Doing Technological Time in a Pediatric Hemodialysis Unit: A Ethnography of Children

by

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for the degree of Doctor of Philosophy

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Abstract

Since the 1960s, hemodialysis has been a common intervention for children with end-stage renal disease. For weeks, months or years, children’s activities are disrupted because they must return to the hospital to be dialyzed about three times a week, for three or four hours. Their childhoods are characterized by on-going temporal disruptions, socio-spatial dislocations and intermittent technological dependence. Little is known about how children experience hospital-based hemodialysis.

The study’s purpose was to describe and interpret the children’s embodied situatedness in the temporal, spatial and technological regimes and relations of a hemodialysis unit. Time, space and technology were viewed as significant interrelated aspects of the unit and the unit was conceived as nested in the broader life contexts of the children. The theoretical framework merged concepts of sociology of children, human geographical and temporal perspectives and philosophy of technology. A focused ethnography with 11 children who received maintenance hemodialysis was undertaken at a Canadian pediatric urban hospital.

The dominant theme emerging from the study findings was the notion of the children doing technological time. The children’s temporal and socio-spatial positions were an effect
of their technologically mediated embodiment and shaped their perspectives, evaluations and expectations. Their accounts revealed that the rituals and routines of the unit were experienced as long and boring. Their situatedness also was comprised of socio-spatial segregation and isolation due to being tethered to hemodialysis machines in the unit’s corners. Adaptations included resignation, resistance and waiting in the short and long term to be released from hemodialysis. Having negative and positive perceptions and responses, the children held multiple and conflicting meanings about the unit’s timespace. The findings suggest that crucial changes in practices and policies are essential to envision ways to create with children an overall positive place that merges and balances technological care with child focused care.
Dedication

For Lianne Zitzelsberger, my sister

Whose courage and humour during her journey over the past years have taught me what is possible.
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This thesis would not have been possible without the support and guidance of many people. Each one of you has made my research experience fulfilling and meaningful in so many ways.

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Chapter 1: Background and Literature Review

Background

Renal Disease and Renal Replacement Therapies

Renal disease can occur at any age due to congenital anomaly, illness, infection or trauma. The kidneys influence all body systems, hence when they fail to function properly, pathophysiological changes occur throughout the body. These changes include uremia, bone disease, infection, anemia and hypertension (Groothoff, 2005; Snethen, Broome, Bartels, & Warady, 2001). End-stage renal disease (ESRD) occurs when kidney function has deteriorated to less than 10%-15% of that of a health kidney. To sustain life, one of two renal replacement therapies - transplantation or dialysis must be initiated (Frank, Auslander, & Weissgarten, 2003). Dialysis and transplantation both necessitate lifelong technological interventions, close medical monitoring, multiple medications, fluid and diet management and lifestyle changes and restrictions (Miller & MacDonald, 2006; Nicholas, Picone, & Selkirk, 2011; Snethen, Broome, Kelber, & Warady, 2004).

Children, Renal Disease and Renal Replacement Therapies

The incidence of new cases of pediatric ESRD has remained fairly stable over the last three decades (Canadian Institute for Health Information, 2008). Since the 1990s, about 70 to 100 children, under 19 years of age, are newly diagnosed with ESRD each year and in 2010, 72 children were diagnosed with ESRD (Canadian Institute for Health Information, 2011). In 2010, there were 536 Canadian children, ages 0 to 19 years of age, with ESRD and 196 of these children lived in Ontario (Canadian Institute for Health Information, 2011). The cumulative
research findings clearly demonstrate that there are numerous physical, emotional and social challenges associated with living with ESRD in childhood (Duquette et al. 2009; Goldstein et al., 2006; Hooper et.al., 2009; McKenna et al., 2006; Nicholas et al., 2011; Snethen et al., 2001; Snethen et al., 2004, Waters 2008). Some boys and girls with ESRD live with altered physical appearance and growth failure, such as short stature and delayed sexual development, as a result of the disease process. They also may have diminished physical strength and stamina, the stresses and responsibilities that a long-term chronic illness entails and shortened life spans. Renal replacement therapies are designed to minimize disease effects and optimize growth and development (Furth et al., 2001, 2002; Groothoff, 2005; Hergenroeder & Brewer, 2001; Miller & MacDonald, 2006; Nicholas et al., 2011).

Since the 1990s, the goal has been to transplant a cadaveric or living donated kidney as soon as possible after a child is diagnosed with ESRD. Kidney transplantation increases survival rates, reduces symptoms, improves overall physical and psychosocial health and enhances quality of life by eliminating the time burden of dialysis treatments (Fischbach, Edefonti, Schroder, & Watson, 2005; Nicholas et al., 2011; Snethen et al., 2004). Pre-emptive transplantation or transplantation prior to instigating dialysis has increased in the last decade. Yet, in 2010 in Canada, only about 22% of children newly diagnosed with ESRD received transplants before dialysis because donated kidneys are in short supply. Many children wait between one to two years before transplantation (Canadian Institute for Health Information, 2011). It is estimated that about 30 – 40 children in Canada are waiting for a transplant on any given day. Hence, the vast majority require dialysis treatments until a kidney becomes available. Furthermore, because 5-20% of transplants are rejected by recipients’ bodies many children must begin dialysis treatments anew following rejection (Canadian Institute for Health Information, 2008).
Through hemodialysis or peritoneal dialysis excess water and waste products are removed from the blood. In 2010, 42 Canadian children 19 years of age and under received peritoneal dialysis and 72 received hemodialysis (Canadian Institute for Health Information, 2011). Peritoneal dialysis often is the preferred option because it is thought to foster better physical, psychological, and social development and quality of life than hemodialysis (Fischbach et al., 2005; Furth et al., 2001; Gillman, 2006; Miller, 2006; Snethen, et al., 2004). Peritoneal dialysis involves infusing several liters of solution into the abdominal cavity to absorb wastes and fluid. After a predetermined length of time, the resulting solution is drained from the body. These exchanges can be carried out several times a day for 30 to 40 minutes while a child is up and about or continuously during the night for 8 to 10 hours (Waters, 2008). Because peritoneal dialysis can be delivered in the home by a registered nurse or trained family caregiver, it offers more flexibility and independence than hemodialysis. However, about 50% of children with ESRD require hemodialysis for medical and physical reasons. Hemodialysis may be some families’ preferred option because it relieves the burden of providing this complex procedure themselves in their home settings (Fischbach et al., 2005; Furth et al., 2001).

**Pediatric Hemodialysis Units**

In comparison to peritoneal dialysis, hemodialysis is more technologically and physically challenging and more socially disruptive. Hemodialysis is highly regimented, occurring about three times a week and each session lasts three to four hours. Treatments involve a large machine that slowly draws the blood out of the body through a central venous catheter inserted in a large vein in the chest. The machine filters the blood to remove excess fluids, wastes, and chemicals before pumping it back to the body (Frank et al., 2003, Waters 2008). In between treatments children typically experience fatigue, diminished attention span, lack of appetite, nausea, and
vomiting. Although these symptoms are relieved somewhat by hemodialysis, children live with cyclical symptoms that correspond to their treatment cycles (Frank et al., 2003; Nicholas, et al., 2011; Snethen et al., 2001).

Hemodialysis necessitates a particular form of intermittent technological dependence in which the body is regulated, externalized, and extended by the machine. Treatment cycles significantly disrupt children’s everyday lives because currently it is usually delivered in specialized pediatric hospital-based units. Although some hemodialysis takes place in community clinics or homes, almost all Canadian children undergo hospital-based hemodialysis (Canadian Institute for Health Information, 2011). Hence, for as long as it is necessary, hemodialysis sessions constitute a central feature of their everyday lives, with significant consequences on domestic, school, day care, recreational activities and relationships with others. Furthermore, many children must spend considerable time traveling to and from regionalized hospitals to be dialyzed. Not surprisingly, the findings of some studies (Goldstein et al., 2006; McKenna et al., 2006; Nicholas et al., 2011; Snethen et. al., 2001; Snethen et al., 2004, Waters 2008) suggest that maintaining educational progress and participating in family life and domestic routines, recreational and play activities, and peer relations are difficult for these children. Because these children must intermittently occupy the hemodialysis unit for lengthy periods each week, their lives differ from those of their peers. There is a need to understand the range of effects of hemodialysis regimens in the settings they take place.

The Research Problem

Children who rely on hemodialysis must spend at least 12 hours a week conjoined to a hemodialysis machine in a specialized hospital-based unit until they receive a transplanted kidney. During this time, their lives are characterized by intermittent temporal disruptions, socio-
spatial dislocations, and dependence on life-supporting technology and associated care. Virtually nothing is known about children’s perceptions of and responses to the temporal, spatial and technological regimens and relations that characterize childhoods that include hemodialysis. In addition, in North America, most children’s lives are shaped by gender and age together with their domestic, educational, and recreational activities (Holloway & Valentine, 2000a; Morrow & Connolly, 2006; Prout, 2000, 2005). However, the extent to how these differences affect their perceptions of and responses to hospital-based hemodialysis remains unknown.

**Research Purpose**

In this study, I describe and interpret children’s perceptions of and responses to the temporal, spatial and technological regimens and relations of a pediatric hospital-based hemodialysis unit. Although the study was anchored in the hemodialysis unit, the unit was conceptualized as nested in the broader contexts of the children’s everyday lives.

**Significance**

The study is both highly relevant and innovative because it addresses a major, although not highly prevalent, pediatric health problem. The findings provide knowledge about the perceptions and responses of children with ESRD to hemodialysis treatments in a hospital-based pediatric setting. The findings also contribute to understandings about the children’s technological embodiment as well as temporality, spatiality, and dialysis technology in the lives of these children. Ultimately, the findings suggest how nurses and other renal health care providers could provide more effective care for children, including creating a more supportive and pleasant environment for them. In hemodialysis units, nurses are the children’s primary care providers. They spend significant amounts of time with the children as they manage the
hemodialysis treatments, monitor the machines and the children’s physiological status, engage them in activities, and provide support and counsel them. They also determine care regimens and influence the layout and design of the unit. The study findings suggest optimal ways that the children could spend time during treatments and/or how aspects of the unit’s physical design, social layouts, aesthetic and architectural features, and care routines could be modified to better accommodate the children. Finally, to some extent, the findings may be useful to similar hemodialysis units and to children with analogous health problems, such as thalassemia, short gut syndrome or blood cancers, who receive similar ongoing intermittent technological treatments in pediatric hospital settings.
Literature Review

Although children’s perceptions of and responses to receiving hemodialysis in a hospital-based setting have not been extensively studied prior to this investigation, three bodies of literature are very relevant to the research and reviewed in turn. First, I provide an overview of research about children, ESRD, and dialysis and summarize what is known about this population. Then, I review research about hospital-based hemodialysis for adults, followed by a review of research about places, time, and technologies of health care. To conclude, I summarize these three bodies of literature and identify overall theoretical, methodological, and substantive shortcomings and gaps.

Children, ESRD, and Dialysis

A considerable amount of research has focused on determining children’s physiological responses to ESRD, psychosocial adaptation and coping (Nicholas et al., 2011; Snethen et al., 2001; Snethen et al., 2004; Water, 2008), and quality of life issues (Goldstein et al., 2006; Grootenhuis, Stam, Last, & Groothoff, 2006; Groothoff et al., 2005; McKenna et al., 2006). Snethen et al. (2001) conducted a study in the United States that elicited 35 adolescents’ perceptions of ESRD and their psychosocial adaptation to the disease. Of the 20 males and 15 females, 29 had ESRD for more than two years, 24 had received transplants, and 11 were on dialysis. The investigators noted the challenges of living with a fluctuating condition, dietary restrictions, and lengthy and invasive medical regimens while simultaneously developing and enacting gendered and age appropriate skills and abilities. Using quantitative and qualitative methods, they identified four factors that described participants’ views of how ESRD affected their lives and their adaptations: 1) normalization; 2) illness intrusion, a barrier to normalcy; 3) illness management, patient-focused, and 4) illness management, self-focused. The investigators
concluded that because adolescents rely on their peers to develop a sense of self and identity, their bodily differences, such as short stature, and time-consuming treatment regimens often disrupted their participation or inhibited their acceptance in social groups, daily life, and peer relationships.

Because of the stresses associated with living with ESRD, Snethen et al. (2004) subsequently analyzed the strategies used by adolescents to cope with ESRD. This study involved data from a self-reported coping strategy inventory from the same 2001 sample. Seven personal characteristics were related significantly to the most frequently used coping strategies. These included age (older adolescents were less likely to vent their feelings and avoid problems and more likely to draw on a wider range of strategies than younger adolescents), being male or female (males used humour more frequently than females), transplant status (adolescents with transplants were more likely to engage in more demanding activities, through which they gained peer acceptance), and religious views (those involved in forms of religion sought spiritual support). Listening to music was reported as the strategy most often used by adolescents. Finally, they noted differences in coping strategies according to the length of time on dialysis. Adolescents who had been dialyzed for more than two years were sought more support from school counsellors, teachers or professional counselors than those less than two years on dialysis. The investigators concluded that the time burdens of dialysis and decreased energy may limit opportunities to utilize other coping strategies, such as peer relationships and activities.

In a qualitative Canadian study of children and adolescents, Nicholas et al. (2011) highlighted that children’s participation in their health care routines is important. Their study focused on the ways in that children and adolescents perceived and managed living with their ESRD. The sample was comprised of 25 children, 14 boys and 11 girls whose ages ranged from 7 to 18 years of age. Of this sample, 12 had functioning transplants, 10 received hemodialysis, 2
received peritoneal dialysis and 3 received renal care, rather than renal replacement therapies. Open-ended interview revealed that the participants perceived “not being normal” (p. 165) when comparing themselves to healthy peers in regard to disease and treatment symptoms, diet and fluid restrictions, body image, loss of opportunities for peer-related activities and the time consumed by receiving treatments. Hemodialysis was considered by the children to limit daily activity more than other treatment modalities. Absence from school was described as challenging and isolating and choices of disclosure of their disease to peers was negotiated by the participants. Variations in knowledge about their condition and levels of involvement in their health care routines were found among participants, with mothers most frequently monitoring and caring for the children. Older adolescents most often reported taking a significant role in their health care, and with increased age, most participants took more responsibility for their health care. Despite frequent challenges associated with living with ESRD, the participants were found to engage in self-care and make adaptive choices to manage their disease and treatment.

In an ethnographic study that took place in a UK urban pediatric dialysis unit with 13 children who received hemodialysis and peritoneal dialysis, 14 parents or caregivers and 36 staff members, Waters (2008) explored the children’s long-term illness experiences, including compliance to treatment regimes. Her methods included the analysis of fieldnotes over 16 months of observation in the unit over 16 months, children’s stories and drawings, interviews and document analysis. The main central theme of renal space pertained to the notion that these children lived in a “bubble of experience and pressures” (p. 3106) and was comprised of two central features conceived as illness labour and the renal world. Illness labour referred to the knowledge and commitment needed to manage everyday life that included diet and fluid restrictions, medications and renal care routines and also sometimes involved coping with multiple renal therapies while waiting for their ultimate goal of kidney transplantation. The renal
world pertained to children’s need to inhabit renal health care spaces as they complied with their time consuming in-unit hemodialysis schedules and their positive relationships, such as those with their nurses whose knowledge was said to be important to the children, in the unit’s social world. The children also were found to have many strategies for noncompliance, especially those related to their medication and fluid intake regimes. Because of their renal conditions, they lived with bodies that demanded constant care and attention, such as constant thirst, bodily changes, such as scarring from catheter insertion and surgeries, and shifts between various states of health and illness. The findings illustrated that the children’s compliance was interconnected with living with a challenging embodiment that included attachment to dialysis technologies that limited their time and capacities to engage in other activities. Overall, the children were found to be not able to do all that was expected of them all of the time and this facet of living with the extreme demands of renal disease often was labelled non-compliance by their caregivers.

The physical, emotional, and psychosocial impacts of ESRD and its treatments affect quality of life (Goldstein et al., 2006; Grootenhuis et al., 2006; Groothoff et al., 2005; McKenna et al., 2006). As described above, studies have identified negative effects of hemodialysis regimens on school attendance, family life and domestic routines, play and recreational activities, and peer relationships (Nicholas et al., 2011). Goldstein et al. (2006) compared self-reports and parent reports, using a health related quality of life assessment instrument of physical and psychosocial health (emotional, social, and school functioning), among 131 healthy children and 85 children between 5 to 18 years of age with transplants, on peritoneal dialysis, or on hemodialysis. Overall, the findings illustrated that children who had been transplanted or on dialysis had significantly lower quality of life, physically and psychosocially, compared to healthy children without kidney disease. There were no significant differences between children receiving hemodialysis and peritoneal dialysis. However, those children on dialysis reported
lower physical health and emotional, social, and school functioning than those with a functioning transplant. Parents of children receiving dialysis reported that their children had lower quality of life in each of these areas, except school functioning.

In a cross-sectional Canadian study, McKenna et al. (2006) studied health-related quality of life in 64 children between 2 to 18 years of age with RSRD using self-reports and caregiver proxy reports. The investigators compared physical, emotional, social, and school functioning among three groups of children that included 17 children on dialysis, 20 with chronic renal insufficiency, and 27 with a transplant. They also compared these three groups to healthy controls. Children in all three ESRD groups scored lower than healthy controls in all areas of functioning. However, children, especially those on dialysis, rated their functioning higher than their caregivers did, the investigators suggested that caregivers not have full understanding of children’s views of living with kidney failure. Corroborating Goldstein et al.’s (2006) findings, significant differences were not found between children receiving hemodialysis or peritoneal dialysis. However, to adjust for the small sample size and increase the power of the analysis, children on hemodialysis or peritoneal dialysis were grouped together.

Long-term impacts of ESRD in childhood related to relationships, family, work, and independence also have been reported. Grootenhuis et al. (2006) and Groothoff et al. (2005) studied the late physical, social, and psychosexual effects of childhood onset ESRD among Dutch adults using quality of life and other measures. Grootenhuis et al. (2006) found that their sample of 39 men and 36 women between 20 to 30 years of age had reached fewer milestones in the areas of autonomy (i.e. at home or outside of home), social (i.e. contact with peers), and psychosexual events (i.e. love and sexual relationships) than age-matched Dutch peers. Among 76 men and 68 women between 30 to 42 years of age, Groothoff et al. (2005) determined that adults with children onset ESRD were more likely to be unemployed than age matched Dutch
citizens. Also, those who had received long-term dialysis in childhood were found to have lower occupational levels (i.e. less educational achievement) and were more likely to live with their parents, especially those who were male.

**Summary**

Most nursing and other clinical researchers have conceptualized children with ESRD in the context of biomedical or psychosocial models of illness. Consequently, much is known about disease processes, quality of life indicators, adjustments, lifestyle, stressors and coping styles. While the cumulative findings have provided examples of the daily and long-term challenges of living with ESRD, many have been derived from health care providers’ perspectives and parents’ responses to standardized and quantitative measures. This review also indicated that ESRD and its treatment regimes are body altering, time-consuming, and affect many facets of children’s lives. Although Waters (2008) conducted an ethnography in a dialysis unit about the children’s experiences of long-term illness, her study examined the children’s overall lives beyond the unit, so that her findings provide limited understand about the children’s experiences in the unit. No research has focused solely on how children perceive and respond to hospital-based hemodialysis.

Methodological shortcomings in the studies reviews included relatively small sample and subgroups sizes or subgroups were uneven in numbers (Goldstein et al., 2006; Grootenhuis et al., 2006; Groothoff et al., 2005; McKenna et al., 2006; Nicholas et al., 2011; Snethen et al., 2001; Snethen et al., 2004; Water, 2008). Also, some researchers (Goldstein et al., 2006; Grootenhuis et al., 2006; Groothoff et al., 2005; McKenna et al., 2006) did not indicate calculation of sample size so that adequacy cannot be assessed. Furthermore, in Grootenhuis et al. (2006) and Groothoff et al. (2005), the refusal rate was 28% and 22% respectively. Hence, how the missing information may have altered the researchers’ conclusions is unknown. In regard to research that
compared quality of life among children with ESRD and healthy children (Goldstein et al., 2006; Grootenhuis et al., 2006; Groothoff et al., 2005; McKenna et al., 2006), the control groups or matching criteria were not described in detail, so that similarities and/or comparability between the healthy controls and study group could not be determined. Among the cross-sectional studies (Goldstein et al., 2006; Grootenhuis et al., 2006; Groothoff et al., 2005; McKenna et al. 2006; Snethen et al., 2004), multiple differences existed in and between subgroups of children with transplants, on peritoneal dialysis, or on hemodialysis in terms of demographic factors (i.e. age, gender, ethnicity, social economic status), disease specific factors (i.e. point in the disease, length of time on therapy), and comorbid factors (illnesses, disabilities). Although the researchers adjusted for and/or analyzed these variables, only Snethen et al. (2004) discussed how children’s characteristics were related to the findings. Finally, only McKenna et al. (2006) and Nicholas et al. (2011) involved children with ESRD who were currently undergoing treatments in a Canadian hospital.

Because many studies (Goldstein et al., 2006; Grootenhuis, et al., 2006; Groothoff et al., 2005; McKenna et al., 2006) were designed to compare quality of life outcomes among children with ESRD on various treatment modalities, the findings offer little insight into relationships between health and wellbeing and renal replacement therapies. Furthermore, in regard to quality of life outcome measures, those pertaining to physical health and psychosocial health (i.e. emotional, social, school functioning) used by Goldstein et al. (2006) and McKenna et al. (2006) and developmental milestones (i.e. autonomy, psychosexual, social) used by Grootenhuis et al. (2006) are not fully described. Finally, because Grootenhuis et al. (2006) and Groothoff et al. (2005) relied on retrospective data about late physical, social, and psychosexual effects of childhood-onset ESRD, the validity of the findings is difficult to assess.
Hospital-Based Hemodialysis for Adults

Most research pertaining to adults with ESRD has identified challenges that are similar to those faced by children and are not reviewed herein. However, some studies have elicited adults’ personal accounts of receiving hospital-based hemodialysis. Because these studies specifically investigated participants’ views of hemodialysis and the hemodialysis unit, I review them here. Several qualitative studies have elicited phenomenological accounts that have been synthesized into collective patterns of meanings, or personal accounts. For example, one study focused on hemodialysis patients’ interactions with their care providers (Allen, Wainwright & Hutchinson, 2011) and two studies focused on the technologies and environments of hemodialysis units (Hagren, Petterson, Severinsson, Lutzen & Clyne, 2001; Nagle, 1998).

Allen et al. (2011) undertook a two year participatory action research (PAR) study with seven patients, three women and four men whose ages ranged from 38 to 63 years, in two Canadian hospital-based hemodialysis units over a period of 18 months. Methods included field observation, non-recorded and audio-recorded in-dialysis interviews, two video-recorded focus groups, five video-recorded life history interviews and five video-recordings of patient receiving hemodialysis. Their analysis revealed that patients viewed health care providers as frequently referring to their noncompliance, for example lying and shutting down, in interactions with them about health problems, illness episodes and transplantation eligibility. Patients described their interactions with providers in the unit as adversarial. The tensions in provider and patient relationships were themed as 1) between the whole person care and ‘assembly line’ treatment: “that connection, it’s not there”; 2) between patient knowledge and medical knowledge: “compliant to a point”; and 3) shared decision-making and “digging to find out”: “Let’s see how we can work this together”. The researchers concluded that “adversarial patient-provider relationships are associated with technology-driven, efficiency-focused care that excludes patient
knowledge” (p. 133) and results in reduced provider-patient collaboration and erosion of trust among patients because their experiences and knowledge are not taken into account by providers.

Through interviews, Nagle (1998) explored the meaning of hemodialysis technology for six men and five women, ranging from 20 to 63 years of age. These participants had received hemodialysis in a Canadian hospital for six months to 25 years. Nagle used Gadamer’s extension of Heideggerian hermeneutics to interpret participants’ accounts of their experiences. Meanings ascribed to the technology were conceptualized into several relational themes that included: “coming to terms with loss and limitation”; “abiding with technology”; and “enduring the treatment environment” (p. 83). These themes were found to be linked by a constitutive pattern described as “being transformed by reluctant partnering with technology” (p. 79). The notion of ‘reluctant partnering’ referred to patients’ understanding of the need for hemodialysis to sustain life while preserving “an embodied self within a context that constantly threatens to disembody them” (p. 90).

In another interpretive qualitative study of how Swedish adults make sense of or ascribe meaning to living with ESRD, Hagren et al. (2001) interviewed seven men and eight women, whose ages ranged between 50 to 79 years, and who had received hospital-based hemodialysis in Sweden for three months or more. Their responses to being asked to describe their experiences of suffering revealed two main themes. The first theme, “the haemodialysis machine as a lifeline” (p. 198), characterized the machine as something that patients’ lives depended on, but restricted freedom and increased their dependency on medical regimens and providers. Hence, the machine was viewed as a source of suffering. Time also emerged as a concern in that the machine was regarded as “something that consumed time” (p. 199) that could not be regained. The second theme, “alleviation of suffering’ (p 198), described how some patients came to accept their
dependency on hemodialysis, hoped for a kidney transplant, and gained personal autonomy by participating in care decisions.

**Summary**

These studies centered on interpretations of adult’s accounts of their personal and collective experiences of hemodialysis. They provide valuable insights into the transforming, challenging, and life-changing effects of hospital-based hemodialysis during adulthood. The collective findings indicate that recipients understand hemodialysis is understood as life-sustaining and necessary, yet is associated with loss, control, restrictions, uncertainty, and a changed sense of self and life. Also, the findings emphasize recipients’ efforts to become active participants in the unit and in their care. In Allen et al.’s (2011) study, the patients’ complained about the disregard for their experiences and knowledge that frequently led to them being labeled as noncompliant in provider-patient interactions. Nagle (1998) and Hagren et al. (2001) highlighted the significance of the unit’s temporal rhythms, space, and technologies. Importantly, these studies describe how adults ascribe meaning to the hemodialysis unit. Hence, this body of work illustrates the importance of the environment where hemodialysis is received in constituting patients’ perspectives of treatments.

The shortcomings of these studies included adults only and they do not explicitly describe the physical, social, and technological aspects of the settings or their effects on participants in much detail. Furthermore, data in all three studies were elicited with small samples and Nagle’s (1998) and Hagren et al.’s (2001) data were obtained only through single interviews that ranged from only from 20 minutes to 1 hour in length. Although participant diversity is described, the reviewed studies did not undertake comparisons among the participants in terms of personal characteristics (i.e. age, social and economic status, ethnicity, gender) and treatment profiles.
Furthermore, the hermeneutic analyses undertaken by Nagle (1998) and Hagren et al. (2001) entailed the interpretation of patterns of shared meanings, situations, and practices across their participant groups, based on the assumption that individuals will have common experiences in the same care contexts. Their assumption and method of analysis did not allow for the exploration of variations among the participants’ accounts of their experiences.

**Places, Time and Technologies of Health Care**

Some researchers have focused on children’s and caregivers’ experiences of time and space in hospital, community, and home health care settings (Bluebond-Langner, 1978; Heaton, Noyes, Sloper, & Shah, 2005; McGibbon & Peter, 2008; McKeever, O’Neill, & Miller, 2002; Place 2000; Tranterab, Donoghueb, & Baker, 2009; Yantzi, 2005). Their cumulative findings suggest that health care regimens and technologies have considerable impact on everyday activities and socio-spatial relations. Two studies (Heaton et al., 2005; Place, 2000) are described in detail here because they respectively illustrate interrelations between time and technology in the home and children’s bodies and technology in a hospital setting. Three additional studies (Bull & FitzGerald, 2006; Marck, 2000; McGibbon & Peter, 2008) are reviewed because they illustrate how the delivery of care and relations between nurses and patients are affected by places and technologies. Finally, I review one study (Tranterab, et al, 2009) that specifically focused on the impact of nurses’ technologically focused care on the patient centered care in an adult hemodialysis unit.

In their description of the daily lives of 36 British families with technology dependent children, 8 of whom were on home peritoneal dialysis, Heaton et al. (2005) explored the temporal organization and time consequences of home health care routines. Interviews were conducted with 46 parents and one grandparent. In addition, interviews, facilitated by the use of
time-line drawings were undertaken with 13 technological dependent children and 15 siblings. Drawing on social theories pertaining to multiple temporalities, this study focused on the temporal patterns of daily life by examining relationships among timeframes pertaining to machines and devices (i.e. amount of time taken by the machine to perform its functions and associated technological/medical care) and social and ‘natural’ timeframes (i.e. institutional routines of school and work, seasonal and bodily rhythms). Heaton et al. found that the temporal and social organization of machine and care regimens placed considerable time demands on children and families. These demands did not always fit with domestic, school, work, and holiday routines and limited family members’ inclusion in school, work, and other social activities. The investigators concluded that disruptions to daily and bodily life varied according to the degree of the child’s technological dependency and the extent that the technologies replicated the rhythms of the body relatively innocuously and autonomously (i.e. pacemakers versus suction machines). Temporal disruptions also varied according to the extent of restrictions of children’s and care providers’ movements in time and space caused by technologies’ design and use. For example, machines that needed to be plugged into specific locations or kept in close proximity to care providers and recipients tended to be more disruptive. These findings highlight salient aspects of technologies and their impact on bodily, socio-spatial, and temporal life for children and families.

Place (2000) emphasized the role of technologies in his ethnographic study of a pediatric intensive care unit located in an urban teaching hospital in the United Kingdom. He focused on the combination of children’s bodies with medical technologies and nurses’ understandings of and relationships with children. Data collection was comprised of 18 interviews with nurses and nine months of observation in the unit. Drawing on Callon’s (1986) and Latour’s (1979, 1987, 1991, 1993) actor-network-theory, Place described the unit’s entrance as a transition of
geographical space and conceptual classification” (p. 174) where child patients literally became dislocated from their typical surroundings and family life. He demonstrated how children’s bodies become particular forms of human-technological hybrids or “quasi-objects” (p. 174) that are known, represented, and intervened on by health care providers through technological and figurative (textual, numerical, and graphical) practices. He argues that in this highly technological, specialized place, the physical body of the child, through attachment to monitors, pumps, and probes, is opened and extended such that the inside of the body is made visible. Becoming composed of both corporeal and technological elements, the body can be “sorted out” (p. 174) through machine-generated representational translations into scientific signs and symbols (i.e. blood pressure readings, laboratory results, observational charts, nursing notes).

Place illustrated that in critical care units “there is little evidence of corporeality which cannot be known without some non-human artifact” (p. 190). Hence, technologies become a process of translation and transformation focused on the physical body and recognition of the lived, experiencing body and embodied relations between care provider and recipient may be diminished. ICU nurses, he posits, are highly invested in these technological perceptual processes that also involve a transformation of their own perceiving bodies and relationships to ambiguous and simultaneous corporeal, technological, and representational children’s bodies. Place concluded that health care places dominated by technologies profoundly affect patients’ bodies and identities and providers’ perceptions and relations with patients.

Other research corroborates the observation that the delivery of care and relations between nurses and patients are affected by settings and technologies. Three studies (Bull & FitzGerald, 2006; Marck, 2000; McGibbon & Peter, 2008) focused on the problems and tensions for nurses that are brought about by technologies in various adult or pediatric hospital settings. Bull and FitzGerald (2006) studied an operating room, Marck (2000) studied acute care environments and
McGibbon and Peter (2008) studied a pediatric intensive care unit. These researchers questioned whether the technological imperative of health care has shifted nurses’ focus to machines and away from patients. Because current and emerging technologies demand new foci and skills, they hypothesised that nurses’ work and their bodily, social, temporal and spatial relations with patients have become readjusted and redistributed.

The ambiguous of technology and nursing work were illustrated in an ethnographic study conducted in an operating room in Australia. Bull and FitzGerald (2006) explored the relationships between care of patients and technological activities among nurses. They concluded that the nurses’ main focus is technological, yet underlying this focus is a patient-focused ethic of care. They suggested that nurses’ technological proficiency needs to be understood in the context of, rather than opposed to, care. In contrast, in a qualitative study that elicited the accounts of 10 experienced nurses in acute care settings across seven Canadian tertiary hospitals, Marck (2000) used a critical hermeneutic approach to “the nature of nursing in a technological world” (p. 66). Marck found that nurses tended to be preoccupied by technologies rather than patients. Furthermore, she concluded that practice settings are “assembly lines” (p 68), focused on the production of patients and health. Marck found that the space of nurses’ work is sped up into a series of continual, endless tasks, the integrity of their work is eroded and the care of patients comprised. She concluded that nursing work has become ‘denatured’ (p. 70) because it has become stripped of its caring and healing properties in contemporary technological environments.

McGibbon and Peter (2008) are concerned with how the use of technology “unfolds in an everyday or every night context” (p.1134) of nurses and its impacts on human experience. In their biomedical technography study conducted in a Canadian pediatric intensive care unit, they depict the ubiquitous, yet disrupting and disturbing, coexistence of biomedical technological
devices among sick or dying bodies. Described effects of ICU nurses’ relations with biomedical technologies include emotional and moral distress among the nurses due to their roles in the prolongation of life of seriously ill infants who will not survive or will be subjected to a life full of painful or invasive medical procedures in the long-term. Additionally, they illustrate that biotechnological interventions now extend to care of dead infants by nurses for the purpose of organ donation. These authors contend that dissonance results from the everyday suffering witnessed, inflicted and experienced by nurses and their involvement in medical processes that end in the objectification of infants, such as textual mediation, through the nurses’ various routine procedures and practices. Informed by Dorothy Smith’s institutional ethnographic approach, the problematic of individual social relations and experiences that are “organized, coordinated, and objectified by another set of social relations beyond the experience of individuals” (p. 1141) is raised. The other set of social relations referred to by the authors are the broadly accepted and taken-for-granted nature of biomedical technology in discourses and practices of westernized medical care. An objective of their work is to press the need for ethnographic inquiries into the human-technological relations in intensive health care to reveal how lives are framed and lived amongst biomedical technologies in the everyday world of institutionalized health care.

In their ethnography conducted in an Australian hemodialysis unit involving 12 months of data collection, Tranter et al. (2009) identified the strong technological focus among dialysis nurses because of structural factors, such as an increased demand for services and patient acuity. Nurses also often were viewed as reluctant to relinquish their hold on their increasing specialized technical skills that they viewed as fundamental to their identities as dialysis nurses in order to address the total needs of patients. The study findings revealed five major themes that were viewed as impinging on the nurses’ patient focused caring role. These themes are: 1) doing more
with less; 2) who gets a machine; 3) technological creep; 4) dialysis centered care; and 5) the bottom line. This study was undertaken to investigate enablers and barriers to the provision of nurses’ patient centered following numerous patient complaints about their diminished quality of life on hemodialysis. The researchers conclude that the nurses’ improved understandings of their roles in the broader social, economic and technological changes in health care accompanied by a shift in the dialysis culture towards recognizing and intervening into patients’ suffering and discomfort is essential.

**Summary**

These studies illustrate that contemporary health care settings and technologies affect the bodies, identities and actions of, and relations between, recipients and providers. They also highlight interrelations among time, space, and technologies in specific high tech settings and the impact these interrelations have on health care providers and recipients. Overall, technologies were viewed as having an ambiguous nature with positive and negative impacts on care recipients and providers and places. These findings echo a persistent and prevalent concern in health care settings in nursing and health care literature about the impact of technologies. Researchers and theorists (Almerud, Alapack, Fridlund & Ekebergh, 2008; Barnard, 2002; Barnard & Sandelowski, 2001; Bennett, 2010, 2011; Bevan, 1998, 2000; McGibbon & Peter, 2008; Poland et al., 2005; Sandelowski, 2002; Tranter et al., 2009; Wynn, 2002; Zitzelsberger, 2004) have called for more research to investigate the nature and effects of technologies in and on specific places of care. Some studies explored nurses’ views (Bull & FitzGerald, 2006; Marck, 2000; McGibbon & Peter, 2008; Tranter et al., 2009) and Allen et al. (2011) and Nagle (1998) identified the need to investigate similarities and differences between care recipients’ and providers’ perspectives of technologies and their settings.
Although concepts of time, place, and technology have become increasingly prominent in health care research, there has been little focus on children’s perceptions of and responses to technological mediated care in pediatric hospital settings or home environments. Although Heaton et al. (2005) studied families’ perspectives of the interrelations of time and technology, Place (2000) studied the translation and transformation of children’s bodies in a highly technological environment, and McGibbon and Peter (2008) studied the dissonance of between human experience and techno-interventions among nurses in a pediatric intensive care unit, children’s views were nominal or absent. Heaton et al.’s data collection was comprised of interviews with 13 technologically dependent children among the 36 families. McGibbon and Peter’s ethnography consisted of researcher reflections, conversations with nurse in the field and interviews with 12 nurses. Place relied on interviews with 18 nurses and observational data pertaining to interactions among nurses, semiconscious or unconscious children, and technologies in the intensive care unit. Also, Place did not describe his techniques of data collection or analysis.

Four studies focused on nurses’ perspectives of patient care in highly technological settings (Bull & FitzGerald, 2006; Marck, 2000; McGibbon & Peter, 2008; Tranter et al., 2009). However, neither Marck (2000) and McGibbon and Peter (2008) described the nurses’ characteristics, other than their length of experience and/or work settings. Similarly, Bull and FitzGerald (2006) and Tranter et al. (2009) did not describe the setting or number of nurses involved in their ethnography of an operating room and hemodialysis unit respectively. Only Marck (2000), McGibbon & Peter (2008) and Tranter et al. (2009) described their techniques of data collection and analysis in some detail. Verification of the findings with participants or others was not reported by the researchers in these four studies.
Gaps in Literature for Children Receiving Hospital-Based Hemodialysis

Because research on children with ESRD has focused on disease processes, renal replacement therapies, psychosocial adjustments and coping, and quality of life, much is known about the physical, emotional, and social challenges of renal failure for children in the short and long-term. Most studies were comprised of subgroups of children with transplants, on peritoneal dialysis, and on hemodialysis. No research has focused explicitly on the effects of hospital-based hemodialysis on children. This is surprising considering the bodily, psychological, and social consequences arising from ESRD and hemodialysis regimes.

A small number of studies have elicited adults’ accounts of their experiences of hospital-based hemodialysis (Allen et al, 2011; Hagren et al. 2001; Nagle, 1998) or have explored technological environments and/or technological embodiments for children (Heaton et al., 2005; McGibbon & Peter, 2008; Place, 2000). These studies have illustrated the importance of health care technologies and places on patients and providers. Hagren et al. (2001) and Nagle (1998) described that hemodialysis is perceived by adults as necessary, yet life-changing and adults’ perceptions were interpreted as a distinctive response to ongoing, intermittent hospital-based hemodialysis. However, despite the acknowledged importance of the hemodialysis setting and technologies, detailed descriptions of the treatment contexts are virtually absent. Hence, how the contexts of hemodialysis with its attendant technologies are viewed by diverse children remains understudied.

