perceived benefits of adhering. All medications were taken on time, as prescribed, up to three times per day, due to the perceived seriousness of the threat of possible rejection as a consequence of not taking the antirejection medications. Physician visits, a component of the prescribed instructions, were regularly attended by the mother and transplant recipient. Often the other parent attended physician visits, based on the perceived benefit of receiving an update on the transplant recipient's status. The prescribed frequency for checking the blood pressure of the transplant recipients varied between twice per day and once per week. The frequency blood pressures were measured varied from once per day to once per month. The perceived seriousness of hypertension as
a complication following a transplant recipient was less than the perceived seriousness of possible rejection.

The degree of perceived complexity and proficiency of Following Prescribed Instructions varied, based on familiarity and previous experience. One mother, previously inexperienced in measuring a manual blood pressure, stated that measuring a manual blood pressure was difficult because she still did not feel confident listening for the heartbeat. The other mothers did not state that it was difficult.

Monitoring.

Monitoring is a daily and continuous routine of checking that things are going well and being alert to something being wrong. The general prescribed care required mothers, or their designee, usually the transplant recipient, to monitor various components of the prescribed treatment up to three times per day. Mothers monitored that the correct medications were taken on time, at the correct dose, and at the correct frequency. Mothers monitored that sufficient amounts of fluids were drunk each day and that urine output had not significantly decreased. Mothers monitored that the transplant recipients' temperature and blood pressure were not elevated, and remained between prescribed parameters. Mothers monitored that the general health status of the transplant recipient was not deteriorating.

The extent and frequency of Monitoring varied among mothers. The frequency of measuring the transplant recipient's blood pressure for one mother was at first dependent on the amount of time that had passed since the transplant, then the responsibility of Monitoring was delegated to the transplant recipient. She stated,
We're good for the first six months . . . We're really good about weekly doing it here at home . . . But he can usually tell physically if his blood pressure's high or low. If he gets feeling weird, he'll know and he'll take his blood pressure to see if that's causing it.

On the demographic information form, this mother recorded Monitoring the blood pressure monthly. The other mothers recorded Monitoring their child's blood pressure once or twice per day. One mother explained Monitoring as follows:

[I] check his blood pressure, make sure that his medication is taken on time, make sure he drinks enough water, takes enough fluids to hydrate the kidney good, [sic] and basically just watch him. You know, make sure he does everything he has to do.

The duration and frequency of Monitoring a discovered variance in health status at home was based on the perceived seriousness of the variance. The perceived seriousness of a variance in health status was how significantly it signaled an increased threat of possible rejection. The duration of home Monitoring a health status variance of low perceived seriousness was until the next physician visit. For a variance considered more serious, such as an elevated blood pressure, the frequency of Monitoring increased for the duration of a couple of days, and if it persisted, the physician was contacted. For a variance in health status perceived as serious and related to an increased threat in possible rejection, such as a fever, a physician was contacted immediately, Monitoring was increased, and plans to see the nephrologist were made. One mother explained, "I would try everything . . . get him on the drugs that would take care of something that wasn't rejection and watch very closely if
anything lingered. I mean, we'd be up [to see the nephrologist] making sure it wasn't rejection."

Mothers varied in Monitoring for increased risks of exposure to infection based on previous experience, the perceived benefit, and the perceived seriousness of the consequence. In the early stages following the transplant, one mother went to great lengths to protect her son from infectious exposure to anyone suspected of being sick. She perceived that due to the required immunosuppression he would contact the flu very easily, and contracting the flu would result in kidney rejection. This mother stated,

That [possible exposure to illness], I was very stern with people. People thought I was rude at times. It was like, you know, they would call and say, well, I'm coming over, and I'm like, fine, I says [sic], do you have a cold, are you sick? If you're cold, or you're sick, I can't have you around [the transplant recipient].

Another mother said she believed the benefits of protecting the transplant recipient from others with possible infection was low compared to the price of isolating the transplant recipient from other people. She also believed that the transplant recipient was likely to be exposed and successfully resist most illnesses. She stated,

If I knew somebody was sick, I didn't invite them over, but I was never real big on isolating him from anything or anyone. It's out there. He's got four siblings. I mean he's bound to get something. . . . Most transplant kids are healthier than normal kids. He gets sick much less than any of the other kids.
Reporting.

Reporting findings of Symptom Management, both variances and stability, is an important component of Caregiving. Reporting findings was a large part of the reciprocal relationship in Sharing the Challenge of Caregiving with the health care team. For example, reporting a series of blood pressure measurements taken at home over a period provided the health care team with more information about the effectiveness of antihypertensive medications than the one blood pressure measured at each physician visit. Reciprocally, the health care team reported the results of tests and assessments of the transplant recipients to the mothers and transplant recipients.

Reporting variances in the transplant recipients' health status to the health care team varied in timing and methods, depending on its perceived seriousness. When a health care variance of low perceived seriousness was discovered, the mother would only try to remember to mention it to the doctor at their next scheduled visit. When a variance of moderately perceived seriousness persisted for a couple of days, the mother contacted a physician by phone. When a variance was perceived to be serious, such as a fever, an appointment with a physician was made that day. A fever was associated with both possible infection and rejection, thus needed immediate attention. One mother explained that if the fever happened soon after transplant, she would have immediately reported it to the nephrology physician or transplant physicians. Yet if a fever happened now, six months following transplant, she would report it to her local primary care physician. If a sibling also had a fever, the mother might believe that the fever was related to whatever illness the
sibling has, not possible kidney rejection. Although she continued to perceive a fever to be serious, it was less serious later than it was earlier post transplant.

**Information Seeking**

Information Seeking emerged as an important component of caregiving related to the core category as a major element of Sharing the Challenge. As presented thus far under the categories of Caregiving and Symptom Management, Sharing the Challenge signifies a high degree of sharing responsibilities among the health care team, the transplant recipients, and the mothers. The responsibilities of Symptom Management and decisions for daily care in some cases were complex. Consequences of heavy reliance on the mother and transplant recipient for Caregiving responsibilities were residual and ongoing informational needs. The resulting implied expectation was for mothers and transplant recipients to actively Seek Information to successfully fulfill their roles in primary caregiving.

Mothers routinely engaged in Information Seeking activities by various methods, depending on the perceived seriousness of the need for information, and the availability of the information source. The perceived seriousness of the need for information was judged by its perceived relationship to the threat of rejection. The intensity of effort of Information Seeking increased with increased perceived seriousness of the need for information. If a situation was perceived to be serious, information would be sought from the physician immediately. If a situation was perceived to be moderately serious and persisted for a couple of days, information would be sought from the physician after monitoring for the two days. If a situation was perceived to be of low seriousness, the mother would attempt to remember to mention at the next physician visit. One mother explained:
We found out he had a wart on his hand, and I asked [sic], I didn't know if I could get something over the counter for that, so when we went back [to the doctor] the last time . . . I asked him, I says [sic] can we get those patches . . . .

