

## Post-transplant Life:

Web-posted Stories of Parents of Children with Kidney Transplants

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*Numerous studies have focused on understanding the well-being and life experiences of parents of children with varying special healthcare needs. However, only a few studies analyze the needs and issues of parents of children with chronic kidney disease (CKD) or a kidney transplant. This study explores the unique life experiences of these parents and identifies important factors that help families enhance their quality of life. Unlike previous studies, this investigation discovers that the majority of parents reported positive post-kidney-transplant outcomes along with positive perceptions of their children's special needs. This positive tone of web-posting stories is similar to previous research indicating that personal storytelling brings to light both resilience and therapeutic benefits. Thus, this study suggests that parental storytelling can be a useful psychosocial intervention that promotes the well-being of pediatric transplant recipients and their family members. Considering that more than half of parents in the study utilized the Internet to connect to other parents with similar experiences, professionals can encourage or incorporate forms of online interaction for parents to obtain information and support.*

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### INTRODUCTION

A significant body of literature indicates that children with special healthcare needs or disabilities place substantial demands on parents/caregivers in terms of finances, employment, and mental and physical health (Gupta, 2007; Looman, O'Conner-Von, Ferski, & Hildenbrand, 2009; Shattuck & Parish, 2008). Among research on children with varying chronic illness, many studies specifically focus on families of children who underwent a solid organ transplant and examine the family's quality of life in terms of parental and sibling psychosocial adjustment and adaptation (Anthony, BarZiv, & Ng, 2010a; Anthony et al., 2010b; Sundaram, Landgraf, Neighbors, Cohn, & Alonso, 2007; Young et al., 2003). These studies reveal that a high level of stress is prevalent among families of children who received organ transplants. One study, measuring quality of life among pediatric kidney recipients and their parents, found that the emotional functioning of these families was negatively affected, regardless of their child's overall health and quality of life (Anthony et al., 2010b).

Although stress is often associated with raising a child with a disability or chronic illness, research employing qualitative (Green, Meaux, Huett, & Ainley, 2009; Tong, Lowe, Sainsbury & Craig, 2008; Tong, Lowe, Sainsbury, & Craig, 2010), quantitative (Glenn, Cunningham, Poole, Reeves, & Weindling, 2009), and mixed methods (Hall et al., 2012; Ylven, Bjorck-Akesson, & Granlund, 2006) has discovered that stress does not always lead to negative family outcomes. For instance, when describing difficulties in meeting their children's special healthcare needs, parents of children with pediatric heart transplants also expressed the blessings of having these children in their lives (Green et al., 2009). Parents can consider their children's disabilities or chronic illnesses as not only fulfilling a special purpose within their families, but

also as enhancing family adjustment capabilities (Lassetter, Mandleco, & Roper, 2007; Trute, Benzies, Worthington, Reddon, & Moore, 2010) and their relationships with others (Ylven et al., 2006).

#### *The Internet as a medium for socialization*

The majority of today's parents use the Internet to find information and support regarding children, health, and family (Plantin & Daneback, 2009). Studies suggest that the Internet can be a medium of socialization for people with similar life experiences (Hamm et al., 2014). For example, the Internet has connected women with breast cancer (Hoybye, Johansen, & Tjornhoj-Thomsen, 2005), parents of children with autism (Fleischmann, 2004; Fleischmann, 2005), and burn survivors (Badger, Royse, & Moore, 2011). Those studies also found that both online interactions and personal narratives are effective psychosocial interventions that may improve these populations' psychological well-being and coping skills. For instance, Fleischmann (2005) reveals that sharing personal experiences on the Internet allows stressed parents of children with autism to extract themselves from isolation and build relationships with others who have had similar experiences.

#### *Benefits of storytelling*

Previous studies demonstrate the therapeutic benefits of telling stories in terms of significantly improving physical and mental conditions, as well as coping skills (Carlick & Biley, 2004; East, Jackson, O'Brien, & Peters, 2010; Pennebaker, 2000). Sharing personal stories not only helps storytellers increase understanding of their personal experiences, especially traumatic events, but also helps form bonds and supportive networks (East et al., 2010). Sharing and listening to stories also enhance awareness of and reflection on life events and hardship. During the reflection process, studies

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found that both storytellers and listeners begin to establish meaning, develop greater self-awareness, and experience decreased emotional distress (Carlick & Biley, 2004; East et al., 2010; Hsieh, 2010).

