The Experience of Mothering a Child with a Kidney Transplant and the Implications of Illness-Related Uncertainty

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Advances in the surgical and immunological aspects of organ transplantation have resulted in significant improvements in long-term outcomes and survival rates, making kidney transplantation the optimal therapy for children with chronic kidney disease (CKD). This study examines the phenomenon of ***sustained uncertainty*** *as an element of the burden of care for maternal caregivers of children who have undergone kidney transplantation. This study indicates these mothers experience uncertainty in two prominent ways: 1) in their subjective sense of time, and 2) in their ongoing fear that their child will experience rejection of the transplanted kidney. Ultimately, this study advocates for nephrology social workers to begin addressing the social and emotional implications of uncertainty in the experience of illness for caregivers.*

INTRODUCTION

Parenting a child with chronic kidney disease (CKD) is understood to have a profound impact on both the ailing child and the family across the bounds of social, emotional and physical functioning (Aldridge, 2008; Tong, Lowe, Sainsbury, & Craig, 2008). Relatedly, advances in the surgical and immunological aspects of organ transplantation have resulted in significant improvements in long-term outcomes and survival rates, making kidney transplantation the optimal therapy for children with CKD (Anthony et al., 2010). The goal of transplantation is no longer simply graft survival and getting children to an acceptable level of physical health, but to improve their overall quality of life.

Despite the anecdotal "successes" of transplants allowing children to live independent of dialysis and enjoy an improved quality of life, the literature reflects parents' feelings that the transplant period brings another myriad set of challenges with which they must contend. Tong et al. (2008) found that parents of children receiving a transplant reported experiencing similar emotions to those whose children were on dialysis, but also struggled with the uncertainty posed by the potential rejection of the kidney graft. The documented narratives of caregivers of children post-kidney transplant indicate that, once the parents have survived the reality of their child's organ failure and subsequent transplant, they must manage the increased risk of their child's susceptibility to illness (Merskhani, 2007). These responsibilities include supporting the child through possible side effects of medications, painful biopsies necessary to assess and treat rejections, hospitalizations, and school reintegration. These are care responsibilities that differ from the particular restrictions and demands associated with dialysis, but are, nonetheless, intrusive and time consuming. In addition, there is evidence that even when children are deemed as clinically "doing well," families report a continuing struggle with the restrictions, imposed limitations, and the intrusions and management of CKD in their daily functioning (Anthony et al., 2010). Sundaram, Landgraf, Neighbors, Cohn, and Alonso (2007) studied 26 adolescent kidney transplant recipients and reported that "caregivers expressed significant negative emotional impact from their child's health condition and on their family activities" (p. 986).

One of the primary challenges associated with caregiving for this population of patients is the implication of illness-related uncertainty. This paper reports on the findings regarding sustained uncertainty from a recent research study that explored the lived experience of maternal caregivers of children who had undergone kidney transplantation. Existing literature does highlight that transplantation is fraught with various forms of uncertainty, including such worries as: "How long is the wait for transplant?"; "Will the procedure be successful?"; "Will the transplant make a difference in the life of the patient?"; and "If the transplant is successful, will the benefits of the procedure outweigh the risks?" (Martin, Stone, Scott, & Brashers, 2010). Several studies that deal with the adult population confirm a strong association of uncertainty with psycho-emotional distress (Mishel, 1999). Although uncertainty has been acknowledged and studied in the context of those waiting for transplant or receiving one, less is known about the role of uncertainty during the entire trajectory of the transplant experience. Overall, existing evidence suggests that uncertainty undermines quality of life and is strongly associated with increased stress and decreased life satisfaction (Mishel, 1999). Research has found that the impact of uncertainty is embedded in the caregiver's experience of the temporal sense of time, and exists within their ongoing fear of their child's rejection of the transplanted organ.

METHOD

Approach to Research

This research utilized a hermeneutic phenomenological approach to examine the lived experience of mothers of children who had undergone kidney transplantation.