In regard to methods, many researchers have used comparative and cross-sectional designs to determine how ESRD and renal replacement therapies impact children. For example, Goldstein et al. (2006), Grootenhuis et al. (2006), Groothoff et al. (2005), and McKenna et al. (2006) concluded that children on renal replacement therapies, especially dialysis, have lower quality of life and increased depression and anxiety than healthy children. In addition, Nicholas
et al. (2011) concluded that children with ERD face multiple psychosocial challenges, including issues with normalcy and absences from school and peer-related activities and many took responsibility for the management of their ESRD and treatment, particularly with increasing age. Yet, because of the designs, results did not offer insights into the relationships between quality of life and various treatment modalities, or children’s efforts to mitigate the effects of treatment regimens. Hence, detailed accounts of the lives and circumstances and why specific treatment regimens affect subgroups of children differently have not been investigated, especially in terms of how children understand and respond to them. Some research has been child-focused, with data elicited from children with ESRD themselves (Nicholas, 2011; Snethen et al., 2001; Snethen et al., 2004; Waters, 2008). However, a number of researchers Goldstein et al., 2006; McKenna et al., 2006) have used quantitative and standardized measures and proxy reports, primarily from health care providers and parents. As well, qualitative research about technological environments and/or technological embodiments for children (Heaton et al., 2005; McGibbon & Peter, 2008; Place, 2000) has not elicited children’s perspectives. Although Allen et al. (2011), Hagren et al., (2001) and Nagle, (1998) directly investigated adults’ accounts of hospital-based hemodialysis, their samples were small. The data collection techniques employed by Hagren et al. and Nagle were not comprehensive as they relied on small samples and single interviews. Tranter et al. (2009) explored nurses’ perspectives on adult hemodialysis care through ethnographic methods, however, they do not describe the setting or participants in detail. Hence, the need for research to investigate more extensively accounts of experiences of hospital-based hemodialysis, from children’s perspectives, through multiple methods of data collection was underscored.

Finally, a number of quantitative (Goldstein et al., 2006; Grootenhuis et al., 2006; Groothoff et al., 2005; Snethen et al., 2001) and qualitative studies (Hagren et al., 2001; Heaton et al., 2005; Nagle, 1998; Place, 2000, Waters, 2008) have demonstrated that the time, setting,
and technologies of hemodialysis have impact on recipients. Yet, researchers focused on children with ESRD have conceptualized children in the context of biomedical or psychosocial models of illness or have focused on quality of life issues. Prior to my study, the effects and meanings of temporality, spatiality, and technology in children’s lives who receive hospital-based hemodialysis has not been expressly investigated.

To begin to address these gaps in knowledge, I decided to describe how children perceive hemodialysis and respond to the temporal, spatial and technological regimens and relations of a pediatric hospital-based hemodialysis unit. In order to explore children’s experiences, in-depth and prolonged immersion in a hemodialysis unit was necessary. To this end, I used a focused ethnographic approach and methods.
Chapter II: Conceptual Framework

Introduction

To frame the study, I have drawn on concepts from contemporary childhood studies, human geography, time and technology studies. Each set of concepts in this chapter are separately discussed for clarity. I first outline my perspective on children with ESRD, focusing on their embodiment and agency. I then conceptualize the place of the hemodialysis unit and discuss space, time, and technology because these concepts were salient to the design of my study about children’s perceptions of and responses to hospital-based hemodialysis. Concepts of time, space and technology are described as interwoven together to conceptualize a more integrated notion of timespace based on May and Thrift (2001). Finally, I present the notion of the children’s embodied situatedness in the timespace of the unit.

Perspectives on Children with ESRD

Embodiment

My research was based on the assumption that children’s perceptions of hemodialysis and their responses to the unit are embodied. I concur with Prout’s (2000, 2005) contention that although perceptions and experiences have bodily dimensions, they are not solely physically or biologically determined. Csordas’ (1994) posits that embodiment is “perceptual experience and mode of presence and engagement in the world” (p. 12). Perceptual experience, in his view, encompasses bodily senses (i.e. sight, hearing, smell, touch, taste), movements, postures, positioning and speaking in conjunction with mental and emotional capacities. He further contends that the body is the reference point for temporal and spatial orientation and the material
possibility for inter/subjective experiences and interactions in social fields. Because individuals inhabit physical and social worlds through and with the body, Csordas views the body as biological and material as well as social and cultural.

Prout’s (2000, 2005) social theory of children also contends that bodily and social lives have material as well as discursive components. In this study, I have assumed that children’s embodied perceptions and experiences are given meaning by social relations and discourses, for example those associated with biomedicine, nursing or place. To emphasize how bodies and societies interact, Prout (2000) argues that bodies are socially and biologically “unfinished” (p.4) at birth and changes occur through both biological and social processes over the life course. However, because children’s bodies rapidly change and cultural ideas that are strong about children’s identities, he posits that childhood is a period when “work on and by the body is relatively intense” (p. 8). Prout contends that although children’s bodies and lives are powerfully shaped by social discourses and practices, children also participate in and shape social processes. Hence, I incorporated his view of children as social actors with their own understandings and experiences rather than being products of adult societies and their biological or developmental stages. Finally, I share Prout’s (2000) notion that children’s bodies, like those of adults, are hybrid entities, “inseparable from, produced in, represented by, and performed through their connections with material objects” (p. 2). Additionally, James & Hockey (2007) remark on the need to acknowledge the potential of technologies, especially biomedical technologies, to radically transform human materiality.

According to Prout (2000, 2005), these views of children differ from those that underlie traditional developmental theories because they assume that children’s bodies and lives have both biological and social components, marked by spatial, cultural, and historical variability, and emphasize children’s knowledge and agency. Other social theorists also contend that although
children are shaped by common age-related activities and interactions in typical childhood places in western cultures, it cannot be assumed that they are the same based on their biological or chronological ages. Instead, their bodily and social experiences vary across times, socio-cultural contexts, and geographical locations (Hill, 2005; Holloway & Valentine, 2000a). Children’s experiences also vary because of their identities and characteristics, such as their gender, illnesses, bodily differences and family and living situations. Thus, I viewed children with ESRD as enabled and constrained by their bodies and the conditions in which they live, and as apprehending, assessing, and/or responding to situations and environments through and with their bodies.

Agency

Prout (2000, 2005) and other contemporary childhood theorists (Barker & Weller, 2003a; James & Hockey, 2007; O’Kane, 2000) claim that boys’ and girls’ bodies and lives are shaped by social and institutional routines and relations, while insisting that children actively interpret, co-produce, negotiate, and resist these processes. For example, studies have documented how children in interactions with adults and peers construct meanings about age and gender and come to discern, embody, and perform expected appearances and behavioural practices (Christensen, James, & Jenks, 2001; Gagen, 2000; Kelle, 2001; James, 2000). Studies also have illustrated that children negotiate everyday sickness behaviours and school attendance with mothers (Prout, 1992) and serious sickness and dying behaviours with parents and health care providers in hospitals (Bluebond-Langner, 1978). Finally, children’s construction of pockets of resistance to adult and institutional control of their time and spaces also has been documented (Holloway & Valentine, 2000a, 2000b; Rasmussen, 2004). Hence, when place and time are conceived and enacted as strategies of discipline and control, they also may constitute resources for children’s
agency. Balen et al. (2006) claim that because children “have first-hand acquaintance with the minutiae of their lives” (p. 31) they have important contributions to make toward their health care. Accordingly, service providers and researchers have demonstrated that most children are able and willing to evaluate their health and social services and that their views often differ from those of adults (Balen et al., 2006; Moss & Petrie, 2002; Rasmussen, 2004). Hence, I considered children receiving hemodialysis as invested and engaged in their health care, while acknowledging the possible vulnerabilities associated with their ages, bodily differences, and/or dependencies on technologies and numerous adults. Because of these reasons, the focus of this study solely is the children’s perspective and responses, and does not seek views or comments of parents’ to articulate their child’s experience or their own understandings of the unit. These perspectives on children’s embodiments, as materially lived, socially produced and technologically mediated, have underlined my investigation of how children perceive and respond to hemodialysis in the hospital unit.

**Conceptualizing the TimeSpace of the Hemodialysis Unit**

Debates about the nature and production of place and space have become a focus of inquiry in many disciplines including sociology (Gieryn, 2000); architecture (Gillespie, 2002; Manzo, 2005); geography (Bondi, 2005; Massey, 1994, 2004, 2005; philosophy (Casey, 1993, 1997, 2001, 2002); cultural studies (May & Thrift, 2001); anthropology (Low, 2003; Low & Lawrence, 2002); disability studies (Moss & Dyck, 2002); and childhood studies (Holloway & Valentine, 2000a, 2000b; Rasmussen, 2004). Geographers as well as health care and nursing researchers have illustrated that places influence the health and wellbeing of people (Angus, Kontos, McKeever, Dyck, & Poland, 2005; McGibbon & Peter, 2008; McKeever et al., 2002; Moss & Dyck, 2002; Peter, 2002; Poland, Lehoux, Holmes, & Andrews, 2005; Rapport, Doel, & Elwyn,

Because the hemodialysis setting was considered significant to my study of children in the unit, three aspects of this place that are space, time, and technology were conceptualized as interrelated components of the unit. I used Andrews’ and Kitchin’s (2005) view of place as “complex interactions of physical and social features” (p. 317) in which people are said to shape and influence places, and in turn, people are said to be constituted in and through places. Furthermore, a focus on the socio-spatial features of place emphasized the embedded power relations in situated social dynamics (Bondi, 2005; Massey, 1994, 2004, 2005; Poland et al., 2005). Finally, my study is informed by perspectives that emphasize the significance of relational effects of technologies in and on health care places (Ihde, 1990, 1993). To maintain a view of the time, space and technology of the unit as intertwined, I have used the concept of timespace by May and Thrift’s (2001) to describe and interpret how the temporal organization, practices, and orientations of the hemodialysis unit are interconnected with the spatial and technical aspects of the unit. I first describe the concepts of space, time and technology, followed by my conception of children’s embodied situatedness in the timespace of the unit that I have used to frame this study.
**Perspective on space**

My conceptualization of place included two interrelated aspects pertaining to space: physical spaces and social spaces (Andrews & Kitchin, 2005). The physical spaces of the hemodialysis unit encompassed the built environment and the material objects that the children interacted with, for example, physical layout, architectural structures, treatment stations, hemodialysis machines and other technologies, such as televisions and VCR/DVD players. The physical spaces also included the unit’s aesthetics and ambience, such as colours, paintings, pictures, sounds and smells. Because individuals are relationally embodied and social interactions, practices, and discourses occur in specific socio-cultural contexts, I have conceived all hemodialysis spaces as relational (Bondi, 2005; Massey, 1994, 2004, 2005). Furthermore, I have considered that social relations are intertwined with dynamics of power associated with gender, age, social and professional status (Bondi, 2005; Massey, 1994; 2004, 2005; Poland et al., 2005). A representation of my concepts of physical and social spaces is provided in figure 1. These concepts of place and space have guided my exploration of how the children perceived and occupied their embodied positions in the unit’s physical and social spaces.
Perspective on time

To tie together concepts of time and space, I drew on the work of critical geographers and sociologists. May and Thrift (2001) claim that the study of social worlds requires envisioning a complex intertwining of time and space. They argue that focusing on either time or space limits understanding of “the extent to which time is bound up with the spatial constitution of society (and vice versa)” (p. 3). Routines and practices of time are viewed as reflected in, constituted by and constitutive of specific places, which in turn, produce the time and space, or rather, in May and Thrift words, the “TimeSpace” (p. 3) of the places that they are set into play. Hence, space and time are inextricably interwoven and are varied and dynamic across settings. Adam (1990, 1995) and Felski (2000) also view time as multiple and heterogeneous because of the coexistence of numerous structures, representations, and realizations that shape discourses, practices and experiences of time. Massey (1994, 2004, 2005) further contends that power relations are embedded in social fields so that interactions of time and space are encountered unequally, producing different perceptions and orientations based on professional and social status, gender, age, ethnicity and other situated identities. Hence, time and space may be perceived and lived differently among and between individuals and groups in local and broader contexts, such as the children and nurses in the hemodialysis unit. I have used these perspectives on time to investigate how the children’s time is embodied in the hemodialysis unit and how it is perceived and spent.

May and Thrift (2001) claim that because perceptions and experiences of time are multiple and varied, then so is the constitution of time in specific locales. In their view, interconnections among the natural-social, biological-technological, material-discursive mutually constitute the
timespace of places. They contend that it is important to explore four domains of temporalities, in which spatiality is viewed as a constitutive part, rather than an added dimension. These domains are not discrete but interrelated and simultaneous, reflecting time’s multiplicity, heterogeneity and unevenness. They stress that “our sense of time is a product of the interrelationships between each, and these relationships are both dynamic and unequal” (p. 5).

The four interrelated domains include: 1) how time is shaped by a series of timetables and rhythms based on cosmic or biological movements, such as bodily rhythms, menstrual cycles, life spans, diurnal cycles, and seasonal cycles. These timetables and rhythms are socially regulated, and rather than being universal or fixed, they vary to the extent that individuals or societies are bound to, interpret, or interact with these patterns; 2) how time is shaped by and enacted through the social and institutional embeddedness of disciplinary/professional routines and practices in specific settings, such as hospitals, schools, or homes. This, for example, pertains to biomedical, nursing, educational and recreational practices in the unit; 3) how time emerges from interconnections with various technologies, instruments, and devices that mark or alter the passages and senses of time and space. For example, clocks, hemodialysis machines, artificial lights, televisions, and VCR/DVD players in the unit; and 4) how time emerges in relation to various texts or documents, as vehicles of translation that “in setting out particular understandings of time return to regulate that which we would codify” (p. 5). Texts include everyday talk, print, or electronic forms, for example, hemodialysis schedules. These four domains of temporality were used to investigate the practices, interactions, and events by which interrelations among time and space were constituted and lived by the children in the hemodialysis unit. Figure 2 represents my conceptualization of these four domains of temporality.
Perspective on technologies

daily life” (p 1). Technologies are defined to include simple and complex material objects, such as eyeglasses, watches, pens, dialysis machines or electrical systems.

Ihde (1990) contends that technologies are not neutral “things-in-themselves” (p. 26) because they transform human perceptions, actions, relations and knowledges. He (1990, 1993) posits that when a technology is used, it mediates or ‘inclines’ an individual’s relations with the world by simultaneously revealing and concealing various aspects of it. In this sense, the world is retranslated in technologically mediated ways, specific to each technology. Although technologically mediated transformations are inevitable, they also are variable as the resulting transformations may be subtle or dramatic and/or positive and/or negative (Kornelsen, 2005). Because of this, technologies are considered as ambiguous and intertwined with bodies and places in complex and diverse ways.

The primary foci of Ihde’s (1990, 1993, 2003b) philosophy are human-technological relations in which embodiment is a key concept. Consistent with Prout’s (2000, 2005) concept of embodiment, Ihde refers to perceptual and bodily experiences in specific settings and forms of bodily incorporation of and/or extension by technologies or device. Because an individual is always “bound up in a technological comportment toward his or her world” (1994, p. 40), distinctions between the natural-social, biological-technological, material-discursive are blurred. Human-technological relations are considered as embodied because bodily perceptions or functions are enhanced through technological mediation. Technologies are said to be encountered as part of the embodied self (Ihde, 1990, 1993; Eason, 2003; Rosenberger, 2009).

Technology also may be encountered as a device or tool that is distinct from the embodied self, which is described as an alterity relation. Humans enact this notion of “technology-as-other” (Ihde, 1990, p. 98) as they act in the world, for example, going through a turnstile at a bus station or driving a car. In a less impactful or sustained manner, technology also may create a context for
perception, such as in the case of home lighting, heating or cooling systems or music played on a radio. Technology as context is described as a background relation (Ihde, 1990, 1993; Verbeek, 2008).

Another related form of human-technological relations described by Ihde (1990, 1993) is hermeneutic or interpretive. This type of relation refers to instruments used to perceive, measure and describe aspects of bodies or environments, for example, monitors that measure children’s blood pressure or flow through hemodialysis machines. The use of such instruments both extends human perceptual abilities and enables previously unavailable aspects of bodies, objects or places to be understood (Eason, 2003; Place, 2000; Verbeek, 2008). Also, what is observed is translated through technology into numbers, words or images, for example, a blood pressure or flow reading. This process is interpretive because it requires specific skills to read the technology or its outputs, and reinterpret the body that is represented. These forms of human-technological relations are viewed as text-like because they extend interpretive or discursive capacities (Ihde, 2003b).

Technologically enhanced or mediated bodies can be conceived as a form of hybridity (Prout, 2000, 2005; Zitzelsberger, 2010). Technological hybridity may result from the incorporation of mechanical parts, such as a pacemaker, artificial organ or artificial joint. Somewhat differently, technologically derived organic hybridity may result from a transplanted kidney. In both cases, the human-technological hybridity takes the form of a more or less permanent state. In the case of hemodialysis treatments, the body sometimes is incorporated with and extended by a machine that takes over the cleansing of blood. I would argue embodiment may be perceived differently when occasionally coupled with a machine than when permanently transformed by human-technological relations. Hence, the term *conjoinment* is used in this study to signify the intermittently coupling of children’s bodies with a hemodialysis machine. Ihde
(1990, 1993) would argue that conjoined to the machine in this particular setting, children perceive their bodies and the unit from this vantage point. Hence, their responses to their bodies and the setting entail bodily, spatial and temporal orientations that are particular to the place where their technological conjoinment occurs.

Ihde (1990, 1993) also focuses on cultural embeddedness of technology. He claims that human-technological relations occur universally, however, the uses and meanings of technologies are culturally and socially embedded in specific times and places. Because “technologies ‘texture’ their own use as well as their users’ perceptions of reality and the social world” (Lupton & Seymour, 2000, p. 1852), the specific socio-cultural context both shapes and limits the uses and meanings of a technology. Hence, places and technologies have been conceived by me as co-constitutive.

In my study, Ihde’s (1990, 1993) perspective on technology was used to investigate the children’s perceptions and responses to their technological embodiment because it emphasizes embodied mediation through human-technological relations and their interrelations within social and cultural contexts. Figure 3 represents this conception of technology.
Figure 3: Perspective on Technology

The children’s embodied situatedness in the timespace of the unit

My perspective on children conceived them as embodied (Prout, 2000, 2005). In this study, I have taken the perspective that a meaningful relationship in and to a place “is intimately bound with the embodied nature of perception” (Massey, 2004, p. 8) and lived meanings and experiences (Manzo, 2003, 2005). This perspective also emphasized senses of belonging and the potential for dis/attachments to and in places (Manzo, 2003, 2005; Peter, 2002). In that places are given positive or negative meanings through interactions, activities, and events in that setting (Manzo, 2003, 2005), the notion of situatedness, or a “sense of place”, (Peter, 2002, p. 67) is considered a salient aspect of the hemodialysis unit. Situatedness refers to the range of perceptions, intentions, and values that individuals or groups give to specific places and their embodied comportments, behaviours and actions in them (Manzo, 2003, 2005; Peter, 2002). In this study, my intention was to determine how the children sensed, assessed, represented, complied with, navigated and created spaces and time in the unit, through bodily practices, language, social interactions, uses of material objects and spatial arrangements. The notion of embodied situatedness has been used to articulate their perceptions of and responses to the timespace of the hemodialysis unit. Furthermore, I have viewed the children’s embodied situatedness in the broader context of their temporal disruptions and socio-spatial dislocations from their everyday lives and their location in the trajectory of kidney disease and treatments.

Summary of the Conceptual Framework

Through merging perspectives of space, time and technology, I developed a conceptual framework through which to explore how the children’s perceptions of and responses to
hemodialysis are structured and interrelated in a pediatric hemodialysis unit. The hemodialysis unit was viewed as a place that produces a range of temporal, spatial and technological regimens and relations, and in turn, is constituted through and by them. A view of place where meanings and responses occur through situated embodied experiences and interactions, and in turn, places are made meaningful was employed (Manzo, 2003, 2005). The notion of embodied situatedness I drew on supported my view that the children perceive and respond to the timespace of the unit in multiple and meaning-making ways through their bodily senses, actions and words (Peter, 2002; Prout, 2000, 2005). Concepts of physical and social spaces facilitated my conceptualization of the unit as constituted by social relations and human-technological relations among providers and recipients of hemodialysis care as well as the physical setting (Andrews & Kitchin, 2005; Massey, 1994, 2004, 2005; Ihde, 1990, 1993). Adam’s (1990, 1995) and Felski’s (2000) perspectives of multiple and heterogeneous time in social fields informed my description and interpretation of children’s perceptions of time in the unit. Because Ihde (1990, 1993) posits that embodied perceptions are interwoven with technologies in specific socio-cultural contexts and technology and culture are mutually constitutive, his philosophy of technology informed my study. Finally, to conceive of interrelations among time, space and technology, I drew on May’s and Thrift’s (2001) claim that time and space are mutually constitutive of and constituted by interactions among cosmic/biological, social and technological domains. These interactions are conceived as producing the timespace of the unit. These perspectives are compatible because all emphasize embodiment, time, space, and technologies in places. They also are non-dualistic in that each conceives of persons and places as composed of interrelated natural-social, biological-technological and material-discursive processes.

Figure 4 combines each conception of the space, time and technology of the hemodialysis unit and represents the unit as nested in the broader contexts of children’s everyday places and
routines. Although the conceptions of time, space and technology are displayed individually for clarity, their overlap in the center of figure 4 illustrates children’s embodied situatedness in the merged set of concepts that comprise the timespace of the unit. My intent here is to graphically depict the relationships among the sets of concepts to facilitate understanding of my overall conceptual framework. However, I recognize that a diagram may represent complex and uneven phenomenon as ordered and static and therefore is limited in an illustrating a more dynamic and multifarious view of the conceptual framework that was used to inform my study.

Figure 4: Conceptual Framework of the Children's Embodied Situatedness in the TimeSpace of the Hemodialysis Unit
Research Questions

In order to describe and interpret the children’s embodied situatedness in the timespace of the pediatric hospital-based hemodialysis unit, my study posed the following questions:

Within their situatedness among the interrelations in the temporal, spatial and technological regimes and relations of the unit:

1. How do the children perceive and embody various senses of time?

2. How do the children perceive and occupy their embodied positions in the physical and social spaces?

3. How do the children perceive and respond to their technological embodiment?
Chapter III: Study Design and Methods

Study Design

The study design and methods were planned to capture detailed, rich descriptions of the experiences of children who received hospital-based hemodialysis. To reiterate, the purpose of the study is to describe and interpret the children’s perceptions of and responses to the temporal, spatial and technological regimens and relations of a pediatric hospital-based hemodialysis unit. Although the study has been anchored in the unit, the hemodialysis unit was conceptualized as nested in the broader contexts of their everyday lives.

I conducted an ethnography of a pediatric hemodialysis unit because I wanted to collect data though observing and interacting with children in the setting where their treatments take place. Ethnographies involve prolonged engagement in the places of those studied (Emerson, Fretz, & Shaw, 2001; Hammersley & Atkinson, 1995; Thomas, 1993; LeCompte & Schensul, 1999a; Patton, 2002). Thomas and Ahmed (2004) would contend that ethnographic methods are ideal for this inquiry into children’s embodied situatedness because of the “involvement in the spaces in which other bodies move and create their environments” (p. 2). Prolonged engagement techniques, such as participant observation, were crucial to generate ‘thick descriptions’ that enabled me to describe and interpret the array of meanings, interactions, practices, and events in the unit (LeCompte & Schensul, 1999a).

Ethnographies focusing on a variety of issues have been conducted in hospital settings since the 1960s. These include Tranter et al.’s (2009) ethnography of nurses in an adult hemodialysis unit, McGibbon and Peter’s (2008) biomedical technographic study of biomedical technology in a pediatric intensive care unit, Place’s (2000) study of children’s bodies and technologies in a pediatric intensive care unit, Bluebond-Langner’s (1978) study of children’s...
interactions in an oncology ward, Bosk’s (1979) study of how surgeons manage medical failures, Goffman’s (1961) study of patients in psychiatric institutions, and Becker’s (1961) study of how male medical students become physicians. Furthermore, ethnographic methods are popular in research with children because of the benefits that may be reaped. Ethnographers spend extended time with children in their everyday settings and most view children as invested and engaged in the places they occupy and in the research process (James, 2001).

Because my study took place in a single hospital-based unit for a predetermined length of time, it was a focused ethnography. Unlike the more open-ended scope of inquiry of traditional ethnographies and long-term field immersion, focused ethnographies have a predetermined focus, concentrate on specific interactions, situations, and activities relevant to the study, and consist of short-term, non-continual field immersion. Focused ethnographies also assume that the researcher has some background knowledge or is member of the field under investigation. As a nurse, I had previous knowledge about hemodialysis units. To augment the relatively short-term and non-continual field visits, I employed multiple methods of data collection (Knoblauch, 2005).

**Setting, Sampling, and Recruitment**

The study was conducted at a pediatric hemodialysis unit in Ontario, Canada. Prior to designing the study, I conducted preliminary field work and informally observed the unit over several months to become familiar with the setting. To gain access, I met numerous times with key contacts who provided their support and permission to conduct the ethnography. The study successfully underwent a scientific review and ethics review at the hospital where the study took place and an ethic review at the University of Toronto.
Sampling

Over the data collection period in 2006-2007, the sample who participated was comprised of 11 children, including five girls and six boys, who were between 7 and 17 years of age. This convenience sample included the majority of the population of children who received maintenance hemodialysis at study site during data collection time frames. The number of children receiving hemodialysis at any given time varies and is unpredictable. However, the study sample size was representative of the number of and the age range of children who typically receive maintenance hemodialysis in the unit. For example, in 2004, the number of children who were dialyzed each month ranged between 12 and 14 children whose ages were between 7 to 17 years. In 2005, the number of children who were dialyzed each month ranged between 7 and 13 children whose ages were between 7 to 17 years. In 2006, the number of children who were dialyzed each month ranged between 5 and 10 children whose ages were between 7 to 16 years. In terms of gender and age, the sample also is represented the unit’s population. The number of boys who received hemodialysis in the unit during 2004-2006 was slightly higher than girls.

Inclusion criteria

Children were invited to participate in the study if they: 1) were between the ages of 4 to 18 years of age; 2) were able to understand and speak English; 3) were receiving ongoing maintenance hemodialysis; and 4) had the capacity to give consent or assent. A broad age range was sought to ensure that a maximum number of diverse children had the opportunity to participate. However, I limited the study to children who were four years of age and over and who were able to understand and speak English to facilitate my engagement with and increase my understanding of their views and behaviours.
The sample size and strategies employed were consistent with ethnographic research that is concerned with information-rich cases in a single setting for in-depth study over time and used multiple data collection techniques per participant (Kuzel, 1999, Morse, 2000; Sandelowski, 1995). Also, Sandelowski (1995) contends that “in qualitative research, events, incidents, and experiences, not people per se, are typically objects of purposeful sampling” (p. 180). She suggests including about 30 to 50 observations or conversations in ethnographies. I investigated children’s perceptions of and responses to hospital-based hemodialysis by gathering information about difficult to measure aspects of their embodied experiences such as how they behaved, moved in and interacted in the unit and how they shaped the unit. This entailed multiple methods of data collection over three time periods, each about three weeks in duration with three different groups of children. Data collection involved numerous direct observations of children in the unit and the elicitations of each child’s self-identified, self-articulated impressions and views through focused interactions and guided activities. These strategies permitted the children to be studied in sufficient depth and breadth and allowed the data to be examined and interpreted from different sources (Stake, 1995, 2000).

**Recruitment procedures**

To facilitate awareness and provide information to patients, families, and staff about the study, two large, colourful signs were placed in the hemodialysis unit and waiting room. The signs included the study’s title and purpose, times of observation and how to obtain more information. I created a logo to identify the study to staff, families, and children and adolescents. This logo was used on information forms and consent and assent forms and on a large banner placed in the unit’s waiting room for the duration of data collection. This banner is depicted in Illustration 1.
All potential participants and/or their parent or guardian were initially recruited by a staff nurse in the unit who was known to them, but not involved in the conduct of the study. The nurses involved in recruitment were informed about the study and recruitment/consent procedures and provided recruitment scripts. These nurses had considerable experience working with children with chronic conditions who vary in age, abilities, and competencies and hence, had the ability to assess children’s capacity to consent. The nurse determined whether to first directly approach the child or the parent or guardian. If a child was approached, he/she was provided verbal information about the study when he/she was scheduled for hemodialysis. With his/her permission, I then was introduced to the potential participant in the unit at the time of his/her choosing to further explain the study and the consent/refusal process. If a parent/guardian were approached, the staff nurse introduced the study by providing verbal information and arranged a time for me to meet with the parent in the unit to further explain the study and the consent/refusal process. After the parent/guardian gave consent, I approached the child to provide information about the study and obtain assent. It is important to note that agreeing to meet with me did not indicate that the child and/or his/her parent/guardian had agreed to participate in the study. Verbal and written information were provided to the children and parents
or guardians that included the study’s purpose, procedures, nature of participation, benefits and risks, and measures to protect the study group’s confidentiality and anonymity. My identity, affiliation with the university and contact information and that of my dissertation supervisor and the site’s principle investigator were provided. See Appendix A: Recruitment Tools.

**Consent procedures**

Consent or assent was sought from the children who met the study criteria and/or their parents. Written consent was obtained from participants able to give consent or a parent if the child was deemed unable to give consent. Participants unable to consent signed an assent form. Before a child was asked to give assent, a parent was approached for consent. Children and/or their parent/guardian were assured that participation or non-participation in the study would not affect their services and care provided by the hospital.

Each child’s capacity to consent was determined by me as a nurse in consultation with the staff nurse at the unit who initially had approached the child. If the child chose to participate and was determined to have the capacity to understand the study, their decision, and the consequences of their participation, he/she was asked to sign the consent form. If the child was determined not to have the capacity to consent, one parent or legal guardian first was asked to sign the consent form and then the child was asked to sign the assent form. The consent or assent forms were read by and/or to each participant and/or parent and guardian and the purpose of the study and requirements for participation discussed. Any questions were answered to the satisfaction of the children and parents. All children and/or parents/guardians who were approached agreed to participate in the study and no situation arose in which a parent consented and a child refused to participate. A separate consent form was used to obtain written consent
from each child and/or one parent or guardian for audiotaping a child-directed unit tour. See Appendix B: Consent and Assent Forms.

As per the hospital’s protocol, a copy of each participating child’s signed assent and/or consent form was provided to the Health Records Department and retained in the patient’s health record. To reduce the number of times each participant and/or his/her parent/guardian had to sign the consent forms (i.e. one for the participant and/or parent/guardians, one for the researcher, and one to be filed in the patient’s health records), the consent forms were printed on carbon copy paper in triplicate.

Consent and assent was considered to be an ongoing process (Barker & Weller, 2003b). All participants were told that they were free to refuse to answer any questions that might arise in conversations, withdraw from any activity and keep any chart, drawing or writing produced in the course of the study or withdraw without explanation at any time. Before every activity, each child was told about its purpose, asked if he/she would like to participate and verbal agreement was obtained. I recognized that at times children did not want to be observed or to talk. They were reminded that they could ask me not to observe or interact with them at these times. Although no child refused to be observed, they occasionally did refuse activities and conversations at times that they were uninterested, not feeling well or tired. Children’s refusal especially occurred when I suggested pre-planned activities designed to elicit data from them and instead they spent time on their own or suggested more preferred activities.

The results of this study indirectly may benefit participants by contributing to knowledge of children’s understandings of the unit with its attendant treatments. A summary of the results will be available to participants, their parents/guardians and unit staff. Participants and/or guardians were asked to indicate on their consent forms if they would like to receive a summary. All participants and parents indicated that they wished to receive a copy through mail. The
mailing or email addresses or telephone numbers of these individuals have been recorded in a password-protected computer file.

Because the study focused on children’s experiences, observations of staff only occurred when they interacted directly with the children. Hence, consent was not obtained from directly the unit’s nurses and other staff members. However, the unit manager gave overall support for the study and the staff were informed of and were involved in supporting the study. As with the children, I recognized that staff members would not want to be observed during some interactions with and care of the children. They were made aware that they could request not to be observed at these times. During the study, the staff did not ask me not to observe or document any such interactions.

**Data Collection Techniques**

**Study time frames**

I engaged in participant observation strategies that constitute the hallmark of ethnographic methods (Patton, 2002). Taking the advice of Hammersley and Atkinson (1995) to ensure my data collection sessions were representative of children’s everyday experiences, I spent discrete and non-continual time frames in the unit. Each time frame was three weeks in duration. Thus, data collection involved immersion in the hemodialysis unit for a total of nine weeks. During each time frame, I observed in the unit at least three days a week, up to five hours per day. Hence, I spent at least 15 hours a week in the unit and observed each child undergoing nine or more hemodialysis treatments.

The first time frame occurred in November and December 2006 over the winter holiday, the second in February and March 2007 over the school mid-winter break and the third in August
and September 2007 during the summer school break and start of the school year. These three time frames were chosen to enable me to observe and determine the effects of social timetables, such as the school year and significant holiday times (i.e. Winter holiday, New Year, spring break, the beginning of the school term), on the children who must receive hemodialysis in the unit at least three times a week, regardless of other occurrences and events in their lives. The third time frame was delayed, however, because the numbers of children receiving hemodialysis at the study site decreased drastically during the spring and summer of 2007.

The ordering of the weekly pattern of observation during each time frame was determined with unit staff members and was scheduled to coincide with the largest number of children who agreed to participate per hemodialysis shifts. The plan followed children’s treatment cycles of receiving hemodialysis about three days a week, for three to four hours each day. It also followed the unit’s three hemodialysis shifts per week that are each about three or four hours in length. Children typically received hemodialysis in the morning or afternoon on Monday, Wednesday, and Friday or Tuesday and Thursday afternoons and Saturday morning. On Tuesday and Thursday mornings, children were booked in the unit for acute hemodialysis or apheresis. These children did not meet my study inclusion criteria.

To facilitate engagement as many participants as possible, I endeavoured to follow groups of children who were undergoing different treatment cycles. That is, in one time frame, I planned to follow the children who received hemodialysis on Monday, Wednesday, and Friday mornings and in the second time frame, I planned to follow the children who received hemodialysis on Monday, Wednesday, and Friday afternoons. In the third time frame, I planned to follow those who received hemodialysis on Tuesday, Thursday, and Saturday. Hence, different groups of children on different shifts would be followed in each of the three time frames. However, although children for the most part follow the hospital-scheduled three hemodialysis shifts, there
were exceptions. For example, during the winter holiday period during the first time frame provided an ideal opportunity to engage with seven children because the treatments shifts were altered and condensed to accommodate staff breaks. During this period I spent up to five hours a day from Monday to Saturday in the unit with the children. During the second time frame, I observed Monday, Wednesday, Friday and Saturday in the unit in order to follow an adolescent who received treatments 4 times a week and another adolescent who received treatments only on Saturdays. In the third time frame, I followed two adolescents two or three days a week who had irregular schedules.

**Data collection strategies**

My participant observation strategies involved structured observations, focused interactions, and guided activities with children. These techniques were designed to interface and inform one another in order to address the research questions (Morgan-Ellis, et al., 2006). This multi-method data collection fit well with a focused ethnographic approach as it supported sampling through my non-continual, short-term engagement in the field. See Appendix C1: Data collection tools: Schedule for participant observation.

I anticipated that some children could find it difficult or uncomfortable to talk about their experiences of kidney disease, hemodialysis and the unit. Hence, efforts were made to minimize discomfort that arose from participation and to accommodate children’s needs during participant observation sessions. I stressed to the children, verbally and in the consent form, that they did not have to talk, answer any question, or partake in any activity that made them uncomfortable for any reason. Furthermore, all children were encouraged to terminate any conversation or activity without explanation at any time. Because the effectiveness of some of the focused interactions (emotion stamps) and guided activities (drawing and writing exercises) is derived from how they
allow emotions to be expressed through reflecting on their bodies, emotions and situations, I endeavoured to be physically present in the unit with the children as they did these activities. Participants also were made aware that they could talk with me at any time. Prior to the end of each study time frame, I asked each participating child what impact the study had had on them. In addition, I had ensured that it would be possible to refer children to a staff nurse, the clinical unit leader or the social worker if needed. I hope that this study provided the opportunity for the participants to explore and clarify their perceptions of and responses to the unit. Thus, they may be better able to understand and evaluate the effects that hemodialysis has upon their bodies and everyday lives.

In data collection periods, I did not disrupt participants’ treatments and care, school work or other activities in the unit. If a child was not feeling well, he/she was not invited to take part in interactions or activities. Because children who were ineligible or not part of the study received treatments in the unit during data collection time frames, I did not observe or document any activity pertaining to them and worked with staff to ensure that my presence did not disrupt their treatments. Any child who was not a participant was able to pull curtains around their stations for privacy or could be dialyzed in a private room rather than the main treatment area that was the primary site of the research. The children’s health records and charts were not reviewed in this study.

*Structured observations*

My main focus was to determine each child’s embodied situatedness in the unit, that is, how he/she perceived hemodialysis and responded to the unit’s time, space and technology. See Appendix C2: Data collection tools: Structured observation criteria guide. To gather information about children’s treatment context, I document my observations of the unit’s physical and social
spaces, temporal routines and events and human-technological relations pertaining to each child as was consistent with my conceptual framework. I observed and documented each child’s movements, postures, how he/she spoke about his/her activities and interactions with other children and the nurses, teachers, volunteers, technicians and nephrology fellows. To gather a multidimensional view, I described and mapped the physical, spatial, and social layouts and aesthetic and architectural details and described the general ambience of the unit (i.e. smells, sounds, comfort, functions, appeal). Digital photographs of the unoccupied unit were taken. Structured observation was extremely useful because allowed me to observe the children in the context of the unit and ensured that my data collection did not solely rely on children’s reports that often took place in a noisy, busy unit with staff nearby in hearing range.

**Focused interactions**

I engaged in many child-initiated conversations and in the everyday activities that the children typically engaged in while receiving hemodialysis, such as watching television, videos, or DVDs, playing games, doing crafts or talking with others. I brought in a large amount of materials that I hoped would appeal to the children, such as arts and craft supplies, coloured paper, toys, emotion stamps and books. In addition, I brought hundreds of stickers that children could use on their artwork. In particular, one collection of stickers were comprised of representations of time, including clocks, butterflies and sayings, such as *a moment in time, time flies, captured in time, timeless, time marches forward, where has the time gone and time stands still*. Activities the children and I did together included making holiday gingerbread houses, collages, drawings, charts, constructing beadwork art and creating and decorating clocks.

