

# Beyond Numbers: The Liminal Experience of Kidney Transplantation Amongst Young Adults Following Transfer of Care

Stephanie Bogue Kerr, MA, MSW; Marguerite Soulière, PhD, University of Ottawa, Ottawa, Canada; Lorraine E. Bell, MD, FRCPC, McGill University, Montreal, Canada

---

*Young adults who receive kidney transplants have unique needs. Adherence with medical therapy and with appointments can be a major challenge for this population, as is the transfer from pediatric to adult care. There is little qualitative research that tackles the experience of transplantation amongst young people, and still less from a social work standpoint. The present article reflects the findings of a qualitative, phenomenological study into the transition experience of young-adult kidney transplant recipients. The study found that for these young people, health professionals were involved in their relationship to their bodies. A major theme that emerged was the relational nature of the transfer of care. Finally, the article closes with a discussion of the micro- and macro-level factors that shape these relationships and the implications of these findings for nephrology social workers and other health professionals practicing in adult care settings.*

---

## INTRODUCTION

In a recent article (Bogue Kerr, Soulière, & Bell, 2018), we shed light on the experience of liminality, that is the “in-between life” of young-adult kidney transplant recipients. Though life and treatment trajectories were different, the experiences converged around what we called the transliminal self. This concept was proposed to render explicit to the professionals who care for this population the lived experience of transplantation. Transplant recipients are indefinitely dependent on rulings rendered by numbers to reveal at regular intervals their state of health and their place between life and death (Bogue Kerr, Soulière, & Bell, 2018). The permanent nature of the incomplete healing process characterizes their experience of daily life and is reflected in their relationship to the medical world and with health professionals.

The present article is addressed to health professionals and is intended to contribute to the improvement of practice in the domain of nephrology, particularly in regard to the transition between pediatric and adult care. This socio-anthropological analysis of the realities of young adults traversing the process of kidney transplantation and its numerous medical follow-ups is especially important to the work of professionals in health institutions, which are governed by a logic of numbers that determine objectives for quality of care on the basis of measurable efficiency. These institutional constraints delimit the intervention possibilities of professionals and mark the relationships between these professionals and those they heal. In this context, the unquantifiable needs of young people living with chronic illness can be easily overlooked, sometimes with serious consequences. We seek to

relate our findings of the experiences of young-adult kidney transplant recipients to the challenges they face within the healthcare system and the implications for social worker practice.

## TRANSPLANTATION & TRANSITION LITERATURE

### *The problem of life transition and transfer of care*

In recent years, the transition and transfer from pediatric to adult care have been the subjects of interest within the field of transplantation. A major concern for this population is adherence to treatments, appointments and blood tests, and loss of follow-up. Poor adherence may lead to serious illness-related events and personal transitions, including acute organ rejection and complications related to intensive antirejection therapy, such as opportunistic infections and increased malignancy risk, graft loss, return to dialysis, or even death (Bell et al., 2008; Foster, 2015). The World Health Organization (WHO) describes adherence<sup>1</sup> as a multidimensional phenomenon with five major contributing domains: (1) user related (e.g. health beliefs, self-efficacy, knowledge, motivation, psychosocial stress, and perceived barriers); (2) condition related (e.g. severity of symptoms, level of disability, comorbidities, and psychological or psychiatric factors); (3) therapy related (complexity side effects and immediacy of beneficial effects); (4) social and economic (e.g. family functioning; social supports; culture; and lay beliefs about illness and treatment, medication, and travel costs); and (5) health-system/healthcare-team related (WHO, 2003). While a number of studies have been conducted on the subject of adherence (Fletcher-Johnston,

**Corresponding author:** Stephanie Bogue Kerr, M.A., M.S.W., Jewish General Hospital, Montreal, Canada; Jewish General Hospital 3755 Côte-Ste-Catherine E-754, Montréal, Québec H3T-1E2; Work: 514-340-8222 ext. 25321; Cell: 514-575-5559; [sboguerkerr@jgh.mcgill.ca](mailto:sboguerkerr@jgh.mcgill.ca)

**Keywords:** transplantation; dialysis; kidney disease; transition; liminality; phenomenology; nephrology social work

Marshall, & Straatman, 2011; Meade, Tornichio, & Mahan, 2009), few have sought to explore the experiences of those who live through the transfer of care (Fletcher-Johnston et al., 2011; Tong, Morton, Howard, McTaggart, & Craig, 2011).

Youth living with chronic kidney disease (CKD) may experience intense disease-related transitions during emerging adulthood (Arnett, Žukauskienė, & Sugimura, 2014), a period of major developmental processes between 18 and 29 years of age. As children mature into adolescence and young adulthood, simultaneous changes in other aspects of their lives are shaping the transplant experience. Many publications acknowledge the challenges children with chronic illness face as they mature in their teenage years and eventually transfer to an adult care hospital (Bell et al., 2008; Crowley, Wolfe, Lock, & McKee, 2011; Davis, Brown, Taylor, Epstein, & McPheeters, 2014; McDonagh, 2005; McQuillan, Toulany, Kaufman, & Schiff, 2015). The Canadian Paediatric Society (2014) recently reaffirmed a 2007 position statement calling for increased awareness of transition processes amongst health professionals and parents and advocating for a comprehensive approach towards the transition process with adapted services, follow-up, and psychoeducational support to facilitate the transfer of care. Guidelines for transition have recently been published by the Canadian Association of Paediatric Health Centres (2016) and Got Transition™ (2018). These guidelines target youth (age 15–29) with special healthcare needs (including physical, developmental, and/or mental health conditions) who require ongoing health surveillance and care to maintain optimal health into their adult years.