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Phenomenology, as a method of social science research, aims at gaining a deeper understanding of the nature or meaning of everyday experiences (Husserl, 1970; Van Manen, 1990). Hermeneutic phenomenology is concerned with the "life world" (or human experience as it is lived) where the focus is on "illuminating details and seemingly trivial aspects within experience that may be taken for granted in our lives, with a goal of creating meaning and achieving a sense of understanding" (Wilson & Hutchinson, 1991, p. 34). The purpose of the phenomenological approach is to identify phenomenon through the perception of individuals located in a specific situation (Lester, 2010).

Participants

Seven mothers shared their experiences of pediatric kidney transplantation, beginning with the first time they became aware that their child had CKD. The mothers ranged in age from 27 to 41 years of age; the children ranged from 6 to 17 years of age. At the time of the study, 5 of the children were 3 to 5 years post-transplant, one was at the 1-year mark and one had been successfully transplanted for 15 years. All 7 children had only been transplanted one time and all had been diagnosed with CKD within their first year of life. Six of the 7 participants were married and residing with the biological father of the transplanted child. All of the participants lived in the Southwestern Ontario, Canada region. This research was reviewed and approved by the Office of Research Ethics at Wilfrid Laurier University. Consistent with research ethics guidelines, measures were taken to ensure confidentiality of data and personal health information, and anonymity of participants. Informed written consent was obtained from all participants.

Data Collection

Data collection procedures were designed to obtain in-depth narratives of the experience of pediatric kidney transplantation from participant mothers in a manner that enabled the exploration of the phenomena from their constructed reality and associated meanings. For this purpose, in-depth, semi-structured interviews were utilized as an instrument of inquiry, consistent with the phenomenological method.

FINDINGS

Time as Uncertain

The mothers' narratives described lives filled with unknowns, which necessitated that they learn how to mentally and emotionally manage this uncertainty. Their lives become defined by an acute sense of time and their feelings of suspension, anxiety, and worry related to its passing. For these mothers, the experience of having a child with a kidney transplant meant learning to live with and be comfortable with uncertainty, because they never can know when a sudden and intrusive change in their childrens' lives might happen.

Coping with uncertainty was a prominent aspect of their experience. One participant recalled, "My mind is already fast forwarded 15 years from now, and I want to know, I'm already stressed out now knowing what's the kidney for him (sic) and where is it going to come from?" Another confided that, "You're always thinking about the 'what ifs.' He goes to camp this summer. What if he doesn't get his medications? It's the day-to-day worry about what could happen and what tomorrow will bring that becomes part of what you always think about." Even when things were going well, the unknowns associated with the future were always in the forefront of their thoughts: "I mean, to me it's like very calm right now, but there's that piece in the back of your mind going, when's it going to hit the fan again? Like you're always worried for that, like that constant little 'what if?'"

The participants also talked about the importance of becoming comfortable with the unknowns as an essential element of coping with uncertainty, or, as one participant described it, the "greys." She explained:

> ...that even though it is black and white on paper, there's always going to be grey areas no matter what it is. I have not run into one person that hasn't had a little bit of grey area somewhere, and just knowing that, you know, that it's going to be up and down no matter what for how long, for the next 30 years it can be up and down.

The ability to make meaning from their unpredictable situations is represented in the mothers' quests to come to terms with the chronic nature of the uncertainty in their lives.

Time as Living in the Moment

Time was an essential feature of the experience in relation to the presence of suspended time, time as "waiting," and the notion of past, present, and future. Embedded in the lived experience of transplant day was the mothers' sense of waited time as their children, and in some cases significant others, were in the operating room. For some of the participants, the day of transplant, in terms of temporality, was described as going by fast: "The day of the transplant seemed to go by very fast. I didn't feel like I did a lot of waiting around at all; that surprised me." For others, however, the length of time spent waiting during the actual procedure was considered a difficult period within the experience: "I'm sitting there waiting. That was brutal, you know, it was eight hours but it felt like twelve"; "The waiting part was really hard. Time really seemed to drag, but I do remember right after the surgery was a relief"; and "It's like a long time to wait—especially when there is no communication from anyone for hours at a time."