Typically, I spent between 20 to 90 minutes with one child at one time engaged in an activity. Time spent was determined by each child. For example, if a child was unwell or did not
want to talk, I did not engage with that child or stopped engaging when the child chose to do so. I did not disrupt children’s care or educational studies. To learn about the children’s perspectives, I engaged them in discussions and asked questions based on the research questions. Some of the activities involved art and/or illustrations and with children’s permission their work was photographed their work before they took it home. All children were agreeable to this. My conversational style and questions were adjusted according to each child’s characteristics, style of communication (i.e. verbal abilities), level of comprehension, willingness to interact and the context. After interactions, I reflected on how different children responded to my inquiries and our conversations so that I could adjust topic areas and/or my wording of questions. Appendix C3: Data collection tools: Focused interaction guide.

Demographic information using a form also was elicited from each child. During conversations, I recorded information and any information that was not revealed spontaneously was asked of each child. In the case of two children who were not able to provide the necessary information, I spoke with a parent or sibling. See Appendix C4: Data collection tools: Demographic collection form.

In tandem with my structured observations and focused interactions, extensive fieldnotes were taken. Recorded in close proximity to the unit, they were a core activity of this ethnography and constituted the original text for analysis. Fieldnotes included my descriptions, impressions, emerging questions and reflections, and commentaries. They were structured using Bogdewic’s (1999) agenda that includes describing: who (and what) is present; what is happening; when does the activity occur; where is it happening; why is this happening; and how is this activity organized. Thus, my documentation included what and where various interactions and events were occurring and who was involved as well as why and how. All fieldnotes were transcribed
into a computer, reviewed, reflected upon and refined as soon as possible after periods of participant observations.

Initially I planned to document using a laptop computer in the unit. After recognizing the intrusiveness of extensive note taking within the unit early in the study, I carried a pen and small notebook in my pocket. In the unit, I recorded initial fieldnotes through handwritten jottings (i.e. keywords, phrases, drawings) or small notes to be detailed more extensively later. During observation periods, I also went to into an unoccupied hallway or private office to record more descriptive notes using a laptop computer or tape recorder. These fieldnotes formed the basis for in-process summaries and memos that are more sustained analytic and interpretive writing outside of the field (Emerson, Fretz, & Shaw, 2001). Because children provided so much rich information, I found it challenging at times to remain patient until it was possible to leave the child’s presence to record the data in more detail. This often occurred as more in-depth talk or observations tended to take place when I was engaged in an activity with a child. To maintain a record of my field work, a diary recorded the planning, decisions, reviews, appointments, dilemmas, personal reflections and time spent in the unit (Bogdewic, 1999).

**Guided activities**

This research involved working with children who had varied verbal and writing skills. It was challenging to establish communication and encourage them to set the data collection agenda. It also required providing opportunities “to handle things rather than just talk” (O’Kane, 2000, p. 137). A number of researchers have advocated an integrated approach that draws on both visual and word-based data collection techniques to explore the multiplicity and complexity of the bodily and social realities for children living with illnesses (Guillemin, 2004; Pridmore & Bendelow, 1995; Punch, 2002). I used such techniques and considered them both a “product and
a process” of how children construct meanings about hemodialysis and the unit (Guillemin, 2004, p. 273).

I initially planned to use four guided activities to enable children to express their perspectives and to gather information not directly observable or obtainable through conversations (Hammersley & Atkinson, 1995). I recognized that many of the children had challenges in participating in these activities because of other demands on them and diminished energy during treatments. On the other hand, some children welcomed these activities while conjoined to a hemodialysis machine for about three to four hours during treatments. Following Hill’s (2006) suggestion that children are able and willing to be consulted on research methods, they were asked what activities they liked or disliked and how activities might be changed to better suit them. They also were asked what activities they thought might help them share their views with me. I discovered that the number of planned activities occupied too much of children’s time and that some were not well liked by the children or were not useful to answer the research questions. Hence, I discarded one planned activity entirely that was called B-Me and focused on how children physically feel during hemodialysis treatments. I focused on three types of activities and reduced the amount of participation required from the children. The three guided activities are described below. In “Appendix C5: Data collection tools” the procedures of these activities are provided in more detail.

All participating children were offered the opportunity to engage in these activities. To develop trust and build rapport, I introduced them near the end of the first week of an observation period after I had spent time getting to know the children and they had time to get to know me. Each activity was conducted during or just prior to the children’s hemodialysis treatments and I provided all materials for the activities. Before each activity, each child was told its purpose and procedure and offered the choice to participate or withdraw at any time without
explanation. During the activity, they were asked to reflect and elaborate on their meanings and the context of their created art and/or illustrations. Fieldnotes were recorded to capture children’s engagements in and feedback about the activities.

Activity # 1

Charts and Maps: To elicit data about how the children accommodated and negotiated hemodialysis regimens in their everyday lives, each child was invited to participate in a chart activities described by Barker and Weller (2003b) and Christensen and James (2000). In a study about children and time, Christensen and James (2000) used charts and diagrams to explore children’s perceptions and use of time, for example how they spent time during the week, meanings attributed to their time, and differences and similarities among children. Other researchers have found that map-making activities lead children to explore, evaluate, and talk about places and things that are significant to them (Barker and Weller, 2003b; Clark, 2005).

Place and time charting were planned to be conducted in week one of the data collection time frame because they provided a way for me to learn about the children and for them to learn about me. The purpose of this exercise was to document places and times on hemodialysis days and non-hemodialysis days. Three children decided to participate in this activity. During and after the activity, they were encouraged to share their thoughts about the places, times, and activities that they had chosen to illustrate and how they accommodated and negotiated hemodialysis regimens in their everyday lives. To demonstrate the map-making activity and provide an opportunity for children to know me, a map that represented the places and times in my everyday life was shown and described.
Activity # 2

*Drawing and/or writing exercises:* To elicit data to answer the research questions about how they perceive and respond to the unit, the children were invited to engage in drawing and/or writing activities. These activities that incorporated drawing, writing, and talk have been used extensively to explore children’s and adults’ perceptions of health and illness (Bendelow, Williams & Oakly, 1996; Guillemin, 2004; Pridmore & Bendelow, 1995, Punch, 2002; Williams & Bendelow, 2000). For instance, Pridmore and Bendelow, (1995) used the ‘draw-and-write technique to explore beliefs about cancer and about health and illness among 100 primary school children in urban centers in England and the perceptions of health among 111 school-aged South African children. To determine how 37 rural-dwelling school-aged Bolivian children negotiated independence, Punch (2002) asked them to draw aspects of their home and community lives. According to Barker and Weller (2003b), drawing works well with children because it allows them to express and communicate freely, especially children with low literacy skills. They add, however, that older children may view drawing as inappropriate because they view writing as a more legitimate form of communication. Punch (2002) claims that drawing works well because it allows children to think about, plan, and change their responses. In addition, drawings may allow the children to reflect on and to express feelings and thoughts that may be challenging to discuss verbally (Barker & Weller, 2003b).

Draw and/or write exercises were conducted in week two of the data collection time frames. Interested participants were asked to choose to draw pictures and/or write about topics pertaining to their perceptions of the unit and hemodialysis treatments. I had developed five specific topics that are described in “Appendix C5: Description of guided activities”. Of the five topic areas, the six children who participated elicited to do only two topics about what they liked the most or the least about the hemodialysis unit. They did not want to engage in the topics
related to what the best or worst thing is about being a girl/boy in the unit and the hemodialysis machine. Following Punch (2002), I encouraged them to elaborate on what they had written or why they decided to draw a particular image and what it meant to them. To gather data about additional interests or concerns, the children also were asked to spontaneously draw or write about any aspect of themselves, having hemodialysis, or the unit (Punch, 2002). Many participants who engaged in spontaneous drawing or writing tended to draw and decorate their name or make pictures representing holidays, such as Christmas or Halloween.

Activity #3

Child-directed unit tours: To elicit data about how the children view the unit, they were given the opportunity to conduct a unit tour with me. This activity was adapted from Clark (2005) who used walking tours to encourage children to convey their thoughts and feelings about a childhood centre on a university campus and from Adams, Theodore, Goldenberg, McLaren and McKeever (2010) who used walking tours to gather children’s experiences about a pediatric hospital lobby to compare with the intention of architects. Because Clark (2005) suggests that having a rapport with children facilitates this activity, unit tours were conducted in week three of the data collection time frames. However, the children were told about the activity in advance so they could plan the tour. Each tour was individual, approximately 8 to 15 minutes in length, and took place immediately before hemodialysis when the children waited for their treatment to begin. On the tour, I asked the children to share their views about the unit, such as where and how they spend time, what they liked and disliked about the unit, and with who, what, and how they interacted in the unit. The children wore a clip on microphone to record their comments that were later transcribed. The staff were consulted about tour timing and any areas or objects that were restricted. Eight children participated in this activity.
To acknowledge each child’s participation in the study, a Certificate of Participation and a modest thank you gift comprised of a gift certificate for a sports, music, toy or accessory store was given to each child at the end of the period of data collection. The gift certificates were tailored to each child after I had gotten to know him/her and had a value of $20.00. See Appendix D: Certificate of Participation

**Data Management**

Collected data included textual data (transcribed observational and children’s unit tour data) and non-textual data (researcher-generated maps, digital photographs of the unoccupied unit, children’s art and/or illustrations). Non-textual data were scanned or photographed if possible and appropriate (i.e. children’s art and/or illustrations), recreated through a graphics program (diagram of the main area of the unit) or stored (digital photographs) and analyzed. Written summaries were prepared of the non-textual data to transform them into text that then were analyzed with the other textual data sources using a word-processing program. Observational data (fieldnotes) and children’s audiotaped unit tours were transcribed by me and a trained transcriptionist. I reviewed and edited the latter to ensure their accuracy. Textual data and summaries were imported into ATLAS.ti, a qualitative software program. ATLAS.ti facilitated the data management and allowed for storage. Attachment of codes to data segments and their retrieval and display allowed data segments to be compared within and between the data (ATLAS.ti, n.d.; Brewer, 2000; Fielding, 2001).

Measures to safeguard the research data were implemented. After the observational data (fieldnotes) and audiotaped unit tours had been transcribed and entered into the ATLAS.ti program, the audiotapes and written notes were destroyed. Data were backed up on computer disks. These and consent or assent forms have been stored in password-protected computer
folders/files or in a locked storage file in my office. Only my dissertation supervisor, the site’s principle investigator and I have access to these materials. Data will be stored by me with the steps taken to ensure security and confidentiality until after the completion of the study and publication cycle when it will be shredded.

Measures have been taken to ensure the anonymity of the participants and the research setting. Protection of the children’s anonymity and privacy has been of paramount concern. Privacy and confidentiality have two aspects: social network confidentiality and public confidentiality (Hill, 2005). Social network confidentiality necessitates concealing identifying information gathered about individual children in inter-participant interactions and with other children, health care providers, family members, guardians, or others associated with the children in the course of the study. The structured observations, focused interactions, and guided activities took place in a unit occupied by other children, staff, and parents. I emphasized to children that they could stop responding to conversations or terminate any activity if they felt that their privacy was at risk at any time. Staff and parents occasionally needed to be reminded that activities and conversations between a child and me were private. During data collection, I suggested to children that we could, if they wanted, have some privacy during conversations or activities by pulling the curtain around the hemodialysis station. However, the children did not choose this option.

Public confidentiality will be maintained by the use of pseudonyms rather than children’s own names on all research materials, except for a locked master file that links the participants to their pseudonyms. Also, on any documents or illustrations that included names, these names have been removed or hidden. Any names that cannot be removed or hidden will not be reproduced for study purposes. Some generalizations about participant demographic identifiers have been used to protect their anonymity. For example, specific diagnoses are not linked to
individual children. Finally, in any public document about the study and/or findings, the names of the hospital, unit, the children or health care providers will not be released.

**Data Analysis**

Framed by the conceptual orientation to children’s embodied situatedness in the time, space and technology in the hemodialysis unit, the analysis of all data were conducted to answer the research questions. This involved thematic analyses of patterns of how the children perceived and responded to their technological embodiment in the unit’s timespace. Data also were analyzed for patterns of how the children accommodated and negotiated hemodialysis regimens in their everyday lives. Examination of differences and similarities among children’s perceptions of the ramifications of hospital-based hemodialysis was conducted. The interpretation attended to the assumption that data were produced amidst powerful discourses pertaining to gender, children and institutionalized and technological biomedicine and nursing. The analysis contributes to the concepts of embodied situatedness, time, space and technology through evaluating, refining, and revising the conceptual framework in light of the empirical evidence.

Typically in ethnographic research, data analysis is conducted concurrently with data collection (Brewer, 2000; Hammersley & Atkinson, 1995; Wolcott, 1999). Data were collected in three short-term, non-continuous time frames from three groups of children. The concurrent process was facilitated by the time gaps between the three data collection time frames. It also was facilitated by my plan in which I observed in the unit followed by one or two days when I was not observing in the unit. Concurrent data collection and analysis facilitated an iterative process that allowed new information to be investigated in subsequent participant observation and the interpretation, evaluation and revision of the developing themes and patterns (LeCompte & Schensul, 1999b).
My general analytic procedures were based on the ethnographic methods described by Wolcott (1994). Wolcott (1994) provides a general framework to analyze ethnographic data through a series of three distinct, but intertwined and sequential, processes: 1) description; 2) analysis; and 3) transformation. Because all three processes entail selectivity, organization, analysis, and focus, they are viewed as interpretive.

**Description**

Description remained closest to data as originally recorded and entailed the compiling, organizing, and condensing of data and writing of contextualized summaries based on field note observations of the time, space, and technologies of the hemodialysis unit and each child’s perceptions and responses in the unit (Wolcott, 1994). This process involved a funnelling approach in which data were progressively focused and reduced (Hammersley & Atkinson, 1995). This process began early in the research process and continued throughout the data collection and analysis so that the data were reduced, enriched and revised.

Morgan-Ellis et al. (2006) remarks that data, generated by different sources that are analytically integrated, result in findings that generate multiplex insights about the phenomenon under study. Multiple data sources (fieldnotes, children’s illustrations, researcher-generated maps and photographs) were examined for how they corroborated or opposed one another (Brennen, 2005). In regard to children’s art and/or illustrations, Barker and Weller (2003a, 2003b) and Guillemin (2004) contend that issues of meaning and interpretation are critical because the researcher can confer their own assumptions and misconceptions on the images. The children’s descriptions of the meanings attached to their illustrations have been included in the data analysis. Hence, the children’s data were comprised of both the images and children’s interpretations. Comparisons were made among the participant’s images and verbal accounts and the context. In addition, my descriptions of the unit, the researcher-generated maps and
photographs were explored for contextual information about the unit’s physical, social, aesthetic, architectural and ambient features. Simple descriptive analysis of picture jottings, maps and photographs pertained to their contents, functions, colours, and scale. General observational data pertaining to the time, space and technology of the unit and summaries of photographs have been used to further provide context to children’s experiences and analyzed in regard to the influence of the unit on their perceptions and responses.

**Analysis**

This process focused on systematically identifying the essential features through coding and indexing the data pertaining to all participants, drawing inferences and describing interrelationships among them (Wolcott, 1994). Data were analyzed using a flexible coding system and reflective memos were written to record insights and propositions about the data relevant to the analysis. The analysis was largely deductive because the initial categories and codes were based on the research questions that are consistent with the conceptual framework. Inductive coding, where codes are drawn from the data, also was used to identify new insights and unanticipated findings to ensure the analysis was comprehensive, generative, and reflective of the participants’ perspectives.

A coding scheme was developed across data sources and codes combined, revised, added or deleted throughout the analytic process. Initial broad-based categorizes of codes were organized by the study thematic areas of time, space, technology. Codes that seemed not to fit (i.e. body image) were included in an *other* category. Data within each larger category of time, space and technology were coded (i.e. passing time, marking time, relating to the machine) and organized or removed so that the coding became more refined. New codes emerged through the data collection period and were added as the analysis proceeded. Multiple coding cycles
facilitated the identification of patterns, reoccurring relationships and conceptual congruence of the relationships among codes (Brewer, 2000; LeCompte & Schensul, 1999b; Wolcott, 1999).

**Transformation**

This process was concerned with drawing of and substantiating broader conclusions about the phenomena under study (Wolcott, 1994) by examining the emerging interpretation in terms of the research questions and theoretical concepts of embodied situatedness, time, space and technology. Data within codes and categories were analyzed for how they elaborate upon, complement or contradict in order to generate a complex, multifaceted view of children’s experiences and to gather multiple perspectives or realities. Reoccurring concepts were identified (e.g. technology as a driving force) across the categories (Brennen, 2005; Hammersley, 1992). Following this process, data were organized into themes. Data transformation was considered complete when the conclusions were logically consistent, incongruences accounted for, and alternate interpretations were explored, integrated or rejected (Brewer, 2000; LeCompte & Schensul, 1999b; Wolcott, 1994).

**Analytic Rigor and Quality**

Several procedures to ensure analytic rigor and quality were integrated into the study design and analytical processes. These procedures included a reflexive approach, triangulation and transparency that are described below.

**Reflexivity**

Postmodern and critical theorists have highlighted the ethical, political, and methodological implications of ethnographic studies and the need to be sensitive to issues of power, researcher
roles and responsibilities, problems of distanced and totalizing representations of others and the authenticity of the research outcomes (Denzin, 1997; Olesen, 2000; Patton, 2002; Sandberg, 2005; Van Loon, 2001). In research with children, James (2001) highlighted that the powerful status of the researcher as an adult is a central issue. Taking the stance that these issues are critical, I endeavoured to take a reflexive approach in the conduct of this research. Reflexivity refers to a critical and dynamic self-awareness, especially regarding the effects of the researcher upon the research process and product (Finlay, 2002, Finlay & Gough, 2003; Ballinger, 2004). Efforts to address, enhance, and mitigate the effects of being a female adult researcher and nurse included reflecting on my assumptions about children and childhood, nursing practices in hospitals and how to maximizing children’s expressions of their knowledge of receiving hospital-based hemodialysis. My reflections also included considering what kind of adult I would be in the unit. I endeavoured to appear to be an adult without authority over the children, unlike the nurses might be, so that the children could be more accepting of me. Rather than spend time with the nurses or occupy the areas adults tended to be, I stayed with or close to the children, so that my time and place in the unit was similar to theirs.

My assumption is that study findings are not discovered in the data but are shaped by interactive, contextual, and interpretive processes throughout all phases of the research process. Embedded in my reflexive approach was the assumption that the participants and me encountered and interpreted the unit from different locations and perspectives mediated through our situated identities, such as social status, gender and age (Ballinger, 2004; Denzin, 2001; Patton, 1999, 2002). As an ethnographer, I occupied a curious position as both insider (by my presence and my nursing identity) and outsider (by my relative lack of knowledge about dialysis care and mutual strangeness) (Ahmed, 2004). I viewed these juxtapositions as valuable because they enabled me to foreground relevant observations and issues, such as that of the sounds of the
unit. Affirming my situatedness was “an active acknowledgement of and participation in the construction of ‘sense’ in everyday life settings” (Van Loon, 2001, p. 281). Ongoing exploration of how intersubjective dynamics affected the research occurred throughout all phases of the study (Finlay, 2002, Finlay & Gough, 2003) and was documented in a field diary.

**Triangulation**

Some researchers argue that triangulation of ethnographic findings can establish the *truth* through the convergence on a single interpretation using different measures, such as the data sources, participants, and investigators (Angen, 2000). This view however, implies an objective knowable reality upon which techniques can converge. Rejecting this epistemological claim, others, for example Morgan-Ellis et al. (2006), suggest that triangulation techniques may be used to capture the complexity and different dimensions of a phenomenon. This was the view of triangulation to which I ascribed. In my study, triangulation pertained to the techniques outlined by Patton (1999): 1) methods triangulation that entailed using multiple means of data collection such as observations, focused interactions and guided activities; 2) triangulation of multiple data sources, such as fieldnotes, children’s illustrations and unit tour transcripts, in order to capture multiple perspectives and situations. This also ensured recognition of how different forms of data complemented or conflicted with one another (Brennen, 2005) to generate a more multifaceted and complex interpretation; 3) theory/perspective triangulation that involved the comparison of my findings with those of other studies and pre-existing knowledges; and 4) analyst triangulation that entailed extensive discussion, but not necessary corroboration, among the research team. Coding schemes, emerging patterns and themes, and corresponding data were discussed with my dissertation supervisor(s), committee members and a senior Nurse Practitioner/Clinical Nurse Specialist in the Nephrology Department. During the periods of participant observation in the
unit, I periodically checked preliminary findings, for example, how the children’s noticed time passing in the unit, with the participating children through informal conversations (member checking) during participant observation periods. On occasion, I also discussed my early findings with the hemodialysis unit staff members to garner their feedback.

Transparency

Research transparency entails an in-depth and detailed disclosure of processes (Ballinger, 2004) to enable public evaluation of a study’s plausibility, value and relevancy. To meet this criterion, an audit trail of my reflexive journaling and a systematic record of research decisions and how data were collected, maintained and interpreted was undertaken. Wolcott (1994) and Ballinger (2004) suggest that when claims to interpretations are made, the link to the data should justifiable. The grounds I used for interpretation were detailed with examples from different stages of the data processing, for example, how the raw data was processed by description, analysis and transformative procedures into final interpretations. Importantly, thick accounts of the participants’ views and the technologically driven context are included in the study findings.

Issues and Limitations of Ethnographic Methods in the Hemodialysis Unit

Engaging with children in the unit

There are a few significant aspects of the children’s and my interactions that required ongoing thought, monitoring and a changed approach on my part. Learning how to interact with each child so that he or she felt comfortable and enjoyed my presence was a careful and thoughtful process. However, although some children easily accepted my presence, others appeared to be somewhat unsure of my intentions during our initial encounters. I reflected that perhaps some children may have considered me an adult similar to those in the unit or hospital.
who interact with them because they are administering treatments, eliciting information or prescribing the responses they desire from them. For one child in particular, any request that seemed to be information-seeking on my part was met with refusal or withdrawal and she clearly indicated what topics of conversation were off limits. In these cases, I tended to ask little of the children until they were more familiar with me and tried to take their cues as to when they felt comfortable to talk or do an activity. Also, an important and effective interactive quality that I endeavoured to develop was to make a comment rather than ask a question in order to elicit information or begin a conversation (Snow, Zurcher, & Sjober, 1982). For example, rather than asking children what they thought about the hemodialysis machine’s noise, I would comment on the sound in a neutral way.

The children also had a variety of other responses to me. Some were very eager and helpful when asked questions or to do an activity. For them, teaching me about their experiences in the unit was taken very seriously. In contrast, some children were not interested in aspects of the study activities, but clearly seemed to like watching television, playing games or socializing with me. Because an important aspect of the study was that of children’s ongoing consent in their participation in the study activities, the children who did not want to engage in study activities were not pushed. I came to realize that my guided activities, although created to be enjoyable, could feel like school work to the children so that some chose not to participate in them. These activities were not as interesting to the children as I had hoped. Also, I considered that I also was one of the few adults in the unit that included parents, nurses or doctors, to whom they could say no to when they did not want to do something. At times, however, children were agreeable to a trade off in which they would do an activity with me and then I would do something they really enjoyed, such as a board or video game.
Initially, my own as well as some of the staff’s assumption was that children would be unoccupied and bored with little to do for a three to four hour period and would welcome a person that was solely focused on them. However, I quickly discovered that most children had established preferred ways of spending time and had developed their own customary routines. Hence, I had to adjust to children’s own routines rather than impose my own. Also, although kids spend a lot of time in the unit tethered to a machine, my difficulty in spending time with them was surprising. The children were frequently and intermittently disrupted while having a treatment, so they often appeared to swing between being busy and then unoccupied and bored. Furthermore, children also often do not feel well as their treatment progresses and may become ill at the end of their treatment or they would be ill with a cold or the flu. I found I had to develop patience and flexibility as well as carefully watch and be present for times when I could spend time with them.

Because of the above issues, a limitation of my ethnographic methods resulted in a data set of children’s guided activities that was uneven. In total, only three of the 11 participants completed a place and time map and six completed a draw and/or write activity. Of these participants, three children completed both a place and time map and a draw and/or write activity. In some contrast to my planned guided activities, a clock decorating or making project was somewhat more popular as six participants engaged in this activity with me. The children were able to take home their finished project. I anticipated that this process would be an effective way to initiate a conversation about children’s sense of time. One boy engaged in a clock making project. In practice, this process was complicated and fully engaged my own and the participating boy’s attention. During clock decorating projects, the four girls and one boy who participated were not interested in talking about time, focusing instead on their creative process. The unit tour proved to be the most popular activity as eight children participated. Of the three...
that did not participate, one was unable due to language and cognitive abilities and the other two refused. In general, the focused interactions proved to be the best method of spending time with the children and learning about their experiences in the unit from them.

**Engaging with nurses in the unit**

Although I engaged with all staff members at times, my interactions with the nurses was the most complex. Because I am a nurse, I found that the nurses engaged with me in a collegial and friendly manner. I believed that I sometimes was viewed more as a nurse than a researcher. For example, at one point during data collection I was asked by the unit manager to report back to her after I spent time with a child who appeared not to be feeling well emotionally. I also seemed to be seen as an extra pair of hands that could be called upon to help out with some unit tasks. On one occasion I was asked to take on a project of investigating and creating a list of movies appropriate for children and adolescents so that the unit’s supply could be replenished. Predominantly, however, I believe I was viewed as a person who could occupy the children’s time, thus decreasing the nurses’ need to respond to the children’s requests that they spend sociable time with them in activities, such as drawing or talking. Because there no longer was a child life specialist in the unit, the nurses may have been trying to fill this gap. Because I was endeavouring to establish myself as more of a companion than an authoritative adult or nurse to the children, being viewed as more of a peer and a colleague among the nurses was a source of tension for me. I tried to mitigate the tensions by spending time with nurses before the children arrived for a treatment cycle. I also remained in the vicinity of the children who were in the corners of the room where the hemodialysis stations are rather than in the staff meeting/lunch room or at the administration desk where the nurses usually resided.
A major ethical issue related to doing ethnography in the open space of a busy hemodialysis unit with children occurred. I found that on occasion children did not seem to be able to freely speak with confidence that their comments or conversation would not be overheard by staff, particularly the nurses. This occurred, for example, on one occasion during a guided activity when a participant was describing to me what he liked and did not like about the unit while I recorded his opinions. He was explaining that he felt that some of the nurses did not listen or respond to his needs and requests. As we were finishing this activity, a nurse appeared and directly asked what the boy had said about the unit. He panicked as I quickly made a joke and changed the subject. This participant was reluctant to continue talking and our activity was shortened. On another occasion while a participant was engaged in a draw and/or write activity about what she liked about the unit, a nurse laughingly commented that the participant should not forget how much she liked the nurses. This participant immediately included that she liked the nurses and doctors in the unit. This statement may have not been part of her intent in the activity. Although most times, nurses were careful not to intrude on interactions and activities, the occasions they did interrupt altered the timing and outcome of my encounter with a child. Because of this, I found that as I had to be mindful of securing children’s privacy by stopping an activity, changing the conversation, or reminding nurses and others that children’s information was private.

Conclusion

This study was designed to produce findings that can inform practice, policy and theory by providing detailed empirical information and a comprehensive interpretation about the children’s perspectives of and responses to a pediatric hospital-based hemodialysis unit. Focused ethnographic methods, involving participant observation over three data collection time frames,
has been used to describe and interpret the children’s embodied situatedness in the unit’s temporal, spatial and technological regimes and relations. The sample was comprised of five girls and six boys, between 7 to 17 years of age, and was comprised of the majority of the children who receiving maintenance hemodialysis at study site during data collection. Wolcott’s (1994) general framework that encompasses three distinct, but intertwined and sequential, processes of description, analysis and transformation was employed to analyze ethnographic data. Using a flexible coding system, data was thematically analysed to answer the research questions derived from and consistent with the research purpose and theoretical framework. My goal is that the contribution of the study findings builds on existing knowledge and promotes further inquiries about children’s embodied experiences of technologicalized hospital-based care.
Chapter IV and V: Findings Overview

Findings Overview

The study findings are divided into chapter IV and V. Chapter IV is titled *The TimeSpace of the Hemodialysis Unit*. I provide a descriptive overview of the participants and the research setting so that the reader can come to know the place of the unit and its people. My goal is to provide a representation of the children, staff and others who occupied the hemodialysis unit during the three time periods of the study and the physical design, layout and everyday general routines of the unit. Chapter IV provides the contextual description for the interpretation of the children’s embodied situatedness among the interrelations in the temporal, spatial and technological regimens and relations that characterize the timespace of the unit that is discussed in chapter V.

Chapter V is titled *Embodying the TimeSpace of the Hemodialysis Unit* because I explore the children’s perceptions of and responses to the hemodialysis unit. Drawing on the study’s conceptual framework outlined in Chapter III, I describe and interpret the children’s embodied situatedness in the timespace of the unit. This chapter is comprised of four sections. In sections A, B and C, I explore the children’s everyday embodied situatedness in the temporal, spatial and technological regimes and relations respectively. In section D, I examine the children’s overall adjustments to and agency in the unit’s timespace and their temporal orientation of waiting to be released from hemodialysis. Also included is an exploration of children’s senses of belonging to the unit. The four thematic sections are titled: A) Time: Everyday Rituals and Routines; B) Space: Everyday Confinements and Constraints; C) Technology: Everyday Life on Hemodialysis; and D) Embodied Adaptations and Interruptions to the TimeSpace.
Chapter IV: The TimeSpace of the Hemodialysis Unit

Introduction

In this chapter, I provide a descriptive overview of the participants and research setting that was recorded during my three periods of participant observation in the pediatric hemodialysis unit. I first describe the study sample, according to their sex, ages, and other characteristics. This is followed by a description of the unit staff. I then depict salient aspects of the hemodialysis unit’s physical design, layout and aesthetics features and finally, the general unit routines. Some identifying information about the research setting and study participants has been aggregated, generalized, altered or omitted to protect the identities of the institution, staff members, families and children.

The Participants

The children of the study sample represent all the eligible participants who received maintenance treatments in the hemodialysis unit during the three participant observation periods. In total, 11 children participated in the study. Two children were followed over both the first and second periods of data collection. The children constituted a diverse group in terms of their kidney pathology, treatment experience, age, and ethnicity. Because of the small number of children who receive hemodialysis in Ontario, some data were aggregated to protect anonymity of individual children.

The sample included six boys, ranging in age from 8 to 17 years and five girls, ranging in age from 7 to 17 years. The majority were between 15 and 17 years of age, followed closely by those between 7 and 10 years of age. Two children were between 11 and 14 years of age. All children lived in Ontario and most lived in the city that houses the hospital where the
hemodialysis unit is situated. Three children lived in other cities and had to be driven to treatments by a parent or support person. This commute took at least one and half hours or longer to and from each treatment session. Over the winter period, I became aware of the difficulty parents could have driving their child in poor weather conditions, occasionally necessitating overnight hospital stays.

All children lived with one or both parents and ten children had siblings. One participant had an older sibling who also has kidney disease. Some of the children were accompanied to the hemodialysis unit by either their mother or father and a sibling, affording me an opportunity to become somewhat acquainted with members of their family. Five participants were in high school and of these, two were on reduced school workloads because of their hemodialysis treatment cycles. One child was home schooled and three went to elementary or middle schools. Two children who had cognitive impairments resulting from their kidney disease went to segregated/special needs schools (see Table 1).

Table 1: Aggregate General Participant Demographics (N=11 children)

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Current living situation</th>
<th>Grade level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males: N=6</td>
<td>7-10 years: 4</td>
<td>Both parents: 1</td>
<td>Home schooled: 1</td>
</tr>
<tr>
<td>Females: N=5</td>
<td>11-14 years: 2</td>
<td>One parent and sibling(s): 4</td>
<td>School for developmentally delayed: 2</td>
</tr>
<tr>
<td></td>
<td>15-17 of years:5</td>
<td>Both parents and sibling(s): 6</td>
<td>Elementary school: 2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Middle School: 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>High school: 5</td>
</tr>
</tbody>
</table>
The socio-economic status of families was difficult to assess, but there appeared to be some differences among the children. My interpretation primarily is based on the children’s reports of their residential addresses, parents’ occupations and the content of conversations. To a lesser degree, the children’s and their family members’ appearance and clothing, such as designer accessories and jewellery, and their comportment gave some clues. One participant and her family appeared to be from an upper class background. Of the remaining ten, one appeared to be from a middle to upper class background, four from middle class backgrounds and six from working or lower class backgrounds.

Reflecting the urban catchment area, the participating children were diverse in terms of ethnicity. Two children described themselves to be of Canadian descent, five were of South Asian descent, two were of East Asian descent, one was of West Indian descent and one was of South East Asian descent. Out of the 11 children, nine had parents who had immigrated to Canada and four children were born outside of Canada. Three immigrated to Canada before they were five years of age and one moved to Canada before one year of age. English was not the first language of three children, although all understood English and spoke at least a little English.

The participants had varied disease trajectories and treatment modalities. Six children had acquired their kidney failure through infection, nephritic syndromes, or as a result of another systemic disease process. The remaining five participants had been born with a congenital condition, such as renal dysplasia or a disease syndrome that affects the kidneys. The children born with wider systemic syndromes tended to have multiple long-term physical problems, such as impaired vision, neurological problems, difficulty walking, and developmental delays. Most of the children had experienced some changes in their appearance or functioning, including delayed growth, short stature, fatigue or weight gain and an enlarged face due to medications.
For clarity, I describe here the duration of time that children received hemodialysis around the study period when they participated. Because of a transplantation failures or ongoing disease processes, it is important to note that some children were dialyzed intermittently over the course of their childhoods. Over half of the participants had begun treatments less than a year prior to the study, although two participants had received hemodialysis earlier in their lives before they switched to a different treatment modality. The remaining participants had been receiving hemodialysis from over one year to over six years. Three had transplantation failures that necessitated other forms of treatments for their kidney disease, including peritoneal dialysis and all returned to hemodialysis. One participant received home hemodialysis and came to the unit once a week for respite hospital-based treatments. Another participant received both hemodialysis and apheresis treatments that took place in the unit with other children. At the time they were participating in the study, seven children were placed on the wait list for transplantation (see Table 2). In addition, during the time I spent at the unit, some children who were ineligible to be study participants received treatments occasionally. These children included those who received acute hemodialysis, were from out of the province receiving treatments temporally or were infants.

Table 2: Aggregated Kidney Disease and Treatment (N=11 children)

<table>
<thead>
<tr>
<th>Kidney disease</th>
<th>Hemodialysis</th>
<th>Transplantation</th>
<th>Other concurrent treatment modalities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Treatments</td>
<td>Duration</td>
<td></td>
</tr>
<tr>
<td>Acquired: N=6</td>
<td>&lt; 1 year: 6</td>
<td>Transplant failure: 3</td>
<td>Home hemodialysis: 1</td>
</tr>
<tr>
<td>Congenital: N=5</td>
<td>1- 2 years: 1</td>
<td>On wait list for transplant: 7</td>
<td>Apheresis: 1</td>
</tr>
</tbody>
</table>
During the study, the number of children receiving treatments in the unit was low due in part, to a higher than usual number of successful transplants. During or just after my study, two children transferred to adult hemodialysis services, one changed to peritoneal dialysis, five received transplants, and one regained sufficient kidney function to stop dialysis. At the end of the three observation periods, only two participants continued maintenance hemodialysis in the unit. During one of the three study periods, only one child was a participant when he exited the unit. See Appendix E for the time graph of the hemodialysis durations that illustrate when participants began hemodialysis and at what period they left the unit during the three time periods of the study. The participants are labeled A to K.

The Staff and Visitors

Nursing staff

Nurses were the largest, most constant and visible health professional group in the unit. A full time information clerk, who supported the nurses’ practices and the unit’s functioning, worked Monday to Friday from 7:00 until 3:00 pm. In addition, one rotating nurse was available to families 24 hours a day, 7 days a week by telephone for emergency support. During the study, the permanent nursing staff was comprised of 6 full time registered nurses and 4 part-time registered nurses, including a full time clinical leader. With only one male nurse, this group was predominantly female. The nurse-patient ratio was 1:2 or 1:1, depending on the illness acuity and if the age of a child was very young. One patient was assigned to one nurse if the patient was

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>2-3 years</td>
<td>1</td>
</tr>
<tr>
<td>5-6 years</td>
<td>1</td>
</tr>
<tr>
<td>&gt; 6 years</td>
<td>2</td>
</tr>
</tbody>
</table>
unstable or an infant. Hence, one nurse cares for a total of one or two children per shift. The nurses tended to interact with one another as well as other staff and the children more frequently than any other staff group.

Nurses deliver care based on a primary care model in which each child is specifically assigned a primary nurse when he or she begins hemodialysis. The primary nurse organizes and manages this child’s care and coordinates professional communication and oversees the treatment plans. When the child’s primary nurse is not working in the unit, care of that child is assigned to another nurse, called a secondary nurse. Typically, the child’s care is taken over by one or two secondary nurses who remain consistent, so that the nurses who care for each child remain relatively stable over time. The primary nurse is responsible for their specific patients and machines during a treatment. For example, when the machine’s alarm went off or the child needed something, this assigned nurse responded, even if others were closer to the child at that moment. I have observed that the other nurses appeared to ignore the child and machine unassigned to them. The children seemed to learn quickly to refer only to their assigned nurse through reminders from nurses and other staff. The nurses tended to stay within or close to the unit, hence their patients, even during breaks in their shifts. Although hemodialysis is a well-established routine and treatment modality, the need for the nurse’s consistent presence reflects the potentially serious problems with the child or machine that can arise suddenly and the need for a nurse to know and monitor their patients well.

**Medical staff and dialysis technologists**

Two nephrologists, along with one visiting nephrology Fellow who rotated every month, visited the unit daily to provide medical care. Their visits to the unit range from 15 minutes to 2 hours in duration, depending on if they are reviewing charts, prescribing treatments or examining individual children. The social worker and dietician are available to the unit for a few hours a
week but did not visit the unit regularly during my periods of observation. However, when needed they assess and talk with individual children and consult with family. A full-time dialysis technologist and two additional part-time technologists are responsible for taking care of the hemodialysis machine and associated equipment. They were available 24 hours per day to respond to staff needs in the unit and throughout the hospital. I would see these staff members in the unit each morning and occasionally throughout the day. Although both medical and technical staff sometimes spoke to or consulted with nurses, only medical staff interacted directly with children on occasion when medical attention was needed.