Mothers sought Information during scheduled physician visits, made telephone calls to physicians, pharmacists, and family members, and researched the problem themselves. One mother stated, "I asked the transplant people, but I also get my own books and look it up." "I'll do drug interactions. I look that up before I start him on anything." Another mother stated,

You have to be able to communicate with the doctors and the nurses. And they're helpful, just learn to communicate with them, and, I ask questions and I'm sure if they know the answer, they'll answer it, or they'll get you an answer.

Mothers stated that physicians were readily available. "I had a lot of support . . . 'cause I would call and say hey, I'm not sure what I'm supposed to be doing with this, you know, and right away they'd be back in touch with me." Another mother stated,

"Twenty-four hours a day you can get ahold [sic] of somebody up there. Somebody's on call, which is a real comfort." Mothers repeatedly emphasized the value of asking questions and communicating uncertainties throughout the transplant process. One mother explained,

". . . I'd rather look dumb for asking a crazy question than, you know, be sorry later I hadn't asked." Mothers routinely used Information Seeking as an important strategy to fulfill their caregiving responsibilities in Sharing the Challenge with the health care team.
Weathering

Weathering is a subcategory of Caregiving and an additional strategy used by mothers of transplant recipients to manage the threat of rejection following the kidney transplant. Mothers' general perspective was positive, confident, and hopeful regarding the short and long term outcomes for their child following the kidney transplant.

When confronted with an increased potential of rejection, such as an elevated blood creatinine level and pending renal biopsy, mothers recited positive talk to themselves and the transplant recipient. They avoided panic by exercising patience to wait until all the test results were available to inform them of the degree of a problem. Mothers employed Weathering, increasing their expression of hope and confidence that the outcome would be good, to manage their fear of rejection. One mother stated the following in response to having just completed waiting for the test results to rule out kidney rejection after the transplant recipient's blood creatinine level had been elevated. The mother had just been told by the physician that kidney rejection had been ruled out. She stated, "We were pretty confident that it would come out to this. . . . You know, that everything would be alright. I think we both are [optimistic]. Yeah, I think we both are. We got [sic] to keep things that way."

When confronted with increasing Burdens of Care such as unexplained complications without resolution, being unable to afford or fund desired medications, and multiple long term health conditions, one mother's Weathering strategy was to minimize them as problems. She commented on how well the transplant recipient has done despite complications and without the extra medications and minimized the threat of rejection.
When recalling being confronted by an extra hospitalization due to complications and an increased threat of rejection evidenced by an increased creatinine level, a mother stated, "We've always made the best of the hospital. It's like a second home to him 'cause he was there so much. Kind of like vacation time. You don't have to clean up after yourself. It's nice."

Reassurance

The ultimate goal of Sharing the Challenge among mothers, transplant recipients, and the health care team was to maintain optimal kidney function by providing comprehensive daily caregiving. Comprehensive daily caregiving lowers the risks and provides early detection of potential kidney rejection episodes. Evidence of extensive participation in caregiving activities by the mothers and transplant recipients at home on a routine basis supported the attainment of optimal daily caregiving, therefore lowered risks and early detection of potential kidney rejection episodes. Comprehensive daily caregiving was the strategy used to Reassure all persons involved in Sharing the Challenge that the most was being done to preserve kidney function.

Additionally the extensive sharing, among the mothers, transplant recipients, and health care team members, of responsibilities, information, and decision-making strengthened mothers' and transplant recipients' Reassurance against the threat of rejection. One mother explained, "... if you watch him closely, make sure they take their medication, they do everything the doctor tells them, I think there's a good chance that everything will go okay."
Mothers expressed feeling supported in their efforts, informed, prepared for complications and rejection episodes, and confident that the transplant recipient was also receiving optimal care from the physician. One mother explained, "... I know that [doctor] is right on top of everything, you know-checking for everything and making sure the medication is right and all kinds of stuff."

Burden of Care

Constant comparative analysis revealed Burden of Care as an additional consequence of Sharing the Challenge with the health care team. As mothers and transplant recipients were more heavily relied on to provide primary caregiving at home, they realized increasing Burdens of Care. In addition, when complications or exacerbations occurred, mothers, transplant recipients, and family members experienced perceived increased Burdens of Care not only in direct caregiving, but also in increased expenses of time, energy, finances, and other resources.

Early in the transplant phase, the frequency and intensity of experiencing the Burden of Care was high. Prescribed physician visits were initially three times per week for a couple of weeks, then twice per week for a couple of weeks, then once per week up, and continued at various intervals. When mothers were interviewed for this study, routine physician visits for transplant recipients were every three weeks, every six weeks, or every three months. When Mothers lived more than one hour from the physician's office, the Burden of Care was greatly increased by required transportation time. When signs of possible rejection were identified, requirements for monitoring, blood studies, and physician
visits increased. Consequently the Burden of Care, including time, energy, and financial expenses, increased.

Besides keeping physician visits, other prescribed requirements were present. Obtaining timed blood studies was important to judge kidney function, progress, degree of rejection, and therapeutic levels of medications. Coordinating the timed blood studies with physician visits, work schedules, and remaining family responsibilities was the most difficult adjustment for one mother following the kidney transplant. She explained,

Figuring out how to get off, how to go up, what to do with the rest of the kids. That was the hardest part really, was figuring out how to get up to clinic. It takes an hour to get up there, an hour to get back, get the lab work from here to up there and if you, when you take Cyclosporin and do lab work, you have to do it at a certain time and that was not always easy, trying to figure that out.

Another mother, who also lived a long distance from the physician's office, was employed outside of the home, and had other children, stated she felt that Burdens of Care decreased over time.

At first I thought it was going to be a big responsibility because it was just me, you know, my husband would be at work, and basically I work, but I'm at home more than he is. But after you get into the routine and habit of doing stuff like that, it's not as much of a burden, you know. It comes naturally, and it gets easier.

Additional expressed Burdens of Care included dealing with insurance companies, the
expenses of prescribed medications not covered by insurance, finding affordable housing while the transplant recipient is in the hospital, and being informed about available funding sources.

Sharing the Challenge

Sharing the Challenge represents the process of a developing relationship among mothers of transplant recipients, transplant recipients, and health care team members with the common purpose and goal to provide the circumstances that will allow the transplant recipient to reach and maintain an optimal level of wellness following a kidney transplant. Maintaining the optimal level of wellness of the transplant recipient includes preserving kidney function, lowering the risks of rejection, and early detection of symptoms of rejection. These goals are promoted by the health care team, mothers, and transplant recipients sharing the responsibilities of Caregiving on a daily and continual basis. The consequences of Sharing the Challenge include daily high quality care, lowered risks of rejection, early detection of rejection and Reassurance for all participants in sharing the challenge that the most is being done to promote the optimal level of wellness for the transplant recipient.