For others, time was notably experienced in the monitoring and giving of medications so emblematic of post-transplant care:

> Yeah it is hard, and then being paranoid about med times. Okay make sure you get this at this time and at this time, and at that time he was on

> three doses a day because he was so little… so we had to wake up in the night to have the one dose because they all had to be 8 hours apart. So to try to manage it all. Sure, then you have to make sure, okay, wherever you are going to be you have all the meds you need and know what time it is. You can't vary even, you know, just a little bit, in case he rejects.

The awareness of time also extended to the hospital environment, where time and its passing, with little control of what it may bring, is not far from their minds: "No showering, feeling like, you know, just sitting there waiting on answers, waiting on blood work, holding him down to do blood work, putting him on IV, watching TV all day, just sitting there and looking and feeling like a zombie."

For the participants in this study, the lapsing of time served to structure their experiences as caregivers and was something that they needed to find ways to cope with and make meaning of on almost a daily basis. For these participants, then, uncertainty meant living in the moment: "[There is] not much you can do about it. It is what it is," and "[You] just have to be thankful for how well he feels right now and know it could change but can't worry about it all the time." Making meaning of the uncertainty and lack of control over one's own time was a major challenge for this group of caregivers.

Time as Fear of Rejection of the Transplanted Organ

The most prominent form of uncertainty in the mothers' lives surrounded the eventual rejection of the transplanted kidney. This reality impacted every aspect of their lives, and their daily rituals were embedded with the fear of transplant rejection. As one mom emphatically noted in our interview, "Is rejection always in my head? Absolutely, it is there every day, absolutely." Kidney rejection was a constant worry for the mothers:

> Like from the minute she [the child] gets transplanted to the minute of every day you think, ok, am I going to get a call that, you know, something's not right. She's gotta come in and we will find out she's rejecting?

For several of the participants, drastic, life-altering change was always around the corner:

> You always have that fear that he [the child] is going to lose it. Rejection is really, really nerve wracking for me and I am always thinking okay, when is this one going to be toast and we have to move on to the next one?

The fear that the kidney would fail was never far from the minds of these caregivers and it is a source of much stress and anxiety, ever-present throughout the life of child with the transplanted kidney. The experience of uncertainty and organ rejection meant living on the "margins" of the child's good health that was experienced in-between the "here and now," and the threat of future loss.

The fear of kidney rejection was grounded in the mothers' realization of the implications of losing the transplanted kidney for their children. For most participants, it meant a return to dialysis for their child. "Yeah, I always worry that something's going to happen for my child. It's horrible and I hate the feeling that one day that he might reject it and we'll be in the hospital again and we'll be living off a dialysis machine," confided one mother. As a result, even something as simple as going to the hospital for a routine clinic visit became a source of anxiety, since "every time you go in the hospital you don't know how it's going to flip. You don't know how that's going to turn out and you will be required to stay overnight or for a month." The result was that the participants' daily lives were imbued with the anxiety that is created by the threat of organ rejection and, as such, a major challenge with which they must emotionally and psychologically cope.

To that end, a source of frustration for several participants was encountering individuals who projected onto mothers' the sense that they should be feeling relief that their child had been transplanted and the perceived freedom from the responsibilities of pre-transplant care:

> I mentioned to a friend the other day that [my daughter] had a kidney transplant and she said, "Oh well she got a transplant, guess you're happy she'll be good for the rest of her life?" It's like, no, she's on medication every single day of her life for the rest of her life, and you don't know when. This kidney could last her for 20 years or it could be gone tomorrow. You don't know.