**Housekeeping staff for the dialysis equipment**

The women who cleaned the hemodialysis equipment played a silent role in the unit as they disinfected the machines and chairs before and after each child’s treatment. This procedure took about 10 minutes. They worked quickly and rarely talk or are talked to by staff or others in the unit. Although surprisingly unacknowledged in the unit, their work is critical to the disinfecting and cleaning of the equipment. These procedures minimize the spread of infectious bacteria that may compromise the children’s health.

**Teachers and child life specialist**

To compensate for the disruptions to children’s schooling, a hospital-based elementary or high school teacher provided up to one hour of instruction to each child in the unit during school months, from September to June. The position of child life specialist had been eliminated in spring 2005, so for the first time in 30 years there was no child life specialist available to the unit. The role of the child life specialist had included supervising volunteers, teaching children and families about living with renal disease and hemodialysis treatments, arranging of celebrations, such as birthdays and the last treatment before transplantation, and participating in multidisciplinary patient rounds. They also interacted with the children directly. It appeared that
the nursing staff and volunteers attempted to fill this gap either spending time occupying children in play activities or most often, arranging solitary entertainment such a television or video game.

**Volunteers**

Volunteers played a significant role in occupying children’s time and overall, the children seemed to enjoy interacting with them. During the study time periods, two volunteers visited the unit about twice a week to play games, read to, or make crafts with the children. One volunteer had been associated with the unit for 10 years and visited the unit on Monday mornings, except during the winter holiday. Other volunteers who visited twice a week for short periods of time were three students fulfilling high school course requirements. In addition, second year nursing students observed and played with the children in the unit, but did not provide direct care. The volunteers and students rotated among the children and spent a few hours each session, never staying for the entire length of a treatment cycle. About once a week, a clown, who was a favourite visitor of some children, entertained the children for up to one hour.

**Families and others**

Not only did staff and volunteers comprise significant groups in the unit, but also parents, siblings and other visitors frequently came and went each day. Over half of participants’ mothers or fathers accompanied their child to the hospital. Of these, a few sat in a chair beside or in front of their child during his or her entire treatment. Other parents visited with one another and the children in the unit or waiting room. Some parents spent time in the hospital’s shops or cafeteria. Frequently, staff from other parts of the hospital passed through the unit. Their identities and purposes often were unclear to me.
The Setting and Routines

The study took place in a hemodialysis unit in a pediatric hospital in Ontario, Canada that provides health care to children less than 18 years of age. Since the 1960s, renal services have been provided through the Division of Nephrology, a subspecialty of pediatric medicine. This division cares for infants, children, and adolescents with complex urological conditions. Treatments for ESRD include hospital-based hemodialysis, home peritoneal dialysis, home hemodialysis and renal transplantation.

The hemodialysis unit

Because of limited space and inadequate technical installations, in the late 1990s, the hemodialysis unit was redesigned, enlarged, and updated. The revised unit was expanded to accommodate up to five or six patients whereas the older version could accommodate fewer patients at one time. Appendix F is a diagram of the physical layout of the pediatric hemodialysis unit and depicts the areas that concern the children. It cannot be considered an exact replication as aspects of the unit, such as the windows, are not drawn to scale. The self-contained unit consists of a main room where the children most often have their treatments. In addition, the unit has ten smaller adjoining rooms, two of which are private treatment rooms. Not all rooms are illustrated on the diagram, especially those on the east hallway that the children do not enter, such as the supply rooms and offices.

Entrances

There are two entrances to the hemodialysis unit on its east and south ends. Upon entering the east-facing doorway and before arriving in the main room, one must pass through the hallway that usually contained no people but was lined with a number of boxes of supplies and pieces of equipment. Rooms attached to this hallway consist of two supply rooms, two staff offices, two
bathrooms, and a private treatment room. This entrance was infrequently used by patients. The south-facing entrance was most frequently used by children and families and is displayed in Photograph 1.

![Photograph 1: South-facing Entrance to the Unit](image)

Looking through this entrance’s doorway into the unit, one can see the administration area and the information clerk as well as a small group of nurses or a doctor who congregate there periodically. Through a short, wide hallway and a turn to the left, one enters directly into the main room where hemodialysis occurs. When the unit is particularly busy, this entrance resembles an obstacle course as one must move past and around the clutter of equipment and supplies. Photograph 2 illustrates the south-facing entrance as seen from inside the unit.
Photograph 2: South-Facing Entrance As Seen From Inside the Unit

As depicted in Appendix F that representations the physical layout of the unit, the main area is surrounded by other functional areas. At one end, separated from the main room are a small kitchen, a meeting/staff room with a large window that looks back into the main area, and a small room containing one hemodialysis station. At the other end of the main area and separated by a wall, is the administration area that is used by an informational clerk and nurses, and less often doctors. Past the administration desk and down the eastward facing hallway, are the rooms described above. Across the hall from the unit, a small, plain waiting room, with a telephone and television, is available for children and families.
The main treatment area

The main treatment area of the unit is comprised of a large square room, approximately 730 square feet, and houses four dialysis stations in each corner. An additional machine can be accommodated if needed. Hence, up to five children can receive hemodialysis during each 4 hour treatment shift. During my study, I observed only one or two instances when a fifth child was accommodated. These instances usually involved a child needing emergency hemodialysis or an out of town family receiving care and instruction in hemodialysis before returning to their home. Typically, two or three children received hemodialysis at one time. Because of the relatively small size of the unit it was impossible to take a picture that captures the entire space. The following photograph 3 shows the view of the main area of unit upon entering from the south-facing entrance.

Photograph 3: Main Area of the Hemodialysis Unit
Overall, the unit has few natural, visually pleasing, or artistic elements. The majority of wall colour is a drab off-white/beige typical of hospitals and the recessed sections of the ceilings are sky blue. The nurses and volunteers sometimes displayed the children’s drawings and paintings on walls and furniture as seen in photograph 4.

Photograph 4: Children’s Artwork

Photograph 4 illustrates children’s artwork that was often made to celebrate occasions, such as Christmas or Halloween, and taped on pillars and wall. The only permanent art is a mural, painted by a commissioned artist, depicting animated cartoon kidneys playing musical instruments. This mural is not in the main area where children receive treatments but in the south hallway occupied mostly by staff and supplies. Photograph 5 exhibits these murals.
Photograph 5: Mural of Animated Cartoon Kidneys Playing Musical Instruments

In the main treatment area, large florescent lights dominate the ceiling in the center of the room and the recessed ceiling above each hemodialysis station center. Very little natural light enters the unit because the only two small north-facing windows are behind two hemodialysis stations. These windows face a brick exterior of another part of the hospital. Frequently the blinds are partially or fully closed. I did not notice these windows until I had spent a week in the unit. Hence, the lighting overall is artificial and bright, although children can, but rarely did, request their station’s overhead light be turned off which softens the overall harsh lighting effect.

Toys, books, board games, craft supplies and videos that children use during treatments were piled on a counter in the south hallway. Additional items were kept in cabinets in the waiting room. Photograph 6 displays these items. These items are old and worn, often with missing parts or pages.
During the time I was in the unit, I did not witness new additions to the collections except for those I provided. It also appeared to me that the entertainment provided in the unit was geared more for younger aged children, such as those in preschool and elementary school. An old model television and video game player on a mobile cart also sat in the south hallway and could be moved to stations throughout the room at children’s request. Because the unit had only one unit for videos games, children would have to wait for their turn if two or more children wanted to play at the same time.

Reflecting the unit’s focus on hemodialysis treatments and lack of storage space, equipment and supplies, and bottles always were placed in doorways, halls or the main room. Often, carts with supplies were stationed in the hallway and main room and machines waiting to be used or removed sat in hallways and doorways. Children’s medical charts were scattered across tables. Bottles of antiseptic solutions lined shelves. Photograph 7 depicts the hallway following the east-facing doorway and illustrates the cluttered unit.
Photograph 7: Hallway by the East-Facing Doorway

**Hemodialysis stations**

Each hemodialysis station occupied one of the four corners of the main room, facing the center of the room. Each station is considered to be approximately 120 square feet (11 feet by 11 feet). This size is needed to accommodate the machinery and supplies associated with the treatment. There were no physical boundaries between stations and the central room, however, the placement of the chair and equipment creates some sense of separateness, much like the arrangement of furniture to form a sitting area in an open concept room. Photograph 8 illustrates the items that formed the core of each station. These items included a large hemodialysis machine, a vinyl covered reclining chair covered by a sheet and a rolling utility table. Children typically received hemodialysis sitting in the chair, although the stretcher was used occasionally. Each station contains a variety of medical equipment including bottles of solutions, a stand-alone
blood pressure monitor, body temperature gauges, a medical service panel with emergency attachments and perhaps a cardiac monitor and leads.

Photograph 8: A Hemodialysis Station

A 24 inch televisions and VCR/DVD players suspended from the ceiling were available for children. A remote control receiver attached to the bed with a wire was available so a child could change channels and sound independently. Earphones also were available, but rarely used. Many hemodialysis stations also had rarely used telephones for children and families as cell phones were not allowed to be used around the hemodialysis machines. There were curtains surrounding each hemodialysis station that moved from a circular track in the ceiling. However, they are used infrequently by staff or children.
Private treatment rooms

The two private treatment rooms situated on the periphery of the main room were used to dialyzed children who require isolation or privacy. Occasionally an older adolescent who was thought to require more privacy was placed in one of these rooms by nurses. They also were used when patient numbers exceed four and for planned staff and patient/family meetings. The private room off the main room was cramped due to equipment and a large round table, has poor lighting and limited TV channels. As photograph 9 illustrates, although separated by a partial glass wall and curtains, children remain visible to those in the main room.

Photograph 9: Private Room off the Main Area in the Unit

The second private room, located down the east hallway, was more spacious, quiet and had a window that allowed in some daylight. It has large glass panels that slide together to create a
door and separate the room from the hallway. This room is visible, although a curtain can be pulled across the glass panels. The privacy these rooms provide, however limited, was enjoyed by some children and disliked by others.

**Sounds and smells**

The high noise levels in the entire unit were striking. Much of the noise was generated by the hemodialysis machines and other mechanical equipment. The hemodialysis machines regularly and rhythmically hummed, vibrated and thumped continuously and produced the occasional shrill alarm and piercing beep that directed the nurses’ attention. Every half hour the blood pressure cuff on each child’s upper arm made a quiet sound of air movement as the cuff inflated and deflated. In addition, nurses tended to play rock music using a radio located near the administration desk. Although children have earphones for the televisions, they were rarely used. Sounds of the various television programs each child may watch also permeated the unit.

Sometimes obscured by or heard above the technological noise, talk among nurses, staff, visitors, family members and children could be heard periodically throughout the day. Noise created by people was much more sporadic and spontaneous than the constant technological sounds. Generally, the nurses tended to create the most noise as they socialized with one another. Social events, such as the annual Christmas party, also were noisy occasions.

Silences also were an aspect of the unit. Periodically, the unit was extremely quiet and still except for the sounds of machinery. Typically these silences occurred when nurses sat at a computer or desk to write in charts and children slept or played quietly in their chairs. They occurred once or twice a day lasting for one to three hours and happened most often in the mornings or mid-shift, especially on Saturdays.
The unit’s smells also conveyed its institutional medical nature in that most were strikingly antiseptic and stringent. Preventing infection among the children was a primary concern for the staff. Hence, the most notable smells emanated from the cleaning fluids and alcohol used to clean the machines and furniture. Predictably these smells were pungent when first used and then dissipated. Given the frequent use of the cleaning fluids, their smell accumulated in and permeated the unit periodically throughout the day. Augmenting these smells are those of the detergents used for frequently hand washing that must be done by staff and visitors before and after touching each patient.

Occasionally I was struck by the overpowering smell of food, most often the home cooked meals of staff. For children, meals made by the hospital’s kitchen are delivered on plastic trays to be eaten by the children while they receive hemodialysis. The children’s food, such as hot dogs, pizza, macaroni and cheese or chicken, had little odour. However, couple times a week, staff members brought in home cooked meals for themselves, heating it in the kitchen’s microwave and occasionally a group ordered takeout, such as pizza or chicken that they ate in the staff/meeting room. These aromas in and around the staff areas were strong, appetizing, and homey, whereas that of the children’s food was bland and barely perceptible.

**General routines of the unit**

The unit was very active on a daily basis for about half of the time I spent there, with many staff, family and others going in and out of the unit. Routines primarily followed hemodialysis shifts and treatment schedules. The unit operates Monday to Saturday in what might be described as extended business hours. Treatments are provided Monday to Friday 8:00 am to 6:00 or 7:00 pm and on Saturday mornings from 8:00 am to 12:00 pm. Cycles of maintenance hemodialysis treatments occurred in the morning or afternoon of Monday, Wednesday, and Friday or on
Tuesday and Thursday afternoon and Saturday morning. Overall there were three main hemodialysis shifts, with each treatment typically four hours in duration. Some children, especially those who were younger or unable to tolerate longer sessions required four treatments per week lasting about three hours. Hence, most children come to the unit three or four times a week, for three or four hours. On Tuesday and Thursday mornings, apheresis (i.e. peripheral stem cell collection, red cell exchanges, and plasma exchanges) or acute hemodialysis treatments were offered. Occasionally, these treatments were scheduled at the same time as maintenance hemodialysis but took place in the private rooms.

To keep the shifts organized, nurses insisted that children be available for their treatment the correct time. The majority of children and families appeared to comply with the schedule, and those who did not were reminded to do so by a nurse. Morning hemodialysis shifts began at 8:00 or 9:00 am and lasted until 11:00 am or 12:00 pm, followed by an afternoon shift that began between 12:00 to 2:00 pm and ended between 3:00 and 5:00 pm. There is little variation between the morning and afternoon shift.

To accommodate patients in high school, late afternoon/early evening dialysis from 4:00 to 7:00 pm on weekdays and on Saturday mornings was offered. Of the 11 study participants, only two older adolescent boys who were in high school followed this schedule during my observation periods. Hence, many other participating children missed a half day of school two to three times a week because of their treatment schedule. Occasionally, a child requested a change in the timing or day of their treatment to participate in a special occasion, such as a sport game, or medical intervention. These requests typically were accommodated.

The children primarily resided at their station in the main room or a private room tethered to the hemodialysis machine and in eye and eye range of the nurses and others in the unit. Because they spend hours attached to a machine, their activities tended to be stationary. These
activities included schooling with teachers, playing a video game, listening to music, watching videos or DVDs, playing games, or doing crafts. Children’s routines also included general education as well as medical care. An elementary teacher and high school teacher visited the unit to provide the children with about 1 hour of schooling per session during the weekdays. A few times a month a special event happened, such as a clown visit or a visit from a celebrity. To recognize children as individuals, birthday parties and goodbye parties for children leaving the unit and special themed days in the unit included pyjama day (for boys and girls) and braid day (for girls) also took place. Only children who had treatments during these events participated. One significant party that I participated in was the annual Christmas party, which was a long-standing tradition attended by many children, families, unit staff and the nephrology division staff, including physicians.

Chapter Summary

In this chapter, I have described the staff and research setting to provide the context for my interpretation of the children’s embodied situatedness in the timespace of the hemodialysis unit that is discussed in the following chapter. I also have described some salient aggregated characteristics of the participants to introduce them. In summary, the unit was a fairly busy, populated place and included children, their families, nurses, medical staff, dialysis technicians, teachers, housekeeping personnel, volunteers and families. The unit’s layout consisted of a small main area with four hemodialysis stations surrounded by a number of other functional areas. There was little storage area in the unit so the staff made use of any corners, spare walls and alcoves to store medical equipment and supplies. The unit appears highly institutional and medical in nature with hemodialysis machines, equipment and supplies cluttered in doorways
and throughout the unit. Mechanical sounds derived from the machines and antiseptic and stringent smells from cleaning agents permeated the unit.

The children’s hemodialysis routines are structured by the duration of the hemodialysis treatments and the unit’s pattern of three weekly shifts. Technologically dependent on treatments for survival, the children must come to the unit three or four times a week for a duration of three or four hours. All the children in the study lived within a reasonable proximity to the institution, however, a significant amount of their time weekly was occupied by coming to and from the unit. Thus, they experienced frequent temporal disruptions and socio-spatial dislocations in their everyday lives outside of the unit. Because they were conjoined to a machine, the children remained at their stations for their duration of their treatment. To make up for school time lost during the week, the children received schooling in the unit. Planned occasional social events interrupted and offered a respite from the everyday unit routines and hemodialysis regimes.
Chapter V: Embodying the TimeSpace of the Hemodialysis Unit

Introduction

This chapter is designed to fulfill the main purpose of the study by providing a description and interpretation of the ways that the children perceived and responded to the timespace of the hemodialysis unit. The participants, staff and others as well as the design, layout and routines of the unit were described in Chapter IV. In this chapter, I elaborate on the unit’s people and place to provide further context to my discussion of the children’s embodied situatedness. To convey the participants’ experiences, I include their thoughts and ideas through their words and illustrations and interweave them with my observations and interpretations. These are woven together in order to present a comprehensive description and interpretation of the children’s perceptions and responses to the hemodialysis unit. The difference in meanings that the children provided based on gender, age or other variables are presented. Because of the size of the sample generalities among groups of children cannot be hypothesized, but patterns within the data are delineated to the extent possible.

There are four sections in this chapter. In sections A, B and C, I focus on how the participants perceived and responded to the central conceptual components of the everyday timespace of the unit, which are the temporal, spatial and technological topographies respectively. The intent of this format is to provide organizational and conceptually clarity, however, overlap among the components is unavoidable. In particular, the data analysis revealed the powerful contouring effects of technology on the temporal, spatial and technological regimes and relations experienced by the children. Hence, discussion of hemodialysis technology threads through Section A, B and C in this chapter.
The primary emphasis of Section A is the unit’s temporality. I examine the everyday rituals and routines that pertain to the primary practices and customs that comprised the hemodialysis regimes. The temporality of the care routines of the hemodialysis machines exerted a temporal effect that structured the unit’s timespace and the children’s embodied perceptions and spending of time in the unit. Themes include: 1) ‘It’s always the same’; 2) Time passing, passing the time; 3) Making up time; and 4) Marking time.

In Section B, I examine the socio-spatial aspects of the unit to illustrate the ways that the children are marginalized due to their technological conjoinment with the hemodialysis machines and their identities as patients. Their embodied positions suggested that their ongoing cycles of hospital-based hemodialysis takes on the character of everyday confinement and constraint that they endured and managed. Themes include: 1) Tethered to the hemodialysis machine; 2) Complexes of human-technological and social relations; 3) Being visible-invisible; and 4) Isolation and segregation.

Section C focuses on technology in the children’s everyday life on hemodialysis. I discuss how the children perceived and responded to their technological embodiment and experiences of kidney disease. Themes include: 1) Relating with the machine; 2) Living on technology; and 3) Food and fluid reprieves.

Section D is titled embodied adaptions and interruptions to the timespace. In this section, I focus more broadly on the children’s embodied situatedness by merging the central conceptual components of the unit’s temporal, spatial and technological dimensions. First, I examine the participants’ overall adjustments to and agency in the unit. The children were asked to give their ideas on how to improve their experiences in the unit. Their responses are a focus of the discussion. Predominantly, the children are viewed as resigning themselves to the unit’s everyday routines. However, some of the children also displayed notable moments of resistance.
I then discuss the children’s more expansive temporal orientations that suggest that most are waiting to be released from hemodialysis in the long-term through transplantation or other means. Finally, I examine some specific occasions that significantly interrupted the technologically driven regimes and relations, making the unit’s sociality rather than technology paramount. These interruptions resulted in observations that provided glimpses into periods when the usual rituals and routines that hold sway are altered or diminished, transforming the children’s experiences in the unit. The children’s dispositions during these interruptions suggest that they perceived the unit as positive and experienced a sense of belonging. Themes include: 1) Resignation and resistance; 2) Waiting to be released from hemodialysis; and 3) Senses of belonging. I conclude chapter V with a summary that more broadly explores the findings generated by the themes.

All participants’ names are pseudonyms. Observations and quotes that I present are chosen as succinct representations of the identified theme. Where quotations are not available, I summarize and articulate children’s viewpoints that emerged in my interactions with them. One or two children are quoted more frequently at some points because their words convey a common perspective in an articulate and concise manner. Children’s quotations and descriptions, unless otherwise noted, are intended to be representative of the larger group or subgroups of children and the experiences explored.

Section A. Time: Everyday Rituals and Routines

A. 1. “It’s always the same”

In Chapter IV, I described the unit’s general routines and cycles of hemodialysis treatments. Clearly, the weekly cycle of receiving hospital-based hemodialysis was a major
routine in the children’s everyday lives. Once entering the unit, they also encountered a highly regimented process. All the children appeared compliant with the orderly processes, even those who were relatively new on the unit. Children-led unit tours and observations proved to be the most revealing way of capturing their treatment regimes. These methods allowed me to witness and document the ritualistic and routinized manner that the children engaged in the hemodialysis regimes. These regimes were carried out multiple times over the three study time periods, demonstrating their strikingly invariable and comparable nature. The everyday rituals and routines, consisting of repetitive and habitual practices, imposed a certain predictable order on the children’s temporal experiences. One participant on our first meeting told me, “It’s always the same”.

Over numerous occasions, I observed the children enter the unit to receive their treatments, arriving on their own or with one or both parents, using transportation for people with disabilities, public transportation, or a car. To know at which hemodialysis station their treatment will be received, the children searched for their chart on the chair or waited until a nurse directed them. About half of the time, the children were dialyzed at the same station by the same primary or secondary nurse. The children placed their personal belongings, such as coats, bags, and clothing, on the station’s table or chair. Then, they stripped down to underwear or light clothing and walked to a scale near the kitchen in order to be weighed. Occasionally the children took their weight by themselves or received help from a parent. This measurement was relayed to their nurse who recorded and used the information to plan the treatment and program the hemodialysis machine. The children, especially those eight years old and above, usually redressed in their shirt and pants. Younger children often remained in underpants and t-shirts. They then proceeded to sit in their chair, waiting for their nurse to take their vital signs and hook them up to a machine, a procedure that took about 10 minutes. Overall, entering, preparing for
the treatment and the hook up process took about 15 minutes, and was followed by the
hemodialysis session.

The following fieldnote excerpt describes the usual rituals to prepare a child to be hooked
up to the hemodialysis machine and was part of a conversation I had with Jimmy, a studious and
quiet 16 year old male adolescent with years of experience of hemodialysis, while on his unit
tour.

HZ: Is this the door that you use usually to come into the room?
Jimmy: Yes, this is the door which I usually get to come into.
HZ: How come you don’t choose the other door to come into?
Jimmy: Well, sometimes I come into the other door too. It depends on which one has
more stuff blocking the way.
HZ: And we’ve got some nice stuff blocking the way here a little bit.
Jimmy: Yeah.
HZ: What do you look at when you walk through, like the bathrooms or anything like
that?
Jimmy: Not much because usually I’m just rushing in.
HZ: You are rushing in. You want to get to your treatment?
Jimmy: Yeah. Just sometimes, it just doesn’t matter. I’m used to that. Sometimes they
tell me to get in quick.
HZ: OK, and which chair are you in today?
Jimmy: I’m in that chair.
HZ: OK, so this is your place today, so what do you usually do to get started?
Jimmy: I come to my chair. Take off some clothes. Then usually I get my weight and
blood pressure and temperature. Then after it I get hooked on and then usually I
have my meal.

Jimmy’s description as he demonstrated his progression through the typical routines of preparing
for a hemodialysis session was representative of all the children’s routines. The rituals at the end
of the treatment were similar to the beginning in reverse and also took about 15 minutes. With
few exceptions, their general regimes rarely varied from patient to patient or on a day-to-day
basis.

Rituals and routines in the timespace of the unit were tightly orchestrated to move the
children in and out of the unit as effectively and quickly as possible in order to accommodate the
next patient. My conception of timespace involves systems of disciplinary/professional routines
and practices as one major domain by which time is experienced and enacted (May and Thrift, 2001). The children’s medical routine was highly regulated and invariable and the children became quickly disciplined to it. Although children inevitably learned and conformed to the unit’s routines once in the unit, they, in turn, reiterated and enforced the routines through their shared participation.

For the most part, the children’s daily routine was structured by the routine of the hemodialysis machine itself. Although remarkable advances have been made in hemodialysis over the past 40 to 50 years, the structure and sequence of treatments are bound by the limits and needs of the machine. The complicated hemodialysis machines and associated equipment required a significant amount of specialized care and attention before and after use, from nurses, technicians and cleaning staff, if they were to effectively and safety cleanse blood to maintain the children’s lives. To function correctly and be available to the children on time, each machine in the unit was maintained on a strict schedule. The technicians and nursing staff arrived at about 7:00 am each morning to assess, prepare and prime the machine prior to the arrival of patients. This process took 45 to 60 minutes, and included programming the computer, processing the dialyzer or filter, sometimes called an artificial kidney, attaching tubing and running lines with dialysis fluids. Because each treatment lasted up to four hours, a machine could be used by two patients each day. If a machine was to be used for a subsequent patient, the machine needed to be sterilized, processed, reprogrammed and reprimed by a technician. Hence, additional time was required to set up a previously used machine for a new treatment.

Once a machine was ready, it could be attached to a child’s body to function as a kidney to remove fluids, wastes and toxins. Conjoined to a machine, each child’s body merged with the machine’s rhythms in a form of human-technological embodiment. To complete cycles of cleaning the blood, the children were conjoined with the machine for three to four hours. Hence,
their time in the unit was structured foremost by the machine’s rhythms. Once a child’s treatment was complete and they were untethered from the machine, cleaning staff appeared on schedule from other hospital areas to carefully and thoroughly clean and disinfect the machine and chair, a 10 to 15 minute process.

Technology-in-waiting also formed a part of the topography of the unit. Typically, an extra machine, if available, was set up in the morning to be ready for use in the afternoon. This reserved machine waited in the unit, not still and silent, but active as fluids pumped through the extensive tubing, until needed. Finally, at the day’s end, all machines were cleaned and readied to be setup for the following day. The ritualistic sameness of children’s routines expressed by them and observed by me also was a feature of the routines of the machine whose care and tuning was carried out in the same manner on an everyday basis.

As part of caring for children, the care of the hemodialysis machine formed a large part of each nurse’s rituals and routines in the unit. Similar to how the children were monitored, the nurses closely and continuously assessed and monitored the machine throughout each treatment. They read, documented and assessed various treatment parameters, for example, blood flow rate, dialysate flow, pressures, and fluid removal. Various beeps and alarms warned that an aspect of the machine was malfunctioning or that attention was needed for the next step in the program. Monitoring and care of the machine typically occurred at regular intervals if all is going well. If there is a problem, extra time often was required. For example, on a few occasions, I observed that the machine or its tubing was not functioning correctly, which occupied the nurse until the problem was fixed. It also delayed the child’s treatment, extending his or her time in the unit.

The children’s technological conjoinment was a main feature of their embodied situatedness in the unit. In addition, because of the centrality of technology, the unit’s nature can be conceived as a form of technological-cultural hybridity. Ihde’s (1990, 1993) conception of
technology-cultural embeddedness involves the type of technology, the range of relations to the humans who use it and the specific cultural context. In the hemodialysis unit, the temporal order of technology, people and place were enmeshed. The function and physicality of the hemodialysis technology systematized the various staff member’s professional routines and practices, especially those of the nurses, technicians and the cleaners. Furthermore, children’s treatments were bound to the rhythms of the machine and the girls and boys were disciplined to the rituals and routines driven by the technology. Hence, the machine exerted a program of coordinated action in which a network of roles, involving the children and staff, was enacted. Rather than a neutral or isolated object, the hemodialysis technology was a dominant force that shaped the temporal topography of the timespace of the unit.

A. 2. Time passing, passing time

One important aspect of the children’s experiences of the unit that I captured was their perceptions of time in relation to their hemodialysis regimes. Overwhelmingly, the participants spoke of time as feeling long when receiving hemodialysis. Comparing time in the unit to other places, Navina, a reserved and withdrawn seven year old girl who had been receiving hemodialysis for about one year, commented that “hemodialysis is long” and “time feels longer than when at home”. In my observations and conversations with her, it was very clear that Navina intensely disliked the treatments and unit. In an illustration of what she does not like about hemodialysis, Chandra, an articulate nine year old girl who seemed mature for her age, included the following remarks: “I get bored sometimes”; “It takes a lot of time and waiting”; and “Getting on [the machine] takes time too”. Illustration 2 depicts Chandra’s perceptions of and feelings about time in the unit.
While creating her drawing, Chandra rummaged through the box of stickers to add pictures to her remarks. Upon finding stickers of clocks and sayings about time, she asked me: “How did you know?” I replied by telling her: “I know you spend a lot of time here.” “Yes”, she said. She then applied stickers of clocks and a saying *captured in time* to accompany her thoughts.

Particular to their experiences in the unit, the children’s technologically mediated embodiment induced a perception of time as lengthened or “a lot”. Furthermore, Chandra depicted that she experienced a sense of being captured in time in the unit. Time and space are viewed as inextricably interwoven (May and Thrift, 2001). Hence, perceptions of time may differ across and within settings. Hence, the children may have perceived time differently in the unit than when ‘unhooked’ from the machine in their other childhood places and routines.

Virtually all children complained of a sense of loss or waste of time to some degree, due to the temporal disruptions and socio-spatial dislocations in their overall lives enforced by needing to receive hospital-based hemodialysis. In his illustration 3 about what he does not like about the
unit, Delroy, a gregarious 14 year old male, chose a stamp with an angry face and remarked being in the unit “gets me mad”, “takes away my time” and I “feel like my time is wasted”.

Illustration 3: Delroy’s Illustration of What He Does Not Like about the Unit

Delroy felt angry with his lost or wasted time. His phrase “takes away my time” suggests that he perceived hemodialysis as robbing him of time that cannot be recuperated. Chandra also seemed to resent the loss or waste of time she experienced by the imperative to spend time in the unit. These comments were made by Chandra during the winter holiday period in December.

Chandra: I feel like it is a waste of my time, like it is a holiday and I am here, not doing something else.
HZ: What would you rather be doing?
Chandra: Going out, go swimming, see friends, having fun with other people.

Her comments also illustrated that action, friendships and fun happened for her outside rather than within the unit. Being in the unit conjoined with a machine that determined the time she must spend at the hospital limited or displaced her from these types of activities. Bridget, a clever and active 14 year old girl involved in organized sports, echoed Chandra’s comments in the following illustration 4 and fieldnote excerpt that recorded an experience of her creation of an art piece depicting her everyday experiences in the unit.
I ask Bridget if she will do a drawing with me to help me understand what it is like for
her in the unit. I have my art boxes with me that she rummages through, finally settling
on stickers to create her picture. I ask her to do something that shows what she likes
about the unit and what she does not like. She pauses and then announces that she wants
to do a picture about what it is like at the hospital and at home instead. Rummaging
through the box of stickers, she makes her choices slowly while chatting with me. On the
right side of the page, she chooses stickers for *at home* that represent, as she tells me, fun,
friends, sports, playing, TV, and her dog. Once she seems satisfied with the at home side,
she finally grabs a marker and writes Zzz..... to illustrate sleeping in the unit on the left
side of the paper. She’s finished! I comment: “You have put lots of stickers on the at
home side”. She motions to the hospital side on the paper with her hand and says “Yeah,
it’s blank”. I ask: “Maybe it feels like that here?” She does not say anything, but responds
by smiling and looking through the sticker box and quickly selects adds stickers to
represent the food she can eat while in the unit, a chair for the hemodialysis chair, and
bubble bath since she cannot immerse her line site in water. She then adds the sticker that
says time stands still. I ask, “Is this how time feels to you?” “Yeah”, she replies, “time
feels long, boring”.

I note as interesting that Bridget placed the figure representing her in the middle of the page, so
that the paper is divided into two sections that separate the hospital and home with her in the
middle. By this design and our conversation, I surmise that the hospital as passivity and boredom
and home as action, relationships and fun are viewed by her as two distinct temporalized spaces in her life with divergent meanings.

A typical conventional notion and sense of time is as progression and movement (Adam, 1990, 1995). Time moves forward from past to future and not vice versa, Felski (2000) claims “this sense of the irreversible nature of time is a fundamental aspect of everyday experience: we grow older rather than younger, just as our cars get rustier rather than shinier” (p. 13). Bridget applied the notion that time stands still (on a sticker beside the cap on her head), indicating the contrary in that time seemed to stop progressing in the unit for her. Although their bodies were undergoing progressive cycles of blood cleansing that eventually end, a sense of time stopped amplified the children’s sense of the lengthiness of their duration in the unit. The relational and constitutive conception of timespace emphasizes places as rich in meaning and activities. Strikingly, the unit’s timespace in which the children were temporally disrupted from their everyday lives as they sat through hemodialysis regimes was perceived as time wasted, lost, taken from them, or stopped. Furthermore, many of the children experienced a sense of vanished time that extended beyond the unit through bodily tiredness or other symptoms that continued following a treatment.

Feelings of boredom were common among the participants. Many children felt similar to Bridget in her comment in the fieldnote excerpt that “time feels long, boring” and Chandra’s comment that “I get bored sometimes” in her illustration 2 about what she liked and did not like about dialysis. When I asked Chandra to tell me more about her remark of “I get bored sometimes”, she exclaimed that she is bored when there is nobody to play with during a treatment. In response, I remarked, that “it may feel lonely being here sometimes”. Chandra agreed with my statement. Tammy also claimed that “there is nothing to do here” and “nobody to talk to”, which heightened her sense of boredom and displaced her from more enjoyable
activities. Despite their complaints of boredom and nothing to do, the children did not have long stretches of undisturbed time as physical assessments, such as blood pressure, were taken every half hour, and a school teacher visited regularly. Perhaps these disruptions became commonplace and another aspect of the monotonous rituals and lengthy routines they endured.

Many children demonstrated their frequent displacements from other aspects of their childhood lives, such as school, play, recreation and home, through words and pictures. This time loss occurred because of the amount of time spent traveling to and from the unit and their treatment time together was as much as seven or eight hours per session. Time was viewed by the participants as something to pass as quickly as possible until they were released from the unit following a treatment. Shen, a serious 17 year old adolescent who began treatments for the first time during the study period, made the following remarks about his time in the unit:

HZ: How does the time, the four hours that you spend here, feel to you?
Shen: Long, yup, long. Yeah, boring, nothing to do. And I just sleep or watch TV.
HZ: Do you do things to make the time go faster?
Shen: Yeah, like what I said before. That works.
HZ: So, sleep and watching TV makes the time go faster?
Shen: Yeah.
HZ: What makes time feel slower?
Shen: Oh, the waiting.

Waiting in the sense that Shen and other children used the term referred to waiting for the treatment regime to be finished so they could be unhooked from the hemodialysis machine. In illustration 2, Chandra depicted this waiting as being captured in time. Similarly, Emily, a talkative and friendly eight year old girl, associated fun with time moving quickly and in comparison, waiting with time moving slowly. She exclaimed that “You might have to come here for a long time, time usually flies when you are having fun, waiting is harder and boring and time goes slower.” Time was experienced as long and boring during a treatment, but the children
also commented about time moving more quickly or slowly depending on the activities they could engage in.

Timespace in the unit was subjective, relative, relational and contextual, based on the position of children and their frames of reference (May & Thrift, 2001). The children’s sense of time as having different qualities depending on their activity or than time outside of the unit refers to their experiential time as opposed to objective, abstract and quantifiable clock and calendar time (Adam, 1995). Furthermore, time can be said to be embodied, performed and practiced as it is reflected and shaped by the subjects within it. A sense of waiting was embodied by children through postures and expressions. Over my time with Chandra, I frequently observed her sitting quietly, her hands in her lap, appearing to do nothing except look seriously at people in the unit without smiling. Daily, I would witness similar bodily comportments of other children who sat quietly, appearing to passively let time pass without effort to fill or occupy the time.

Because time felt long, boring, slow or stopped in the unit, many of the children shared strategies they used to occupy their time to make the treatment feel shorter or faster, and thus more tolerable. Watching television and sleeping were the most frequent activities that the children engaged in, particularly by the older boys, such as Shen and Delroy. Jay, a mature 17 year old male adolescent, has spent most of his childhood receiving hemodialysis in the unit. He shared that watching television and sleeping were two main strategies used by him to pass time.

HZ: What type of things do you do when you’re having hemodialysis?
Jay: Mostly watch TV. That’s the only thing that I can do, like homework and stuff that are really hard to do cause the fistula is in my right arm; so you can’t really write; so mainly I just sleep and watch TV.
HZ: Does that help to pass the time?
Jay: Sometimes, sometimes not. If I fall asleep then no, I’d be done right when I get up or something but usually when I’m awake then it take longer.
HZ: So sleeping makes time feel shorter?
Jay: Yeah, cause you’re sleeping and all time passes. You don’t know what’s doing, so, yeah.
The most persistent use of sleep to escape boredom and waiting was employed expertly by Delroy, who often slept from the beginning to end of his treatment. He was rarely awake during a treatment over the three periods that I observed the unit, even appearing to sleep through his blood pressure cuff inflating and deflating while a nurse checked his blood pressure every 30 minutes. In addition to helping time to pass, sleeping also appeared to be a successful strategy for Delroy to disengage from activities and interactions in the unit. By sleeping, he managed to avoid conversations related to his kidney disease, eating habits, treatments and care with nurses and other staff. He told me that he disliked talking these aspects of care because he perceived the staff as controlling and disciplining. Although appearing disengaged in the unit, there was a marked difference in Delroy’s demeanour before and after treatments when outside of the unit in that he was highly entertaining, talkative, and full of smiles. Delroy and some of the other children appeared to have more engaging and energetic liveliness when unhooked from the machine and the demands of its rhythms on their bodies and the unit’s routines.

Many of the girls preferred to pass time in social activities. Tammy was a 15 year female adolescent, interested in her appearance and friends outside of the unit. She began treatments for the second time during my observation periods due to a transplantation failure. She often attempted to interject a shared focus and sociality based on her interests that had little to do with her care and treatment regime within the unit. She remarked that “It’s too boring to sleep. I like to see people and talk”. Compared to other children, Tammy frequently attempted to engage the younger female nurses in social conversations that were gendered, containing talk of clothes, accessories, shopping and female pop stars. For example, on multiple occasions, she called nurses to come to her while she received her treatment to show them a designer jewellery piece or handbag she had with her. Her strategy appeared to be effective in gaining attention from the female nurses and engaging them in talk not related to hemodialysis or her care. Conversely,
Tammy became silent and unresponsive when nurses paid attention to her but attempted to talk with her about her care and treatments. She also tended to be unresponsive if I attempted to talk with her about her kidney disease, treatments or the unit. Hence, Tammy seemed to try to interject a sense of herself into the unit, beyond a patient receiving treatment.