Rejection of a transplanted organ is the human body’s physiologic response following transplantation. Rejection is the strongest threat to the health of a transplanted kidney and preservation of kidney function. Therefore, lowering the risks of rejection and early detection of rejection were primary goals following the kidney transplant. A property of the threat of rejection, timing, began immediately following surgery. The duration of threat of possible rejection was for the life of the transplant recipient. The intensity of the
threat of potential rejection was highest immediately following the surgical transplantation, especially for the first year following transplantation, then lowered as time post transplant increased. The intensity of the threat of rejection increased with evidence of possible rejection, such as an elevated blood creatinine level or a fever. The intensity of the threat of rejection also increased with illness and infections. Mothers feared rejection the most immediately following transplant, and again whenever evidence of possible rejection was detected.

Sharing the Challenge was a process by which the health care team, mothers, and transplant recipients combat the pervasive threat of rejection. Following a kidney transplant, the health care team assumed responsibilities in managing the preservation of the transplanted kidney and the transplant recipient's health. The health care team relied on the primary caregiving parent, in this study, mothers, to Accept Responsibilities in optimizing the preservation of kidney function and the transplant recipient's health. Subsequently, mothers delegated Caregiving responsibilities to the transplant recipient. Therefore, Sharing the Challenge united the health care team, mothers, and transplant recipients in the common goals of preserving kidney function, decreasing the risks of rejection, and early detection of rejection.

Sharing the Challenge encompassed the Caregiving techniques of Learning, Symptom Management, Information Seeking, and Weathering. A property of Sharing the Challenge, timing, began when it was apparent that a kidney transplant was needed. Learning the intricacies of caregiving was shared between mothers, transplant recipients,
and the health care team. Mothers were partially informed by the health care team and found additional resources to support their informational needs.

Another property of Sharing the Challenge, extent, was greatest immediately following the transplant. Frequent physician visits, blood studies, and caregiving tasks created a Burden of Care for the mothers and families of transplant recipients. The extent and frequency of caregiving responsibilities lowered over time as the transplant recipient's condition stabilized and confidence in the newly functioning transplanted kidney developed. When variances in the transplant recipient's condition were discovered, the strategies of Symptom Management and Information Seeking were increased to rule out possible rejection and find out what needed to be done. Evidence of possible rejection increased Caregiving responsibilities and the Burden of Care until rejection was ruled out or successfully treated, and the stability of the transplant recipient's condition was reestablished.

Weathering was a strategy used by mothers throughout the transplant process. Hope, patience, and a positive outlook were these mothers' general perspectives. When the threat and subsequent Fear of Rejection increased and the Burden of Care increased, mothers increased their expression of using Weathering techniques to survive the episode.

Sharing the Challenge resulted in mothers feeling informed, prepared, confident, supported and Reassured that all efforts were in progress to maintain their child's optimal level of wellness and kidney function. Mothers, transplant recipients, and their families also experienced a Burden of Care as a result of Accepting Responsibility in Sharing the Challenge of Caregiving with the health care team. Yet evidence of frequent caregiving
strategies provided Reassurance for mothers, transplant recipients, their families, and the health care team against the primary threat of a transplanted kidney, rejection.

Summary

Chapter IV described the informant characteristics and emergence of the core category. Based on the constant comparative analysis of data obtained from interviewing the informants, Sharing the Challenge was identified as the core category. Subcategories were identified in support of the core category in terms of causal conditions, strategies, and consequences. The causal condition was identified as Fearing Kidney Rejection in response to the threat of rejection. The subcategory of Caregiving was identified as the major strategy to combat the threat of rejection. Subcategories identified for Caregiving were Learning, Symptom Management, Information Seeking, and Weathering. The resulting consequences of the Caregiving strategies for Sharing the Challenge were Reassurance and Burden of Care.
CHAPTER V

CONCLUSIONS AND IMPLICATIONS

In Chapter V conclusions resulting from the grounded theory study of information needs, perceived by parents, regarding symptom management of their adolescent following a kidney transplant are presented. The relationship of the results to the conceptual orientation and literature reviewed for this study are discussed. The conceptual areas of the impact of chronic illness, parental information needs, and adaptation as parts of the conceptual orientation for this study are compared and contrasted with the findings of this study. The findings of the identified core category, Sharing the Challenge, and the identified supporting subcategories Fearing Kidney Rejection, Caregiving, Reassurance and Burden of Care, are discussed. Implications for nursing research and practice are discussed. Recommendations for future research and study limitations conclude the chapter.

Relationship of Findings to Conceptual Orientation and Literature Review

A basis for this grounded theory study of the perceived information needs of parents regarding symptom management of their adolescent following a kidney transplant was that it was important to ask the parents themselves. Exploring parents' perceptions of their ongoing informational needs was believed to offer views of processes by which they identify and learn to manage their adolescents' condition and symptomatology. The conceptual orientation for this study was formed by a preliminary review of the literature of parents of chronically ill children. Three dominant concepts emerged as a result of the
preliminary review of the literature: The impact of pediatric chronic illness on parents and family, parental informational needs, and parent and family adaptation processes.

The literature reviewed revealed that the impact of chronic illness on parenting and families was significant (Cohen, 1993; Dracopoulos & Weatherly, 1983; Whyte, 1992). Findings in this study concur with findings of previous studies. Due to transplant recipients' chronic condition following a kidney transplant, the normal stresses of parenting are compounded by recurring health crises and the chronic burdens of caregiving, time constraints, and financial hardships. Additionally, the threat of kidney rejection generates fear and uncertainty of the future.

The literature review of parents caring for a chronically ill child revealed that their information needs were paramount and ongoing, and included both medical and nonmedical information (Horner et al., 1987; Meerpol, 1991; Weichler, 1990, 1993; Subsequently, parents actively sought information as a method of managing (Weichler; Youngblut et al., 1994). Findings of this study are consistent with the preliminary studies. Because of the reliance on parents, families, and transplant recipients to accept comprehensive daily caregiving responsibilities, specific medical information was needed to fulfill the management requirements of prescribed care at home. Additionally, parents required information on available resources for finances, health insurance, and support. Mothers in this study actively sought information as a strategy to fulfill their primary caregiving role.