### *Purpose of this study*

Many studies have analyzed the needs and issues of parents of children with chronic kidney disease (Carolan, Smith, Hall, & Swallow, 2014; Tong et al., 2008; Tong et al., 2010), as well as parents of children who received kidney transplant (Anthony et al., 2010a; Anthony et al., 2010b; Brennan & McEnhill, 2011; Hsieh, 2010; Lerret et al., 2014). This study aims to expand the existing research on parents' and children's post-kidney-transplant experiences by: 1) exploring the unique life experiences of parents of children with a kidney transplant; 2) identifying important factors that help families enhance their quality of life; and 3) examining these parents' perceptions of their children's special needs to further understand the associations between the tone of their stories and the therapeutic aspects of storytelling. Rather than using researcher-guided interviews that explore caregivers' experiences, this study examines personal stories that were web-posted by parents of children with kidney transplants.

## **METHODOLOGY**

### *Study design*

This study used the Internet, via Google Search, to collect stories shared or posted by parents of children with kidney transplants. Two stages of data collection were conducted. In the first stage, five sets of key words were used to search relevant websites (e.g., "my child with kidney transplant, blog" and "blog, kidney transplant story, children"). To increase the study samples, this study employed a purposive sampling strategy, and also directly collected data from the Children's Organ Transplant Association's (COTA) website. COTA is a nonprofit organization that provides fundraising assistance for families of children who are undergoing transplantation. Many of those parents continue to update their children's and family's stories on the COTA's website after their child's transplant.

### *Data collection*

Approximately 150 stories were retrieved from personal blogs or organization websites as a result of Internet searches between February and June 2013. This study had four screening criteria to select eligible stories: 1) the story was shared by the parent(s) or the guardian(s) of a child with a kidney transplant; 2) the length of story was 245 words or more; 3) the majority of the story was related to the child's post-kidney-transplant experiences; and 4) the family resided in the United States or Canada. As a result, 45 stories were found to be eligible for this study.

### *Analysis*

This study utilized NVivo 10, a qualitative research software, to help the researcher analyze the content of the study samples. First, the researcher used the focused coding strategy (Bailey, 2007) to organize the data. The researcher wrote memos while coding and reflecting on the data. The researcher then analyzed the content by finding key words and counting the frequencies of relevant words and phrases. Lastly, the researcher identified themes by thoroughly examining the interactions and connections between the researcher's written memos and the results of the content analysis through NVivo 10.

### *Ethical concerns and protection of human subjects*

The Institutional Review Board (IRB) of the University of Kentucky indicated that this study does not meet the federal definition of research (45 CFR 46.102(d)), thus, this study did not need an IRB review. According to Eysenbach and Till (2001), Internet content can be used for research purposes when the website and its content are considered to be publicly available information. This study's sample stories had the following features qualifying the content as publicly available information: 1) none of the sample stories had limited access that required registration to enter the website; 2) all the websites, including personal blogs or organizational websites, were designed to be viewed by the public at large, and many of them provided links and relevant services to others; and 3) the purpose of these personal blogs was to advocate for their children's special needs and to offer assistance to others in similar situations. To further protect people contributing materials, any information related to personal identities was deleted or de-identified.

## **STUDY RESULTS**

### *Sample demographics*

This study consists of a total of 45 web postings shared by parents of children with kidney transplants. These samples were collected from different types of websites, including personal blogs and foundation and hospital websites. Forty-two percent were collected from personal blogs ( $n = 19$ ), 42.2% of the stories ( $n = 19$ ) were located on foundation websites (e.g., The Atypical HUS Foundation, ARPKD/CHF Alliance) that provide health, social, and financial support for families dealing with kidney disease or other medical conditions, and 16.6% ( $n = 7$ ) were from hospital websites (e.g., University of Maryland Medical Center, Boston Children's Hospital). Out of the samples collected from foundation websites ( $n = 19$ ), 9 were directly retrieved from the COTA website.