Emily told me that at first she found the unit “dark” and “scary” until she met a friend who also was a patient. For Emily, playing and friendship with girls were her strategies to pass time. She explained her strategies through the comment: “If playing, time goes fast, if not playing it seems like a long time. It’s best to pass the time away”. The following illustration 5 and accompanying fieldnote excerpt summarizes Emily’s thoughts as she described to me an art piece she created about what she liked best in the unit at my request.

Illustration 5: Emily’s Illustration of What She Likes Best in the Unit

Emily explains that she met a friend in the unit and this is what she likes best. The figures on the left represent her and her female friend. She tells me that she likes the stickers that have people on them and she has dressed up the stickers representing herself and her friend for fun. She chooses a darker skin face sticker to represent her friend’s ethnicity. The hands touching indicate that they are meeting each other and are close, they are connected. I ask, “Why having met a friend is the best thing?” “Because we do things together and it’s fun.” I ask, “What things do you do together?” She writes down a video game called Game
Boy. The upside down friends with computers in the bottom middle of the page, she tells me, shows that they like to play these games. The girl with the pizza and ice cream is there because sometimes they eat together in the unit. She tells me: “But we can’t have ice cream, well I can, a little.”

Illustration 6 is a close up of the right side of Emily’s illustration 5. This illustration displays more detail about her depiction of how her friend and herself were physically positioned and conjoined to the hemodialysis machine while they played in the unit.

Illustration 6: Close Up of Emily’s Illustration of What She Likes Best in the Unit

Emily choses the stickers of girls sitting at a desk to show me how they bring their tables across their chairs to play that she represents by the crayons on both the desks. I ask where the hemodialysis machines are when they are playing. She replies where the time stickers are. The black square is the hemodialysis machine. The sticker that says time stands still, timeless, and the clock hands that touch the hemodialysis machine illustrate the lines that run from their chests to the machine. I read what it says in the middle, “moments in time and time flies when you are having fun”. When I make a comment about these ideas, she likes this and says “yes, yes, yes”.

Having a friend was important to Emily to pass time, however this desire was gendered as she told me that: “I don’t like boys in the unit. I like to play with girls”. She demonstrated that only girls, and not boys, are those she wanted to play with as she created and explained her art piece about what she liked least in the unit. See illustration 7 and the fieldnote excerpt below.
When I write “what I like least” on the paper for her to draw, she has to think for a bit. I ask her to look around the unit and put down what comes to her mind. She tells me “not having anyone to play with”. This is represented by the upside down girls scribbled out on the top of the page. Because her friend does not have treatments today, I ask her about how she feels about that. She says “there are just boys here”. I ask her if she plays with boys. “No!” she says emphatically. She puts some stickers that say boys and all boys on the page and puts two sad female faces by them. She takes some time to consider the stickers available to her. She takes the ones that say laugh, fun, play, pals, buds, bus stickers, stars and puts a happy girl face on them. She looks through the stickers some more and takes a sticker that says tough – she starts to put it on the boy side but then puts it on the girls’ side and says to me: “girls are tough”. She looks at a sticker that says “dirty” and decides that’s a boy sticker and then adds a sticker that says “rough” to the boy side as well. Then, she adds two pairs of friends with smiling girl faces, to represent her and her female friend.

The friendship Emily felt was reciprocated by the girl that she has referred to and represented.

Although Emily and the female participant became good friends, they only shared two treatment times together a week. Also, even when together in the unit, they sometimes were placed in chairs too far apart to interact or their treatment times were not aligned so that one of the girls remained alone at the beginning or end of their treatment. At these times, their demeanours were
more subdued and quiet as they sat or played alone. If I was in the unit at the time, I tended to be their substitute playmate.

**A. 3. Making up time**

For many North American children everyday time is divided up among various places, each with its own temporal patterns and schedules. Their typical circuits of moving among places of home, school, social, worship and recreational activities illustrate a sense of their typical geographical and temporal topography (Holloway & Valentine, 2000a; Mayall, 1996). For the children, their intermittent time in the unit caused considerable displacement from their other routines and places. Not being able to consistently attend school daily with their peers was noted by some children as a major drawback of coming so frequently to the unit. Some girls, such as Chandra and Bridget, mentioned that they are not used to full school days anymore. They said that they have felt more tired since being on hemodialysis so that a full school day now is exhausting. For older adolescents, such as Jay, missing school was a particular concern because of his future academic and employment plans.

Jay: Yeah, every week when I come I miss half a day…. So, it [home hemodialysis] works out better than coming here three to four times a week where I miss like almost the whole week.
HZ: Is school the main concern for you?
Jay: Kind of right now, yeah. I want to get my education done and a good job.

To compensate for lost school time, there was an effort to impose a school routine in addition to the hemodialysis regimes in the unit. Hence, the children’s everyday routine included schooling. In a sense, they attended a second school in the unit in addition to their primary one outside of the unit. Each child was compensated with up to one hour of one-on-one time with a teacher while undergoing a treatment. The children seemed to respond in various ways to schooling sessions. Many of the younger children enjoyed the young female elementary school teacher. I
observed that they seemed to be much livelier and talkative with this teacher than other staff in
the unit. For example, Nafi, a shy, quiet seven year old boy who understood but did not speak
much English and who typically did not engage or make eye contact with many staff in the unit,
would become interactive when working with the elementary teacher.

It’s 10:00 am and the teacher for elementary school just arrived. Nafi looks up as she
walks toward him and wiggles in excitement his chair. He is excited. As they play a game
using a board, he looks directly at her and talks with her. This is surprising to me, I was
not sure if Nafi could talk or speak in English and he seems to be doing both with the
teacher. She works with him for about 35 minutes. Before the teacher leaves, I look at
Nafi from across the room, and he notices. He looks back at me and smiles holding his
hands in front of his face. I wave and he waves back. I am very surprised that he seems so
friendly and happy to see me.

I spent a few minutes with Nafi’s older sister and asked about her impressions of Nafi’s
schooling in the unit. She claimed that since working with the teacher Nafi has been talking
more, reading more and has been more engaged and active in the unit and at home. Undoubtedly
the hemodialysis treatments and medical care have facilitated Nafi’s improvement overall health.
However, this teacher also seemed to have made an impact in Nafi’s intellectual and social
development. Azed, a cheerful 11 year old boy who has been receiving treatments for seven
years, also appeared excited when working with this teacher and has benefited intellectually from
his lessons with her. Most children responded very positively to the school routines imposed by
this teacher as she clearly worked hard to engage them with her upbeat and friendly demeanour
and the use of interactive learning games. Furthermore, she spent one-on-one time focused on an
individual child. This individual attention may be perhaps more important than the school lesson
itself to some children, as they had minimal social interactions with each other and adults and the
child life specialist program was removed the previous year from the unit. Perhaps, they
experienced their school time as infused with a sense of play time because of the individual
attention and social and fun quality of the interactive games.
Not all children were enamoured to discipline themselves to school lessons while undergoing treatments. May and Thrift (2001) contend that types of time construe the meaning of one another when enacted in the appropriate setting, for example, “‘work’ time gives shape to ‘family’ time or ‘leisure’ time (and vice versa)” (p.4). Strong reactions may be evoked when a type of time is out of place, for example, when work time is imposed upon by the domestic demands of family. The intrusion of the additional school time discipline imposed on the children seemed to be resented and resisted by some of the children who were trying to pass time quickly. For example, I observed the elementary school teacher attempt on a number of occasions to engage Bridget who looked bored and uninterested. After one such observation, I asked her how she felt about having to do school work and the only response I received was an apathetic “It doesn’t matter”. Delroy also did not care for school work and was often woken up for his lessons by his high school teacher. I observed Delroy on at least three occasions avoid the teacher by pretending to sleeping when he arrived. He commented to me that “it is okay to have classes at the hospital, but it is not the same”. He clearly disliked the overlap of the school routine while being dialyzed. For these children, the simultaneous disciplinary demands of both school routines and technical and medical rituals and regimes may have felt like a double load of disciplined time, that mutually magnified and augmented one another, and consequently both felt onerous. To compensate for the loss of their school time, four of the adolescent boys stated that they opt to do school work while having treatments in order to not fall behind their peers. Yet, I did not witness them doing school work very often. Perhaps these boys believed that they should be using treatment time in what would be perceived as productive, but in reality seldom carried it out unless forced by a teacher.
A. 4. Marking time

In my first observation period, I noticed how intently most children actively marked the time of their hemodialysis regimes in order to countdown the time until they were released from their treatment and able to leave the unit. This was a significant ritual among most children who knew exactly how much time had passed and how much time was left in their treatment. Some children spontaneously mentioned this form of marking time without my prompting or questioning them, indicating its importance to them.

Although two large, clearly visible analog clocks hung on a wall on both sides of the main unit, the children did not look at them. Instead, they focused on the time remaining indicator on their hemodialysis machine. The amount of treatment time left was displayed by digital numbers that were easily seen by children during their treatment. Tammy remarked that the time remaining reading was the most important number on the machine for her. Delroy also exclaimed that he always looked at how much time he had left in his treatment. In a conversation with Jay, he expressed what he focused on in terms of the machine this way:

HZ: So you notice the hemodialysis machine. That’s something that’s really obvious to you?
Jay: Yeah.
HZ: Do you look at it when you’re having treatments?
Jay: Sometimes.
HZ: What do you look at it for?
Jay: The time I have left.
HZ: That’s the major one, the time?
Jay: Yeah, the time I have left.

Similar to Jay and other children, Emily also watched the reading on the machine that indicated when her treatment is over. In illustration 5, Emily depicted the importance of playing with her friend. She also exemplified the significance of the time remaining reading to her and how its form differed from that of the analog clocks in the room through including a representation of
Emily then decides to put a clock on both sides of the girl’s stations. I ask her why? She says “because that’s how you know how much time is left to play.” But, she tells me, the hands on the clock don’t say the time because the machine does not display time like that [clock on the machine is digital rather than analog]. She tells me that her and her friend’s treatment times are not usually the same but are close. One clock means eight minutes are left and the other that four minutes are left in their treatments.

Relationships with technologies in places transfix or alter senses of time (May and Thrift, 2001). This may be more influential when the technology itself functions to mark time as people mark time by the device. The children’s readings seemed to orientate them both to the machine’s rhythm and their time passage in the unit in an explicit manner. Marking time through reading the time remaining indicator was a form of human-technological interpretation on the part of the children. The number was a textual representation of a measurement of the progress of their technologically conjoined body undergoing a hemodialysis cycle. Through interpreting the number, children translated an embodied process into a number representing time. In this sense, when conjoined with and read through the machine, their bodies became the reference point for their temporal location in the hemodialysis regime.

Another significant domain posited by May and Thrift (2001) that impacts meanings and experiences of time are texts as “vehicles of translation” (p. 4) that codify as well as regulate perceptions of time. The time remaining indicator on the machine can be viewed as a significant representation that translated the children’s bodily cycles through hemodialysis into quantifiable and observable time. The children had an embodied response to this observable time in anticipation of their treatment conclusion. They began to glance more frequently at the machine’s timer, stopping the activity that they were engaged in and either sat patiently and quietly or became excited or fidgety. The most striking instance of a change in demeanour when
about to be taken off the machine was demonstrated from Nafi. I often observed him just sitting in his chair quietly looking around at the people in the unit. With the exception of the elementary school teacher, he habitually, but not always, seemed uninterested in interacting with me or the nurses. During the last half hour or so of his treatment, however, he noticeably became restless or perky. The following fieldnote excerpt describes typical behaviour from Nafi during my observations of him near the end of his treatment.

I walk into the private room to spend time with Nafi. Sitting beside him, I asked Nafi if he would draw a picture of the room with me. He picks up crayon, shakes his head and puts it down. He does not want to draw. I begin to draw items in the room and ask him to point them out to me. He follows my instruction with little enthusiasm. The nurse comes into the room. Nafi points at his stomach and then the hemodialysis machine. I hold up eight fingers to show eight minutes are left for his treatment. He looks at the time indicator on the machine and holds up eight fingers and smiles in response. About every minute or so, he smiles broadly and claps his hands, moving his body up and down in the bed as if he was jumping. He seems very happy that his treatment is almost over. Rarely, is he this animated. When the nurse takes him off the machine, he continues to smile while making eye contact with me.

Because Nafi has limited speaking and reading ability, I became curious how he knew his treatment was coming to end. On one occasion, I was sitting with Nafi and had the opportunity to ask his sister, who sometimes accompanied him to the hospital, this question. She replied that she is not sure, but believes that he watches what is happening around him and can read clues for how long he has been in the unit, including that of the machine’s time remaining indicator. As we talked, Nafi pulled up his sleeves and pointed to each wrist. He understood we were talking about time, specifically his time in the hemodialysis unit that was almost over.

Conclusion

Technologies that mark or alter the passages and senses of time and space are one of four interrelated domains that structures the nature and experiences of timespace in places (May and Thrift, 2001). In the unit, the hemodialysis technology appeared to be the major force
determining the timespace of the unit and by extension, how children perceived and embodied time. Similar to the children, each hemodialysis machine underwent its own routine to prepare to be conjoined with and removed from a child’s body to deliver a treatment. The machine had a specific temporality that structured and enmeshed with the rhythm of children’s bodies, the professional routines and practices of staff, such as nurses and technicians, and the overall unit scheduling of hemodialysis cycles. Hence, children’s regimes and routines in the unit were regulated by the temporal technical operations and limits of the machine. Children were well-disciplined in the unit’s technically-driven routines, and conformed readily. Although the children’s and machine’s routines differed, both shared a quality of invariable everyday sameness and predictability in their patterns, tempos, and practices. In addition to the nurses’ careful monitoring of their patients’ treatment cycles, most children also ritualistically kept an eye on the remaining treatment time indicated on the hemodialysis machine that was a textual representation of their bodies progress, marking time until their treatment end.

Virtually all of the children discussed experiencing their time as long, as wasted, as lost as boring or as taken from them. Time for them was to be passed as quickly as possible. Their embodied sense of time cannot be said to be objectified, quantified or universal among the children, as their sense of time as fast or slow varied depending on their activities in the unit, which demonstrated some gender and age-related differences. The older boys, such as Shen, Jay, Delroy and Jimmy and some of the girls, such as Tammy, Emily and Chandra tended to have different strategies to pass time that seemed to create different experiences of time based on gender. To make time move faster, boys used more passive and avoiding activities, such as sleeping and watching television, whereas the girls used more interactive social and play activities with other females. Embedding time in social relations in the unit, the girls actively attempted to transform a sense of time as boring to as fun or enjoyable. The gendered differences
in perceptions of and responses to time among some of the children demonstrated time’s multiplicity and heterogeneity, skewing the assumption that time is experienced or constituted universally in a particular setting (Adam, 1990, 1995; Felski, 2000; May & Thrift, 2001). Additionally, the girls’ desire to entertain themselves in the unit also may have been an attempt to recuperate some of the play, socialization and recreation they are displaced from due to their time spent in the unit.

Furthermore, the children were subjected to an overlapping of places and routines of medical care and school that are typically separate for healthy children without kidney disease. For some children, the combination of schooling with hemodialysis treatments seemed to alleviate boredom to some degree by providing stimulation and socialization. For others, the school routine seemed more of a burden to be avoided if possible.

Because I tended to follow the children’s routines in the unit, during my second period of data collection, I became highly aware that the routines of children in the unit rarely varied from day-to-day. My observations and records became a chronology of the *same* everyday, in which a given day could be interchangeable with another. I reflected that I initially experienced a vividness of the space, people, and activities at the beginning of my first period of data collection that progressed over time to a dulling of experience.

**Section B. Space: Everyday Confinement and Constraints**

**B. 1. Tethered to the hemodialysis machine**

Hemodialysis treatments involve blood being moved out of children’s bodies to be technologically cleansed and then pumped back into their bodies by the machine in a closed circuit. Hence, the children undergoing hemodialysis regimes must remain seated in a chair
attached to the machine by plastic tubing for a number of hours. In one of our first encounters, Chandra explained the treatment to me like this: “It’s like sitting in a chair with a line.” The children literally were tied to the machine that restrained their bodies in a specific physical location. In addition, the children must restrict their movements in the chair as not to occlude the tubing, often referred to as a line. For example, sitting too far down may impact the movement of fluid going in and out of their bodies and rolling over may block the line. The children seemed to have a sense of how to position or hold their bodies in such a way as to not interfere with the lines or their treatment. In illustration 2, Chandra also depicted that “sitting and not being able to move” was something she did not like about hemodialysis. Jay described how it feels to be tethered to the machine and forced to sit in one place for an extended period of time:

The chairs are comfortable but then you feel like, I don’t what the word is, like you feel uncomfortable, like you want to move. You feel like you have the energy. You want to move around. You don’t feel like just sitting here doing nothing. Like then otherwise all you are doing is watching TV or playing video games. You don’t want to do that. You feel like running around. But I don’t mind it, like it’s not comfortable but you know, you’re used to it after all these years.

Although uncomfortable, Jay also indicated that he has become accustomed to and complacent with this sedentary and tethered position over the years. Similar to some other children, Chandra and Jay emphasized that the sitting and stationary posture that they must maintain for treatments was not well liked.

The hemodialysis technology directly structured the children’s situated socio-spatial positions in the unit. In addition to the children’s tethering to the machines, the physical placement of the hemodialysis machines and stations structured the reference point from which the children experienced the unit spatially, temporally and socially and determined what they could and could not do. In chapter IV, the physical space of the hemodialysis unit was outlined in detail. As well as the time required from the nursing, technical, and cleaning staff in care
routines, the machines commanded space in the unit. Hemodialysis machines are large, rectangular units that occupied a sizable area beside each chair at stations. The location of the stations and the children were compelled by the needs of the hemodialysis machines. Requiring electricity to operate, each machine must be plugged into wall receptacles that limit the ability to move the device. Furthermore, each machine is associated with a larger complex water treatment and solution delivery system that resided outside the unit. Each functioning machine is attached to this treatment and delivery system through a series of pipes in the unit wall that run to large tanks in another room. Electrical and pipe sources are close to walls in the unit. Tethered to these machines, children must sit at their hemodialysis stations in the four corners of the room except when entering and exiting the unit. In my view of place, social and physical spaces interact with one another (Andrews & Kitchin, 2005). The hemodialysis machines exert a spatial effect, so that both technology and the built environment are mutually constitutive of the other, while shaping the children’s embodied positions (May & Thrift, 2001; Poland et al., 2005; Prout, 2000, 2005).

In addition to structuring the children’s situated socio-spatial positions, the hemodialysis technologies also constructed the overall socio-spatial configuration of the unit. The children and adults typically occupied different spaces in the unit. For example, in the middle of main unit area, two circular tables that held computers were used by staff to access information and health records and to write notes. During shifts, doctors and nurses sat at these tables to work. Mothers or fathers also sometimes sat at these consoles while their child was dialyzed. Because of their location in the unit, I noted that children rarely sat in these areas. Similarly, the children did not enter the windowed room off the main room used by the staff for lunch and meetings, unless specifically invited when not connected a machine, such as during a scheduled party. Hence, the children’s embodied situatedness involved spatial restrictions that resulted in a limited ability to
move and interact. The contrast between the children’s physical segregation was striking in comparison to the professional staff members’ and family members’ capacities to move around in and come and go from the unit. Hence, the children’s positions in the unit’s timespace radically differed from all others, including mine, while they spent time in the unit.

The children’s technological embodiment diminished their capacity for agency and action and created their dependency on others. For example, items that children may want, such as drinks, food, games or books cannot be accessed by them. Desired items must be asked for by children or offered by others and then brought to the location of the child as he or she waited. Most books, games, crafts and videos were stored in locked cupboards in the waiting room or scattered around the unit rather than where children spent most of their time. I observed that over time children learned the items that were available and asked staff, parents, volunteers or me to retrieve them.

The view that children’s embodiments are “inseparable from, produced in, represented by, and performed through their connections with material objects” (Prout, 2000, p. 2) facilitates my understanding of how the hemodialysis machines and built environment directly impacted the children’s embodied position in the unit. Their lived space in the corners of the main room appeared small and limited, and was comprised of a hemodialysis chair, rolling table and a machine. So that a parent, volunteer to staff member may sit near them, a chair could be pulled into the space. The children’s physical confinement in a chair beside a machine in a hemodialysis station located in the corners of the main room or a private room may be viewed as analogous to being confined to a cell-like space. Because they cannot escape being conjoined to the machine, the machine acted as prison guard that confined the children temporally and socio-spatially in the unit’s timespace for the duration needed to complete its routine. Because of their technological
dependency, the children are conceived as subjected to an intermittent sentence of hemodialysis that was technologically derived within the everyday routines of the unit.

**B. 2. Complexes of human-technological and social relations**

My conception of children’s embodied situatedness in the unit is framed by a view of place as comprised of complex interconnections between physical and social topographies (Andrews & Kitchin, 2005). Significant to the setting was the effect of the hemodialysis technologies on the social relations as well as the built environment. My observations confirmed that the particular way the hemodialysis technologies were culturally embedded (Ihde, 1990, 1993) structured the staff groups’ relationships with the children and each other. The unique socio-spatial characteristics of the professional and nonprofessional groups emerged from their particular position within complexes of both social and human-technological relations in the unit.

Depending on their role, the staff members interacted with the hemodialysis technologies to differing degrees and the degree of their human-technological relations impacted their interactions with the children. Some professional groups that provided direct care to children, such as the social worker, dietician and teachers, interacted with the children and each other about the treatment plan and care of the children. These professional groups did not directly interact with the technology, and thus, were less tied to the unit. For example, the social worker and dietician only on occasion visited the children and the teachers only spent a few hours with children daily to provide school lessons in the unit. Although these groups directly related to the children and not with the technology, nevertheless they had to come to the unit because of the children’s conjoinment to the hemodialysis machine.

Much like the dietician, social worker and teachers, the physicians did not directly interact with the hemodialysis technology and thus, also were less tied to the unit. Their technological
relation with the machines may be described as indirect as their role encompassed prescribing dialysis treatment programs that were carried out by the nurses. A physician entered the unit once or twice a day and occasionally interacted with a patient and his or her nurse. Typically, I observed them quietly checking charts and writing notes by hand or on the computer and then leaving the unit.

Some of the staff groups’ human-technological relations played a particularly significant role in their place within the unit’s social and technological structure. With the exception of the nurses who cared for both the machine and child, the stronger a staff member’s role focused on the direct care of the hemodialysis machinery and equipment, the less likely he or she was to interact with the children or other staff groups. This phenomenon pertained mostly to the technicians and the staff who cleaned the machines before and after treatments. The technicians interacted primarily with machinery and only occasionally with the nurses when they periodically entered the unit to prime and configure a hemodialysis machine. Notably, the non-professional staff who cleaned the machine following a child’s treatment tended to be ignored and ignore others despite the amount of intermittent time spent in the unit each day. Hence, clear cut demarcations among the staff groups and children due to the overall interconnections among established human-technological and social relations permeated the unit. The degree of each staff group’s human-technological relation seemed to be inverse to the degree of their social relations with children. Hence, the human-technological relations among the staff groups shaped the configuration of their socio-spatial interactions among the people and place of the unit’s timespace.

The nurses were the only group that interceded between the technology and the children, having both strong social and human-technological relations in the unit. They were the largest staff and adult group, and the most significant to the children because they spent the most time
with them. My documented observations recorded that the nurses had the strongest presence and
appeared *at home* in comparison to all other staff groups who seemed to be, more or less, visitors
to the unit. A few children remarked that “I see mostly nurses, I don’t see doctors very much” or
“doctors once in a while they come around, you know if you’re sick or something. But nurses
are always there.” The nurses also were the only other staff group who experienced a form of
strong non-physical tethering to the hemodialysis machine although they were not as profoundly
physically or socially restricted as the children. Because of their primary nursing role, the nurses
must be available at all times to monitor the machine and treatment progress and respond quickly
to problems. Because of this, they must remain in the unit near the children. On only a few
occasions I witnessed a nurse leave the unit for a break. Typically these breaks typically were
less than one half hour and were planned among all the nursing staff. Furthermore, their time was
bound to the cycles of children’s bodily progress through hemodialysis that they monitored by
the machine’s numerical recordings.

Within their relations with the children, the staff nurses often *read* the child through the
numerical outputs represented by numbers on the hemodialysis machine or other medical
equipment and tests. For example, blood work and weight taken prior to a hemodialysis session
provided a representation of the children’s physiological status that must be interpreted to
become a perception or information. These recordings as texts act as “vehicles of translation”
(May & Thrift, 2001, p. 4) for the complicated assessment parameters. The children’s bodies
were translated through these numbers that then dictated the treatment goals in terms of fluid and
waste removal. Ihde (1990) considers this type of human-technological relation as having a
somewhat “objectness” quality (p. 97). Similarly, the physicians, whose role encompasses care
of the children, routinely appeared to assess the children with information derived from charts,
reports, or lab results that are on computers or in hard copy documents rather than directly
interacting with children. As such, the nurse and the physicians engaged in a hermeneutic interpretive process of discerning the children’s physical status, such as their body chemistry or blood pressure, through their translation into technologically derived numbers, words or images, rather than their material bodies or through live interactions (Ihde, 1990, 1993).

The children were caught up in the complexes of the human-technological and social relations that transformed how their bodies were conceived. No longer can the children’s bodies be viewed as, nor did the nurses and doctors treat them as, natural entities. Instead their bodies can be viewed as comprised of discursive, technological and biological qualities (Prout, 2000, 2005). Place (2000) claims that if “the corporeal body…and exists only in so far as it can be made visible then the form of visibility is the phenomenon” (p. 173). The form of the children’s visibility was part of the situated knowledge production in the hemodialysis setting that ultimately impacted how the child becomes known. In Place’s (2000) terms, these interventions are a process of the “sorting out” of a child (p. 174). The primacy of the children’s visibility as technologically enhanced data rather than as embodied beings had consequences for the children’s embodied position. How the children’s identities and roles primarily as patients took shape is discussed in the following sections.

In Ihde’s (1990) view, any use of technology mediates the user’s relationship to the world. In this case, the world refers to the children and their nurses’ care roles. The nurses clearly provided meticulous and expert services as they diligently executed actions related to children’s care and needs. Specifically trained in techniques of hemodialysis, a large part of their role must entail a focus on the hemodialysis machines to provide safe and effective care. In the nurse and child relations, the nurses encountered and interacted with the machine as an instrument by which they cared for the child. Because of this, the nurses may be considered as relating to the machine more as “technology-as-other” (Ihde, 1990, p. 98) unlike the children’s technologically
mediated embodiment. As pointed out previously, the nurses’ human-technological relations shaped their social relations with the children. I observed that they often appeared to attend more to the hemodialysis machines than the children. For example, I frequently noticed a nurse standing in front of a machine, adjusting a setting or looking at the outputs represented by numbers with his or her back to the child, rather than tending to the embodied child sitting before them. Hence, they appeared to be primarily activated by or on call for the machine rather than the children. Observing the nurses over time demonstrated that their human-technological relations in the unit often overshadowed their social relations with their patient.

Among the nurses, some almost exclusively engaged with a child only about treatments and physical care and in turn, the children did not engage much with them. On one afternoon, Delroy and I discussed the people he sees in the unit, such as the nurses, the social worker and the dietician. He confided to me that “I have no use for those people because they just try to make me do stuff” and that he liked some nurses but not others. Some nurses also engaged with the children more personally and played games or did crafts with them on a regular basis. These nurses seemed to be well liked by the children who talked fondly about them. In one of the few instances he spoke positively about a nurse, Delroy pointed out the male student nurse to me on his unit tour and said, “that’s [male student nurse], my boy. You know, he always picks on me, but we’re still friends. You know, he’s the best nurse.” The following fieldname excerpt describes one of the few times I observed Delroy enjoy relating to the nurses in the unit.

When I arrived on the unit, my eyes are drawn to Delroy as he sitting up and playing with the student nurse, rather than sleeping like usual. I walk over and discover that they are playing a computer version of “Who wants to be a Millionaire”. Delroy is very animated, with bright eyes and is talking loudly while calling out answers to the questions. Nafi’s sister and I sit at the console nearby and join the game. Our excitement catches the attention of three nurses who come to watch and then join the game, also calling out answers. Delroy is very excited when he wins money by answering a question correctly. He dances with his upper body and arms and yells – whoo, whoo! This is by far the most joyful that I have seen Delroy. He begins to fantasize what he will do with the money and
says he will be a rapper with lots of clothes, jets, and houses. In a generous gesture, he also says he will give me and each nurse five jets and five houses, each with a movie star in them. Also, that we have to be around him, all dressed up and ‘rich-looking’. We tease him by saying he wants us to be his entourage and groupies. Right then, the male student nurse walks by and Delroy said “It is good to have him here because he is a guy.” He said, “Guys are the best” and beat his chest with both hands.

In this instance of unusual playfulness with the nurses and me, Delroy imagined a gendered music video-like scenario, with him as a rapper encircled by “dressed up” and “rich-looking” women. Male companionship and camaraderie, in a unit where nursing and other staff are predominantly female, appeared significant and enjoyable to Delroy. Interactions with nurses of the type described above involving Delroy were less frequent than expected given that nurses spent the most time with the children because of their role. As children and patients in the unit, the children infrequently had the opportunity to present themselves and be acknowledged as persons, who are gendered within a range of interests and desires beyond those associated with their chronic illness and medical interventions. However, my focus on both human-technological and social relations reveals the complex position of the nurses who must attend to both the hemodialysis machines and the children unlike any other staff group in the unit.

B. 3. Being visible-invisible

In the conception of place that I use, physical space and social space are mutually constitutive and space is viewed as the medium and outcome of social relations, intersected by individual and group differences, such as professional and social status, gender and age (Bondi, 2005; Massey, 1994, 2004, 2005). I also view human-technological relations, as well as social relations, among the children and the staff groups, as playing a key role in constituting identities in the unit. The hemodialysis technologies can be understood as “inescapable mediators in the construction and reproduction of lay and professional identities” (Poland et al., 2005, p. 175)
through their impact on the unit. Predominantly, the children’s situated socio-spatial position in
the unit’s main area was derived from their technological embodiment. Their position entailed
that they virtually were always visible and audible to the nurses, other staff and visitors. The
children also were visible in the two private rooms due to their large windows, but not quite as
much as when in the main room. Positioned within eye and ear range undoubtedly enhanced the
nurses’ ability to provide care in a timely and effective manner. However, the children were
afforded little privacy and choice about who may observe or disrupt them at any given time.

In general, all the children endured a lack of bodily and social privacy in the open
environment of the unit. The routine when preparing for the beginning or end of a treatment
required that the children disrobe in front of others. This ritual allowed the children to be
accurately weighed and their fistula, graft or catheter site, which was often in the chest, accessed
by a nurse so that the line from the machine could be attached to their bloodstream. Typically,
the girls did not strip down completely to their underclothes as the younger boys, and sometimes
the older boys did. Yet, I learned from one girl that exposing her body in any way was a problem
because of her religion and her father’s disapproval. One adolescent boy claimed he did not care
about getting undressed in the unit, but one day remarked about this unfairness to me by saying:
“I don’t understand why Nafi, Azed, and I have to get undressed to be weighed and the girls
don’t. I think we all should have to get undressed”. His comment communicated a sensibility
about the unevenness and unfairness of gendered privacy in the unit. While some allowances
were made for the adolescent girls, this sort of lack of bodily privacy transformed the status of
both girls and boys into patients that included a reduced identity as an individual who is
gendered or has specific preferences.

The children’s routines highlighted the focus on medical care of their physical bodies that
also diminished a sense of their embodiment. For example, the nurses ritually pulled the curtains
around the station for medical procedures, such as sterile dressing changes and to access the line at the beginning or end of hemodialysis to decrease the possibility of infection transmission, but did not use the curtains at other times. It appeared that the curtains were used for the children’s protection from infection rather than for their privacy. However, I did note that no child requested that their station’s curtain be closed at any point while I was in the unit. Hence, the depersonalization in their roles as patients demonstrated by their lack of privacy also was an aspect their sentence of hemodialysis that children endured. Often, the embodied individuality of the children was rendered invisible even though they were physically visible.

Because individuals also are relationally embodied in places, the experiences of the children also were structured by situated social relations and discourses in places (Prout, 2000, 2005). Certainly the children’s tethering to the hemodialysis machines in the open physical space of the unit led to their lack of privacy. This constant visibility amplified their identity and roles as patients rather than individuals. In most institutions, adult patients also are afforded little privacy in multiple ways. However, given that the patients in this unit are children, I question if children’s lack of power and status relative to adults also played a role in their lack of privacy.

In my conception of place, the children are viewed not only as shaped by place, but also as active participants in its constitution (Andrews & Kitchin, 2005; Prout, 2000, 2005). However, children’s continuous visibility prompted me to consider the extremely limited ways that the children were able to create a quiet, private space when they did not want to be noticed or interacted with in the unit. Often, their attempt to accomplish some privacy was through their bodies, such as turning away from people, not smiling or making eye contact. Even so, the children experienced frequent disruptions, regardless if sitting quietly, consulting with the dietician or social worker, or playing a game. Many disruptions were unavoidable because nurses
must make adjustments to their treatment programs via the machine or take blood pressure every half hour.

**B. 4. Segregation and isolation**

The children’s technologically conjoined embodiment directly impacted their participation in social relations in the unit. On most days and times, the hemodialysis unit was a busy place, with health care providers, cleaners, family and visitors coming and going through the unit. The center of the main room was the thoroughfare that people must pass through to go into adjunct rooms, such as the staff meeting/lunch room or kitchen. Busy periods frequently occurred on weekdays when three or four children received treatments and about twelve staff or family members visited or occupied the unit. Some children remarked on how inhabited the unit seemed to be. For example, during one early meeting with Navina, I asked “what surprised you most when you first came here?” Her reply was, “How many people are here, I thought I would be more alone here”. Despite the number of people in the unit, the children experienced long stretches of time with limited friendly and sociable interactions.

Ihde (1990, 1993) remarks that a machine’s use in any setting alters bodily, spatial and temporal orientations as it mediate one’s relations in and to the place. The children’s social segregation and isolation was an effect of the patterns of the social relations and human-technological relations among the people and the technologies in the unit. The unit’s physical arrangement of hemodialysis stations did not well accommodate socializing among patients, limiting the children’s ability to talk or play with one another. Furthermore, the fact that children constantly were within view of the staff and their roles as patients also may have inhibited their ability to interact with one another. Because of their segregation and isolation, the children complained about feeling lonely and alone. Developing friendships with other children receiving
hemodialysis often was difficult. Chandra, on multiple occasions, expressed to me the importance of socializing with a peer to pass time in the unit. In particular, she desired to play with Emily, who was close in age to her. This often was achieved if they directly asked the nurses if their chairs could be moved close together, which sometimes was not accommodated by their nurses. Shen, who was a newcomer in the unit during my third observation period, told me that he felt alone and that “it would be more fun if there were more people here”. He expressed a desire to make friends which I recorded in this field note observation.

“I would like to make friends in the unit but…” Shen gestures with his hands, he opens his hands with his palms facing up and shrugs his shoulders. I understand this to mean there is no one in the unit he can get to know to get to know. I ask: “Have you met anyone here you could get to know?” “No, he sleeps all the time (gesturing at Delroy) and there are babies.” He says he wants to go to sleep, and after I walk away, he does for the rest of his treatment.

Shen indicated that he would like to make friends, specifically with another boy who shared his experience of kidney failure and hemodialysis and had a similar treatment schedule to himself. This was reinforced by the fact that Shen was not very enthusiastic about spending time with me, even if we did an activity he wanted, such as watching television. Of the 11 participants, only two or three appeared to know one another through receiving care at the institution prior to beginning hemodialysis. Participants on different shifts rarely had contact with one another, except at annual events, such as the Christmas party. Both Chandra and Shen had limited opportunities for gender-based peer relationships as the children dialyzed at the same time were often of a different age or gender.

A number of the children also elected to not interact with other children. For example, I observed that children on the same treatment schedules often did not look at or acknowledge one another’s presence, even though they were placed in chairs directly across from one another. Frequently, the boys did not interact with one another or with girls. Over two observation
periods, I noticed that two boys, Nafi and Delroy, typically had treatments at the same time at least two or three times a week. Often they were placed in chairs that were directly across from one another or side by side. In only a few instances, I witnessed one of these two boys acknowledge or talk with the other.

Over my time in the unit, I discovered that a sense of community existed among some participants and their family members, but not within the space of the unit. The waiting room was the place in which the most frequent and friendly social interactions occurred. About half of the participants and their families used this room and staff rarely entered it. While their child was having treatments, some parents and siblings talked to each other or watched television together. Before and after treatments, some children also spent time with other children who had a treatment on the same shift, such as Delroy and Nafi. Lunch or a snack sometimes would be eaten together. Conversations overheard between children and families and with myself were warm and personal. This amount and type of interaction shared by certain children and families rarely was evident in the hemodialysis unit.

**Conclusion**

Overall, the children’s everyday routines in the unit progressed in an invariable and repetitive rhythm so that the temporality of the timespace was integral in shaping their embodied experiences. The effect of the hemodialysis technologies on the built environment and social relations also played a key role. The children’s socio-spatial positions in the corners of the unit magnified their isolation and constrained their ability to interact with others. Their position was an effect of the machine’s need to be physically placed to access to a continual power and water supply that was derived from lines that come from walls. In comparison, the staff and visitors occupied the center of the room or accessed all areas so that the adults and children inhabited
different areas of the unit. Many items were inaccessible to the children who were dependent on others to retrieve them. Hence, the hemodialysis machines exerted a powerful spatial and social influence on children’s embodied situatedness. I have conceived of the machine, when conjoined with the children’s bodies, as a prison guard that incarcerated them in the unit’s timespace.

Fairly predictable and stable patterns of social and human-technological relations occurred among the staff members and children. Most staff groups, for example the technicians and cleaners, who spent the most time caring for the technology, spent the least amount of time caring for or interacting with the children, except for the nurses who straddled both social and human-technological relations. However, the predominant preoccupation of the nurses’ appeared centered on the children’s technological or medical needs. I occasionally observed nurses spending time with children in a social manner that incorporated a boy’s or girl’s individuality and identities. However, the strong focus on their human-technological relations was comprised of interacting with the machine as a means to care for the children. Also, their interactions included using the machine’s textual representations of body processes to provide critical patient information rather than the embodied child. These human-technological relations reiterated the predominant view of the children’s identities and roles as patients foremost. The nurses’ unique role that required engagement in both social and human-technological relations is worth noting here as their relationships with the children were deeply implicated. The dehumanizing and alienating effect of technology on the nurse and patient relationship has been well-documented, and was seen in the unit. Often, highlighted also is the nurses’ complex position among both technologically-focused and person-centered dimensions of caring (Almerud, Alapack, Fridlund & Ekebergh, 2008; Bennett, 2010, 2011; McGibbon & Peter, 2008; Tranter et al., 2009).