### *The psychosocial problem of pediatric kidney disease*

Many researchers have observed the integrated nature of illness within a person's life story (Kleinman, 1988; Lewis, 2013; Richards, 2012). For children with kidney disease, growth and developmental processes can be significantly affected, depending on the child's age at its onset (Bawden et al., 2004; Bell, 2007). The disease can affect motor skills (Bawden et al., 2004), cognition (Bell et al., 2008; Meade, Tornichio, & Mahan, 2009), intellectual and academic performance (Meade, Tornichio, & Mahan, 2009), and psychosocial development (Bell et al., 2008). In a school setting, academic and behavioral issues, as well as problems with anxiety and depression, have been observed amongst children with kidney disease (Annunziato, Jerson, Seidel, & Glenwick, 2012). The challenges these children experience are exacerbated by stress associated with schoolwork, social exclusion, and sometimes by bullying. The interaction of these factors can make it difficult for these children to master developmental milestones that gradually prepare them to be independent and autonomous young adults (Annunziato, Jerson, Seidel, & Glenwick, 2012).

Health-related transitions are an important characteristic of CKD (Hutchinson, 2005; Kierans & Maynooth, 2001) because of the progressive nature of the disease and the consequent changes in treatment options and requirements over time. For youth with CKD, transitions associated with a major disease occur alongside biopsychosocial developmental processes. In this perspective, it is important to remember that adolescence is a transitional period during which the developmental task of individuation is worked through (Liakopoulou, 1999; Loughran, 2004). The delicate balance of parental involvement in adolescent life is especially sensitive for those with chronic illness (Annunziato & Shemesh, 2010; Anthony et al., 2009; Bell et al., 2008; Gorter, Stewart, & Woodbury-Smith, 2011), for whom normal adolescent experimentation can result in serious health issues. A youthful reluctance to accept the values and advice of authority figures like teachers and health professionals, may exacerbate these challenges (Bell et al., 2008). For an adolescent effectively raised in a healthcare setting, this may symbolize a developmentally appropriate rebellion associated with the processes of separation and individuation (Liakopoulou, 1999).

During this period, adolescents become increasingly aware of their changing bodies. A negative body image may bring about a particular form of suffering, making the side effects of immunosuppressive medications (including acne, weight gain, and accelerated hair growth) particularly difficult to tolerate. These side effects are also believed to influence normal developmental processes related to sexuality and sexual relationships (Canadian Paediatric Society [CPS], 2007; Meade, Tornichio, & Mahan, 2009; Schweitzer & Hobbs, 1995). Infrequent school attendance during childhood may result in less developed social networks for these adolescents, presenting difficulties for their transition into adulthood, resulting in feelings of loneliness and issues related to self-esteem (Kaufman, Pinzon, & Canadian Paediatric Society, 2007).

Despite the developmental, psychosocial (Meade, Tornichio, & Mahan, 2009), and experiential (Fletcher-Johnston, Marshall, & Straatman, 2011) complexity of this stage, much of the literature regarding the issue of care needs of these young people focuses on correcting behaviours (such as adherence to medication) (Fletcher-Johnston, Marshall, & Straatman, 2011; Meade, Tornichio, & Mahan, 2009). This has led some experts to call for integrated supports that address the complexity of their needs (Bell, 2007; Bell et al., 2008; Crowley, Wolfe, Lock, & McKee, 2011; Kaufman, Pinzon, & Canadian Paediatric Society, 2007). Others call for the adoption of a biopsychosocial approach to transition care that would emphasize the holistic nature of the experience (Crowley, Wolfe, Lock, & McKee, 2011), while accounting for the individual's particular family situation, preferences, and personality (Gorter, Stewart, & Woodbury-Smith, 2011).

---

<sup>1</sup>The WHO differentiates the use of the terms *adherence* and *compliance*. For this organization, adherence reflects the active involvement of individuals in their own care. It is thus understood that adherence requires that the individual agree to the treatment plan (WHO, 2003).

### *The problem of transfer of care*

The cultures of care in pediatric and adult hospitals are generally different. In the pediatric setting there is usually an integrated interdisciplinary team of health professionals who treat children with chronic illnesses, encouraging a family-centered approach and promoting trusting relationships among health professionals, the children, and their families (Anthony et al., 2009). Upon arrival at the adult care hospital, young adults are typically expected to show independence in life skills, present themselves for appointments without their parents, have knowledge of their disease, be able to ask questions and participate in decision making, know how to access resources, and adhere to pharmacological treatment (Bell et al., 2008; McDonagh, 2005). Transitions related to adolescent neurodevelopment and those stemming from the organization of health services are challenging for young adults with CKD and are often further complicated by a lack of knowledge and familiarity with the adult care setting. These simultaneous transitions are further confounded by a lack of familiarity amongst adult care nephrologists not only with the developmental period of adolescence but also with pediatric kidney diseases (Bell & Sawyer, 2010).