Preliminary review of parents' caregiving of a child's chronic condition showed that adaptation processes were positive occurrences over time, promoted by parents' learning
and the ability to integrate caregiving requirements into their daily lives (Deatrick & Knafl, 1990, Jerrett, 1994; Rawlins, 1991). These preliminary studies also revealed that parents' increased involvement in caregiving and symptom management for their child increased their confidence as primary decision-makers (Deaton, 1985; Jerrett, 1994; Lynn, 1986). Parents' increased confidence as primary decision-makers contributed to improving their child's long term outcomes (Deaton, Jerrett). This study strongly supported the principles revealed in these preliminary studies. Sharing the Challenge was the strategy explicated in this study to promote comprehensive and daily caregiving to transplant recipients by promoting a high degree of involvement of mothers, transplant recipients, and families with the health care team. United involvement of the health care team, mothers, transplant recipients, and other family members was promoted by actively sharing information, responsibilities, knowledge, and support. The consequences of Sharing the Challenge included the Burden of Care, but also showed that mothers were confident that the most was being done to promote the transplant recipients' optimal level of wellness, thus were reassured against the threat of rejection.

An appropriate expansion of the conceptual orientation through concepts explicated in this study was to view findings in relation to the life-span development framework. The life-span perspective postulates that developmental growth is a consequence of the varying combinations of biological, psychological, social, historical, and evolutionary influences and their timing across individuals' lives (Thompson, 1988; Weekes, 1991). The life-span developmental approach for viewing adolescents with a chronic condition and their mothers, such as in this study, would be to consciously account
for the previous experiences of these individuals beyond what their current experiences might be as related to this investigated post kidney transplant phase (Thompson, 1988; Weekes, 1991). For example, two transplant recipients in this study were a similar age group, mid-adolescence. However, one transplant recipient had experienced a heart transplant nine years previous to the kidney transplant. This mother's and the transplant recipient's previous experience with organ transplant, immunosuppressive medications, and rejection prepared them differently from the transplant recipients who had not experienced previous organ transplants. The transplant recipient with previous organ transplant experience had accepted a larger extent of related caregiving requirements than the other transplant recipients. The mother with previous experience of a child receiving an organ transplant had relinquished a larger extent of caregiving responsibilities than the other mothers. Additionally, previous experience with successful organ transplantation had influenced this mother's and transplant recipient's perception of the gravity of kidney rejection. They did not express the same degree of fear of rejection that the other mothers expressed or that is reported in the literature.

Principles within the context of the life-span developmental theory are reflected by the extent of involvement of the transplant recipients in self-care (Thompson, 1988). The principles of plasticity and individuals as producers of their own development are demonstrated by the adolescents' willingness and readiness to accept responsibility for portions of their symptom management, and mothers' willingness and readiness to delegate portions of symptom management to their sons. Both exemplify individuals actively engaging and responding to their circumstances and by that producing their development
and parts of their destiny. The adolescent, as a participant in his symptom management, is creating his ability to participate in self-care that demonstrates an increasing level of development and adjustments to external influences (Thompson, 1988). Adolescents, with a chronic condition, taking on self-care responsibilities of symptom management are actively moving toward or developing their maximum responsibilities for self-care, thus producing their own development as a person.

An additional principle of life-span development illustrated in the findings of this study is that non-normative events are major contributing factors of developmental change (Thompson, 1988; Weekes, 1991). The occurrence of kidney disease requiring a kidney transplant resulting in a chronic condition represents the non-normative event. In response to the non-normative event, the adolescent accepts self-care responsibilities for symptom management. Adolescents accepting self-care responsibilities for symptom management demonstrate their increasing complexity and advancing development. Correspondingly, mothers of transplant recipients are actively engaging in developing as evidenced by acquiring new and increasing responsibilities and learning new information to manage the caregiving requirements of the transplant recipient. Development as a result of a non-normative event is illustrative of a central life-span developmental principle (Thompson; Weekes).

Discussion of Findings

Sharing the Challenge was identified as the core category and strategy used by the health care team, mothers, and transplant recipients to achieve their common goal of providing the circumstances that promote the transplant recipient to reach and maintain an
optimal level of wellness following a kidney transplant. Maintaining the optimal level of wellness of the transplant recipient included preserving kidney function, lowering the risks of rejection, and early detection of symptoms of rejection. Sharing the Challenge represents the process involved for mothers, transplant recipients, and health care team members to share responsibilities for caregiving through delegation and acceptance of tasks and responsibilities, sharing knowledge and information, and giving support.

Accepting Responsibility, the commitment to fulfill caregiving requirements, was identified as a closely integrated subcategory of Sharing the Challenge. The health care team, mothers, and transplant recipients readily accepted responsibilities of Caregiving decided to promote an optimal level of wellness for the transplant recipient following the transplant. The findings of this study support the literature reporting that mothers usually assume the primary caregiver role for a child with chronic illness, with the next highest percentage of caregiving responsibilities being assumed by the chronically ill child (Turner-Henson et al., 1992). An exception in this study was that one mother stated she delegated most caregiving responsibilities to the transplant recipient. Although transplant recipients were delegated and accepted responsibility for portions of their symptom management, mothers in this study accepted primary caregiving responsibilities. Caregiving responsibilities involved numerous duties, including being accountable for Symptom Management and the adolescent's response, learning who to contact, when and how to contact health care team members, managing finances and health insurance, and coordination of health care duties with other family responsibilities.
The threat of rejection provided the impetus for the involved parties, mothers, transplant recipients, and health care team members to combine their efforts (Share the Challenge) to provide the extent of caregiving necessary to lower the risks of kidney rejection and provide early detection of signs of rejection. The findings of this study supported the findings of previous studies that Fearing Kidney Rejection is significant and ongoing following an organ transplant (Dracopoulos & Weatherly, 1983; Weichler, 1990, 1993). The findings of this study show that the fear of kidney rejection decreases over time and with increased experience, but increases intermittently with evidence or signs of rejection. The findings of this study bring attention to the distress mothers, transplant recipients, and families endure in response to the unknown. Questions of the unknown include when and to what extent will kidney rejection occur, what will the blood creatinine level be, and what will the test results reveal? The findings of this study also suggest that the perceived seriousness of the threat of rejection provided increased motivation for all involved persons to perform caregiving responsibilities perceived to provide direct protection of the transplant recipient from the risks of rejections.

Caregiving is the label for a broad category of strategies done to preserve kidney function, lower the risks of rejection, and detect signs of rejection early. Learning was a subcategory of caregiving and a shared responsibility among the health care team, mothers, and transplant recipients. Learning how to do Symptom Management was requisite to doing Symptom Management, therefore the health care team had a significant responsibility to educate mothers and transplant recipients before discharge from the hospital, and continuing through recovery. Mothers learned at varying speeds and depths
and preferred varying methods of Learning. Most of what mothers learned was based on what they were taught by the health care team, although mothers also sought and learned information from other sources. Mothers reported they experienced gaps in the information they were taught and had learned and they continued to discover information they needed. The literature supports mothers' desire and requirement to learn a great deal of information to fulfill the responsibilities of managing prescribed care at home (Horner et al., 1987; Meerpol, 1991; Weichler, 1990, 1993). The ease or difficulty by which mothers learned was influenced by their familiarity with the information. Unfamiliar caregiving responsibilities were perceived as more difficult to learn. Some ongoing information needs resulted from the difficulty of comprehending unfamiliar information, such as the side effects of medications and the signs of rejection. Findings in this study concur with the findings of previous studies showing mothers valued Learning from peers who had previously experienced a child having an organ transplant (Weichler, 1990).