Considering the view that people shape and influence places, and in turn, people are constituted in and through places (Andrews & Kitchin, 2005), I conclude that the socio-spatial
arrangement of the unit obscured differences among the children, such as gender, and stripped their individual identities to that of a patient. The children had a lack of privacy unlike the non-patients in the unit. They also had constraints in their ability to create a space for themselves where they were not visible to others and their conversations could not be overheard. In addition, the physical and social features of the unit did not well accommodate connections between children, allowing them to socialize and make friendships. Hence, the unit had a highly specific form of technological-culture embeddedness that shaped both the people and place. Nevertheless, on the few occasions I happened to bump into some children and their family members outside of the unit, such as the waiting room, and was struck by how well acquainted and friendly they were to one another.

Because children were tethered to their machines in the corners of the main room unable to leave their chairs for hours, I endeavoured to stay in the unit while they received treatments to put myself in their situations as much as possible. Typically, I left the unit only to record jottings or fieldnotes in the unit’s adjoined hall or in the bathroom. My goal was to try to experience being socio-spatially confined like the children, and included staying in the periphery of the room in corners with them. As my time progressed through the study periods, I increasingly found being in the unit for hours restricting and uncomfortable. I missed the ability to leave the unit to get something to drink or to be away from the noise and people to have some time in private. Sitting in the corners, I also felt less apart of the unit’s social life. Most surprisingly, my confinement contributed to my own feelings of everyday sameness, similar to that described by the children. However, unlike the children, I could stand and move around the unit if I chose. I also was included in the peer relationships among nurses, and staff and other adults who accepted me as similar to themselves. Hence, as an adult, nurse, researcher and a non-patient, my status also differed from that of the children. These experiences assisted my understandings of
the way in which the children’s embodied situatedness was foremost derived from their human-technological relations with the hemodialysis machine.

Section C: Technology: Everyday Life on Hemodialysis

C. 1. Relating with the machine

The technologically driven timespace of the hemodialysis unit structured the both the children’s temporal perceptions and socio-spatial positions and relations. The children also experienced a variety of human-technological relations as part of the technological topography of the unit. During hemodialysis, children’s bodies were conjoined with a machine that takes over kidney function. According to Ihde (1990, 1993) this type of relationship is embodied as the technology mediates between the person and their world. The children’s technologically mediated embodied form of treatment was highly visible and tangible as well as time consuming and spatially restricting to children. One of my study goals was to investigate the ways that children perceived and responded to their technological conjoinment. In a chat with Emily, she recalled what she thought and felt when she was first attached to the hemodialysis machine.

HZ: What did you think the first time you saw the machine?
Emily: It was like whoa… like… It was cool.
HZ: It was cool?
Emily: Yeah, the blood.
HZ: Yeah?
Emily: I was scared of it.
HZ: You were scared of it?
Emily: Mmm hmm
HZ: Oh, how come?
Emily: The line, the blood. It’s going around and around.

Emily, who was fairly new to the unit, articulated the anxiety and wonder of technological embodiment, when her body was incorporated with a machine and observed to be extended
beyond its usual physical boundaries. She was one of the few children who responded to my questions or comments about their bodily attachment to the hemodialysis machine. Somewhat unexpectedly to me, many of the children did not, nor could not, talk about how they perceived their bodies in relation with the machine while they received hemodialysis. After reflection, I considered that their silences may be because the hemodialysis event was occurring in the immediate moment so that contemplation of their technologically conjoined embodiment at that time was very difficult emotionally. Conversely, the lack of their verbal responses may be the result of some of the children relating with the machine more as an object (Ihde, 1990, 1993). A few children confirmed this view when they rationally conversed about the technical aspects of the machine with a high level of technical knowledge. One day while sitting with Shen, I asked what he noticed about the machine. He replied, “I like it. It’s interesting, seeing my blood go in it and get cleaned and everything. I like it because it is, like, science.” Although Shen talked about watching blood move out of his body and into the machine, referring to the machine as science suggests a relationship with the machine that can be conceived as mechanical, distant and distinct, rather than as part of his embodied self.

Some of the children’s remarks suggested a viewpoint of the machine as neutral, rather than transformative or meaningful. I have taken the view that technologies are non-neutral entities that impact human perceptions, actions, and relations and construct and reveal the world in ways specific to that technology (Ihde, 1990, 1993). When a person embodies a technology, Ihde (1990, 1993) claims that the world is mediated through it, shaping the way a person perceives or relates to their environment. Technological mediation may be perceived as interference between oneself and their environment and in this case, the person remains aware of their bodily relationship with the technology. Emily’s and Shen’s points of view represents this position. Alternatively, the machine may be well integrated into oneself allowing smooth
functioning in an environment. In this case, the bodily relationship with the technology is no longer perceptible (Ihde, 1990, 1993). Chandra’s experience suggests this type of embodiment. When I asked her about receiving hemodialysis, she remarked that her line doesn’t bother her much and she rarely notices that she is hooked to a machine. Her comment suggests that she has become habituated to her technological mediated embodiment so that the machine and tubes have become taken for granted over time as an extension of her body. Hence, the machine may recede from awareness once the children have become more or less accustomed to treatments so that it is perceived as just another feature of the unit.

My observations of the children’s human-technological relations confirm that their embodied situatedness in the unit was directly entwined with the physicality, function, and demands of the hemodialysis machine. Although the children may not notice the machine, it profoundly affected their temporal perceptions and socio-spatial position and participation. In section B, I posited the notion of the hemodialysis machine as a prison guard that shapes children’s experiences in the unit’s timespace. Rather than viewing the machine as other or adversary to the children, their conjoined status is the factor that captivated them in a highly specific temporal and spatial manner. The children’s need for human-technology coupling bound their bodies to the rhythm of the machine that dominated the unit’s temporality and spatiality, which then shaped their temporal and spatial experiences.

The children, as others in the unit, also experienced the hemodialysis technology through the sounds produced by its machinery. The mechanical sounds of the unit were described briefly in Chapter IV. I particularly found that the noise generated by hemodialysis machines conspicuous and ever present. The machines rhythmically hummed, vibrated and thumped as blood was pushed through the tubing in and out of a child’s body in a rhythmic manner. Occasional shrill alarms and piercing beeps alerted the nurse to the status of the machine and
patient. Sudden and dissonant, I often was often jarred by these sounds. Furthermore, the mechanical sounds occurred in an automatic and pre-programmed manner. These sounds contributed to and created the sense of a rhythmic and routinized order to the unit. I questioned over half of the children about how they experienced the machines’ noises. All children asked remarked that they are not bothered by the sounds and do not notice them. It appears that the mechanical noise receded from these children’s awareness, becoming a ubiquitous element within the background of the unit. In this situation, the human-technological relation is distinguished as a background relation that shapes the context of the unit, but is not experienced directly as embodiment or through interaction (Ihde, 1990; Verbeek, 2008). The children have become accustomed to the technological background of the unit unlike me for which the mechanical noise never dissipated.

The children’s embodied situatedness was located among interplay of natural-social, biological-technological and material-discursive processes that were constitutive of the unit’s timespace. Although not considered by Ihde (1990, 1993) to be an embodied relation, such as that with the hemodialysis machine, the children also were engaged in human-technological relations with many technological instrumental devices that are intervening. For example, they were subjected to multiple technologically generated representational translations through which their physical bodies became visualized and known. Although many of the children paid little attention to their physiological status and progress, they participated in the rituals of these medical assessments. For example, blood pressure was taken every half hour and talking or movement may influence the accuracy of the measurement. The children were well-trained in that they stopped talking and moving their bodies, ceasing any activities for a minute or so until the procedure was completed. Some children helped the nurses by putting on or taking off the cuff. The first number of times I sat with a child while he or she did this, I did not understand the
routine. The children disciplined me to the rules by either ignoring me, shaking their heads, or, in the case of Jimmy, putting a finger to his lips to indicate that I needed to stop talking. They clearly took seriously their job to helping to ensure that reading be as accurate as possible. Not following these rules were probably the times I felt most like an outsider, out of place in the well-established and well-understood rituals and routines of the unit. The children appeared to be as disciplined in these types of human-technological relations, as in the routines of preparing to be hooked on or off a machine.

**C. 2. Living on technology**

Although children often did not comment directly on their bodies and the hemodialysis machine, some bodily effects of kidney failure occasionally were evident to me. Urea, a by-product of protein metabolism, typically is flushed out of the body through urine. When kidneys fail to function, urea and other uremic toxins accumulate in the blood. A goal of hemodialysis is to remove these waste products. At times, I could smell the sharp odour of urine or ammonia on some of the children’s breath and skin. The bodily consequences of kidney failure also were readily felt by the children. Because children with ESRD are unable to excrete urine, they must severely restrict and carefully monitor their diet and fluid intake. Similar to other children, Jimmy noted at one point “I am thirsty all the time”.

A question I asked of all children, who were able or willing to respond, was “what is the hardest thing about having kidney disease?” Seven children responded, as did Delroy, with the answer of “not being able to drink very much”. Furthermore, some children displayed a great deal of understanding about the amount of fluid allowed each day. Delroy explained that he used to be able to have 1000 ml per day, and then this amount dropped to 900 ml per day, and now he can only have 600 ml per day. This amount is the equivalent of about two to three juice boxes.
Chandra also answered that “Not being about to drink – that’s really hard” in response to my question. Similar to Delroy, she also had an acute awareness of the daily amount of fluid allotted to her. “I have now 700 ml a day. I used to have 150 ml at first and used a 30 ml cup to drink out of”. Both Delroy and Chandra described to me in detail how much fluid is in various containers, such as those for pop and milk.

In that fluids and thirst were so frequently commented on by the children, feeling constantly thirsty can be considered as one of the most arduous and agonizing aspects of living with kidney disease endured by the children. Unable to speak very much, Azed’s behaviour over my time with him suggested his attention to fluids. I recorded this encounter with Azed in my fieldnotes.

Sitting in his stroller alone in middle of the unit waiting for his caregiver, Azed had just finished his treatment. I squat down to be eye level with him and say hello. He leans against me with his head down, and mumbles quietly. I can’t make out what he is saying but I know that he is not talking to me. I am holding an unopened bottle of cold juice in my left hand that I was taking to the staff room to drink. He reaches over and quietly touches the juice bottle, tracing the bottle with his fingers and touching the condensation. He doesn’t try to take it away, just touches it all over with circular motions while he continues to mumble, not looking at me.

In this encounter, Azed was totally engrossed with my bottle of juice. On another occasion, Azed told me it was his birthday and asked if I was going to give him a present. When I asked what he wanted, he replied, “ice machine”. He followed this desire by making a sound like the ice machine in the kitchen. He repeated the words “ice machine” four more times in the next 15 minutes. In another instance, Azed talked about Christmas and asked: “Is it over? I want an ice machine!” His focus on the ice machine was further emphasized when we had our unit tour. Azed virtually ignored all aspects of the unit to quickly lead me to the kitchen to show me the ice machine. My recording of the tour consists primarily of sounds of the ice machine as Azed requested that I turn it on multiple times for him.
Clearly fluids were a major preoccupation of the children due to the severe restrictions they endure daily. Many children also were concerned with the possibility of too rapid fluid removal and dehydration during a treatment and these preoccupations were the most noticeable responses regarding their bodies on hemodialysis. Most of the children understood that intake of fluid is connected to their weight prior to the beginning of a treatment and this weight corresponds to the amount of fluid that must be removed from their bodies by the hemodialysis machine. The amount of fluids to be removed is calculated based on the difference between their predetermined typical dry weight and the weight that they begin their treatment. The amount of fluids that must be removed from their bodies, for the most part, determines the length of their treatment. A few children observed their treatment very closely in terms of how much fluid is removed from their bodies. I recorded this incident involving Jimmy when he watched his blood pressure as an indicator of fluid removal:

Jimmy says he is feeling hot and wants to lie back. He checks his blood pressure himself. I realize that he knows how to operate the machine and then again when he uses the recall data function button to retrieve this number when nurse comes to check his pressure. The nurse tells him his pressure is fine. I am unable to see the number. Over the next 15 minutes, he checks his blood pressure three times and records it. Concerned, I ask what is happening. He is worried that his blood pressure is dropping too fast, he tells me that his pressure went from 130/85, to 110/72, and then to 90/61. I think, yes, that is very rapid, too rapid? He tells me that he doesn’t want to come off the machine early because he will not have enough fluid removed. Jimmy seems agitated and angry. The nurse soon removes him from the machine about half an hour earlier than his usual four hour treatment and tells him that he can come for an extra treatment this week if he needs to. He seems unhappy. After weighing himself, he becomes relived that his weight has gone down enough. “It’s okay, it’s okay” he says and seems calmer as he walks out of the unit.

Jimmy had reason to be concerned. If not enough fluid was removed during the treatment, the consequence for Jimmy may be that his fluid limit would be further reduced until the next treatment and/or he may have to have an extra treatment during the week. Both consequences would be an undesirable price to pay for not having enough fluid removed.
On the other hand, being *dried out* can occur during hemodialysis treatments and also has uncomfortable bodily consequences. I documented the following fieldnote excerpt while observing Chandra.

Following her treatment, Chandra gets on the scale to be weighted. She asks the nurse “why did you dry me out?” Chandra doesn’t smile and her eyebrows move tighter together and downward. She appears to be concerned or annoyed about the extra weight taken off. She stands still, just looking at the nurse with a grim face.

Chandra’s stance and attitude suggested that she was angry and wanted a further explanation from her nurse. Over my time in the unit, I came to understand the children’s concern with being dried out during their treatment, as they can become rapidly ill when too much fluid is removed or when fluid is removed too quickly. These children’s responses to their treatments suggest that, perhaps, at times, they are more aware of the ramifications of their technologically mediated embodiment than they recognized or could discuss.

Technology derived illnesses happened fairly frequently. Based on my observations in the unit, illness occurred in about two out of ten times a treatment is received. Considering that at least four or five children received treatments daily, a treatment induced illness occurred at least every other day. The following fieldnote excerpt is a record of observing Emily near the end of a treatment.

Emily is sitting quietly beside Chandra. This is unusual as they typically are playing or talking. Both appear quiet and subdued. I say to her “You are quiet” to which she does not answer. A nurse walks to Emily and takes her blood pressure and heart rate. Emily begins to vomit into a kidney basin and she complains of cramps. She suddenly looks drawn, with dark circles around her eyes. Emily’s treatment is immediately stopped by the nurse about one half hour earlier than usual and she is unhooked from the machine. Emily rests lying down with a wet cloth on her head.

In this episode, Emily appeared pale and said she felt nauseated and weak with a headache. Her play activities with her friend ceased, as she sat quietly, closely monitored by her nurse who brought her a cold towel for her head and adjusted her chair position so she sat more upright.
Treatment-induced illnesses were very unpleasant and tended to be managed quickly by nurses to decrease the possibility of further complications. Consequences included lethargy, nausea and vomiting and a headache that may last hours after the treatment, further curtailing children’s lives and typical routines outside of the unit.

Living on technology had multiple dimensions for the children. Many did not appear to perceive their technologically mediated embodiment if all was going well. Yet, if a child became ill on his or her treatment, his or her conjoinment came into sharp focus and the limits to imperceptible technological mediation became apparent to them. In my view of technologies’ effects, at the point when the human-technological relation becomes disrupted, the perception of the embodied technology that has receded into the background moves into the foreground (Ihde, 1990, 1993; Poland et al., 2005; Verbeek, 2008). The children’s technological experiences bore out this viewpoint. Furthermore, the children’s technological embodiment then had beneficial, as replacing a vital function of their bodies, and negative, as detrimental when causing illness, aspects, which illuminates the ambiguity of hemodialysis technologies (Ihde, 1990).

C. 3. Food and fluid reprieves

Having kidney failure necessitated that the children endure fairly severe fluid restrictions on an everyday basis as their bodies were unable to expel excess fluids or wastes on their own. Some of the children, at least among those with acquired kidney disease or a previous transplantation, expressed a remembrance of their bodies with functioning kidneys. The vividness of remembering a previous form of embodiment was expressed well by Delroy. In one conversation, he stated that sometimes he “forgets” that he does not have kidneys. I asked what he meant by this and he answered that he feels his body as “like it is” before when he had kidneys. He remarked, “Like I’d have a drink in my hand, like a juice box, and I would just drink
it. Like I could pee”. When telling me about times when he could drink as much as he wanted without worry or others’ reminders, Delroy became very animated and loud, making large gestures that involved opening his arms and pulling imaginary things towards himself to stuff into his mouth. The lack of ability to drink freely and quench one’s thirst may be conceived as another layer of bodily constraint that the children experienced during their sentence on hemodialysis.

Because the machine removes fluid and wastes during hemodialysis, most children were allowed to drink a little more fluid and to enjoy foods that were restricted on days between treatments. This was perceived by the children as a highly positive benefit of their technologically mediated embodiment. Once again, I surmise that the children were, at times such as these, quite aware of their human-technological relations with the hemodialysis machine. Meals were delivered to the unit just before a child’s treatment and were eaten prior to or at the beginning of a treatment. This timing allowed the chemicals and fluids to be removed from their bodies throughout the remainder of the hemodialysis treatment. Over my time in the unit, I came to grasp that eating and drinking just before or during the beginning of a treatment was perhaps the most enjoyable and significant routine in the unit for the children.

Although waiting for their hemodialysis treatment to end felt long, tedious and boring to the children, eating and drinking while on a treatment permitted freedoms not experienced outside of the unit. These freedoms altered the children’s perceptions of the technologically driven timespace of the unit. Bridget exclaimed that this is the only aspect of the hemodialysis rituals that she wished would not be shortened in the following fieldnote excerpt.

As I sit with Bridget, I look around the unit and say: “I wonder what there is to do here?” Bridget replies that she likes the television and videos in an unenthused voice. She says, “I wish everything you liked was long and everything you didn’t like was one sec.” I asked her, “Would you like the hemodialysis treatment to go faster?” She replies, “Just the eating and drinking part longer and then the treatment one second”.

Unlike some children who disliked receiving hemodialysis both on Friday afternoon and Saturday morning because it disrupted their free time outside of the unit, Jimmy preferred to have treatments on both of these days. Having a treatment on Saturday allowed him to be able to drink more on Fridays during and after dialysis because extra fluid that did not come off on Friday could come off on Saturday. Sometimes, he happily told me, “I can have a couple extra 100 ml of fluid on Fridays. While playing with Play Doh with Navina, we talked about what she does and does not like about hemodialysis.

Navina: The thing I don’t like is when I don’t get my favourite food.
HZ: Oh, when you don’t get your favourite food. What’s your favourite food?
Navina: Pizza!
HZ: Your favourite food is pizza? That’s your lunch today!
Navina: Mmm Hmm.
HZ: How often do you get pizza when you’re here?
Navina: Uh… I get it all the time. And sometimes Coke too.
HZ: So sometimes you can eat and drink things that you usually can’t?
Navina: Yes
HZ: And that makes it better here?
Navina: Uh Huh

Navina continued to tell me that she can eat anything she wants on her treatment days and that onion rings are her favourite, which her mother is going to bring her when she comes back to the unit. She also told me that she likes the hospital because the food is better than at home. The children appreciated being able to eat foods typically enjoyed by other children without kidney disease, such as hot dogs, fries, pizza, and ketchup and the extra fluid allowance in the form of soft drinks and juice permitted when having hemodialysis.

Being able to enjoy food typically off limits when outside of the unit was a significant aspect of the children’s routines in the unit. This routine may have provided the children with a sense of bodily and social normalization unable to be experienced outside of the unit’s timespace. For some, the extra food and fluid consumption, because of their technological
embodiment, especially if the human-technological relation is imperceptible, may have facilitated some children to recover a sense of their pre-dialysis embodiment similar to that Delroy still remembered and hoped he will experience in the future.

**Conclusion**

Although natural kidneys continuously function, the hemodialysis machine acting as a kidney when conjoined to the children’s bodies was able to sufficiently remove enough toxins and fluids from the blood to sustain life in three to four hours over three to four times sessions a week. Thus, the children’s conjoinment to the machine occurred on an intermittent, rather than continual basis. This intermittency may have played a part in how the children perceived and responded to the hemodialysis treatments and machine. The children’s experiences illustrated the multifaceted nature of their technological embodiment. For the most part, the children’s lack of responses to their technologically mediated embodiment suggests that they may have experienced the machine more as distinct from themselves, such as a mechanical or scientific object, or as a taken for granted part of the unit, rather than as part of the embodied self. However, at points, their conjoined embodiment was implicitly or explicitly perceivable to them, for example when illness occurred during a treatment. Although the hemodialysis is a common renal replacement therapy, illness due to dehydration and fluid shifts happen fairly often illustrating the technological effects upon cycles of the body. Hence, some children paid close attention to the possibility of being too dried out during a treatment because of its physical consequences and further temporal disruption and socio-spatial dislocation from their routines outside the unit.

In the highly technologically driven environment, the children sat amidst multiple types of technologies. Their human-technological relations also included interactions with a variety of
monitoring instruments and devices, such as the blood pressure machine, associated with their treatments and the technological sounds of the machine provided background context for them.

Observing the unit over time, I became aware that much of the unit’s activities, concerns, and language were focused intently on bodily fluids, in terms of how much children were carrying and how much needed to be removed during treatments. Additionally, I noticed the amount of fluid used in treatments that are contained in the jugs and containers that populated each hemodialysis station and the cleaners and other fluids that are spread around the room. It seems paradoxical that children must sit in a room filled with large amounts of various sorts of fluids, yet they were dehydrated and thirsty. Although nurses frequently would wander around the unit holding and drinking cups of coffee or cold drinks, I quickly stopped doing this in the unit once I understood the children’s situation. Making visible my freedom and ability to drink felt unfair and unkind to the children. However, a benefit to the children’s technologically mediated embodiment was the reprieve experienced by an ability to eat and drink in a way that is typically off limits outside of the unit. This reprieve appeared to be the most significant form of freedom the children were able to enjoy because of receiving hemodialysis in the unit.

Section D: Embodied Adaptations and Interruptions to the TimeSpace

D. 1. Resignation and resistance

In my conception of the hemodialysis unit, I viewed the place as both producing and produced by a range of temporal, spatial and technological regimes and relations that are interrelated. These routines constitute the timespace of the unit that shaped the children’s embodied situatedness. Over my study periods, I came to understand, with the children’s assistance, that the hemodialysis treatments per se were not the most salient issue for the
children. Instead, the temporal and spatial dynamics of their monotonous lengthy routines and their segregation and isolation were the aspects that they found hard to bear. Overall, most of the children seemed to be resigned to their time in the unit. As we chatted about what it was like for her to have to come to the unit, Chandra characterized the unit as an aspect of her life now taken for granted. She remarked, “I think it is just part of my life, dialysis.” Her statement surprised me because she began treatments about five months prior, a relatively short time compared with other participants who have spent years receiving treatments in the unit. She also gives voice to my impression that children fairly quickly assimilate into the everyday routines and their identities and roles of a patient. I consider that perhaps the tedious and predictable nature of the everyday in the unit, although complained about facilitates this process. Chandra further explained her perspective in the following fieldnote excerpt.

She suddenly asks me why I want to learn about kids in the hemodialysis unit. I say “I know that kids spend a lot of time here and I wonder what it is like.” She replies, “Some people say we should be happy we can have hemodialysis, but it is really hard coming here”. [Due to family circumstances, her family would drop her off and leave]. She tells me she has to come here because “if you don’t you die”.

Chandra offered a very pragmatic response that exposes the reality of all the children’s predicament. The alternative to not receiving treatments is illness and death. Yet receiving treatments multiple times a week indefinitely was “hard” as the children seemed to find the rituals and regimes oppressive and arduous. Their temporal sense on the machine was time taken rather than generated for them. Furthermore, her remark that depicts the benefits and consequences of hemodialysis also elucidates a fundamental tenet of Ihde’s (1990, 1993) philosophy that technologies are not either solely beneficial or detrimental and they may be both.

In this study, I conceived the children as not merely subjected to the regimens and relations in the hemodialysis setting, but also as actively interpreting, embodying, co-producing, and negotiating them (Prout, 2000, 2005). Throughout my time with them, the children expressed
numerous times in myriad of ways, through words, behaviours, actions and bodily comportments, that they disliked or resented the temporal disruptions and socio-spatial dislocations that they endured by coming to the unit so frequently. This sentiment was reiterated by Tammy on the first day we met.

HZ: And do you like being here?
Tammy: (Chuckle) I don’t think so. Nobody likes being here. I don’t. I would rather be somewhere else. Yeah, Yeah.
HZ: You’d prefer not to be not here if you could?
Tammy: Yeah, yeah.

Nevertheless, very few children had direct suggestions for improvement when I asked what they would like to see changed about the unit to make their time more enjoyable or comfortable. A long time veteran of hemodialysis, Jay has spent most of his childhood receiving treatments in the unit. He remarked, “Like they could make it a little bit more comfortable but you know that’s the best they can do. It’s good.” When asked about what she likes or dislikes in the unit, Bridget answered, “If I like or don’t like, it doesn’t matter”. A note of reluctant acquiescence is conveyed by Jay’s and Bridget’s words. I surmise that the children have come to discern and perform the expected attitudes and behaviours of patients, which may have resulted in their overall stance of passivity and complacency that I observed among the children while in the unit.

Many children tolerated the limited available possibilities for entertainment and socialization in the unit. Shen, who was unable to find a male peer to befriend in the unit, remarked that he wished that a computer was available for his use to occupy his time talking with his friends outside of the unit. Other than Bridget who occasionally brought a laptop, the children did not bring socializing or entertainment gadgets to the unit, such as MP3 players, laptops or small DVD players that could be used for talking with friends, gaming, listening to music or watching their favourite movies. Instead, they relied on what was available in the unit, which was limited to televisions, an old DVD player and a few video games. Other items for
entertainment, such as the smallish collection of well-used books, movies and board games were tolerated by children without complaint. I rarely observed any child being accompanied by friends or siblings with whom they could visit.

The children also expressed a lack of interest in the aesthetic elements intended by the staff to brighten the unit for the children, such as the mural and their own artwork. The nurses, volunteers and student nurses encouraged, and sometimes assisted, the children to create art and pictures that were hung around the unit’s main area. Efforts also were made by the nurses to decorate the unit for holidays, such as Christmas, Halloween and Easter. Nevertheless, no child remarked on the decorations during our unit tours unless I prompted them. Their responses tended to be hesitant and lukewarm, for example, “pretty nice” or “It’s okay”. The unit had a fairly recent inclusion of a mural of animated cartoon kidneys playing musical instruments on the walls of the south hallway. On his unit tour, Jimmy responded in the following manner to my questions about this mural.

HZ: Do remember when the pictures weren’t here?
Jimmy: Yeah, I remember.
HZ: Do you prefer them here or do you prefer how it [the wall] was before?
Jimmy: It doesn’t… It doesn’t really matter.
HZ: Do you like, notice they’re kidneys?
Jimmy: Not really.

Similar to Jimmy, almost all children asked conveyed a lack of interest in these images. Neither their own art work hung to decorate the unit nor other unit aesthetics, the musical animated cartoon kidneys for example, seemed to make much impact on their sense of the unit as an inviting, entertaining or sociable place for them.

Most of the children did not take or suggest initiatives to create their own events in the unit enjoyable to themselves, although celebrations, such as birthday, holiday and goodbye parties, and themed days, such as pyjama day or braid day, were planned by nurses on occasion. Only
once did I witness this type of initiative coming directly from a child. Chandra arranged an early evening skating party at a nearby rink for the children, nurses and other staff in January. When I asked why she chose to do this, she replied “so they [nurses and other adults] see that I am a person who can do things, not just someone who sits in a chair.” This comment indicated to me her resistance to a status as a patient and an attempt to construct a preferred way of being seen by others. Unfortunately, Chandra was ill the day of the skating party and unable to attend.

Prout (2000, 2005) contends that although children’s bodies and lives are powerfully shaped by social discourses and relations, they also participate in social processes. The forms of children’s adaptations strongly suggest that they often embodied the identity and role of patient. Positioning oneself as patient is not just a conceptual process, but also a physical and social process that involves incorporating certain appearances, interactions, and behaviours. Moreover, adopting a social position requires an awareness of the various power relations and social statuses in the context. Perhaps the children’s restricted movement and autonomy in the routines and relations of the unit stunted their expectations and expressions of agency or resistance. The children also may have been enacting a general social discourse about children’s perceived lack of ability to impact their world and/or the discourse of patienthood in which model patients are compliant, grateful and passive regarding care received. Chandra represented this notion of patienthood when she commented that “some people say we should be happy we can have hemodialysis” in the above fieldnote excerpt. By her phrase “some people”, I assume Chandra was referring to health care providers and other adults who acknowledge the vital importance of the development of life-sustaining hemodialysis technologies to the children’s lives. However, Chandra’s comment highlights that her understanding of hemodialysis, grounded in her childhood experiences of kidney disease, may differ from general discourses that focus solely on the benefits of this form of health care.
Although the majority of children did not suggest many modifications to make their time more enjoyable, a few of the children were able to conceive of playing a role in construction of the unit’s timespace to better suit them. Jay proposed a design change to the hemodialysis machine so that treatments would not require staying in a chair for three or four hours. This was a treatment change that he would like.

HZ: Is there anything that you would have preferred to do or have when you’re here to help get through the treatment?
Jay: Somehow make it able to so you could do anything while you’re on the machine like walk around and stuff but you can’t do that. Somehow, you know, get it like, you know, like IV machine, make it smaller you walk around with it. No sitting in the chair, you know. …You know. If they would make a portable hemodialysis machine, that would be good. More freedom like that.

Jay was the only child who imagined a different type of technologically mediated embodiment that did not necessitate being tethered to a large, heavy and stationary machine that demanded each child sit quietly in a corner confined to a singular location in the unit. Because the unit’s timespace was regulated by the machine and associated technology, this kind of technological change could transform significantly the children’s perceptions and responses in the unit.

Chandra was the only participant who explicitly acknowledged her attenuated identity and expressed a desire for a more fully realized presence that would endure in the unit as illustrated in this fieldnote excerpt:

Chandra: I think that we should do something too, not just anybody else but like we should do some kind of decorations to remember when, like we go away and we get better so they can remember us by it, like something we do on the walls.
HZ: So to kind of leave something of yourself here when you stop coming?
Chandra: Yup.

Chandra wanted to contribute a visible symbol of her place in the unit that could remain through time. Jay and Chandra were unusual in that they envisioned and articulated the possibility of a
different sort of embodied situatedness by expressing ideas of a place where technology does not dominate and is primarily for and about them.

Some children also actively resisted the imposed identity and role as patient. These children intentionally avoided interacting with nurses and other adults in the unit. Navina was new to the unit when we first met and appeared to have a very difficult time feeling comfortable with the staff, routines and space. Navina’s strategy involved ignoring the nurses as well as me.

The following note describes the nature of my early encounters with Navina.

I notice two nurses standing near Navina who is accompanied by her mother, and talking about her treatment. Navina is lying on her side with her back to them. I walk up to her and say hi. She does not look at me, staring at the machine. I kneel down close to her eye level, and she slightly turns her body away from me. Another nurse arrives and stands beside me, attempting to talk with Navina who does not make eye contact or verbally respond to her. The nurse continues to try to engage her in a conversation. Her mother, the nurse and I start talking together to take our focus off Navina. Slowly, she begins to listen and look at us. I then ask her a few questions about her favourite things to do to which she replies to. Finally her mother and the nurse walk away, leaving the two of us alone. Navina immediately becomes quiet and withdrawn, and will not make eye contact with me.

Navina continued avoid looking at me and turned her body away over my next few visits, clearly indicating that she did not want to interact with me. Being relatively new to the unit, her behaviour may be a result from feeling unsure what others wanted from her or feeling uncomfortable because she did not understand what was taking place around her. Over time she became more familiar and comfortable with the unit and me. On one occasion she agreed to create a picture that depicted how she felt about the unit. Using stamps with faces representing feelings, Navina illustrated some of her feelings in and about the unit in illustration eight below.
The strong emotions of confusion, anger, unhappiness and fear that are expressed revealed that Navina experienced the unit as a highly unpleasant and difficult place. On another occasion she confided to me: “I don’t like dialysis”. I then asked if she liked to talk to people, like the nurses, to which she replied, “Sometimes I am in a very bad mood when I have dialysis and don’t talk to anyone”. Like this morning, I was in a bad mood because I had to come here”. Unlike the other children who often were more emotionally restrained, Navina expressed her emotional perceptions of the unit through silence or anger, often resisting others attempts to provide care or talk.

Tammy, who returned to the unit following a transplantation failure, also consistently and expertly, deflected answering questions or engaging with me about her experience in the unit. I recorded this instance of struggling to interact with her that occurred after we had both spent four afternoons together in the unit with multiple attempts on my part to engage her.

As I approach, she looks directly at me and smiles. Then she adverts her eyes and her mouth straightens while turns her body away from me. Her face looks bright for a
moment and then goes to flat and blank. I reflect that there are moments when she reacts with interest, openness, and anticipation and then seems to quickly correct herself. I read her posture as her signalling to me ‘I don’t need you’, which may indicate a need for connection and recognition that is quickly defended. As always, I find myself unsure how to approach her. I stand beside her chair and say “Hi” with a big smile. I hope to indicate to her that I am pleased to see her and have time to do something if she wants. She says hi quietly and looks at me directly with her typical direct unwavering stare. I think about what to say next as small talk, what might engage her.

The following fieldnote excerpt records another attempt to engage Tammy to learn about her experiences in the unit through a clock decorating activity.

She asks “What are the clocks like”. I tell her about them and she decides that she wants to decorate one. I am surprised she initiated this activity as it has been difficult to engage her in anything but I then remember that she likes crafts. I bring two clock kits – one for her and one for me. I set up the stations with paper to protect the tables and the paints, glitter, etc. She directs me how this should be done and that the paint should be diluted for the base colour of the clocks. Clearly, she feels confident in organizing how she feels things should be done. We work together silently for a while, making comments occasional comments about the paint and our decorating decisions. Finally I say, “There is a reason why I thought decorating clocks would be a good activity to do”. She looks at me silently. I say, “Can you think why I might have thought that?” No response. “Because I know you and other kids spend a lot of time here and I wonder what that is like for you. This is something I am hoping to learn about from kids like you.” No response. “Some kids say time feels very slow here, that treatments feel long”. No response. “Do you sometimes feel that way?” No response. Tammy then asks: “Why are you doing your clock that colour? That won’t work”. I give an answer and then try to reinitiate a conversation about time. “How does the time you spend here feel to you?” No response. “Is it something you have thought of?” No response. I stop this line of questioning because it is clear that she doesn’t want to share her thoughts with me. We continue to work at our clocks quietly. I decide to not push her and to give her time to get used to me. I feel it is a missed opportunity to talk while we do this clock activity. A nurse comes up to us and compliments Tammy on her clock. Tammy does not respond or look up for a few moments as the nurse stands there. Then Tammy says: “It’s not great” and criticizes her clock colour and decoration.

Over time and with effort on my part to engage her on her terms, Tammy, similar to Navina, looked forward to spending time with me as I came to understand how she wanted to relate to me and the activities she enjoyed to occupy her time. Tammy made clear to me that she would not tolerate my directly asking for information from her. Most often, she would not respond to any question or comment from me that she considered as information-seeking. Resisting being
characterized as a patient and research subject, she directed conversations to her love of scary movies and roller coasters that we shared. She also endeavoured to reinforce her gender identity by talking about shopping, her clothes and accessories and how she spends time with her friends. Even her preferred activity in the unit was gender-based as we spent many hours doing beading activities together. Because I had never beaded before, Tammy’s exchanges with me were centered on how things should be done and on telling me what to do. At one point, as we sat beading she remarked to two nurses who passed by, “I am her teacher”. By doing so, I assume that she was attempting to exert her agency, be seen as a young woman with interests and capabilities, and disrupt the usual power relations between adults, like the nurses and myself, and patients in the units.

For a few children, refusal to engage in conversation about their illnesses, treatments or care was common and occurred with the nurses and other staff, as well as myself on occasion. Navina and Tammy especially resisted the imposed discipline administered by nursing staff and enforced by the unit’s routines. I consider that their behaviour is a reaction to their relatively powerless status as patients and children. Perhaps refusal to engage was one of the few avenues available to children to help them cope with an environment where they had little control over who approached them or what happened to them.

D. 2. Waiting to be released from hemodialysis

Spending considerable time in the unit over three periods permitted me to learn from the children how the process of the hemodialysis treatments unfolded for them along the trajectory of their kidney disease. The everyday waiting for a session of hemodialysis to end in the short-term was a significant adaptation on the part of the children. More profoundly, a number of the children I observed abided a longer term deep-rooted sense of waiting for a transplant or for their
condition to improve as a result of drug therapy targeted at eliminating the need for hemodialysis treatments altogether. This temporal sense may be termed *life time* (Felski, 2000). Life time encompasses a sense of longer durations of time by viewing oneself as a subject in and through time. For Felski (2000), the notion of life time and everyday time interact and merge through the connection of segments of daily experience that imbue life with shape and meaning. These temporal levels are not separate but indispensable to one another as each shapes the other.

Despite their desire, full recovery of kidney function rarely occurs for children with ESRD. For those children able to receive transplantation, a new kidney holds a great deal of importance. Transplantation was viewed by the participants as the way out of the unit to attain or return to a typical childhood. At one point in a conversation, Chandra remarked to me “I am waiting for a transplant. That’s what I want. Then I will be normal again”. Emphasizing his longing, Delroy declared that if a new kidney became available “he and his mom would be right there”, and would “go running” or “take a cab, anything” to get to the hospital as quickly possible. One day, he hoped to “drink whatever I want” because of a new functional kidney. Since the availability of a kidney from a living or cadaver donour is uncertain, these children must wait indefinitely on a sentence of intermittent hemodialysis in the unit. This sense of life time waiting occurred over the course of the children’s lives within and beyond their everyday temporal experiences in the routines and relations of the hemodialysis unit.