The struggle against the social misunderstanding of transplant as a "cure" versus a treatment was a challenge echoed by several participants in this study.

DISCUSSION

The findings of this study highlight that uncertainty begins at the time of diagnosis and continues throughout all stages of a child's development and treatment of their CKD. Although a definitive diagnosis might bring a sense of assurance of what lies ahead for some patients who are facing chronic illness, the mothers in this study painted quite a different picture of what constitutes uncertainty in their families' lives. As a therapy, transplantation means a tenuous future that is reliant on timelines for transplant, as well as the managed prevention of organ rejection.

In the context of the lived experience of mothers whose children had undergone a kidney transplant, it becomes difficult to talk about the implications of living with sustained uncertainty without relating it to temporality (as it exists as an existential element of experience). Temporal time—as it relates to past, present, and future—structures our lives and becomes part of our temporal experience of living. The dimensions of time serve to create our personal sense of continuity in life (as most events organized in this way become the timeline of one's life). Such a timeline typically constitutes developmental milestones such as birth, graduations, marriage, and the introduction of children, to name a few. For the population of caregivers with chronically ill children, this timeline becomes disrupted with the news of the diagnosis, "as it challenges the very sense of continuity that time consciousness constitutes" (Woodgate & Degner, 2002, p. 24). As a result, the timeline continuity for the child becomes warped, and, essentially, the transplant signifies the beginning of a new life with an unpredictable and different future. This disruption of a "normal" timeline is evident in the participants' narratives about the ongoing unpredictability of illness and the uncertainty attached to the future. The temporal consequence for participants, then, is that they expressed becoming existentially trapped in a future that belongs to the changing needs of the present.

Uncertainty is also closely tied with the significant amount of time the women spend in suspended or waiting time. This "suspended time" includes the time that is taken up waiting for clinic visits, waiting for phone calls about blood work and test results, and the period of time leading up to and during the transplantation procedure. These mothers describe how much of this waited time is the result of a system of healthcare that has its own timelines and delivery procedures. For these mothers, this suspended time is also imbued with uncertainty related to the possibility of poor blood work results, potential necessity of hospitalization, further testing, or changes to medication regimen. Waited time becomes part of the daily reality for these individuals and they perceive that a significant period of their life is spent "waiting and wondering." As with other uncertainties associated with transplant, these mothers are aware that the unexpected can occur on any day (i.e., a poor blood work result that will require hospitalization, or even a rejection of the transplanted kidney). The uncertainty associated with waiting, therefore, is the source of great stress and anxiety. Despite the difficulties of this reality as expressed in the mothers' narratives, however, this waited time and its impact on these women and their families is significantly disregarded by healthcare providers.

Martin et al. (2010) studied uncertainty across the transplant trajectory in adult patients and identified that uncertainty came in medical, social and personal forms. One significant finding in their study was how uncertainty during the post-transplant period was related to amount of time that had passed since transplant. The importance of "time passing" (or passage of time), however, is not without anxiety: "the reality that the longer time without rejection, however, does not exclude the possibility of future rejection" (p. 54). This reality was notable for the mothers in this study, because their narratives reveal that they give little credence (in terms of "success") to the amount of time that has passed since their child's transplant. The passing of "time since transplant" was a notable element of experience, but not necessarily one that was celebrated and embraced as a sign of ongoing success, for many of these mothers. Instead, the longer the time period that passed since the transplant, the closer the mothers felt they were to returning to dialysis and a repeat transplantation.