In recent years, advances in biomedicine have allowed more children with kidney disease to survive into adulthood, leaving these young adults with the disadvantage of being among the first to transfer into the care of nephrologists accustomed to working with adult-onset diseases (Bell & Sawyer, 2010). Pediatric specialists are not only more familiar with childhood diseases, but in many cases, they have followed individual patients since the onset of a disease. Often they have spent years developing a relationship with these patients, have come to know them as people, and have firsthand knowledge of how their diseases and their selves have evolved. Research concerning the information and support needs of adolescent and young-adult kidney transplant recipients (Davis, Brown, Taylor, Epstein, & McPheeters, 2014; Tong, Morton, Howard, McTaggart, & Craig, 2011) and their experiences (Fletcher-Johnston, Marshall, & Straatman, 2011) is limited.

In light of this, we undertook this study believing that a contextualized socioanthropological interpretation of the experience of kidney transplantation amongst young adults would allow for a deeper understanding of the challenges such individuals face, the risks they might take, and how they might be better supported in their transition to adult care.

### **METHODOLOGY**

As mentioned in the introduction, this article is based on a study conducted between 2013 and 2015, which sought to understand the lived experience of young adults who have had kidney transplants.

Phenomenology proposes a qualitative approach to research, which concerns itself with the study of lived experience. For Merleau-Ponty (1945/2012), a 20th century French philosopher, phenomenology is a search for truth, accessible only through our experiences of our bodies and of our perceptions. It emerged as an alternative to the prevailing empirical, positivist position of the natural sciences (Blaikie, 2007) and emphasized the relevance and complexity of everyday experience, thus broadening the discussion about what it means to live (Hughes, 1990). Phenomenology considers that all knowledge derives from subjective experiences of the world (Matthews, 2006) and, as such, contends that different epistemological positions complement rather than compete with one another (Creswell, 1998). Seen in this way, biomedical and subjective perspectives on transplantation are equally valuable and allow for a deeper understanding of the phenomenon.

Five in-depth interviews were conducted in a major Canadian city with young adults (two men and three women), all of whom had been followed at the same pediatric teaching hospital and subsequently cared for in the same adult teaching hospital transplant center. Participants were invited to share their health and illness experiences, the medical interventions they had undergone, as well as about their experiences of pediatric and adult care. They were also asked about the larger context of their lives as adolescents and young adults, including their family, social, academic, and career experiences. Interviews were recorded and later transcribed for analysis.

The table below summarizes the characteristics of the participants.

Gender	Age range <sup>2</sup>	Transplanted in	Dialysis?	Complications	Donor
Female	Early-to-mid-20s	Pediatric Care	Yes	Multiple surgeries, organ rejection, second transplant, cancer	Living
Male	Late 20s to early 30s	Adult Care	No	Primarily side effects of medications	Deceased

Of the three young women, one received her transplant during childhood and two in adolescence; the young men underwent transplantation during young adulthood. The young women had more complex experiences early in their illnesses, including multiple surgical procedures, regular dialysis treatments, and longer hospital stays. All three received a kidney from a living donor in their families. At the time of the interviews, these women were all in their early-to-mid-20s; only one was working, though another reported plans to return to school.

The two young men had less complex illness trajectories; neither had undergone dialysis nor experienced multiple surgeries. Both had received deceased donor kidneys when they were in their late 20s to early 30s. At the time of the interview, the men were in their mid-to-late 30s and both were working.

The interviews were analyzed by combining elements of both narrative analysis (Labov, 2013) and analysis through writing (Paillé & Mucchielli, 2010). Narrative analysis was applied to gain insight into the context or orientation (Labov, 2013) of the participant's story (who, what, when, and where), and his or her perception of the experience, through close examination of the language used to describe the experience. This included attention to evaluative commentary ("they were *amazing*"), negative verbs ("*they wouldn't tell me*"), modal verbs ("*would they take care of me?*"), future tense verbs ("*I'm going to go to school*"), and literary devices, including similes ("*what feels like a leash*") (Bogue Kerr, Soulière, & Bell, 2018).

A process of analysis through writing, which involved writing detailed descriptive summaries of each participant's interview (Paillé & Mucchielli, 2010), was then undertaken. In reading and re-reading these summaries, similar accounts of experiences became increasingly evident, which made way for an analytical rewrite of the narratives. Through this process emerged a shared experience in regard to the nature of relationships with their bodies and with health professionals in the context of the institutions, whether pediatric or adult, where they received care.

This method of analysis is in keeping with the phenomenological framework of the study, which perceives research as an intersubjective search for meaning. The objective of this study was not to produce generalizable findings but rather to gain insight into the lived experience of the participants.

The researchers approached their work with reflexivity, or self-awareness. As is common in qualitative studies, researchers kept a self-reflective journal, the purpose of which was to keep a record of the experiences, assumptions and biases that emerged (Butler-Kisber, 2010; Morrow, 2005).

Approval for this study was obtained from the research ethics boards at both the university through which this study was conducted and the teaching hospital through which participants were recruited. All participants provided written informed consent.

### Limitations

Several of the potential participants the staff of the pediatric transplant clinic had identified were unable to be reached. By broadening the criteria, the researchers were able to recruit the intended number of participants. This resulted in a wider range in age and of disease trajectories within the sample; participants had suffered from different kidney diseases, had undergone different surgeries and treatments, and had experienced different transplant-related complications. Nonetheless, participants shared common experiences of illness, and the saturation point was considered to have been reached.