The total 45 web postings represented 47 children who had received at least one kidney transplant at the time of data collection. Out of these children, 68% were male ( $n = 32$ ) and 32% were female ( $n = 15$ ). Two of these families had two children who had undergone transplantation. One of the families had a boy and girl of different ages, and the other

family had a set of fraternal twins. Among these children, two had already received their second kidney transplant and the other three had both liver and kidney transplants in their lifetimes. For the majority of children, either their biological mother or father was the kidney donor ( $n = 28$ ). There were two families in which neither parent was a good match for their child, so the parents participated in paired kidney exchange programs. While parents made up the majority of donors (60% ;  $n = 28$ ), 17% were family members or family friends ( $n = 8$ ), 17% were altruistic living donors ( $n = 8$ ), and 6% were cadaver donors ( $n = 3$ ).

## THEMES

This study identifies three primary themes to demonstrate how these parents described their experiences regarding their children post-kidney-transplant, how they perceived their children's special health care needs, and what support they obtained to help them cope throughout their children's pre- and post-kidney-transplant journeys. These themes include positive outcomes with constant challenges, positive perceptions of the child's special health needs, and being embraced by support networks.

### *Positive outcomes with constant challenges*

The majority of these parents ( $n = 44$ ) shared positive post-transplant outcomes, including improved development and health of their children and their families' adjustments. Most of the children physically and mentally developed better and faster after the transplant. Many of the children started eating a variety of foods, instead of only consuming low-potassium or low-sodium foods. Many of the children became strong enough to sustain typical school hours. In one parent's words, "He had an amazing year at the 'Big Boy' school and finished first grade. He did better than we could have ever imagined. He only missed four days of school and he had one of the best attendance records." Another parent said, "A\_\_\_\_\_ is now running around and loving the independence. He is trying more things and we keep working on this [sic] eating skills daily. He is growing like a weed; we couldn't be more excited about his progress."

The posted stories described quality of family life as better after children received their kidney transplant. For instance, these families started trying things that their children's health did not allow them to do before transplantation. Some of the young children started attending daycare or preschool a few days a week, so that the primary caregiver, usually the mother, could have time to rest or complete educational or career goals. Without the need for and inconvenience of medical equipment (e.g., dialysis machines or feeding tubes), many of the families said that they had gone on several trips. Children with transplants could now have sleepovers, as well as participate in outdoor activities. The following story describes the family's gratitude for their new post-transplant lifestyle:

[Thankful] for allowing him to have sleepovers, go to the beach and get in the water, for having a

POOL birthday party and eat all the ice cream he wanted at it. For not being hooked up to a machine for 10 hours every night of his life, being afraid of infections constantly, for not being weighed and blood pressure checked every morning and night, for not being on more blood pressure medicine than his own grandfather, for and for and for—you get the picture. We could literally go on all day.

As many parents mentioned, "transplant is not a cure but a treatment." All parents acknowledged that their children might face organ rejection or might need another kidney later, even though they had experienced a more positive life after transplantation. Receiving a pediatric kidney transplant did not mean an end to their children's medical difficulties. Instead, they started experiencing different types of medical interventions and treatments. For instance, dialysis was replaced by numerous antirejection medicines and ongoing lab work. It was also common that these families faced varying bumps in the road when their children had kidney rejections or infections. Two of the children in this study already had their second kidney transplant due to rejection. After the first rejection, these two families underwent the agony of a second search for an organ donor match. During this process, these children were back on dialysis treatments. The following parents' story described one child who received a second kidney transplant.

Over the last 7 years, E\_\_\_\_\_ has had over 40 surgeries, multiple infections and countless hospital stays. E\_\_\_\_\_ has a J-tube for feeds, because during his second attempt to redo a Nissen fundelplacation his stomach prorated, and he became very sick. E\_\_\_\_\_ has a mitrofanoff, which we catheterize him through his belly button to get his urine out. E\_\_\_\_\_ also has a M/ACE which use [sic] for bowel flushes. Oct[ober] 2009, our lives would change again. E\_\_\_\_\_ became very sick and was rejecting the kidney. He went into three types of rejection.

During the post-transplant stage, these parents not only continued to meet their children's medical needs, but also spent time and effort to improve their children's developmental and mental needs through education and rehabilitation. Many of these children have developmental delays as a result of their kidney failure, as well as other congenital or genetic disorders. Thus, they were in need of varying therapies, medical interventions, and special education to promote their development. The following story demonstrates how the parents of twins with kidney transplants address their children's disabilities on a daily basis.