Because transplant recipients in this study were the ones primarily in charge of taking their prescribed medications each day, there is the possible inferences that transplant recipients learned the name, usage, dosage, and frequency of their medication. Additionally, mothers expressed that transplant recipients were accountable for maintaining adequate hydration and informing their mothers if their urine output had decreased, additional evidence transplant recipients had learned details of their symptom management.

Symptom Management included Delegating caregiving responsibilities, Following prescribed instructions, Monitoring, and Reporting findings to the health care team following the kidney transplant. Symptom Management was a major element identified in
Sharing the Challenge. The health care team relied on mothers, and mothers relied on transplant recipients, to closely follow prescribed instructions, keep abreast of the transplant recipients' daily health status, be alert for any signs of rejection and infection, and notify the health care team of variances in health status expediently. The findings of this study suggest the degree to which mothers and transplant recipients followed prescribed instructions, monitored, and reported to the health care team was based on their perception of the benefits and their perception of the seriousness of consequences if omitted. Perception of the seriousness of consequences was based on its perceived relatedness to increasing the risks of rejection. This study revealed that both mothers and transplant recipients made decisions regarding what symptoms to be concerned about, the length of time to monitor at home, and when to report the findings to the physician, or to their mother. The amount of time that had passed since the transplant negatively influenced one mother's and transplant recipient's diligence toward some aspects of monitoring, though the mother indicated she would respond quickly to signs of rejection.

Findings of this study are consistent with previous studies finding that mothers of chronically ill children actively seek answers and information to successfully accomplish their caregiving responsibilities (Weichler, 1990, 1993; Youngblet et al., 1994). Mothers in this study routinely obtained information from the health care team but also developed supplementary information networks. Supplementary informants were sought who were located more locally to the mothers' home, thus regarded as more conveniently accessible. The findings of this study showed that mothers considered the health care teams to be readily accessible by telephone because they responded without delays. The health care
teams' high availability served to positively reinforce mothers to actively Seek Information from them.

Burden of Care is supported in the literature as a consequence of caring for a chronically ill family member (Cohen, 1992; Dracopoulos & Weatherly, 1983; Whyte 1992). Consistent with previous studies, this study also found that the Burden of Care was not only a result of caregiving responsibilities involved in the Symptom Management, Learning, and Information Seeking aspects of Caregiving, but also included the related burdens of inadequate financing, transportation issues, conflicting schedules, and dealing with the health insurance company. The findings of this study are also consistent with previous research finding that the Burden of Care lessened as time passed (Jerrett, 1994). The Burden of Care decreased for families because caregiving responsibilities, such as frequent physician visits decreased, and families successfully integrated caregiving responsibilities into their day lives. The findings of this study suggest that in response to the Burden of Care, mothers delegated portions of caregiving responsibilities to the transplant recipient. A primary strategy used by mothers in this study to Share the Challenge and combat the fears of rejection was Weathering. Weathering represents the perspective adopted by mothers to deal with the fluctuating and risk-filled environment following a kidney transplant. In general mothers in this study practiced and exhibited a positive outlook, patience, confidence, and hopefulness. There was indication that mothers felt it necessary to exhibit a positive outlook for the benefit of themselves and their adolescent, especially when confronted with increased evidence of possible kidney rejection. One mother's method of weathering strategy involved actively minimizing many
fluctuations and complications following a kidney transplant, including the threat of rejection.

Significant findings of this study were consequential to Sharing the Challenge of Caregiving. Reassurance characterizes the positive results of integrating the efforts of the health care team, mothers, and transplant recipients to provide comprehensive daily caregiving. Mothers felt supported, informed, prepared, and confident of physician care, resulting in mothers feeling reassured against the threat of rejection. The findings of this study support that sharing responsibilities, information, and decision-making strengthened mothers' Reassurance against the threat of rejection. Previous studies support that the provisions of adequate and timely information reduce stress and support parents' caring for chronically ill children (Lynn, 1986, Weichler, 1990, 1993; Whyte, 1992).

The findings of this grounded theory study support that parents, in this study mothers, transplant recipients, and the health care team had significant roles in preserving kidney function, lowering the risks of rejection, and providing early detection of signs of rejection following a kidney transplant. Caregiving following kidney transplantation was complex. Most mothers in the primary caregiving role were adjusting to a new role added to their regular parenting responsibilities. Mothers and transplant recipients required education, information, and support to adjust to their new roles and promote the circumstances that allowed the transplant recipient to reach and maintain their optimal level of wellness following the kidney transplant. Reciprocally, the health care team required a degree of commitment from the family members to provide comprehensive, daily caregiving, and timely information of variances in health condition.
Member checks with each informant (mother) revealed unanimous agreement that the core category, Sharing the Challenge, represented the primary strategy they used to manage the caregiving responsibilities for their adolescent following a kidney transplant. Informants also agreed that Caregiving and its' subcategories were the strategies employed to manage the threat of rejection. Additionally, all informants agreed that the consequences of Sharing the Challenge with the health care team included both Burden of Care and Reassurance that the most was being done to promote the transplant recipient's optimal level of wellness since the kidney transplant.

Implications for Nursing Practice

Improving the quality of care the transplant recipient receives on a daily basis potentially improves the preservation of kidney function by lowering the risks of rejection and providing early detection of possible rejection (Fine et al., 1987). The descriptions of the core category, Sharing the Challenge, and the related and supporting subcategories, grounded in the experience of the informants, provide a framework for understanding the process by which mothers and transplant recipients fulfill their roles in caregiving following a kidney transplant. Exploring mothers' perception of their information needs heighten health care professionals' awareness of their needs, thus providing the groundwork necessary to develop educational and support programs to satisfy their needs (Weichler, 1990, 1993; Whyte, 1992).

Mothers' preferred methods of learning varied. Mothers' familiarity with information concerning their child's kidney transplant varied. The extent and depth of information mothers' learned about their child's kidney transplant and consequent care also
varied. Therefore, implications for nurses as health care team members in sharing responsibilities for caregiving are multiple. Caregivers', patients', and family members' familiarity with educational material must be assessed. Nurses must recognize that most information distributed is new information and may require multiple reiterations over time, using varying methods to optimize learning. The fact that adolescent transplant recipients play a significant role in their own symptom management has implications for including transplant recipients in educational and support programs and designing developmentally appropriate educational and social programs.