### RESULTS

The divergent illness trajectories of the young adults we met shaped the formation of significant relationships in their lives. The chronic illnesses with which the young men had been diagnosed in childhood required regular follow-up at the pediatric hospital, but this seemed to be minimally disruptive to their attendance at school and the development of friendships with peers. For the young women, however, the intensity of their treatments called for frequent visits and admissions to hospital. Thus, crucial moments in their lives unfolded within the institution, and relationships with health professionals were formed over the course of several years. These relationships emerged as a major theme in the lives of these young-adult kidney transplant recipients, the importance of which was illuminated by the transfer from pediatric to adult care.

#### *Transfer of care for young adults: A relational issue*

Prior to their transfer, three of these young adults viewed the transition positively and anticipated that adult care would be more or less the same as in pediatrics, with care provided by different people. For them, the transition was viewed as part of a developmental process that paralleled their drive for more independence and autonomy. Two of the young women expressed feeling "scared" about the transfer, with one (Catherine) stating she did not want to "leave behind such amazing people" and another (Melissa) wondering, "Why are you guys trying to kick me out already?" The three women who were transferred as transplant recipients reported being prepared for the transition by engaging in discussions about adult care with the pediatric team, being encouraged to advocate for themselves, and being accompanied by their pediatric nurse to visit to the adult hospital. They reported feeling prepared and supported throughout the transfer of care. They spoke little about their parents' involvement during this time, except to say that their parents seemed more concerned about the transfer than they themselves were. Both men who transferred as young adults with chronic illness shared that they received little to no education about the transfer of care, nor had they identified this as a need at the time. Transfer of care was experienced as more abrupt for these participants, whose illnesses had not required them to spend as much time at the hospital in their childhood and who, consequently, had more distant relationships with the pediatric institution and its professionals.

Each young adult we met experienced adult care differently than they had expected. Although relationships with health professionals in both pediatric and adult care were, overall, experienced positively by the transplant recipients, the way in which they contrasted their experiences of pediatric and adult care suggested different perceptions of their relationships with these professionals. Pediatric care was associated with “feeling safe,” “cared for,” “known,” “seen” and was said to communicate a sense that “you’re someone to them.” These statements contrast the vulnerability of illness with the security of being cared for. In their experience with adult care, these young adults remembered “not feel[ing] comfortable at the hospital” and health professionals who were “busy,” “didn’t care,” or “didn’t really know me.” The attentiveness of their pediatric specialists and the continuity of pediatric care were contrasted with a perception of a more disorganized, time-stressed environment in the adult clinic, and checkups that were less personal and less thorough. Many of these statements referred generally to professionals within the institution as a whole and were not necessarily specific to their transplant doctors and nurses. Despite feeling their transplant doctors and nurses had less time to dedicate to them, which they tended to comprehend, these patients missed the opportunity to develop strong relationships with their doctors and nurses. For Melissa, being referred to other specialists by her adult care team seemed to reflect a compartmentalization of her person and her care: “It’s less of a team, to be honest.... They refer me to other people if I have other problems. It’s not like they take care of everything.”

Throughout their interviews, the younger transplant recipients gave examples of ways in which they believed health professionals at the pediatric care hospital had gone above and beyond to care for them. They were all still in touch with the same nurse from their pediatric transplant unit, whom they described as someone they had known a long time, whom they could trust, and with whom they had a special relationship. Catherine spoke more extensively about the relationships she built with her pediatric dialysis nurses than she did about her treatments or her body, revealing a sense of accompaniment throughout this developmental period:

Dialysis, I’ve always said this, was the best year of my life.... [The dialysis nurses] were amazing, they were amazing. I must have been so jerky when I was a teenager, all I would talk about is boys, and they would talk to you about boys for the entire three hours, they would just constantly talk to you, because it’s what you needed.

Despite this, there were difficult circumstances in pediatrics that seemed to strain the trust that had been built. Participants provided examples of times when they were disappointed by the pediatric team’s inability to restore them to full health, illustrating to some extent a displacement of emotion in regard to their physical vulnerability—be it be frustration, sadness, anger or guilt—onto health profession-

als. Moreover, these charged moments that threatened to destabilize trusting relationships tended to occur in times of crisis or uncertainty, when the individual may have felt particularly endangered. Speaking about a serious health condition triggered by her prescription drug treatment, Emily stated that she was given medication that was supposed to make her better, but that it caused other serious health problems. Melissa expressed feelings of betrayal when she was referred to a psychiatrist for assessment, which she experienced as a rejection by her pediatric team. She felt that rather than listening to her and appreciating how difficult it was for her to be ill, she was shuffled off to a different professional:

I had an attitude as a child. Like I was just very angry at the world and angry that this was happening to me. I was always at the hospital and I basically made it my life to take it out on [the doctors and nurses], more or less. I didn’t mean to, I didn’t realize I was doing it, but I made everything so difficult. I didn’t realize I had to go through this pain in order to live, so I would just scream and cry, and not let anyone do anything to me.