To be eligible for a transplant, the children encountered terms of release from the unit. They must be deemed physically and medically ready to undergo surgery in order to successfully accept the new kidney. During the duration of the three study periods in the unit, I witnessed two children receive transplants that allowed them to be released from cycles of hemodialysis. One kidney came from a living donour and the other was from a cadaver donour. These children were not study participants in the period when their transplants occurred. Where their new kidneys
come from was not discussed by the children while I was in the unit. The staff only spoke to me about this when out of hearing range of the children. After a few visits to the unit due to medical issues related to their transplant or to say hello while in the hospital, I did not see these two children again in the unit. Although I did not have a chance to speak with them in-depth, previous conversations indicated that their sense of life-time waiting would be altered or ended when they no longer needed to receive treatments in the unit. However, some children with ESRD who receive a transplant must cope with the possibility that their donated kidney might fail. Hence, living with kidney disease will be a life-time project for some of the children.

Transplantation or an improvement in their condition is not possible for all children. Two of the eleven participants were unable to receive a transplant due to the nature of their congenital kidney disease. Hence, hemodialysis and the everyday waiting to be released will continue into their adulthoods. Although the sentence of hemodialysis continues, these children must exit the pediatric unit and move to adult hemodialysis services at 18 years of age. Jay was in the process of moving to adult services and discussed with me what this change felt like to him.

HZ: Can you tell me a little bit of how it feels to be leaving this place?
Jay: I don’t feel like leaving. I feel like staying longer but I can’t, cause you only change when you go to a different hospital. So far I’ve already like experienced it. It’s hard cause you have to go through all the training again and they have different ways of doing it sometimes. It makes it, life, difficult just for that time period in the beginning and then it should go easier.
HZ: Because you lose all the familiarity of the unit?
Jay: Mmm, just getting really used to new faces now.
HZ: Is getting used to the people a big part of it?
Jay: Kind of, yeah. Not knowing the people at all. What to talk to them about. And stuff.
HZ: Is it more than just then someone who is technically good at getting you hooked up to a machine. I mean, they could do that without talking to you.
Jay: Yeah, yeah, just being friendly with nurses off and on and being friends with them kind of thing.
HZ: So, getting to know them?
Jay: Yeah, getting to know them. Being different. Yeah, you know, remembering all the new names, all the nurses, so many new nurses and the staff. Gotta remember all their names.
HZ: Like it’s hard to start again, like starting a new school.
Jay: Yeah.

The notion of starting again evident in Jay’s remarks was similar to how some children viewed entering the pediatric hemodialysis unit initially when beginning their treatments. Although most children would prefer not to come to the unit, becoming accustomed with the people and routines of this place seemed to instil a sense of comfort and familiarity. Hence, an ending to some of the children’s time in the pediatric unit means starting anew in an adult unit as cycles of intermittent hemodialysis will be endured throughout their lives.

The unit’s timespace was comprised of the everyday sameness of well-established rituals and routines. All the children expressed that the temporality of the hemodialysis regimes felt long, monotonous and time-consuming for the most part. To some degree, this sense of time was felt and shared by me during the three study periods as I lived the repetitive sameness of the day-to-day routines in the unit. However, I was able to observe or hear about pivotal shifts in the majority of the participants’ lives brought about by their exit from the unit during or after the study periods. These transitions punctuated the fact that time passes even while the children endured the seemingly indefinite sentence of hospital-based hemodialysis. Some of the children began their hemodialysis journey anew whereas others’ sense of life time waiting ended.

D. 3. Senses of belonging

A goal of my study was to understand the “the meaning, intention, felt value and significance” (Peter, 2002, p. 67) that the children attributed to their place of hemodialysis by observing the children’s embodied situatedness in the unit. Furthermore, my perspective on place encompassed senses of dis/attachments to and in places that I also endeavoured to learn about from the children (Casey, 1993, 1997, 2002; Malone 2003; Manzo, 2005; Peter, 2002). The
notion of the hemodialysis unit as a place well suited for the children’s physical, emotional and social needs beyond those of medical and technical care arose in various ways through my time in the unit. The nurses were the staff group that verbally promoted the unit to me as a child-focused and friendly place. Typically their dialogue referred to the unit as a “second home” for the children. This discourse was reiterated by a number of the children. In the second study time period, Jay, who would leave the unit in a few weeks to enter an adult hemodialysis center, mentioned this sense of the unit in a conversation with me:

HZ: And you’ve been coming for how many years?
Jay: Fourteen years, since I first got sick.
HZ: That’s a long time. How does that feel?
Jay: It’s kind of like a second home.
HZ: Like a second home?
Jay: Yeah, and now I’m leaving… hmmm.

Delroy also characterized the unit as a “second home” that he literally has grown up in through his years spent in this setting. His role as a guide on our unit tour was taken very seriously by him. Escorting me through the unit, he spent considerable time telling me about the kitchen, offices, front desk and meeting room. These are areas of the unit that other children usually do not go. I was somewhat surprised that to see so much intimacy and familiarity with the unit and staff because Delroy usually appeared detached, sleeping through his treatments and leaving the unit as quickly as possible at their conclusion. The following is a conversation about his view of the unit.

HZ: You kind of make yourself at home, huh?
Delroy: Yeah.
HZ: Do you generally make yourself at home in the unit?
Delroy: Yeah. I always do. It’s like a second home. It’s the hospital.
HZ: This is like your second home?
Delroy: Yeah.
HZ: And how long have you been coming to this unit? You told me but I can’t remember.
Delroy: Well, a long time – almost 10 years now.
HZ: Wow! That’s a long time. Everybody’s seen you grow up.
By their use of the phrase “second home” ascribed to the unit, these boys seemed to imply the unit as an intimate and enduring place where they belonged and were well habituated, known and cared about by others (Casey, 1993; Manzo, 2003, 2005). Certainly, the unit provided life-sustaining treatments and had taken for granted and unswerving rituals and routines as do many home settings (Felski, 2000). However, this characterization of the unit as a “second home” seemed at odds with the multitude of the children’s complaints and bodily inhabitations that reflected the unit’s boring nature, their daily efforts to pass time as quickly as possible and their desire to be released through a transplant or other means. One explanation for some children’s’ viewpoint of the unit as a “second home” may be that some of them absorbed and restated this dominant view of the unit held by nurses and other staff. Also, in that people may hold multiple and conflicting meanings about a place, I assume that the children may hold different views of the unit at one time (Manzo, 2003, 2005; Massey, 1994, 2004, 2005; May & Thrift, 2001).

During my time in the unit, I witnessed instances when the typical technologically driven routines were interrupted by special events planned for the children’s enjoyment. In these occurrences, the children conveyed a counter viewpoint to the notion of the unit as a place of imprisonment that they were waiting to escape. Possibly these were the times when the unit was affirmed as a “second home”. Chandra explained how she felt special as a hemodialysis patient:

It’s hard to wait to get a transplant because then you can be normal, but dialysis makes you special because people care, people come and visit you, like the hockey player and Santa. Also, you are special because your body is different and you need to do different things, like come to the unit. Also you are normal too most times.

Chandra’s comment is illuminating as she juxtaposed being ill and thus “special”, with being “normal” at other times. The chronicity of ESRD unsettles the boundaries of states of health and illness as being “both and neither at the same time” (Moss & Dyck, 2002, p. 15). However,
Chandra had indicated that being “normal” referred to her life outside the unit whereas being ill referred to time in the unit, where being “special” granted some opportunities that would otherwise be unavailable. Where and when Chandra’s sensed of herself as ill or “normal” is an interesting comment on the nature of health and illness in kidney disease in which the children are only intermittently conjoined to a machine in a hospital-based setting, rather than continuously needing technological interventions or residing full-time in a hospital. Nevertheless, many of the children appeared to have a sense of themselves and the unit as “special” when the unit’s dominant technologically driven timespace was interrupted by a novel event. In such events, the usual nature of children’s positions and participation were configured differently such that their usual sense of the unit’s timespace was interrupted.

A significant seasonal interruption was the annual winter holiday party that was highly anticipated by the staff, families and children. Many of the children and families do not follow Christian traditions, yet the party incorporated a Christmas tree, a Santa, and presents. In this event, the people, not the technology, were the center of the unit, which transfigured its everyday temporal, spatial and technological features if only for a brief time period. The annual winter party was a long standing ritual customarily held on a Saturday around 11:00 am so that parents, caregivers, siblings, friends and all staff from the unit as well as other units can attend. I noted that nurses who were not working that day did not come to the party, yet the elementary school teacher, dieticians, some nephrology doctors and the nephrology nurse practitioner all made an effort to attend on their day off. All the children, including Chandra, Emily, Navina, Delroy, Azed, Nafi, Jimmy and Jay, who were receiving hemodialysis in the unit during December of the first study period, were present and their treatments were scheduled before and after the party to provide time for them to attend. The festivities took place primarily in the staff/meeting room where the children typically never go.
Clearly routines, roles and participation of this party had been established over the years. As such, they too had a ritualistic quality. Some staff and parents prepared and brought a variety of food, chips and dips, bread, shrimp, pizza chocolates as well as pop and juice. Some staff members and family members upheld a tradition of making certain dishes for the party, such as homemade cookies, squares and other baked goods, jerk chicken, turkey with gravy and samosas. Food and fluid discipline was lessened as the children were allowed to eat and drink in moderation even though it was not within the scope of their regularly restricted diets. The party food fostered a very different atmosphere on the unit. The smells were appealing and the sight of the food appetizing. I noticed that some parents and staff monitored and/or restricted some of the children’s consumption of the feast. Yet, most children were reminded about their food intake more gently than usual.

Time to socialize was clearly the party’s intent. Highlights included one child and his parents leading Christmas songs and a visit from Santa Claus. Jimmy was accompanied by his parents and piano teacher, and together they set up an electric piano and distributed Christmas carol song books. Jimmy’s piano teacher played Christmas carols, while his mother and father sang and encouraged others to join in. Sounds of music and people singing filled the room and continued for at least one half hour. Jimmy also displayed his talent in playing the piano. In the latter part of the party, one of the doctors re-entered the room dressed as Santa with bags of presents. The presents were donations from the public that are given to the hospital. Each child received two to four presents each and siblings who were present received one present. Clearly the gifts were chosen by staff to be age and gender appropriate and accounted for the children’s individual interests. The children were appreciative, excited and pleased to receive gifts.

Following the party that lasted about one and a half hours, the visitors left, food was put away, and dishes and paper cleaned up. Three children had received hemodialysis prior to the
party and seemed fatigued. The unit immediately reverted to its distinctive technologically driven atmosphere as the four children scheduled for treatments were quickly tethered to machines and sat in the unit’s corners for the remainder of the afternoon.

Witnessing the party revealed to me that staff, children and families, at least those with who had spent considerable time in the unit, knew each other well. In fact, they appeared much more familiar and comfortable with each other than I had presumed based on my daily observations in the unit thus far. The change of rhythms and relations, the relaxed atmosphere, food and beverages, and shared fun of the festivities were striking in comparison to usual daily unit routines. Furthermore, the unit’s typical unrelenting mechanical sounds of this place were virtually silent for a few hours as treatments ceased and human or musical sounds dominated the space. During the party, the children seemed agents in co-creating the social and physical space in meaningful ways to them along with staff, parents and others. Manzo (2003) claims that people often relate to everyday places in a taken for granted way over time because of their familiarity and regularity. This process may be viewed as similar to how the children described the hemodialysis machine receding from their awareness. Because the novel nature of the Christmas party disrupted the taken for granted everyday routines, the event strongly illuminated the children’s positive experiences that may foster their affirmative attachment to the unit.

Some occasions less radically interrupted the typical regimes and relations in the unit, but nonetheless revealed the children’s positive attachments to the unit. During my second study period, I witnessed Jay’s period of hemodialysis in the unit come to an end as he was transferring to an adult hemodialysis unit. The following observation excerpt records the party that was held to recognize his transition out of the unit.

Jay arrived with his mom and two sisters for the lunch that has been arranged. Jay and his family brought lots of food – two plates of sandwiches, samosas and sauce, sweets, pasta salad, and green salad. This was their thank you to the staff, which was laid out in the
staff lunch/meeting room, with the food. During the goodbye party, I saw the nurses in
the unit that day, the social worker, two home care nurses, and a few other hospital staff I
have not seen before. I did not see a doctor that I recognize.

Only a few staff members as well as Jay and his family participated in this goodbye party.

Delroy and Nafi were receiving hemodialysis at the time, and I observed that they, as well as
Nafi’s sister, were not invited nor did they include themselves. I remarked on this observation to
Delroy who replied that they do not know Jay very well. His reply surprised me because all three
children usually received treatments on Friday afternoons or Saturdays mornings. Furthermore,
Delroy and Jay have been receiving treatments in the unit since their early childhood. I surmise
that the lack of relationship between these boys may be because of their age differences, and
perhaps more importantly, the socio-spatial segregation and isolation they experienced in the
unit. While Jay and his family enjoyed the occasion with some staff members, the remaining
children continued their technological routines. The remainder of this observation excerpt
documents the friendliness, warmth, and sadness between Jay and the staff while saying goodbye
to one another.

A photograph book of kids over the years is brought out and pictures of Jay from many
years ago are looked at. He is given presents. The picture on the front of the card given to
Jay by the staff has a young boy looking like a traditional hobo with a pole and tied rag.
The poem inside the card has this line, “Now you are leaving home” and the word home
is crossed out and dialysis written in. Staff lingers in the room, the lunch is not quick and
the party lasts about 1 hour. Jay tells me he is very sad to be leaving; the unit is like a
home to him. I notice tears in a nurse’s eyes at some point. As he is leaving, there are
many hugs between Jay and the nurses, but not many involving the other staff. Because
Jay is usually quiet and somewhat shy, I am surprised that he initiates hugs with the
nurses.

This interruption was one of my first glimpses of the unit as a place where a child was positively
attached with accompanying emotions of gratitude, warmth, and affinity and sorrow when
having to say goodbye. Other times in the unit when the children could feel “special” included
their birthdays. On Azed’s birthday, I observed the nurses acknowledge and give him a gift.
Azed anticipated and cherished his day, repeatedly talking about it a few weeks before and after the event.

During my time with the children, I asked them what they liked the most and least about the unit. In particular, most children mentioned enjoying visits from important outside visitors, such as celebrities or athletes. During the study periods, I did not witness these encounters, but some of the children said they greatly appreciated them. Jay remarked that these drop-ins were the most favoured experiences for him in the following fieldnote excerpt.

HZ: What’s been the best thing about your experience here over the years?
Jay: Of being here? I guess getting tickets for games and stuff. It’s been good. And you know all those celebrities coming, sports teams coming by and people come by.
HZ: And the worst part?
Jay: Just being here I guess, yeah. That’s it.

Jay’s remark “just being here” in response my question about the worst part of receiving treatments seems to point to his overall occupation in the unit. Hence, the children’s experiences may be viewed as a double-edged sword, as their time in the unit had favourable and unfavourable consequences. In my view, place was comprised of varied and multiple senses and structures pertaining to time and space (May & Thrift, 2001). Relationships to places also are dynamic because both positive and negative experiences are part of meaning-making processes (Manzo, 2003, 2005). As Jay illustrated, both positive and negative experiences contributed to the overall relationships and attachment that a child may have to this particular place.

Older adolescent males, such as Jay and Jimmy, especially enjoyed visits from well-known athletes and free tickets to sporting events. For the children under ten years of age, the clowns were especially appreciated. Navina, who had a difficult time relating to and trusting adults in the unit, always welcomed visits from the hospital clown.

HZ: The clown’s your favourite?
Navina: Mmm Hmm
HZ (Chuckle) How come she is your favourite?
Navina: Because she always is fun.
HZ: And do you play games with her?
Navina: Mmm Hmm
HZ: And do you see her every time you come in the unit?
Navina: Sometimes she’s not here. But she gives me a message.
HZ: She gives you a message?
Navina: She writes me a card and then she says when she’ll be back.

Rather than provide care or instructions, the clowns’ objectives were to entertain and engage the child on their terms. I imagine for some children, like Navina, this was a welcome change from the typical disciplining behaviour of other adults, such as the nurses and her parents. The nurses made special efforts to ensure that Navina received frequent visits from the clown. Enjoyable times for the children virtually always involved interacting with someone, such as a volunteer or student nurse, staff member, clown or celebrity, who was willing to be there solely for them, doing what they enjoyed, rather than expecting or demanding certain behaviours.

Most of these novel events and interactions were integrated into the annual or weekly unit routines, yet they stood out as more or less exceptional moments in contrast to the typical daily technologically driven timespace. Nonetheless, these occasions reveal the unit’s timespace as multifaceted and diverse in nature as is the children’s range of experiences. All the children were literally physically tethered and cornered in the unit and this position was complained about and resigned to by them. As such, I have conceived of the unit primarily as a place in which the children were doing time, which suggest a type of sentencing or imprisonment. However, many children also appeared to have strong positive emotional attachments to and affection for the unit. Manzo (2003, 2005) concedes that negative experiences in a place may become significant to meaning-making because they sharpen awareness and appreciation of the positive aspects of a place. For example, the absence of their overall monotonous and boring everyday routines and restrictive and isolating socio-spatial positions when disrupted by novel events may have
heightened the children’s awareness and appreciation of their positive associations and experiences in the unit. Conceiving the children’s embodiments as the mediating vehicle of time and place, the children’s situatedness is viewed as heterogeneous and multiple.

**Conclusion**

Although the children protested being disrupted and dislocated from their everyday routines and places outside of the unit, in general they seem resigned to the dominant technologically driven timespace of the unit. For many, the unit was viewed as “just part of my life”. When asked, most of the children had few opinions about the ways that the unit’s timespace could be altered to better suit them or to create a place for and about them. Conceiving children as agents views them as constructing meanings through interactions with disciplinary structures and adults and peers and enacting these meanings through their performance of expected attitudes and behaviours in particular places (Christensen, James, & Jenks, 2001; Gagen, 2000; Kelle, 2001; James, 2000, Prout, 2000, 2005). In the unit, the children appeared to conform to the dominant demands imposed by the main technological purpose and operations and their identities and roles as patients. During the time I spent in the unit, I also observed some of the children resist the imposed identity and status of patient through their interactions with the nurses and other adults, such as myself. In addition, two participants explicitly suggested possibilities that could radically transform their current forms of embodied situatedness in the unit.

The children’s everyday waiting to be unhooked from the machine to leave the unit’s timespace temporarily was a routine part of their everyday hemodialysis regimes. Waiting to be permanently released from the sentence of hemodialysis also was a profound aspect of the children’s life with kidney disease. Until this event occurs through transplantation, drug therapy
and other medical modalities, the children are dependent on a hemodialysis machine, which is essential for their survival by taking on the role of their kidneys. A quality of waiting in the longer term that I have termed as life time was experienced by some children concurrently with their daily waiting during cycles of hemodialysis. This appeared to be a significant temporal experience for many of them.

May and Thrift (2001) contend that perceptions and experiences of timespace are varied, multiple and dynamic in and across settings. The notion of a “second home” is one meaning some children ascribed to the unit. This notion is paradoxical to my overall interpreted characterization of the unit as a technologically driven place in which the children are intermittently captured. However, moments do occur when the children seemed to perceive the place as invaluable, homely and enjoyable, and possibly their presence as “special”. Many of these moments manifested during interruptions, such as birthday and goodbye parties, celebrity visits, and the annual winter party, to the everyday regimes and relations and occurred sporadically. On these occasions, the dominant technological regimes and relations were decentered or deferred for a period of time. Importantly, at the annual Christmas party, the unit’s timespace was altered dramatically as the strict disciplinary routines of eating and drinking were reduced and the children’s segregation and isolation was lifted, permitting them more physical and social freedom. Some interruptions, such as visits from celebrities and clowns, were less striking because they occurred while the children received their treatments, but nonetheless provided important sources of fun and interaction. Witnessing some of the children’s perceptions and responses during interruptions exemplified their positive attachments to the unit that was not initially apparent to me. Also, a strongly reciprocal fondness and affection among the children and staff, especially those who provided direct care, such as the nurses, manifested at these
times. Hence, the children’s embodied situatedness consisted of multiple, conflicting, and sometimes simultaneous, perceptions of and responses to the unit’s timespace.

Chapter Summary

Because of their dependency on life-sustaining technology, all of the children came intermittently to the hemodialysis unit to receive treatments, which was temporally disrupting and spatially dislocating to the everyday routines and places in their overall lives. In section A, B and C of this chapter, my intent was to examine the children’s embodied situatedness within the unit through exploring their everyday perceptions of and responses to the temporal, spatial and technological regimes and relations that characterize the timespace of the unit. In section D, I focused on the children’s overall adaptations to the unit’s dominant technologically driven topography and their positive sense of the unit when interruptions to the dominant timespace occurred for them.

May and Thrift’s (2000) conceptualization of timespace that entails four interrelated domains, consisting of timetables and rhythms, disciplinary/professional routines and practices, technologies and texts, informed my views of how time and space are constituted and lived by the children in the hemodialysis unit. Based on my observations and participation, I posit that the constituting influence of each domain is unequal and uneven. The impact of the hemodialysis technologies shaped all domains, as the domains shaped the unit. Predominantly, the routine of the hemodialysis machine and associated equipment structured the everyday regimes and relations of the children and the schedules of some staff groups, such as the nurses, teachers, technicians and cleaners, but not all, such as the physicians, social worker and dietician because these groups interacted less with the hemodialysis machines. Hence, the disciplinary and professional routines that the children must submit to, particularly the nursing and educational
practices, were shaped by the embedded technologies in the culture of the unit. The main principle of the timetables within the unit’s timespace was to move the children in and out of the unit as efficiently and quickly as possible in order to accommodate the next patient.

Through my observations and participation with the children, a theme of everyday sameness because of the invariability and predictability of the temporality and spatiality of the unit was threaded. Furthermore, emerging from my encounters with the children, the notion of waiting became prominent. Waiting appeared to take to two central qualities. The children were seen to be waiting for a cycle of hemodialysis to end so that they could return to their pursuits outside of the unit. They also seemed to experience a more profound overarching linear or durational sense of waiting that I have characterized as life time (Felski, 2000). This temporal frame was experienced by most children as they passed through the hemodialysis unit for long or short periods as part of their journey of living with ERD.

The materiality and assembly of the machine sequestered the children in the unit and had implications for their identities, social relations and agency. Some gender and age-related differences were observed among the children in term of how they engaged and are engaged in the unit; however, their socio-spatial positions as patients by the staff, for the most part, obliterated the differences among them. The children were actors in attempts to pass time, and some strategies used were more or less gendered or age-related. Three girls purposefully altered their experience of time by playing or socializing so that their time felt speed up whereas the four older adolescent boys tended to watch television or sleep. The nurses were the most significant source of socialization and care, however, due to their roles in the overriding technological nature of the unit, their attention was most often focused on the hemodialysis machine rather than the children. Some of the children demonstrated a resistance to the regimes and relations in the unit. However, the overall prevailing attitude to the timespace seemed to be complacency on
the part of the children and they had few suggestions for improvement. Their lack of suggestions was surprising considering how much time they spent in the unit. Although many of the children become resigned to the unit, this is not to say that their experience could not be enriched in numerous ways through some basic or more extensive alterations to the unit.

May and Thrift (2000) contend that many organic processes of the body or nature are not universal or fixed, but are socially regulated depending on their importance to structuring time in various cultural settings. Dependent on hemodialysis for survival, the rhythm of the children’s biological bodies were intermittently conjoined with the rhythms of the machines that dictated when and how often the children must receive treatments in the unit. Hence, their biological processes concurred with social and technological regulation. The children made few explicit comments about the machine or their bodies on hemodialysis, however, they were seen to respond to the machine in various ways. For example, the machine was used to mark or alter their sense of time passage. Textually marking time via the machine, which translates their physiology while dialyzed into a numerical output on the time remaining indicator located on the machine, oriented the children to their time on the unit. Although the children differed in terms of their disease trajectories and living situations, care of their bodies that required strict discipline in terms of limiting their eating and drinking was a central part of living with ESRD, and seeped into the unit, where children were permitted to drink more than usual and enjoy foods customarily forbidden outside of the unit. This benefit was expressed as a highlight of the unit and may have imparted a normalizing effect on the children’s lives.

The children held positive as well as negative views of the unit. Interruptions to the unit’s dominant technologically driven timespace, such as events that occur annually or weekly, were important sources of fun, interaction and stimulation. Importantly, the everyday repetitious and monotonous rituals and regimes and socio-spatial segregation and isolation experienced by the
children were minimally or significantly transformed, as was their perceptions of and dispositions in the unit. At these times, the predominant casting of the children as patients was lessened as they tended to be viewed as gendered individuals of a specific age group, with their own preferences, personalities and agency. Hence, some of the children related to the unit in multiple ways that I have characterized through the notions of the unit’s timespace as a place of imprisonment and a “second home”. The children’s negative and positive attachments may simultaneously coexist, yet, the differing manifestations of the unit often appeared temporally disparate.

Based on my observations of and interactions with the participants over nine weeks divided into three time periods, I primarily conceive of the unit as a technologically driven place where the children are depersonalized, dependent and confined to serve a sentence of hemodialysis while waiting to be released through transplantation or other means. Based on these ideas, I will explore the notion of Doing Technological Time in the Chapter VI discussion. However, some children also expressed positive regard and fondness for the unit and its people, at least at times. As an alternative viewpoint, this sense of situatedness and its possibilities are important to consider. Because of this, the children’s multiple perceptions of and responses to the nature of the unit also will be discussed.
Chapter VI: Discussion: Thinking about the TimeSpace of the Hemodialysis Unit

Introduction

The dominant theme emerging from the study findings is the notion of children doing technological time in the pediatric hemodialysis unit. Their treatment regimens do not cure their underlying kidney disease, but allow life to continue despite having a condition once considered fatal. Prout (2000, 2005) claims that children’s bodies are hybrids, simultaneously technological and natural, because their embodiments are inseparable from artifacts, machines and mechanical devices in their environments. This was the nature of children’s technological embodiments in the unit. Although humans cannot be conceived of as “pure”, their “varying degrees of (technological) hybridness” (Poland et al., 2005, p. 176) are significant in understanding relations in and to a place. Unique to these children’s circumstances is that doing technological time occurred only intermittently in a specialized hospital-based setting, unlike those who may be permanently dependent on technology residing in homes and communities or full time in a hospital. Hence, I have conceived of the children’s temporary technological embodiment as a form of conjoinment, rather than hybridity, because it occurred only in the hemodialysis unit. However, their treatment cycles must be precisely timed in order to maintain their bodily health and ensure continued survival. Hence, doing technological time in the unit has far-reaching temporal and spatial effects for the daily routines and places of children living with ESRD.

In Chapter IV, I described the people and place of the unit and in chapter V, I provided interpreted findings that illustrated the children’s embodied situatedness in the timespace of the unit. Grey (2003) claims that a focus on human experiences calls attention to the context because “while experience describes the everyday ‘way of life’, it is also the key to analyzing the relations that construct that reality” (p. 28). Because the children’s everyday embodied
experiences and their overall adaptations were constituted by the unit’s timespace, I endeavoured to describe both in the findings. In this chapter, I draw from the data presented in the findings to summarize the children’s views, while looking more closely at how their characterizations of time, socio-spatial positions and roles and identities as patients were produced amidst a technologically dominated environment. The pervasiveness and reach of hemodialysis technologies upon the children profoundly textured their situations in the unit and shaped their perspectives, evaluations and expectations. First, I discuss my overall conception of doing technological time. The following sections then elaborate further on this concept. These sections include: 1) The children’s technological embodiment; 2) The children’s perceptions and embodiment of time; 3) The children’s technological and emplaced embodiment; and 4) The children’s adaptions and attachments to the unit.

In this discussion, I draw on the key concepts of the study of embodied situatedness, time, space and technology as they relate to the children’s doing technological time in a hospital-based hemodialysis setting. Contemporary human geographers contend that both “time and place are central categories in conceptualizing the transient, ordinary nature of everyday life” (Rasmussen, 2004, p. 155). May and Thrift (2001) critique the theoretical limitations imposed by dualistic notions that conceptually conceive of time and space as being different in kind. Their project is to explore theoretically time and space as interdependent and mutually constituting. In that time may manifest in varied and dynamic ways, so may the spaces where time is constituted. To capture the intertwined time and space of the unit, I have used May and Thrift’s notion of timespace to frame my study. Technologies are one of the four domains viewed by May and Thrift (2001) as essential in constructing and shaping senses of timespace. In my analysis, I particularly emphasized the effect of hemodialysis treatments on the children’s everyday experiences and viewed the technologies and unit as mutually constituting (Ihde, 1990, 1993;
May & Thrift, 2001). To capture the nature and experiences of timespace as multiple and heterogeneous in places, my discussion also was informed by Adam (1990, 1995) and Felski (2000). The notion of situatedness is described by Peter (2002) as “having a sense of place” (p. 676) that refers to the meanings, significance and possibilities ascribed to various social settings (Manzo, 2003, 2005). I have used the concept of embodied situatedness that views children’s materiality as not merely an object in or a product of a setting, but indispensable to their perceptions, orientations, inter/actions and agency (Prout, 2000, 2005). Deeply embedded throughout all operations and relations, the hemodialysis technologies dominated the unit’s timespace that included the technological embodiment of the children.

**Doing Technological Time**

I have conceptualized the children’s experiences in the unit as doing technological time. Ihde (2002) claims that one’s body as both a site of lived experience and a cultural and social process is “traversed” by technology. Not only did the children have highly regimented routines in the unit, a routine of care was set for each hemodialysis machine, and children’s time was inseparable from machines. In a physical sense, children’s physiological processes were bound to the rhythm of machines, while their bodies were tethered. The children were socio-spatially segregated and isolated in the stations in the corners of the main room or in private rooms of the unit because the built environment must meet the needs and limits of the machine in terms of its placement, electricity, and fluid and solution supply lines. The children’s placement in the unit resulted in their socio-spatial segregation and isolation. Hence, their spatial, temporal, and social positions were an effect of their technologically mediated embodiment within a high-tech environment. Based on my observations and interactions in the unit over the three study periods, I have characterized children’s weekly cycles of hemodialysis as a technologically derived
indefinite sentence or form of imprisonment from which most of the children were waiting to be released.

**The children’s technological embodiment**

In my analysis, I have conceived of the hemodialysis machine as a prison guard. It is important to emphasize that without being conjoined to children’s bodies, the machine would hold little sway. The nature of the human-technological relation between the child and machine was the medium that mediated experiences of time and space in the unit. This human-technological relation involved the machine’s incorporation into the child and his or her world (Ihde, 1990; Verbeek 2008). The children’s mediated experiences were not entirely human as such experiences would not occur without their technological conjoinment. Hence, the children’s perceptions of and responses to their situations that I have characterized as a sentence occurred by way of the machine. To depict their senses of time in the unit, some children elected to use stickers with sayings about time that were provided by me while we did art work. As illustrated by a sticker chosen one child, the children are *captured in time* as well as space.

Ihde (1990) considers that once a technology is embodied, the machine or device recedes to some degree into the background. The withdrawal of awareness of the device signifies a high degree of habituation and fit between the user and technology in the setting it is applied. The term *transparency* is used by Ihde (1990) to refer to a technology that is no longer perceptible as it meditates between a human and his/her environment. The more transparent a technology, the less it is noticed and the more it is taken-for-granted in extending the embodied self. If one accepts this conclusion as a condition of embodiment, the children’s overall lack of responses to my questions about their technological embodiment may reflect their habituation to the hemodialysis machines. However, I question the stability and degree of the hemodialysis
machine’s transparency among the children. Some children mentioned that they did not notice the machine whereas other children viewed the machine more rationally as “science” or a technical object, suggesting a sense of disjuncture between their embodied selves and the technology. Some children also complained about their tethering and mobility restrictions. Their complaints suggest that the machine’s transparency may vacillate for them. Furthermore, because the children were concerned with the illness and distress from being dried out during a treatment, they had a tacit awareness of their bodies while receiving a treatment. Hence, the children’s perceptions of the transparency of their technological mediation shifted during treatments, forming an aspect of their embodied situatedness. Overall, the hemodialysis machine may be said to be experienced by children across a continuum of partial transparency (Ihde, 1990).

The healthcare providers in the unit also were engaged in human-technological relations, however, their relations differed from the children’s. As a reason for the proximity of the children to their care providers, the hemodialysis machine had a paradoxical effect on the provider and patient interactions. In the foreground for many of the staff, especially the nurses, the machines compelled their time and attention, more so than the children. The nurses’ focus was directed at the machine as they interacted with it as “technology-as-other” (p. 98). The nurse and machine interaction is characterized as an “alterity relation” (Ihde, 1990, p. 97). This relation describes a form of ontological separation in which the hemodialysis machine is viewed “as a device that is separate, at least conceptually, to the values and experiences of the person attached” (Barnard, 2002, p. 17). In their study of nurses in an adult hemodialysis unit, Tranter et al. (2009) discuss their notion of “technological creep” (p. 35) that refers to how practitioners who acquired increased technical skills drop other aspects of their role. They exclaim that this is a major feature of the hemodialysis unit as it is in most other contemporary health care places. The participating nurses were seen to highly value their specialized technical skills as essential to
their identities as dialysis nurses, yet they often had limited insight into the eroding effects of
technology on their patient’s identities. Because of the serious nature of hemodialysis and its
technological demands upon nurses, this phenomenon also was discernable, at times, in the nurse
and child relations in the unit.

In conjunction with an alterity relation, some staff groups, such as the nurses and doctors,
also had hermeneutic relations with the machine as a way to know the children’s bodies. The
nurses monitored and textually read the children’s biological responses and treatment parameters
represented by the machine’s outputs. Any technological reading obscures children’s
experiences of technological embodiment, while “simultaneously referring beyond itself to what
is not immediately seen” (Ihde, 1990, p. 82). In this case, what was not readily apparent except
via the machine was the internal dynamic physiological processes of the children that frequently
were of foremost concern. In their study of nurses’ care of very sick or dying infants in a
pediatric intensive care unit, McGibbon and Peter (2008) use the term ‘dissonance’ to refer to the
disconnection between nurses’ experiential stories of distress due to witnessing or causing
suffering and their clinical textual records. These clinical records are textual mediations of
human-technological relations interpreted into numbers, procedures and protocols that are
delivered in a detached scientific, bureaucratic manner. These forms of textual mediations have
become expected and commonplace in a biomedical institutional setting. In the hemodialysis
unit, a similar dissonance occurred in the technologically mediated relations in which little of the
child’s conjoined embodied experiences was seen and accounted for by the staff in the unit.

**The children’s perceptions and embodiment of time**

Adam (1995) claims that time is “implicated at all levels of being from the most physical
of planetary movements via physiological rhythms to patterns of social organization” (p. 17).
How time is known, experienced, measured and regulated is produced by the intertwined effects of natural, social, and technological processes. The collection of the children’s descriptions of their sense of time in the unit, gathered through talk, illustrations and observations, reveals that they perceived and embodied time in a variety of ways. Still, their overall senses of time were remarkable similar. Virtually all shared the perspective that their time was “wasted” and “lost” during the periods spent in the unit. This perspective is similar to the findings of Nicholas et al. (2011) who notes that, of all medical challenges associated with living with ESRD, hemodialysis is viewed by children as the most difficult because of the time consumption involved that limits other activities, such as school, recreation, religious activities, friendships, and home life. Hemodialysis dramatically extends the children’s lives. Hence, their views of time as misspent or taken from them, in regard to their qualitatively felt time in the immediate present and the longer linear duration of life time, is a paradox. Their views emerge from the time imposed on them through the unit routines and hemodialysis machines that have come to dominate their overall lives.

Most children also perceived time as “long” while conjoined to the machine, unless treatments coincided with an enjoyable activity or event. Emily remarked that “time usually flies when you are having fun, waiting is harder and boring and time goes slower.” Over my time in the unit, I also noted that although their lengthy regime was expressed as long and boring, paradoxically the children frequently were subjected to routine assessments and care carried out by the nurses or school teachers so that they often did not have long stretches of undisturbed time. This facet of their temporal experience illustrated the children as being busy with nothing to do. The children’s sense of time, as “wasted” or faster or slower, may be referred to as relative time (Adam, 1995) that is conceived as qualitative, inter/subjective and contextual based on their relative position in space and frames of reference. For the most part, the children referred to
these sorts of temporal perceptions to express their lived time while receiving treatments in the
unit.

Most children also perceived another sense of time as intervals or durations imposed upon
them by their technological regimes that corresponded to their notion of time as taken from them.
Time on the machine is quantifiable because the program of treatment must be precisely
regulated according to the biological status of the child. This objective form of time is linear,
representing the interval of ultrafiltration between their pre-dialysis weight and post-dialysis or
‘dry’ weight. This notion of quantifiable and measurable time may be characterized as absolute
time. In absolute time, time, duration and motion are linked so that it is conceived as linear and
invariable (Adam, 1990). Time is said to exist independently of and externally to social life or
individual subjectivity. This time is materialized through the clock that incorporates time as
measure as it measures time (Adam, 1995). The children’s marking time through the
hemodialysis machine illustrates this point. The majority of children did not, or could not,
express feelings about their conjoinment to the machine, yet almost all talked readily without
prompting about the machine’s time remaining indicator. The number that represented the time
left until the treatment ends had a measurable quantity and significance to children as a reference
point for their release from the unit. As a spectator in the unit, I also eventually marked
objectified, linear time through the machine along with the children as I sat with them. However,
as a participant, I felt my time as qualitatively stretched and lengthened, in a similar way to the
children. Hence, through different frames of reference, the children perceived and lived various
temporalities, including absolute time derived through the machine’s clock and their felt time
relative to their embodied positions in the unit. Their orientations arose from practices that
 correspond with interrelations among natural and social timetables and rhythms, professional
disciplinary routines, technological devices and texts that comprised the four domains of
timespace outlined by May and Thrift (2001).

The children’s particular temporal topography in the unit was interconnected with their
socio-spatial positions. Ultimately all time is social because it is experienced in social fields
through a variety of interactions, power relations, discourses, technologies, clock and calendars
and artifacts (Adam, 1990, 1995). Informed by my theoretical framework, I recognize that
timespace may be perceived and practiced in multiple ways among people in a setting due to
differences in situated identities among individuals and groups, such as professional and social
status, gender and age (Bondi, 2005; Massey, 1994, 2004, 2005; May & Thrift, 2001, Poland et
al., 2005). Based on this perspective, the temporal and spatial qualities of the unit cannot be
conceived as the same for the different groups in the unit. Because of the study’s focus, I am
unable to directly compare the adult’s experiences, such as those of the nurses, other staff
members or visitors, with the children’s sense of time and place. Despite this, I posit that
children’s sense of time as wasted, lost, stopped, long and boring was not shared, or as acutely
felt, by others based on my interactions and observations. In this study, neither time nor place is
viewed as an abstract or neutral medium. A relational notion of time and space centers on
embedded social relations in a place. Relational space is considered foremost cultural and
political because of unequal power relations by which individuals are able to constitute their
social and material worlds and, in turn, be constituted by them (Andrews & Kitchin, 2005;
Massy, 1994, 1999, 2004, 2005). Time in the unit for all staff was primarily commodified and
productive work time, comprised of a series of spatialized routinized chores, schedules and
deadlines employing the notion of absolute time measured by the clock (Adam, 1995). Unlike
the children who expressed time as taken or lost, the staff’s procedure-driven time may be
viewed as “a valuable resource and a quantity irreducibly tied to work and economic exchange” (Adam, 1995, p. 87).