Mothers and transplant recipients made decisions regarding symptom management, such as when to call the physician and what to monitor more closely. Mothers and transplant recipients made their decisions based on their perception of the benefits of finding out and their perception of the seriousness of findings, primarily related to the threat of rejection. Therefore, implications exist for nurses to present information accurately and concisely, provide explicit directions for what to do based on findings, provide parameters and explanations for what qualifies as urgent or nonurgent and the relevant response. Additionally, dispensing printed information that can be taken home and used as a reference by parents and patients is extra assurance they will be informed of how to respond to a situation.

Significant findings in this study that provide implications for nurses include the positive consequences of readily available information sources. Readily available information sources provided support and positive responses for mothers to seek information when faced with uncertainty. Literature supports that addressing the

The burdens of care and nonmedical information needs experienced by mothers and their families during comprehensive caregiving for the transplant recipient provide nursing implications for the continued development of information and support networks for families. Inadequate health care resources continue to plague families in this study. The implications for nurses include an increased awareness of resource requirements by patients and their families, identification of available resources, linkage of identified needs to available resources, and promotion of the development of needed resources. Nursing Case Management is a developing speciality of advanced nursing practice designed to effectively address the health care resource requirements of patients and their families (Ethridge, 1991; Smith, 1993; Smith, 1994). Nursing Case Managers, educated in advanced nursing practice, expertly identify both client health care needs and effective and available resources (Ethridge, 1991; Smith, 1994). Effective identification of ongoing health care needs of patients and their families and linkages to available and beneficial resources grant the circumstances that allow patients and their families to reach and maintain their optimal level of health (Smith, 1993). Through early identification of variances in health, skilled management, and appropriate resource utilization, Nursing Case Managers employ strategies to prevent illness exacerbations and promote clients' and families' optimal health status.
Finally, nursing implications are noted for the positive consequence of the process of Sharing the Challenge in this study, Reassurance. Nurses can actively promote interdisciplinary sharing of information, knowledge, and responsibilities with families and patients. Patient and family education and positive and open communication are integral ingredients to successfully Share the Challenge of Caregiving. Sharing the Challenge of Caregiving promotes the achievement and maintenance of an optimal level of wellness for the patient and their family.

Recommendations for Future Research

This grounded theory study provides the initial phase of the development of an emerging theory. Recommendations for future research based on the results of this study include supplementary grounded theory study with the collection of additional data to continue to explore, support, and refine in this emerging theory the core category and subcategories identified in this study. Informant data indicated the positive role Sharing the Challenge contributed as a strategy to provide optimal caregiving following a child's kidney transplant. Further development of the core category, Sharing the Challenge, as a basic social process of providing comprehensive, high quality caregiving of a chronic condition is advocated. Additionally, further development of the major supporting subcategories Fearing Kidney Rejection, Caregiving, Reassurance, and Burden of Care and additional subcategories is necessary to further explicate the influential factors surrounding Sharing the Challenge.

Additional recommendations for future research are to replicate this study with families of varying demographic circumstances. Examples include replication of this study
on families whose transplant recipients are a younger age group or of a diverse ethnic, cultural, or social situation. It would also be beneficial to replicate this study using the transplant recipients as informants.

Study Limitations

There are several limitations of this study. There was a limited number of available informants. Due to the limited number of available informants, saturation was achieved in some, but not all subcategories. Ethnic orientation of informants was not identified, therefore ethnic consideration was not applicable in analysis. Pursuing ethnicity of informants as potentially influencing participation in information sharing would have strengthened the study. This study may have also been strengthened by using a diversity of transplant recipient age groups to determine the similarities and differences of participation by the primary caregiving parent.

Summary

The processes of how parents manage informational needs due to caregiving requirements following the kidney transplant of their adolescent were explored. Sharing the Challenge was explicated as the emerging core category. Sharing the Challenge was the strategy used by mothers, transplant recipients, and health care team members to achieve their common goal of providing the circumstances that promote the transplant recipient to reach and maintain an optimal level of wellness following the kidney transplant. Sharing the Challenge was achieved by sharing responsibilities of caregiving through delegation and acceptance of tasks and responsibilities, sharing knowledge and information, and giving support.
Sharing the Challenge and comparison of results to the conceptual framework and to other literature were presented in Chapter V. Implications for nursing practice, recommendations for future research, and limitations of the study were also addressed.
APPENDIX A: HUMAN SUBJECTS APPROVAL
5 June 1995

Judy H. Bergman, BSN
c/o Kathleen M. May, Ph.D.
College of Nursing
Arizona Health Sciences Center

RE: INFORMATION NEEDS, PERCEIVED BY PARENTS, REGARDING SYMPTOM MANAGEMENT OF THEIR CHILD POST RENAL TRANSPLANT

Dear Ms. Bergman:

We have received documents concerning your above cited project. Regulations published by the U.S. Department of Health and Human Services [45 CFR Part 46.101(b) (2)] exempt this type of research from review by our Committee.

Thank you for informing us of your work. If you have any questions concerning the above, please contact this office.

Sincerely yours,

William F. Denny, M.D.
Chairman
Human Subjects Committee

WFD: js

cc: Departmental/College Review Committee
MEMORANDUM

TO: Judy H. Bergman, BSN
College of Nursing
Arizona Health Sciences Center

FROM: Carolyn Murdaugh, PhD. RN. FAAN
Director of Clinical Research

DATE: June 8, 1995

SUBJECT: Human Subjects Review: "INFORMATION NEEDS, PERCEIVED BY PARENTS, REGARDING SYMPTOM MANAGEMENT OF THEIR CHILD POST RENAL TRANSPLANT"

Your research project has been reviewed and approved by William Denny, M.D., Chairman of the University of Arizona Human Subjects Committee, and deemed to be exempt from review by their full committee. A brief summary of your project procedures will be submitted to the Committee for their endorsement and/or comment. You will be receiving a confirmation letter from Dr. Denny. In addition, your project has been reviewed and approved by the College of Nursing Human Subjects Review Committee.

We wish you a valuable and stimulating experience with your research.

CM/wo
APPENDIX B: FACILITY APPROVAL BY ATTENDING PEDIATRIC NEPHROLOGIST
May 25, 1995

TO WHOM IT MAY CONCERN:

Judy Bergman has requested that she be introduced to our renal transplant patients. Judy has identified our renal transplant patients as a group suitable for her masters research database. She will be interviewing the parents of our pediatric renal transplant patients. Judy will be assessing the special needs of transplant patients after they have been discharged from the hospital. I am very much in favor of her proceeding with her research in this area. Specifically, her research will help to point to areas where patients require further information after their transplant is performed. Overall, I think that she will be performing a service to our patients and to ourselves. I am in full support of her research proposal.