Relational challenges evolved after the transfer to adult care, reflecting a greater distance from health professionals. These young adults each had examples of times they perceived their questions or concerns as not being received or heard by adult care health professionals in the way they had hoped. Transplant recipients depend on the privileged knowledge and insight of their health professionals to keep them alive. They are aware they rely on highly specialized professionals, whose analysis of their delicately balanced state of health is based on quantitative measures, while their own subjective experience of their body remains confined to its boundaries. David recalled living with “unbearable dizziness for a period approaching a year,” during which time every possible cause was ruled out, until it was identified as a side effect of his medications, a connection he had hypothesized since the symptom’s onset. He understood the dilemma:

To some extent getting good care, you don’t want to be some quack who thinks they know better than the doctor when they don’t, especially if they got it from the Internet. But I’m not like an uneducated guy, and I’ve been dealing with doctors my whole life; if someone’s sort of persistent about a symptom then, I mean, they live with themselves. If they’re not proposing some new age craziness, if they’re just saying, look I think it’s this drug, it’s really worth taking seriously... they may not be aware of cause and effect but they’re certainly aware of correlation. This happened and then that happened, and that’s worth looking into.

Ralph disclosed feeling moral pressure from his treatment team, after requesting information regarding the impact of recreational marijuana use. From his perspective, he sought to access scientific knowledge that would allow him to make an informed decision but was met with expectations about how he should live his life:

Like you're expected to be super cautious and grateful afterwards, so why would you drink or smoke, or do drugs? Because it would be a waste. It's difficult... It's like I have to be better than everyone else, or more cautious than everyone else.

This was supported by other transplant recipients, who alluded to a sense of guilt about being "less careful" than they should be in regard to their health. Most of the young adults spoke about defying biomedical authority in some way, whether by smoking marijuana, having a few drinks, or leaving the house during the isolation period following transplant when the immune system is particularly suppressed.

These young people expressed a desire to assert control over their own bodies. David attempted to rein in the body's functions through exacting self-care routines. Melissa explained that having some control over the pain inflicted on her body was a way for her to cope with the experience. She recounted how she had learned to do a number of things herself while on dialysis, such as cleaning the stitches around her catheter and giving herself needles. In some cases, the lack of control over the body and ultimately its uncontrollable nature was expressed outwardly as frustration towards doctors and nurses.

The young adults in this study expressed nuanced needs that were relational in nature, thus difficult to categorize and quantify within the current paradigm of resource allocation in healthcare. Their experiences can bring about preventable illness-related transitions. In light of the importance of adherence to medication and to medical advice for transplant recipients, it seems relevant to consider how complex issues of control over the body's unpredictable nature influence individuals and their relationships with those professionals responsible for keeping them alive.

## DISCUSSION

Earlier in this paper, the high risk of transplant-related complications and graft rejection amongst young adult transplant recipients was identified. Some of the literature regarding this issue addresses the transfer of care and highlights the developmental challenges associated with meeting the high expectations of autonomy in adult care settings (McDonagh, 2005). In reflecting on their transition experience, the participants of this study expressed feeling well-prepared for the transfer of care. Rather, the young adults we met identified the main difference between pediatric and adult care as relational.

These young adults also spoke about the challenges of post-transplant life: the uncertainty related to the delicate balance of the immune system; the continuous engagement with their mortality; the sense of vulnerability in relation to their reliance on the specialized knowledge of health professionals to keep them alive; and the complex feelings associated with issues of having control over their own body. All of these experiences of their bodies and of their illnesses play out in

their relationships with health professionals, which charges appointments with emotion and meaning.

The system in which these young people are treated, however, does not account for the emotional and symbolic weight of medical appointments. Instead, they are approached from a logic of productivity, efficiency, and cost cutting. Health professionals find themselves stuck between these two competing paradigms, with their working conditions shaped by the logic of New Public Management,<sup>5</sup> according little importance to qualitative and experiential aspects of life. The young adult enters into this time-stressed environment for medical follow-ups, carrying with them the weight of their illness experience, their mortality, and their complex relationship to their body and, consequently, to health professionals. Without the conditions to allow these subjective experiences to be shared, heard, and worked through, medical appointments are limited to quantifiable measures of health accessible only to health professionals. In this context, it is challenging to develop relationships with health professionals, who have the exacting responsibility of overseeing, to the best of their knowledge and ability, the body of another.

The relationship between transplant recipients and health professionals is shaped by the interaction of macro- and micro-factors. Collective values and political choices shape social structures and healthcare organizations, creating the conditions that frame professional practice, and meeting with the individual's biochemical processes and subjective experiences of illness. This echoes the five dimensions of adherence<sup>6</sup> identified by the WHO outlined earlier in this paper (De Geest & Sabaté, 2003). Participants of this study contrasted their experiences of person-centered pediatric care with the "chaotic, overworked, disorganized" environment at the adult care hospital. In the context of a system concerned with readily quantifiable measures of efficiency, this is unsurprising. It takes time to listen to people's narratives, to build relationships with those seeking care, and to understand how they perceive their illness. These qualitative interventions emphasize the intersubjective nature of these encounters, allow health professionals to account for the multiple and interrelated factors that influence adherence, and encourage them to adjust their approach to the individual, all of which are recommended by the WHO in addressing the issue of adherence (WHO, 2003).