But realizing that as he is so heavy now and still unable to support his head and therefore most difficult to carry, that upstairs is not really an option, so we are trying to figure out where to settle F\_\_\_\_\_ in. I won't say they are small challenges, because they are not. In some ways dealing with their disabilities



is more challenging than dealing with kidney stuff. Less terrifying but more upsetting. But, at the end of the day, although these issues can make us worried or sad, they are not life-or-death issues. The babies are healthy and for the most part happy! They have overcome tremendous obstacles and we stand amazed at where they are at. And we feel lots of hope!

### *Positive perceptions of the child's special health needs*

Although some parents expressed negative feelings during their children's medical crises and during the complications, either before or after the kidney transplant, the majority of these parents ( $n = 44$ ) described a positive outlook on having a child with special healthcare needs in their lives. These parents often perceived or described their child as a "true soldier," "a fighter," and their "hero," as well as being "strong." Most of these parents felt "blessed" and described how their lives were enhanced when they observed how strongly their children fought their diseases, and experienced the support of their family and friends. Although they understood that their lives were not going to be easy, they felt grateful and blessed that their children were with them. Parents with religious beliefs described these hardships as either temporary tests from God, or a special blessing to strengthen their life and faith. The following story shows how the parents found comfort and strength through their religious beliefs.

He [child with transplant] continues to amaze and inspire us all with his passion for life and how hard he works. Every day he faces challenges with his disabilities and medical issues, but God has given him the gift of "Innocence," where he takes each day like it were typical. We are reminded every day what a "Miracle" he is and how much he struggled to be alive and healthy today.

On the other hand, less religious parents described how they had come to terms with reality and accepted their children's special needs. Parents sometimes claimed that their child made them better and stronger people, with a different perspective on life. The following story demonstrates this:

All of the surgeries, hospital stays and visits, dialysis treatments, tests, therapy sessions, blood draws, the sleepless nights and all of the tears—we lived that. Not only did we live it, but we survived it, and I am so proud of who we have become because of the journey that we chose to live. It was a journey of struggle and heartache, but it was also a journey of determination and love for one little boy. A little boy who has taught us more in his three years of life than we have learned in our 28–30 years of life.

### *Embraced by support networks*

According to these parents' posted stories, they all showed great appreciation of their family members, friends, or donors who had supported them throughout the transplantation

journey. Many of them wrote about how they obtained information and emotional support from people with similar experiences through the websites of foundations and organizations, including personal support networks, social media (e.g., Facebook, Twitter), and personal blogs. Many parents described how they not only used the Internet to connect with similar people, but also to advocate for their children's special needs by getting involved in various activities (e.g., hosting fund raising events, sharing their stories publically, organizing support group). In addition to posting stories on personal blogs, two of the parents even began a social networking website for other parents of children with special needs who were inspired by their children's diseases. The following example shows how a parent had interacted with similar families before and after their child's transplant.

The day after we learned about his PKD, I agreed to volunteer for the PKD Foundation and start their Atlanta Chapter. I'm thankful for the PKD Foundation and their staff for many reasons, but most of all, being a part of it has made me a better advocate for the kids. In addition, I've made friendships with other parents who share our challenges.

I have found an amazing group of moms on Facebook, and they keep me sane. It's nice to have so many moms (and one dad) that know what we are going thru (sic) and can understand when I need to vent.

### *Discussion*

Overall, the majority of parents reported positive post-kidney-transplant outcomes, including improvement of their children's medical conditions and development, and better quality of family life. The most striking change was that these families started trying things that their children's health did not allow them to do before the kidney transplant. These new changes in life included attending preschool or sustaining longer hours at school and learning activities, as well as having overnight family trips, sleepovers with other children, and various outdoor activities.