If you have any questions, you should feel free to contact me by dialing 626-6182.

With best regards.

Sincerely,

Peter Yorgin, M.D.
Assistant Professor of Pediatrics (Nephrology)
APPENDIX C: SUBJECT DISCLAIMER

TITLE Information needs perceived by parents regarding symptom management of their adolescent following a kidney transplant

You are being asked to voluntarily participate in a study exploring your information needs regarding managing the care of your child since the kidney transplant. The purpose of this study is to help nurses identify and document the information needs of parents related to symptom management of their child post renal transplant. By responding to questions in an interview you will be giving consent to participate in the study.

The interview will take place in a location convenient for you and will last approximately one hour. A second, shorter interview will be requested to discuss the results from the first interview. With your permission, a tape recorder will be used. Your identity will not be revealed and your confidentiality will be maintained in all reports of this of this project. After the interview has been transcribed from the audiotapes, the audiotapes will be destroyed. The researcher, transcriber, and the thesis committee are the only persons who will have access to the transcribed interview.

You may choose not to answer some or all of the questions. You make ask questions about the study and your questions will be answered. You may withdraw from the study any time with no consequences, including no effect in the care you and your child receive. There are no known risks involved in your participation. There are no known benefits except the opportunity to share your perspective.

Your participation is appreciated.

Thank-you

______________________________

Researcher: Judy H. Bergman, RN, BSN

______________________________

Date

P. I. Telephone number: (602) 323-3785
APPENDIX D: PARTICIPANT DEMOGRAPHIC DATA

Code # of Interview:

Date of Interview:

Renal Transplant Recipient

Age:

Gender:

Years of Education Completed:
(if applicable)

Diagnosis:

Date of Diagnosis:

Date of Transplant:

Participant/ Parent

Age:

Gender:

Marital Status:

Years of Education Completed:

Relation to Renal Transplant Recipient:

Number of Persons Living in Home:
Age and Relations

Annual Income: <$10,000
$11,000-$20,000
$21,000-$30,000
$31,000-$50,000
$51,000-$100,000
> $100,000

Source of Income:
APPENDIX E: INTERVIEW GUIDE

Introduction: As the parent and primary caregiver of a child following a kidney transplant, what are your information needs and what process(es) do you use to meet the informational needs regarding symptom management of your child since the kidney transplant?

1. What do you do (did you do) to provide care for your child since your child's kidney transplant? Immediately following discharge? A few weeks later? Now?

2. What kinds of feelings do you recall concerning being responsible for your child's care after the kidney transplant? Preparing for discharge? A few weeks later? Now?

3. As you reflect over the past several months, what do you feel you have needed to know (to feel good) about managing the daily care of your child at home after the kidney transplant?
   Immediately following discharge? A few weeks later? Now?

4. How would you go about obtaining the information you perceive to need?

5. What aspects of your child's care do you feel you need to know more about?

6. What essential information do you feel is important for you to know to manage your child's care?

   Investigator may ask participants about the following areas after participants completed response to this question.

   medications    temperature    rejection    school
   lab studies     urine output   blood pressure activity limitations
   infection      daily weights   emotional behavior future issues

7. If you were going to prepare another parent for their child to be discharged home after a kidney transplant, what information would you want to share with that parent?

*Note: Based on the participants' responses, further questions may be asked to further clarify data. For example: So, what did you do? How did that go?
### APPENDIX F: EXCERPTS OF DATA BITS USED TO ILLUSTRATE OPEN CODING. INITIAL DEVELOPMENT OF CATEGORIES, AND THEORETICAL NOTES

<table>
<thead>
<tr>
<th>Excerpts of Raw Data</th>
<th>Open Coding</th>
<th>Properties</th>
<th>Dimensions</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;Just check his blood pressure, make sure that his medication is taken on time, make sure he drinks enough water, takes enough fluid to hydrate the kidney good [sic], and basically just watch him. You know, make sure he does everything he has todo.&quot;</td>
<td>performing tasks</td>
<td>being accountable</td>
<td></td>
</tr>
<tr>
<td>&quot;&quot;Just check his blood pressure, make sure that his medication is taken on time, make sure he drinks enough water, takes enough fluid to hydrate the kidney good [sic], and basically just watch him. You know, make sure he does everything he has todo.&quot;</td>
<td>monitoring</td>
<td>timing</td>
<td>on time... not on time</td>
</tr>
<tr>
<td>&quot;&quot;Just check his blood pressure, make sure that his medication is taken on time, make sure he drinks enough water, takes enough fluid to hydrate the kidney good [sic], and basically just watch him. You know, make sure he does everything he has todo.&quot;</td>
<td>monitoring</td>
<td>amount</td>
<td>enough...not enough</td>
</tr>
<tr>
<td>&quot;&quot;Just check his blood pressure, make sure that his medication is taken on time, make sure he drinks enough water, takes enough fluid to hydrate the kidney good [sic], and basically just watch him. You know, make sure he does everything he has todo.&quot;</td>
<td>monitoring</td>
<td>extent</td>
<td>sufficient...not sufficient</td>
</tr>
<tr>
<td>&quot;&quot;Just check his blood pressure, make sure that his medication is taken on time, make sure he drinks enough water, takes enough fluid to hydrate the kidney good [sic], and basically just watch him. You know, make sure he does everything he has todo.&quot;</td>
<td>watching</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;&quot;Just check his blood pressure, make sure that his medication is taken on time, make sure he drinks enough water, takes enough fluid to hydrate the kidney good [sic], and basically just watch him. You know, make sure he does everything he has todo.&quot;</td>
<td>being accountable</td>
<td>extent</td>
<td>everything...something</td>
</tr>
<tr>
<td>&quot;&quot;Just check his blood pressure, make sure that his medication is taken on time, make sure he drinks enough water, takes enough fluid to hydrate the kidney good [sic], and basically just watch him. You know, make sure he does everything he has todo.&quot;</td>
<td>monitoring</td>
<td>status</td>
<td>required...unrequired</td>
</tr>
</tbody>
</table>

**Theoretical Note:** (I 1. p. 1. lines 18-23)  Responsibility/ Delegating/Symptom Management

"make sure" he does everything he has to do

The mother of the transplant recipient is holding self ultimately responsible that all prescribed treatment is followed, even though tasks such as taking medications seem to be delegated to the transplant recipient.

"watch" "on time" "enough"

The mother of the transplant recipient monitors and judges the extent to which prescribed treatment is carried out -> symptom management

"I would watch it for about a day or two and if I seen [sic] that it's not going down or it stays up, I would give the doctor a call. That's what they have us do, is call him and let him know."  