<sup>5</sup>This approach to governance of public systems was born of neoliberal ideals that sought to put an end to the welfare state in the Western world (Merrien, 1999). This approach embraces the colonization of public services by the principles and values of the market economy, which manifest in the privatization of public services and restrained government spending (Merrien, 1999) that have come to shape public healthcare across Canada and other Western countries (Soulière, Saulnier & Desaulniers-Coulombe, 2017)<sup>6</sup>.

The WHO identified five dimensions of adherence: (1) user related, (2) condition related, (3) therapy related, (4) social and economic, and (5) health system/healthcare team related (De Geest & Sabaté, 2003).

As mentioned in the introduction, we recently introduced the concept of transliminal self (Bogue Kerr et al., 2018), to encompass the in-between nature of life as a young-adult kidney transplant recipient, existing between life and death, sickness and health, self and other. The transliminal self is incompletely healed and never fully emerges from sickness, thus requiring lifelong care from health professionals and within the institutions that frame these relationships.

The ambiguous state of the transliminal self, being neither sick nor healthy, can render their experiences, and thus their needs, invisible to health professionals, thereby affecting these relationships, and the care they receive within the healthcare system (Bogue Kerr, Soulière & Bell, 2018). The highly specialized care required to maintain the precarious normality of posttransplant life is dependent upon their acceptance of the involvement of professionals in their relationship to their body and their life. For the transliminal self, their body is not entirely their own.

Participants of this study were aware that a critical infection, a rejection episode, or onset of a serious disease could pose a risk to their survival. Despite this, some questioned the privileged insight of health professionals into the functioning of their bodies, and many rejected, in one way or another, the passive role of object into which their “patient” status cast them. These young adults each provided examples of ways in which they rebelled in small ways against biomedical authority. For those in a sustained liminal state, these transgressions embody a repossession of and control over one’s body (Little, Jordens, Paul, Montgomery, & Philipson., 1998), particularly in the context of a developmental stage characterized by increased independence and questioning of authority figures.

Treatment plans based solely on the principles of New Public Management may not account for important subjective factors that can influence treatment outcomes. Evidence suggests that addressing the issue of adherence amongst those with chronic illness, half of whom do not adhere with medical advice, would have a far greater impact on public health than advances in treatment and would reduce healthcare costs by preventing avoidable and costly complications (WHO, 2003). In this study, participants’ lack of control over the body and ultimately the body’s uncontrollable nature were in some cases expressed outwardly as frustration towards doctors and nurses. In light of the importance of adherence with medical advice for transplant recipients, power struggles within the relationship between the individual and their health professionals could potentially have serious consequences.

Kleinman (1988) affirms the importance of health professionals’ attentiveness to subjective experiences of illness, believing that they can provide insight not only into how a person lives with their illness, but sometimes even to the evolution of their disease. In this perspective, a shift towards narrative medicine acknowledges the emotional

and complex relationships people have with their bodies (Lewis, 2011) and by extension, with health professionals. Felitti and Anda (2010) found that a truly biopsychosocial approach to care, in which health professionals are aware of traumatic experiences in the lives of those they heal, resulted in a significant reduction in visits to the doctor (35%) and to the emergency room (11%), as well as fewer admissions to hospital (3%).

## CONCLUSION

The practice of nephrology social work unfolds in the crevices between the quantification of resources stemming from New Public Management and the quantitative approach to health from a biomedical perspective. Social workers are faced with a dual focus on numbers. Biomedical analysis contextualizes the individual’s disease and treatment trajectories, while limited resources constrain the patient’s care to efficient, quantifiable short-term interventions. However an interdisciplinary approach that invests more time in understanding the perspective of the individual can provide insight into the complex relational factors that unfold with their health professionals (WHO, 2003).

Social workers have a key role to play in advocating for the needs of transplant recipients in adult care. First and foremost, they must resist the pressure to reshape their analysis and their practice in accordance with neoliberal<sup>7</sup> demands aimed at streamlining human experience. In order to sensitize other health professionals to the nonquantifiable suffering of the transliminal self, they must first carve out conditions in their own practice that will allow these experiences to emerge. Social workers are often perceived, by themselves and by others, as problem solvers (Dybic, 2012), which may lead some to feel uncomfortable in situations without clear and concrete solutions. In the same way that healing in medicine involves both science and art, so too does healing in social work involve practical, critical, and therapeutic elements.

Narrative medicine draws on theories from a range of perspectives in an effort to embrace the complexity of the human experiences of sickness and healing (Lewis, 2011). For a social worker, this involves seeking deeper understanding into individuals’ perception of their illness, their goals in life, and the challenges they perceive as standing in their way (Dybic, 2012). This may well provide the social worker, and by extension other health professionals, with insights into how they may reframe their role as allies who accompany the individual on their journey, rather than mediators in the relationship to their body.

Social workers can play a role in supporting holistic healing, which extends beyond the body and involves the interaction of developmental, psychosocial, and existential

<sup>7</sup>Neoliberalism refers to a political-economic practice based on free market principles (Gallop, 2013).

processes that unfold alongside concerns regarding physical health. The *transliminal self* may never fully emerge from physical illness, but healing on other levels is possible nonetheless. This concept may serve as a reference point for social workers to help them deconstruct the narrative of transplant recipients who may be struggling to put words to subtle existential experiences and can sensitize other health professionals to the multilayered nature of post-transplant life. In the context of New Public Management, this is an act of resistance that challenges qualitative assessments of care. In order to acknowledge and join with the transliminal self, social workers must challenge themselves to feel comfortable in the ambiguous space between sickness and health. Here, there are no concrete problems to solve, no strategies to employ, no resources to provide. This is what makes it difficult for the healthcare system, and the professionals practicing within it, to see beyond numbers; they are challenged to remain present in the face of questions that confront us at once with our vulnerability and our reliance on others.