This study's findings have similarities and differences when compared to the previous studies (Anthony et al., 2010a; Anthony et al., 2010b; Young et al., 2003). Consistent with prior studies, these parents stated that the kidney transplant did not alleviate their responsibilities. They still had to meet their children's post-kidney-transplant needs, even years after the transplant surgery had occurred. For instance, parents stated that "transplant is not a cure but a treatment," as they still experience different types of medical interventions and treatments after the transplant. Unlike the previous studies that indicate the constant nature of the responsibilities and worries of parents of children with an organ transplant (Anthony et al., 2010a; Anthony et al., 2010b; Green et al., 2009; Lerret et al., 2014; Tong et al., 2010), the parents in this study often used a positive tone

when describing their “tough” experiences meeting their children’s medical and developmental needs. Many parents described in great detail how they had addressed post-transplant treatments and adjustments to their new lifestyles. Although they had been through various challenges, and sometimes had bad days throughout their children’s pre- and post-transplant journeys, they viewed the process of coping with their children’s special healthcare needs as an enriching experience. Many of them even perceived themselves becoming better, stronger people from raising their child. At the end of these parents’ stories, most of them expressed optimism about their children’s progress as they faced never-ending parental responsibilities, whether or not they disclosed having a religious belief.

### **Implications**

In light of the findings, this study suggests several avenues for practical interventions as well as for future research in promoting better quality of life of parents and children with kidney transplants. Before deliberating the implications of the findings, several study limitations should be noted. First, even though this study established a set of sampling criteria, selection bias needs to be noted, especially when a personal blog published more than one story that met this study’s sampling criteria. It should also be recognized that one single story can never fully represent the writer’s holistic life experiences. For instance, this study found insufficient information about the extent to which parents utilized online support networks. The tone of the story could also be affected by the writer’s emotional state at the time.

The complicated medical conditions of children with kidney disease or a kidney transplant make these children medically fragile, and this is the primary reason that these children and their family’s social lives are limited. Formal and informal support seem to play essential roles in supporting these parents throughout their journey dealing with their children’s kidney disease. For instance, many of the parents stated that the qualified and supportive care provided by their children’s medical team helped to eliminate their stress and worries. In addition, this study reveals that these parents utilized the Internet to connect with people with similar experiences, as well as to advocate for their children’s special needs. Considering social media technology is commonly employed for seeking information and support from others, this study suggests that interaction on the Internet could be an adaptive way to enhance practical connections with others for those who have restricted contact with the public due to their medical and health concerns. Also, as suggested by previous studies, the Internet has become a medium of socialization for people who have similar life experiences, including women with breast cancer, parents of children with autism, and burn survivors (Badger et al., 2011; Fleischmann, 2004; Fleischmann, 2005; Hoybye et al., 2005). Knowing the benefits of online interaction, health-related professionals and researchers have attempted to develop effective and integrated online interaction among people

with chronic illness, traumatic experiences, or disabilities to engage in support groups or medical interventions (Carolan, Smith, Hall, & Swallow, 2014; Paterson, Brewer, & Stamler, 2013). Thus, this study suggests that professionals who are involved in assisting parents of children with a chronic disease or a kidney transplant should incorporate any forms of online interaction (e.g., origination, support group) for these parents to obtain information and support. Connecting these families to organizations and parent support groups not only increases their social opportunities with similar people, but also enlarges their support systems.

Healthcare professionals should note that there might be parents who have limited resources and access to the Internet. The study of Paterson and colleagues (2013) indicates that certain characteristics could affect the likelihood of people seeking information and support on the Internet, even though it is challenging to identify these people. Thus, this study suggests that healthcare professionals should consider issues with Internet access when referring patients and families to online support networks. Future research is needed to identify effective online intervention strategies, including characteristics of parents who are less likely to engage in online social support groups.

These web-posted stories demonstrate that these parents considered their children’s disabilities or chronic illnesses not only as fulfilling a special purpose within their families, but as also enhancing family adjustment capabilities. This positive tone in describing their distress and hardship in meeting their children’s medical and developmental needs is different from the past studies’ findings regarding the quality of life of children with a kidney transplant and their parents and families. This positive outlook is similar to other studies’ findings that indicate the advantages of personal storytelling (Badger et al., 2011; Carlick & Biley, 2004; East et al., 2010; Fleischmann, 2004; Fleischmann, 2005; Hoybye et al., 2005; Hsieh, 2010; Pennebaker, 2000). Storytelling can be an intervention strategy promoting the well-being of pediatric transplant recipients and their family members (e.g., parents and older siblings). Therefore, this study suggests that professionals should promote the benefits of oral and written storytelling, and encourage parents to share their feelings and experiences with online support groups and blogs as they cope with the stress of raising a child with special healthcare needs.

### **AUTHOR NOTE**

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