**Theoretical Note:** (I 1. p. 2. lines 59-63)  Symptom Management

The mother of the transplant recipient watches, monitors, reports, follows prescribed instructions

Mother has learned desired parameters for blood pressures, knows what to do, who to call when B/P elevated. Mother makes judgement when to notify physician regarding B/P elevation.

Watching is a component of monitoring, so will label both monitoring, Monitoring, Following Prescribed Instructions, and Reporting are all components of Symptom Management, so will be on the lookout for other examples of symptom management.
APPENDIX G: EXCERPTS OF RESULTS OF CONSTANT COMPARATIVE ANALYSES, CONCEPTS FROM DATA BITS COMBINED AND CONCEPTUALIZED INTO CATEGORIES

The following is an excerpt of conceptual development of the previously open coded data:

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Properties</th>
<th>Dimensions</th>
</tr>
</thead>
<tbody>
<tr>
<td>being responsible</td>
<td>extent</td>
<td>some...all</td>
</tr>
<tr>
<td>delegating</td>
<td>extent</td>
<td>some...all</td>
</tr>
<tr>
<td>performing tasks</td>
<td>frequency</td>
<td>daily...bid....tid...weekly</td>
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<tr>
<td>following instructions</td>
<td>status</td>
<td>required...not required</td>
</tr>
<tr>
<td>monitoring</td>
<td>timing</td>
<td>on time...not on time</td>
</tr>
<tr>
<td>&quot;making sure&quot;</td>
<td>amount</td>
<td>sufficient...insufficient</td>
</tr>
<tr>
<td>&quot;watching&quot;</td>
<td>extent</td>
<td>enough...not enough</td>
</tr>
<tr>
<td></td>
<td>length of time</td>
<td>one-two days...</td>
</tr>
<tr>
<td>reporting</td>
<td>timing</td>
<td>expediently...early..late</td>
</tr>
<tr>
<td></td>
<td>parameters</td>
<td>hi....lo</td>
</tr>
</tbody>
</table>

Theoretical Note: (11, p. 1 & 2; lines 18-23 & 59-63)
Categories: Caregiving; Symptom Management
Mothers accept varying degrees of responsibility for Caregiving and delegate some to transplant recipient. Performing tasks, following prescribed instructions, monitoring, and reporting encompass what I consider Symptom Management. Symptom Management is a part of Caregiving.

Excerpts of Results of Constant Comparative Analyses
Relationships of Categories to Subcategories Developed Through Axial Coding

The following is an excerpt of Axial Coding:
Axial Coding
Causal Condition: Threat of kidney rejection
Phenomenon: Symptom management
Context: Under conditions of the threat of rejection, mothers accepted responsibilities and delegated responsibilities for symptom management to the transplant recipient. Under conditions of mothers knowing prescribed instructions, perceiving the benefit, and perceiving the seriousness of omitting, following instructions is done at prescribed intervals (up to three times per day) to lower the threat of rejection and detect signs of rejection early
Under conditions of parents and transplant recipients receiving positive feedback and answers to uncertainties when reporting variances of conditions, mothers are positively reinforced to seek information and report variances in condition expediently
APPENDIX G: (CONTINUED) AXIAL CODING OF DATA

Strategies: Delegating, Following prescribed instructions
Monitoring, Reporting

Intervening Conditions: Inclinations of mother; willingness of transplant recipient
Misconception of perceived benefit of performing
Misconception of perceived seriousness if not performed

Consequences: Variances in health condition are discovered, reported, treated
Receive information, answer to uncertainty
Comfort
Comprehensive daily symptom management

Causal Condition: Parental Role, Child Status Post Kidney Transplant,
Fearing Kidney Rejection

Phenomenon: Caregiving

Context: Under conditions in which a parent has a child who has undergone a kidney transplant, then the threat of kidney rejection produces fear of kidney rejection and parents perform daily caregiving to assist the health care team in preserving kidney function and lowering the risks of rejection.

Under conditions that mothers accept some responsibilities and delegate to the transplant recipient some responsibilities for caregiving, comprehensive caregiving is performed on a daily basis to the extent of the perceived benefit and the perceived seriousness of omitting.

Under conditions where mothers and transplant recipients were taught by the health care team and sufficiently learned how to perform symptom management, comprehensive symptom management is performed on a daily basis.

Under conditions of the perceived benefit of the condition did not outweigh the perceived seriousness of omitting, comprehensive symptom management was not performed as prescribed.

Strategies: Accepting responsibilities
Delegating responsibilities
Learning
Symptom Management

Intervening Conditions: Inclinations of mothers; willingness of transplant recipient
Extent and methods of being taught
Familiarity; previous experience
Perceived benefit
Perceived seriousness

Consequences: Burden of Care
Comprehensive caregiving, symptom management
Reassurance
When axial coding was completed on all major categories and subcategories, the following questions were asked of the data: What is going on in the data in relationship to the focus of the study, and identified as a problem for participants? What processes were utilized by the participants to deal with the problem? What explains the major action in the situation under study? In all categories, what seems to be the main storyline, pattern, or theme? What category do all other categories seem to be leading up to or pointing to?

In response to these questions the following short story was explicated:

**Theoretical Note:** The storyline: SHARING THE CHALLENGE

The main story seems to be about how mothers, transplant recipients, and physicians and nurses team up, develop a relationship to promote their commonly shared goal: achieving and maintaining the optimal level of functioning of this newly transplanted kidney. The strategies employed to accomplish this common goal are numerous. The health care teams have responsibilities to teach what needs to be done, how often, by what method, what the symptoms of rejection are, and what to do if they are discovered. Mothers extend themselves as parents to be health caregivers. They learn symptom management and how to deal with the threat of rejection. The threat of rejection is what fuels everyone's motivation for comprehensive caregiving. Transplant recipients join the team by accepting responsibilities such as taking their medications and letting their moms know when they feel ill. Parents delegate caregiving responsibilities, much as they might delegate noncaregiving responsibilities, like taking out the trash. The results of this united effort of caregiving are that all participants are reassured that everything that can be done to optimize the health of the transplant recipient and the functioning of the transplanted kidney is being done.

After the core category, Sharing the Challenge, was explicated, then all other major categories were related to the core category by means of the paradigm model. Categories were also grouped along the dimensional ranges of their properties as described in narrative of the findings under Sharing the Challenge.

**SHARING THE CHALLENGE**

**Accepting Responsibility**

<table>
<thead>
<tr>
<th>Causal Condition: Threat of Kidney Rejection causing Fearing Kidney Rejection</th>
<th>Strategies: Caregiving Learning</th>
<th>Consequences: Reassurance Burden of Care</th>
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<tbody>
<tr>
<td></td>
<td>Symptom Management: Delegating, Following Prescribed Instructions, Monitoring, Reporting Information Seeking</td>
<td>Weathering</td>
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</table>
REFERENCES