## REFERENCES

- Annunziato, R., Jerson, B., Seidel, J., & Glenwick, D. (2012). The psychosocial challenges of solid organ transplant recipients during childhood. *Pediatric Transplantation*, *16*, 803–811. doi: 10.1111/j.1399-3046.2012.01749.x
- Annunziato, R., & Shemesh, E. (2010). Tackling the spectrum of transition: What can be done in pediatric settings? *Pediatric Transplantation*, *14*, 820–822. doi: 10.1111/j.1399-3046.2010.01404.x
- Anthony, S., Kaufman, M., Drabble, A., Seifert-Hansen, M., Dipchand, A., & Martin, K. (2009). Perceptions of transitional care needs and experiences in pediatric heart transplant recipients. *American Journal of Transplantation*, *9*(3), 614–619. doi: 10.1111/j.1600-6143.2008.02515.x
- Arnett J. J., Žukauskienė R., & Sugimura K. (2014). The new life stage of emerging adulthood at ages 18–29 years: Implications for mental health. *The Lancet Psychiatry* *1*(7), 569–576. doi: 10.1016/S2215-0366(14)00080-7.
- Bawden, H. N., Acott, P., Carter, J., Lirenman, D., McDonald, G. W., McAllister, ... Crocker, J. (2004). Neuropsychological functioning in end stage renal disease. *Archives of Diseases in Childhood*, *89*, 644–647. doi: 10.1136/adc.2003.037093
- Bell, L. (2007). Adolescents with renal disease in an adult world: Meeting the challenge of transition of care. *Nephrology Dialysis Transplant*, *22*, 988–991. doi: 10.1093/ndt/gfl770
- Bell, L., Bartosh, S. M., Davis, C. L., Dobbels, F., Al-Uzri, A., Lotstein, D., ... Dharnidhak, V. R. (2008). Adolescent transition to adult care in solid organ transplantation: A consensus conference report. *American Journal of Transplantation*, *8*(11), 2230–2242. doi: 10.1111/j.1600-6143.2008.02415.x
- Bell, L., & Sawyer, S. (2010). Transition of care to adult services for pediatric solid-organ transplant recipients. *Pediatric Clinics of North America*, *57*, 593–610. doi: 10.1016/j.pcl.2010.01.007
- Bogue Kerr, S., Soulière, M., & Bell, L. (2018). The transliminal self: The ebb and flow of the kidney transplant experience. *Qualitative Health Research*, *38*(4), 561–571. doi: 10.1177/1049732317743937
- Blaikie, N. (2007). *Approaches to social enquiry* (2nd ed.). Cambridge, UK: Polity.
- Butler-Kisber, L. (2010). *Qualitative inquiry; thematic, narrative and arts-informed perspectives*. London: Sage.
- Canadian Association of Paediatric Health Centres (2016). A guideline for transition from paediatric to adult health care for youth with special health care needs: A national approach [updated July 12, 2017; cited 2018 May 30, 2018]. Retrieved from: <https://ken.caphc.org/xwiki/bin/view/Transitioning+from+Paediatric+to+Adult+Care/A+Guideline+for+Transition+from+Paediatric+to+Adult+Care> .
- Canadian Paediatric Society (2014). Position statements and practice points. Retrieved December 12, 2014, from: <https://www.cps.ca/en/documents>
- Creswell, J. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA, USA: Sage Publishing.
- Crowley, R., Wolfe, I., Lock, K., & McKee, M. (2011). Improving the transition between paediatric and adult healthcare; A systematic review. *British Medical Journal*, *362*(8), 548–553. <http://dx.doi.org/10.1136/adc.2010.202473>
- Davis, A. M., Brown, R. F., Taylor, J. L., Epstein, R. A., & McPheeters, M. L. (2014). Transition care for children with special health care needs. *Pediatrics*, *134*(5), 900–908. doi: 10.1542/peds.2014-1909.
- World Health Organization (2003). *Adherence to long-term therapies: Evidence for action*. Geneva, Switzerland: World Health Organization.
- Dybicz, P. (2012). The hero(ine) on a journey: A postmodern conceptual framework for social work practice. *Journal of Social Work Education*, *48*(2), 267–283. doi: 10.5175/jswe.2012.201000057