In essence, the way that these mothers chose to cognitively manage this tension of time since transplant was likened to "the glass being half-full or half-empty." It is important to note that the mothers had to negotiate and manage the messages they received from people who may view a kidney transplant as the end of the journey. Several mothers spoke about their feelings of frustration when friends and neighbors asked them why they were not more content or celebrating the transplant as a victory. During this part of the interview process, the participants became noticeably agitated as they spoke about having to deal with people who did not understand that transplant was not a time to rest their fears, because tomorrow was still filled with uncertainty and ongoing challenges related to managing their child's health. As Martin et al. (2010) noted, in the face of transplant, "uncertainty does not wane over time, it is constant" (p. 232). This contention highlights the reality that the social discourse of "transplant as cure" does not take into consideration the uncertainty embedded in the experience. While transplant is a significant step in providing a child with a better opportunity for an improved quality of life, the experience nevertheless contains many unknowns which maternal caregivers must cognitively and emotionally manage.

The uncertainty they experience, as noted by Cohen (1993), goes beyond simple "not knowing," because the mothers anticipate change in the future, but are uncertain as to when it will occur. In the case of pediatric kidney transplantation, uncertainty carries similar fears relative to the trials and tribulations associated with dialysis. I believe it is difficult to fully appreciate the salient elements that contribute to the fear of rejection without acknowledging its association with the experience of dialysis; however, the nature of this relationship is beyond the scope of this study.

LIMITATIONS OF THE STUDY

This study has several limitations. First, the findings reflect only the experiences of the 7 women who voluntarily participated and therefore cannot be generalized to reflect the experience of all women who act as caregivers to children with kidney transplants. Second, this research focused solely on the perceptions, thoughts, and feelings of these 7 women and did not take into account the experience of siblings, partners, or the transplanted children themselves. Third, the researcher had a previous clinical experience with this population of caregivers, which may have influenced elements of the research process, including the development of the interview schedule, data collection, and analysis. Alternatively, the researcher's familiarity with the women in this study and clinical experience of this population may have offered benefits to the project, including engagement with participants and an appreciation for their experience as caregivers.

IMPLICATIONS FOR PRACTICE AND FUTURE RESEARCH DIRECTIONS

For social workers providing service in the area of pediatric nephrology, the findings from this study have far-reaching implications for practice. For one, the results of this study can be used toward the development of an approach to practice that recognizes the challenges and implications posed by the presence of sustained uncertainty that surrounds the experience of caregiving for a child who has had a kidney transplant. Through the course of providing adjustment and supportive counseling, social workers can, with caregivers, acknowledge and validate the presence of uncertainty as a major challenge inherent in the disease process itself. By doing so, they will be able to enable individuals to move toward the development of healthy coping strategies as a means to decrease or manage the uncertainty and challenges. Such strategies may include increased education about uncertainty, facilitating caregivers to assume a more active role in care decisions, or assisting to initiate connections with others who have been through the experience. Uncertainty is an element of the caregiving experience in pediatric transplantation that is identified in the professional literature, but is a topic that rarely gets discussed in the clinical setting.

A topic for future research in the area of uncertainty as it pertains to caregivers of children with kidney transplants may be the link between sustained uncertainty and positive personal growth. As Mishel (1999) asks, does this uncertainty for these mothers lead to a process of rediscovering oneself on some level and making meaning of the experience? Mishel suggests that perhaps these mothers redefine themselves and their abilities, strengths, and attributes in a more positive way amid the challenges of caregiving. To that end, an identified area for future research lies in the further exploration of this link between managing the uncertainty embedded in the pediatric kidney transplant experience and also uncertainty's role as a catalyst for positive personal growth for caregivers.

CONCLUSION

It is well-documented that the experience of caring for a child post-kidney transplant creates for maternal caregivers a myriad of social, emotional, and practical challenges. Anecdotal evidence suggests that uncertainty, as it found in the experience of solid organ transplant, is not a new concept for nephrology social workers, but little research exists in pediatric nephrology that points to uncertainty as an area of clinical importance for social workers as we support and intervene with caregivers of pediatric CKD patients. This study identified that the social and emotional implications of uncertainty for caregivers of pediatric kidney transplants is a daily challenge, and one that needs greater attention in the clinical environment as an element of caregiving experience that has the potential to impact clinical outcomes of transplanted children.

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