- Felitti, V., & Anda, R. F. (2010). The relationship of adverse childhood experiences to adult medical disease, psychiatric disorders, and sexual behavior: Implications for healthcare. In R. Lanius, E. Vermetten, & C. Pain (Eds.), *The impact of early life trauma on health and disease: The hidden epidemic* (77–88). Cambridge, UK: Cambridge University Press.
- Fletcher-Johnston, M., Marshall, S. K., & Straatman, L. (2011). Healthcare transitions for adolescents with chronic life-threatening conditions using a Delphi method to identify research priorities for clinicians and academics in Canada. *Child: care, health and development*, 37(6), 875–882. doi: 10.1111/j.1365-2214.2011.01318.x
- Foster B. J. (2015). Heightened graft failure risk during emerging adulthood and transition to adult care. *Pediatric Nephrology*, 30(4), 567–576. doi: 10.1007/s00467-014-2859-7.
- Gallop, C. J. (2013). Knowing nothing: Understanding new critical social work practice. *Journal of Applied Hermeneutics*, July 2013. ISSN 1927-4416. Retrieved May 31, 2018 at <https://jah.journalhosting.ucalgary.ca/jah/index.php/jah/article/view/44>.
- Gorter, J., Stewart, D., & Woodbury-Smith, M. (2011). Youth in transition: care, health and development. *Child: care, health and development*, 37(6), 757–763. doi:10.1111/j.1365-2214.2011.01336.x
- Got Transition™ (2018). The National Alliance to Advance Adolescent Health. *Health care transition resources*. Retrieved May 30, 2018 from <http://www.gottransition.org/resources/index.cfm>.
- Hughes, J. (1990). *The philosophy of social research (2nd ed.)*. New York: Longman.
- Hutchinson, T. (2005). Transitions in the lives of patients with End-Stage Renal Disease: A cause of suffering and an opportunity for healing. *Palliative Medicine*, 19, 270–277. doi: 10.1191/0269216305pm1028oa
- Kaufman, M., Pinzon, J., & Canadian Paediatric Society (2007). Transition to adult care for youth with special health care needs. *Paediatrics & Child Health*, 12(9), 785–788.
- Kierans, C., & Maynooth, N. (2001). Sensory and narrative identity: The narration of illness process among chronic renal sufferers in Ireland. *Anthropology & Medicine*, 8(2-3), 237–253. doi: 10.1080/13648470120101381
- Kleinman, A. (1988). *The illness narratives: Suffering, healing and the human condition*. New York: Basic Books.
- Labov, W. (2013). *The language of life and death: The transformation of experience in oral narrative*. New York: Cambridge University Press.
- Lewis, B. (2011). Narrative Medicine and Healthcare Reform. *Journal of Medical Humanities*, 32, 9–20. doi: 10.1007/s10912-010-9123-3
- Lewis, L. (2013). *Searching for good grief? Meaning making through an ESRD illness narrative* (PhD dissertation, Concordia University, Montreal, Canada).
- Liakopoulou, M. (1999). The separation-individuation process in adolescents with chronic physical illness. In M. Sugar (Ed.), *Trauma and adolescence* (pp. 93–107). Madison, CT: International Universities Press.
- Little, M., Jordens, C. F. C., Paul, K., Montgomery, K., & Philipson, B. (1998). Liminality: A major category of the experience of cancer illness. *Social Science & Medicine*, 47(10), 1485–1494. doi: 10.1016/S0277-9536(98)00248-2
- Loughran, M. (2004). Psychodynamic therapy with adolescents. In H. Steiner (Ed.), *Handbook of mental health interventions in children and adolescents: An integrated developmental approach* (pp. 586–620). San Francisco: Jossey-Bass.
- Matthews, E. (2006). *Merleau-Ponty: A guide for the perplexed*. New York: Continuum Publishing Group.
- McDonagh, J. (2005). Growing up and moving on: Transition from pediatric to adult care. *Pediatric Transplantation*, 9(3), 364–372. doi: 10.1111/j.1399-3046.2004.00287.x
- McQuillan, R. F., Toulany A., Kaufman M., Schiff J. R. (2015). Benefits of a transfer clinic in adolescent and young adult kidney transplant patients. *Canadian Journal of Kidney Health and Disease*. 2(1) doi: 10.1186/s40697-015-0081-6.
- Meade, M., Tornichio, S., & Mahan, J. (2009). Chronic and end-stage renal disease. In W. O'Donohue, & L. Woodward Tolle (Eds.), *Behavioural approaches to chronic disease in adolescence* (pp. 233–251). New York: Springer.
- Merleau-Ponty, M. (2012). *Phenomenology of perception*. (D. Landes, Trans.) New York: Routledge. (Original work published 1945).
- Merrien, F.-X. (1999). La Nouvelle Gestion publique: Un concept mythique. *Lien social et politiques*, 41, 95–103.
- Morrow, S. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology*, 52(2), 250–260. doi: 10.1037/0022-0167.52.2.250
- Paillé, P., & Mucchielli, A. (2010). *L'analyse qualitative en sciences humaines et sociales*. Paris: Armand Colin.

Richards, R. (2012). *"You look very well for a transplant": Autoethnographic narrative and identity in chronic kidney disease, kidney failure and the life post-transplant.* (Doctoral dissertation, Stellenbosch University, Faculty of Arts & Science, 2012)..

Schweitzer, J., & Hobbs, S. (1995). Renal and liver disease: End-stage and transplantation issues. In M. Roberts (Ed.), *Handbook of pediatric psychology, 2nd Edition* (pp. 425–445). London: Guilford Press.

Soulière, M., Saulnier, G., & Desaulniers-Coulombe, E. (2017). Qualitative research for health and social service renewal: Two examples of the interior. *Recherches Qualitatives*, 36(2), 133-152.

Tong, A., Morton, R., Howard, K. McTaggart, S., & Craig, J.C. (2011). "When I had my transplant, I became normal." Adolescent perspectives on life after kidney transplantation. *Pediatric Transplantation*, 15(3), 285-293.