Because of their socio-spatial positions and identities and roles as patients, the children had limited participation in the construction of the unit’s timespace. Technological and educational routines occurred concurrently to make up the children’s lost school time. However, many older children resisted, perceiving this routine as an additional burden rather than of productive value. Moreover, the children occupied a very specific physical position in the unit, as the only group with an extreme inability to move freely, due to their tethering to the machine and cornering at their stations. They also did not display much ownership of the unit’s design and materials, such as the artwork or the chair that they sit in to receive a treatment. Hence, the children were granted little agency. Prout’s (2000, 2005) insists that children are active subjects in their own representations and lives rather than the culmination of social relations or discursive processes. Overall, most of the children’s adaptation to the unit seemed to be one of resignation, however, at moments some of the children actively resisted their attenuated identities and roles as patients. In the networks of power circulating within the social relations in the unit, the timespace was not felt or shared universally or equally among children and their care providers, according to each group’s position, level of control and perceived benefits or detriments. No studies to date have focused explicitly on how children perceive the hemodialysis unit. Understanding children’s perceptions of time and space may prove to be practically useful. Considerations of how time might be perceived as valuable rather than taken or lost among children may facilitate opportunities, co-created with children, for more enjoyable and purposeful ways that their time could be spent in the unit.

Experiences of waiting were expressed by the children. My purpose in highlighting them here is to illustrate the children’s temporal orientations as grounded in both their everyday
routines and a sense of life time. To extrapolate concepts of everyday time and life time in regard
to the children, I draw primarily on the work of Felski (2000). Similar to Adam (1990, 1995),
Massy (1994, 1999, 2000, 2005) and May and Thrift (2001), Felski’s (2000) project is to explore
notions of difference and sameness in perceptions of time among individuals and groups. She
illustrates how people co-existing at the same historical moment might inhabit both the same and
different times through interactions among geographic locations, social relations, individual
autobiographies and circulating cultural discourses. Two temporal levels, everyday time and life
time, are distinguished by Felski that facilitate comprehension of the types of waiting that the
children endured. These conceptions are conventionally and metaphorically distinguished by
notions of “time as an arrow” and “time’s cycles” (p. 82). Adam (1995) refutes a linear and
cylical opposition, claiming that both are inherent in natural and social processes. She remarks
that “whether we see linearity or cyclicality depends fundamentally on the framework of
observation and interpretation” (Adam, 1995, p. 38). Felski (2000) also maintains that all
individuals are embedded in linear and cyclical time as “repetition always involves variation; it
takes place within rather than outside the irreversibility of time” (p. 20). In addition, memory,
extensions into past and future and the birth-death parameter add other dimensions to that of
cylicality and linearity (Adam, 1995). Hence, distinguishing between everyday time and life
time is a largely heuristic maneuverer because the levels intertwine and merge.

Everyday time consists of the more or less repetitive, habitual day-to-day routines and
milieu, such school, domestic and hospital routines that impose a certain order on rhythms of
embodiment and daily lives. Socially constructed, these activities tend to be cyclical and
“conform to diurnal rhythms that are in turn embedded within larger cycles of repetition: the
weekend, annual holiday, the start of a new semester” (Felski, 2000, p. 81). In regard to the
study’s focus and setting, the children’s everyday time in the unit consisted of their cycles of
hemodialysis treatments with its attendant rituals and regimes. In addition, Felski (2000) remarks that everyday time also refers to perceptions and uses of time, such as the children’s impressions of their time as “wasted” or faster or slower while conjoined to the hemodialysis machine. Because of associations with repetition and habit, the notion of the everyday also is closely tied to the ordinary, mundane or taken-for-granted nature of existence (Adam, 1990, 1995; Felski, 2000). The perceptions of sameness and monotony complained about by the children in regard to their medical and school routines, and experienced by me, form the background of the unit environment. Even complications or delays, for example, if a central line becomes blocked so that it had to be flushed out or a child feels ill, happened quite frequently so that these problems, although disrupting, tended to take on a sense of the ordinary and predictable in children’s routines. Hence, the children’s sense of day-by-day waiting to be released from the machine and unit temporarily until the next treatment cycle was an effect of the unit’s everyday routines and mediated through the specificities of their situated embodiment.

Emerging from the data, the children expressed a sense of waiting that is longer in duration that was concurrent with their shorter term cycles of everyday waiting. I have used the notion of life time to refer to this long-term and linear sense of waiting. Life time refers to the creation of oneself as an autobiographical subject and the “process of understanding one’s life as a project that encompasses and connects segments of daily experience” (Felski, 2000, p. 17). Felski claims that a temporal sense of life time occurs from the present vantage point as well as temporal extensions of memories of the past and anticipation of the future, so that one makes sense of his or her identities by imbuing them with a temporal Gestalt. Nicholas et al. (2011) found in their study of 25 Canadian children and adolescents with ESRD that a hope for normalcy following transplantation was highly typical and transplanted children perceived their life as more normal than being on dialysis. During a conversation, one child remarked that “I am waiting for a
transplant, that’s what I want, then I will be normal again”, illustrating her orientation towards a future that does not include weekly cycles of hospital-based hemodialysis. This orientation was present among a number of the children in the unit. Hence, the children’s accounts of their perceptions of time spent in the unit depict temporal levels involving cyclical and linear conceptions of time that I have conceptualized as everyday time and life time.

The children’s technological and emplaced embodiment

The children’s time in the unit that I have characterized as an indefinite sentence was comprised of waiting in the everyday and longer term until released through transplantation, a different medical treatment modality or perhaps a transfer to adult services. I suspect, however, that a transfer to an adult hemodialysis unit, as Jay did during a data collection period, would not radically alter the senses and qualities of time that are lived through receiving hospital-based hemodialysis because little changes in the regimes and relations. Although entailing embodied situatedness in a different unit and thus, in the timespace particular to that setting, my overall premise is that the limits and needs of the hemodialysis machines and associated equipment drove the rituals and routines of the hemodialysis unit. Because the machine and treatment course remain essentially the same for children and adults, the variable able to effect some change is the body attached, by which I mean the physiological differences between individual adults and children. I concede, however, that difference between adults’ and children’s senses of time also may exist. However, a small body of literature specifically has studied adult experiences of hospital-based hemodialysis, focusing on the ramifications of hemodialysis technologies on the participants’ bodies and lives (Allen et al., 2011; Hagren et al., 2001; Nagle, 1998). Among these studies, as a whole, are shared narratives of time consumed, restricted freedom, increased technological dependency, suffering, disembodiment, and dehumanization
through living in the hemodialysis environment as a dialysis patient. These themes, derived from studies undertaken in adult settings, resonate strongly with those that have emerged from my study located in a pediatric hemodialysis unit and my overall conception of the children doing technological time in the unit. Hence, in many ways adults’ and children’s accounts of hemodialysis regimes appear comparable.

The children’s embodied situatedness in the unit was a microcosm that reflects a much broader system of biomedicalized and institutionalized medicine in Western culture. A third level of time articulated by Felski (2000) is large-scale time that refers to historical “long-term processes that transcend the limits of our personal existence” (p. 18). Large-scale time includes shared pasts and futures fashioned on broader collective structures of power, cultural knowledges and narratives about group identities, such as gender, nationality, religion, and ethnicity. In general, issues of history, continuity and disruption are broad, complex and beyond this study. The problem of large-scale time, Felski (2000) explains, is that it tends to involve the illusion that there are overarching laws governing temporal social processes and experiences that obscure or trivialize the specific details and concreteness of time experiences and practices in the everyday. Large-scale time “denies real differences by assuming a common existence within a temporal medium that unifies and ultimately transcends all differences” (Felski, 2000, p. 10).

However, in this discussion, large scale-time can be applied to consider how people are born in historical periods when specific cultural events occur. Over the past four or five decades, new health care technologies have emerged rapidly in North American culture, including life-sustaining hemodialysis technologies, that have transformed existence for individuals with ESRD. Furthermore, the hemodialysis machines and the treatments they offer provide the impetus to construct specialized hospital units and disciplinary specialties such as dialysis nursing. Hence, the unique characteristics of the hemodialysis setting emerge from their
“particular and dynamic position within a complex of social relations that stretch out far beyond any particular place” (Bondi, 2005, p. 142).

In one of the only broader socio-political and economic critical examinations of the hemodialysis context of that I am aware, Bevan (1998, 2000) focuses on the medical and cultural history of renal health care to illustrate the temporal and spatial impacts of hemodialysis technologies on people and place in a hospital setting. He claims that the emergence of the hemodialysis machine has produced contemporary problems associated with hospital-based treatments. During the 1960s, the evolution of hemodialysis technologies established the possibility of prolonged survival of those with ESRD, altering the condition from a fatal to a chronic condition. Concurrent with an increased demand for treatments, health care rationalization and restructuring have reformed meanings of renal health care places and the actions of those within it. He remarks on the busy tempo of hemodialysis settings because now the demand for treatments often outstrips the availability of machines. In his view, the contemporary hemodialysis unit has become a “processing line, a conveyor belt or production line of patients” (Bevan, 1998, p. 731) that suggests a type of spatial, temporal, and social distribution and ordering driven by the hemodialysis technology. In addition, the machine’s availability structures patients’ broader lives by directing their timing of transport to and from the unit. Therefore, control and power operate in and through the time, space and technology in the hemodialysis unit and extend into daily lives of hemodialysis recipients.

In regard to the setting of the study, the temporality and spatiality of the unit both structured and were structured by its paramount purpose. The intent of the regimes and relations in the unit was to function in an optimal, timely manner to ensure a steady progression of children through their everyday cycles of hemodialysis. Similar to all health care places, Bevan (1998, 2000) contends that the nature of care in hemodialysis units is overwhelmingly centered
on the technologies to the detriment of provider and patient interactions. Poland et al. (2005) remark that while some places, such as prisons or psychiatric institutions, are designed as “apparatuses of capture” (p. 174), the intent behind health care settings is more benign or benevolent. Nonetheless, based on my analysis of the children’s perceptions of and responses to the hemodialysis unit, my overall thesis includes the view that children are technologically sentenced to do time in the unit. McGibbon and Peter (2008) offer important insights about the effects of the prevalence of increasingly unquestioned normalization of biotechnologies in health care institutions that obscures the “nature of what happens at the juncture of technology and human experience” (p. 1136). They remark that local everyday experiences are structured by a broader set of extralocal social networks and discourses, rarely evident in the specific time and space in which they are enacted. In Felski’s (2005) terms, a fundamental difference exists in the notions of “living at the same time and in the same time” (p. 23). This distinction is crucial because it stresses that individuals and groups in the everyday do not live in the same time although they may live in large-scale historical periods at the same time. To return to the hemodialysis unit, over the past five decades the development of a machine that can function as a kidney has radically shaped the children’s experiences and overall lives. Unlike healthy children without kidney disease, the children with ESRD experienced time disruptions and socio-spatial dislocations due to their technological dependence on hemodialysis in a hospital-based setting. The children’s accounts depicted that their time is structured significantly differently than other children.

When asked how the unit may be made better for them, the children provided few positive responses. The children’s unenergetic and disinterested responses contained a certain logic that corresponds to their socio-spatial position in the unit. I believe that their human-technological relations play a significant role. In Ihde’s (1990) view of the technological embeddedness in
cultures, situated technologies are ambiguous as they may be put to a number of uses. However, the possibilities of human-technological relations are finite to that setting. This technological phenomenon is termed “multistability” (p.44). Embodying a machine or device requires forming a coherent, expedient association so that the relation produces useful results. Rosenberger (2009) applies the term relational strategies to refer to “the particular configuration of bodily habits, intentions and conceptions that make it possible to take up a particular stable position” (p. 16). Strategies refer both to bodily and cognitive processes in which the person must have an idea of the purpose of the machine and familiarity with its use. Through understanding and adjusting to the machine, technological embodiment becomes established. Furthermore, the more stable the human-technological relation, the more transparent (or less noticeable) the machine and its mediating effects on experiences of the world (Ihde, 1990). The possibility of the hemodialysis machine being used for another purpose is possible, such as a table where to place an object. However, this interaction would not be experienced as useful in the unit. Instead, the machines have a very specific use, and based on my observations, the staff and children were highly adjusted to its use-pattern. Hence, the human-technological relations in the unit are highly stabilized. The stability of the children’s embodied technological relation requires that they comport themselves in particular ways, such as staying in the chair, placing their arms so not to occlude the line and following the rituals of being hooked on and off a machine. Their conjoinment with the machine conditioned the children’s comportments and behaviours, and perhaps their perspective that little can change about the unit to better suit them. Following Ihde’s line of reasoning, the children would need to develop preferred ways of being in the unit without disrupting the stability of their embodied technological relation. Furthermore, because all the staff in the unit also must form stable relations in order to work efficiently and effectively, the technologies tend to recede from awareness so that its effects on the place and people may be
rendered invisible to them as it is to the children. This notion is similar to the McGibbon’s & Peter’s (2008) view of the dissonance in the nurses’ institutional textual mediations of care that conceals their emotionally-charged experiences of caring for suffering or dying infants or Tranter et al.’s (2009) view of dialysis nurses’ strong attachments to their specialized technical skills as integral to their role in hemodialysis units. Hence, relations with a technology, such as a hemodialysis machine, incline the user towards perceiving and acting in a setting in ways particular to that technology (Ihde, 1990, 1993). The challenge for those interested in the children’s wellbeing beyond their technical and physical needs while receiving a treatment is the conscious examination and mitigation of the negative effects on the children.

**The children’s adoptions and attachments to the unit**

Through my observations and participation in the unit, the children appeared to have become well socialized to the routines and relations of the unit, assuming a position as a dialysis patient. In regard to almost all children’s behaviours, I found that it was difficult to discern through observation whether they were newcomers, long timers or somewhere in-between. Although some gender and age-related differences appeared in the data, the children’s overall assumption of the role and identity of patient obscured individual difference among them. However, to assume that the children did not contest or negotiate their position would be inaccurate. James and Hockey (2007) and Prout (2000, 2005) demonstrate that in childhood places of discipline and control, such as schools and hospitals, children interact within the opportunities and limits of the institutional and social processes. In the unit, forms of agency and resistance were expressed, for example, Emily and Chandra were persistent in requests to the nurse to alter the physical arrangement of their station in order to play together. Navina and Tammy successfully thwarted my attempts to gather information from them and Delroy
pretended to sleep to avoid his teacher and school lessons. Still, the children possessed limited
power to influence how their treatment would unfold or to express their individuality in
interactions with the nurses and other staff who provided direct care. The findings revealed the
children as often resigned to the timespace of the unit while undergoing their hemodialysis
sentences.

I have conceived of the children’s experiences in the unit overall as doing technological
time based of their perceptions of hemodialysis and responses to the unit. I would, however, be
remiss if I did not also discuss the children’s coexisting perceptions of the unit. The children also
experienced a sense of belonging and felt positive attachments to the unit that was most visible
during the periods when the dominant technologically driven routines and relations were
interrupted. The annual Christmas party provided a strong example of such interruptions and the
children positively responded to the festivities and people in the unit. The staff and families
collaborated and contributed food, presents, and fun to ensure that each child felt recognized and
welcomed. Some interruptions to the dominant timespace were less dramatic than the annual
Christmas party but nonetheless demonstrated the positive aspects of being in the unit for the
children. For example, the children frequently and enthusiastically commented that they are able
to eat and drink in a manner typically enjoyed by children without kidney failure when connected
to the hemodialysis machine. This reprieve was received as a welcome consequence of
hemodialysis that may have had a normalizing outcome on the children’s sense of self and their
lives. Interestingly, this sense of normalization may have only occurred while receiving
treatments in the unit rather than when disconnected from the machine in their typical childhood
routines outside the unit, such as home, school or activities with peers. Furthermore, there were
observable moments of positive sociality in the daily relations among the children and among the
nurses and the children, such as Delroy’s occasional guy talk with the male student nurse. While
these manifestations were fairly infrequent and often exceptional in the everyday technologized regimes, they nevertheless provided important information about the hemodialysis setting from the children’s viewpoints.

Some children referred to the unit as a “second home” that indicates a very different sense of the unit than as a technological place for medical care. Felski (2000) notes that “home is not just a geographical designation, but a resonant metaphysical symbol” (p. 86) of security, familiarity, belonging and everyday routines. This sense was evident among some children on our unit tours, at social events, such as Jay’s goodbye party, and occasionally during the everyday routines. Although this characterization predominantly appeared to be held by long-timers, such as Jay, Delroy and Azed, fairly recent newcomers, such as Emily and Chandra, also seemed positively attached to the unit at times. Based on the findings of her study about the nature of people’s emotional relationships to places, Manzo (2005) remarks that “it is not simply the places themselves that are significant but rather what can be called experience-in-place that creates meaning” (p. 74). Attachments result from significant experiences in a place “for better or worse” (p. 82). Hence, Manzo (2003, 2005) claims that a relationship to a place may be viewed as encompassing a range of positive, negative and ambivalent emotions. Among the children, their positive attachment seemed to be a result of social interactions comprised of mutual camaraderie, caring, rapport or friendship. However, their more negatively characterized human-technological relations also significantly shaped their experiences, and perhaps forming an aspect of their overall attachment to the unit. Some of the children may be adept at incorporating both positive and negative meanings and experiences into their sense of the place of their renal care.

In a relational view of place, individual identities are viewed as forged through contextualized social relations and are not rooted or static but are mutable, ongoing productions
(Massey, 1994, 2004; Bondi, 2005). This relational view also extends to the notion of place as having multiple or hybrid identities as do the individuals within the setting (Massey, 1994, 2004). A place’s “multiple identities can be a source of richness or a source of conflict or both” (Massey, 1994, p. 153). Even home, remarks Felski (2000), “like any other space, is shaped by conflicts and power struggles” (p. 87). Based on this perspective, the hemodialysis unit may be perceived simultaneously among the children as both a technological and medical place they temporarily wish to escape in the everyday and permanently in the long-term and a “second home” to which they feel attached.

**Chapter Summary**

The interrelations among the children’s bodies, time, space and technologies in the hemodialysis setting were the focus of my study. The predominant nature of the unit has been conceived of as technological, in which the children are doing technological time. However, because the timespace of the unit was multiple and heterogeneous, the children’s relationships to the setting may have resulted in multiple meanings and different forms of dis/attachments. Framing the unit solely in terms of its controlling, oppressive and dehumanizing effects on the children does not provide a comprehensive and accurate picture of its multidimensional and complex social and human-technological relations and overall nature. Receiving hospital-based hemodialysis treatments was undoubtedly beneficial to the children in myriad of ways. Still, a need remains to articulate the children’s everyday experiences of technological embodiment, as told by them, in wider discussions about the effects of hemodialysis on children and the increasingly taken-for-granted use of technologies in health care environments in contemporary western societies.
Chapter VII: Implications and Limitations

Introduction

My overall conceptualization of the children’s embodied situatedness in a hospital-based hemodialysis unit is doing technological time. This conclusion is based on my findings that revealed the powerful and overarching effects of the hemodialysis technologies on the timespace in the unit that structured the children’s experiences. My research contributes to practical knowledge about children’s perceptions of and responses to hospital-based hemodialysis that has not been well studied or understood to date. This work also contributes to a number of theoretical fields, such as contemporary childhood studies of children’s embodiment in health care places and technologically-focused studies that highlight the effects of health care technologies on time and space in hospital settings. In this chapter, I first offer some practice and policy suggestions that may contribute to improving the time spent in the unit among children. Acknowledging that all studies have theoretical and methodological limitations, I then discuss the limitations of my conceptual framework and study methods while suggesting implications for further research.

Implications for Health Care Practices and Policy

The study findings suggest a crucial need for changes in the practices and places of pediatric hospital-based hemodialysis. I begin with what some of the easier changes to improve the experiences of children and then move to the changes that would require greater commitment and resources on the part of funders, practitioners, administrators and policymakers. The inclusion of children’s views in processes of change cannot be emphasized enough. Many settings typically occupied by children have been designed and designated by authoritative or
professional adults as “places for children” (Rasmussen, 2004, p. 155) without children being involved in the design. That children have important insights to share about the health and social services that they receive and their perspectives may differ from adults is highlighted by various theories and researchers (Balen et al., 2006; Moss & Petrie, 2002; Rasmussen, 2004; Nicholas et al., 2011). Also, children may relate to informal places or areas that are unrecognized by the adults around them (Rasmussen, 2004). For example, the waiting room outside of the unit rarely was entered by health professionals. However, the findings revealed that some of the children and family members spent time socializing in personal and familiar manners with one another in this room in ways that were not evident in the unit. Because the findings illustrated that children receiving hemodialysis were subjected to numerous technological interventions at the expense of their social and emotional care, my assumption is that it is essential to include their views in all aspects of the creation of a more overall positive place that merges and balances their technological care with child focused care.

The children expressed in multiple ways that their time on hemodialysis felt like a burden that took away time from their other everyday pursuits. The reality of their kidney disease necessitates a great deal of time spent receiving treatments in the unit. To help alleviate the boredom and monotony felt by the children, taking action so that their time may be perceived as more enjoyable or purposeful would prove fruitful. Supplying the unit with computers and other devices for entertainment and socializing with outside peers may provide benefits that outweigh the cost of these technologies. This would be particularly significant for some children, such as those participants who desired a gendered peer relationship in the unit but were not able to develop one. Social support is known to play an important role in the health and wellbeing of children with chronic conditions and disabilities that limit their abilities for peer interactions and increase the possibility for isolation, loneliness and depression (Barnfather, Stewart, Magill-
Evens, Ray & Letourneau, 2011; Stewart, Barnfather, Magill-Evens, Ray & Letourneau, 2011). Because the children were quite isolated and seemed to find face to face socializing while conjoined to a hemodialysis machine difficult, the technological capacity to reach out beyond the unit may provide social interactions unavailable in the unit. The development of a computer-mediated support and social groups for children with ESRD and other chronic conditions, for example the construction of an online social network which can be tested such as that described by Barnfather, et al. (2011) and Stewart, et al. (2011) could be highly beneficial to the children. Likewise, efforts to facilitate the development of relationships between children by configuring the stations prior to the arrival of the children may enrich their time in the unit.

The children had limited ability to construct or control the space of the hemodialysis station where they received treatments. Measures that provide children some agency would help address this facet of their experiences and could include allowing children to choose where to sit and encouraging the pulling of curtains at least partially around a station for privacy if desired. Although school lessons are unavoidable, providing the children with a schedule of their schooling would permit them to prepare for the teacher. A schedule that indicates if and when the social worker or dietician is visiting them in the unit also may assist them to know how their treatment time will unfold in that session. Preferably each child’s schedule during a hemodialysis session would be discussed and negotiated with him or her prior to the treatment. In addition, including children in plans or projects to improve the appearance of the unit also would help to ensure that the place is pleasing and memorable to them. The children could be involved in the choice of aesthetic inclusions, such as professionally prepared murals or paintings, or in the creation of their own art work to decorate their stations and the unit to enhance the space for them.
The findings suggested that some children held multiple views of the unit that included its characterization as a “second home”. This characterization appeared to be tied to novel events and interruptions in the typical technologically driven routines and relations. These events and interruptions provided opportunities for the children to socialize with peers, the staff and visitors and to step out of their usual technologically-focused routines. Creating opportunities for these events more frequently, such as birthday celebrations, goodbye parties, seasonal parties or celebrations of transitions, such as graduating from elementary school, would personalize the unit and recognize the children as individuals. This may mitigate the predominant casting of children as patients. This might be achieved by reinstating the role of the child life specialist who focuses on multidimensional aspects of children’s care, including their emotional and social needs. Child life specialists also are skilled at conversing with children in supportive and encouraging ways and at assisting the staff in their care of each child’s individual needs. Continued concentrated efforts on discovering with children what makes the unit feel like a good place for them would facilitate knowledge and the creation of the elements described as positive.

A stronger view of the hemodialysis unit as child-focused could be expanded to include that also of family-centred principles that includes collaboration, information-sharing and recognition and respect for the uniqueness of each family (Darrah, Wiart, Magill-Evans, Ray & Andersen, 2010). In their study that investigated the practices of family-centred service in pediatric rehabilitation programmes for children with cerebral palsy in Alberta, Canada, Darrah, et al. (2010) found that although some programmes espoused a commitment to family-centred care, indicators of this approach and formal processes for its delivery often were deficient. Although the parents, caregivers and a sibling sometimes accompanied a child to the unit, little provisions for everyday family interactions or for making the family members feel at home in the unit were accommodated. Because of the time spent in the unit, children receiving hemodialysis
experience reduced opportunities for domestic routines and family life (Nicholas et al., 2011) and family time in the unit may mitigate some of this lack. Increased sensitivity to the social, comfort and coping needs of the family members who also spend a significant amount of time in the unit would assist in creating a place that recognizes the multiple needs of children and their families. During a child’s treatment time in which the child, parent and health care providers are in the unit together may prove to be an ideal opportunity time for information sharing and collaboration about the treatment and management of ESRD. Furthermore, the facilitation of a more family-centered unit may provide opportunities for the parents to receive social support and practical information through parent to parent interactions.

More elaborate and larger-scale changes include that opportunities be taken to reconceive the built environment of pediatric hemodialysis units so that the technological needs of the machine, as far as possible, do not eclipse the comfort and social needs of the children. My study illustrated the profound effects of hemodialysis technologies on the children’s situated embodiments. How the hemodialysis technologies might impact pediatric hospital unit should be explicitly examined before their design and construction to mitigate the effects of the technology. Furthermore, discussions should include multiple viewpoints, such as those of clinicians, children and their families, designers, engineers, technicians and scholars who study the impact of technology on human life. Ihde (1990, 1993) repeatedly has pointed out that technologies are not neutral tools because they transform the ways that individuals perceive and interact with their worlds, which include the immediate perceptual, socio-political and cultural realms. A perspective that respects the “complexity of the phenomenon” (Ihde, 1993, p. 117) must be undertaken so that appropriate changes to hemodialysis unit can be made. Including multiple viewpoints would be highly beneficial to envision alternative designs when building new pediatric hemodialysis unit. For example, the hemodialysis machines’ electrical and water and
fluid delivery systems sources were close to walls in the main area of the research setting. The
effects of this design were that the children were tethered to machines that resided in the four
corners of the main room whereas the staff and visitors resided in the central areas. Placing the
sources of electricity and water and fluid supply in other areas of the room may alter the spatial
layout so that the children can occupy a more central place in the unit. Furthermore, providing
inviting accommodations, such as comfortable arrangements of chairs and tables, would create a
place for families and friends to spend time with a child or one another.

The findings of this study and recommendations for change may have broader applicability
outside of hemodialysis. The findings provided insights into the circumstances of the children
who depend on intermittent hemodialysis in a technologically dominated institutional setting.
Because the findings have generated theoretical propositions from the data about the phenomena
investigated, (Hammersley, 1992) they may be generalizable, to some extent, to similar pediatric
populations. The descriptions of the children’s perceptions and responses have established in-
depth accounts of their embodied situatedness while receiving specialized hospital-based
services. These descriptions, through theoretical inference, may be applicable to other children in
similar circumstances, such as those with thalassemia, short gut syndrome or blood cancers, who
receive intermittent technological interventions in pediatric hospital settings (Stake, 1995, 2000;
Williams, 2002). Similarities among children who experience similar intermittent
technologically-focused care and children who receive maintenance hemodialysis warrants
further investigation to understand how the study findings and recommended changes may
benefit them. Research in this area may suggest design changes to other hospital units as well as
actions to increase these children’s comfort and agency while they receive their form of
treatment.
Implications for nurses

The findings illustrated the critical importance of the nurses to the children’s care and socialization in the hemodialysis unit. It is worth mentioning the exceptional position of the nurses who straddle both social and human-technological relations in this technologically dominated health care environment. The dehumanizing and alienating effects of technologies on nurse and patient relationships have been well-documented (Almerud, Alapack, Fridlund & Ekebergh, 2008; Barnard, 2002; Barnard & Sandelowski, 2001; Bennett, 2010, 2011; Bevan, 1998, 2000; McGibbon & Peter, 2008; Poland et al., 2005; Sandelowski, 2002; Tranter et al., 2009; Wynn, 2002; Zitzelsberger, 2004) and contributions to this discussion are beyond the scope of this dissertation. While beneficial and welcomed at times, nursing work has become increasingly reliant on health care technologies as the means to know and care for patients. Health care technologies increasingly are the priority form of care in the contemporary North American health care system. The study findings illustrated that technological imperatives impelled the staff nurses to be increasingly available to the care routines of the hemodialysis machines so that they were both “embedded and the culprit” (Zitzelsberger, 2004, p. 247) in this high-tech, specialized hemodialysis unit. I strongly urge that nurses from clinical, administrative, academic and research domains continue to work towards new understandings of the integration of technologies into caring work with children and develop opportunities for innovation and change. For example, McGibbon and Peter (2008) have highlighted that nurses often are unaware of the pressures exerted by extralocal relations and discourses that propel them towards technologically-focused care rather than human-focused care. Increasing nurses’ awareness of their position may facilitate their integration of technology as “a ‘part’ of care and not ‘the’ care (Bennett, 2011, p. 249), enabling them also to incorporate a stronger focus on personal and individualized nursing care. The fact that children spend a great deal of time over long durations
with nurses in pediatric hemodialysis settings may be an advantage. Spending relatively long periods of time together may support nurses’ efforts to establish warm and personal relations with children (Bennett, 2010, 2011).

Conceptual Limitations and Implications for Future Research

Conceptual limitations

At the beginning of the study, I conceptualized that the children are temporally disrupted and socially dislocated because of their technological dependence on hemodialysis. Based on an understanding of the importance of time, space and technology in these children’s lives, my research questions focused on their perspectives and responses to the temporal, spatial and technological aspects and their interrelations in the unit. The vast array of theoretical literature in the fields of human geography, perspectives on time and perspectives on technology does not explicitly incorporate and integrate the three major concepts or frames of time, space and technology in this study. Yet, depending on the primary focus of theories in these fields, the notions of time, space, or technology may be there, but implicitly. For example, a major focus of Ihde’s (1990, 1993) philosophy of technology describes the embedded nature of specific technologies in particular cultural settings. Although place and technology are fundamental in his work, a robust conceptual perspective on space or place is not developed. In addition, many human geographical theories, including health care and nursing geographies, do not explicitly incorporate the effects of technologies in places. There is, however, an increasing focus towards the inclusion of technologies in contemporary geographical literature and studies (Andrews & Evan, 2008; Lehoux et al., 2007; McGibbon & Peter, 2008; Poland et al., 2005). Because of the lack of a framework that explicitly incorporated the three frames, I developed a conceptual
framework that explicitly incorporated perspectives on time, space and technology in place to answer my research questions and inform my data collection and analysis. Because I assumed that children’s experiences are materially lived, socially produced and technologically mediated, Prout’s (2000, 2005) notion of children’s embodiment was employed. To investigate children’s embodied situatedness, the theoretical framework merged concepts from human geographical perspectives (Andrews & Kitchin, 2005; Manzo, 2003, 2005; Massey, 1994, 2004, 2005; May & Thrift, 2001; Peter, 2002), temporal perspectives (Adam, 1990, 1995; Felski, 2000; May & Thrift, 2001) and philosophy of technology (Ihde, 1990, 1993). There were advantages and limitations to this approach.

Disadvantages include the challenge of endeavouring to give equal weight to the three conceptions of time, space and technology in the course of the study. Efforts to maintain a focus on all three conceptions limited the possibility of an expanded, in-depth and rich discussion that each of these aspects of the hemodialysis unit deserves in shaping the children’s embodied situatedness. Time, space and technology on their own are complex, multifaceted and abstruse aspects constituting the unit and thereby the children’s experience within it. Furthermore, although my framework conceived of time, space and technology as inseparably intertwined to illustrate their operations I found that I needed to separately discuss them for clarity. I did, however, endeavour to merge them at points in my interpretative findings and discussion chapters. There were limits to maintaining conceptual coherence when incorporating the impact of the three conceptions of time, space and technology on the children’s embodied situatedness in my analysis and presentation of the findings.

I applied May’s and Thrift’s (2001) notion of timespace to develop an integrated conception and analysis of time and space in specific places. The notion of timespace was highly beneficial to an integrated notion of time and space, allowing me to study how the two are linked
in the unit, for example, the impact of the children’s socio-spatial segregation and isolation on their perceptions of time. Furthermore, May’s and Thrift’s (2001) four interrelated domains that include natural-social timetables/rhythms, disciplinary/professional routines, technologies, instruments, or devices as well as texts provided a means to explore how timespace was structurally constituted in the unit. However, a limiting aspect I found when working with their conception of timespace was the lack of provision of reference points to conceive of how time and space is felt or sensed by the individuals and groups in the unit, despite their claim that their conception does so. I drew on work from Felski (2001) and Adam (1990, 1995) to analyze and discuss the children’s felt sense of time and how it may be characterized. In addition, Manzo’s (2003, 2005) work on multiple dimensions of the meaning of place provide the concepts needed to discuss the various ways that the children appeared to be negatively and positively attached to the hemodialysis unit. These additional sources proved helpful in filling out the gaps in May’s and Thrift’s (2001) notion of timespace to analyze the children’s perceptions and responses.

**Implications for future research**

The challenges associated with merging sets of concepts of time, space and technology should not discourage attempts to explore how all three are implicated in health care places in future research. Framing the study using human geographical, temporal and technological concepts provided the possibility of a deeper critical analysis of the relations between the social and technological than might have been possible otherwise. A number of theorists (Bondi, 2005; Massey, 1994, 2004, 2005; Poland et al., 2005) highlight that social relations are comprised of power relations among individuals and groups in regard to professional roles and statuses, gender, and age. Hence, technologies are used in health care networks filled with power relations among various situated identities and roles. This viewpoint contributed to an understanding that
differing identities and roles structure diverse people’s experiences of technologies in places. Although technologies are socially transformative, their effects may be unequal among individuals and groups. The children differed in their relationships to technology relative to those of the adults and health care providers, such as the nurses, physicians, technicians and parents. For example, I illustrated that the children, due to their tethering and cornering in the unit’s main area, had differing social and material experiences than any other group and that their embodied positions directly impacted their perceptions, negotiations and expectations. Employing human geographical, temporal and technological concepts also permitted an understanding of interconnections among social and human-technological relations within the various divisions of labour in the unit and how these shaped health care providers’ interactions with the children and one another.

My particular theoretical focus on the embedded nature of hemodialysis technologies within the context (Ihde, 1990) and interplay between human-technological relations and social relations excluded to some degree other dimensions of the social world in the unit that may be better understood with specific or alternative conceptual frameworks about place. For example, my findings illustrated the children’s perspectives included their positive characterizations of the unit as a “second home” as well as a place of imprisonment from which to escape. Further research that expands and deepens understandings of the children as holding multiple and simultaneous perceptions of the hemodialysis unit may prove to provide fruitful results. Employing relational theories of space that center on people’s attachment to places may specifically express children’s complex relations with their health care places. I suggest further research that explores both positive and negative emotional connections to hospital-based hemodialysis settings would provide important information that may assist to maximize the possibility for children’s positive experiences and attachments. I consider this to be of utmost
significance because children receiving hemodialysis are radically displaced from their personal homes, schools, and other familiar places. The findings of such studies could be theoretically informative as well as practically important for designers, planners, architects, health administrators and health care providers to construct and operate hospital-based units that address the social and emotional needs of those children who spend considerable amounts of time in a hemodialysis unit.

Another fruitful research direction might be to explore the mediating role of technologies that are understood to be both temporally and spatially co-constitutive in complex social networks, such as those described in the collection of theories that comprise Actor-Network Theory (Latour, 1996, 1999). Unlike Ihde (1990, 1993) who is primarily concerned with technological embodiment, Latour (1999) views both humans and technologies as actors. He posits a more symmetrical view of humans and technologies that are said to interact in reciprocal exchanges to produce new modes of actions and meanings not quite embedded in either actor’s original intention. Research grounded in this view may yield other important dimensions of human-technological relations in the technologically dominated hemodialysis unit.

Finally, differences also may exist between children who are intermittently conjoined to a machine in a hospital-based setting in comparison to those who continuously need technological interventions, such as ventilator use, whether residing in homes, communities or hospitals on a fulltime basis. I have used the term conjoinment to signify that the children’s technological relation with the hemodialysis machine is temporary. I assume that substantial differences in embodied experiences may exist among children who experience a permanent human-technological hybridity across multiple settings versus those who experience intermittent technological conjoinment in a specific setting. In addition, those children who have received transplants embody an organic hybridity derived through technological intervention. I have
argued elsewhere about the powerful potential of biomedical technologies to transform bodies so that they transgress the bounds of what may be considered wholly human. Biomedical technologies produce “a wide variety of bodily conditions or functions, whether permanent or transitory” that “destabilize culturally constructed standards that define ‘normal’ and ‘human’” (Zitzelsberger, 2010). The many possible forms of technological embodiment among children who required life-sustaining technological support was not a focus of my study. Nevertheless, I believe that investigations along these lines would contribute to the current limited knowledge about the variety of children’s technological embodiments across a range of places.

Methodological Limitations and Implications for Future Research

Methodological limitations

I discussed some issues and limitations of my immersion in the hemodialysis unit in regard to my engagements with the children and the staff nurses in chapter III. In this section, I discuss some broader issues related to the methodology chosen for the research. Some limitations in data collection and analysis can be traced to my focused ethnographical approach and my focus on a group of children who received hemodialysis in one setting. These limitations have implications for the study findings applicability to broader populations of children receiving hemodialysis in hospital or home settings and differences among the children due to gender, age and other differences, such as the various trajectories of the course of their kidney disease and associated treatments.

I conducted a focused ethnography that involved discontinuous short-term periods in my field of interest focused specifically on the children’s situated embodiment in the time, space and technology in the hemodialysis setting. Focused ethnographies frequently are used in
sociologically-focused and applied research that has a predetermined rather than open-ended scope of inquiry. They are characterized by a focus on a specific phenomenon in a setting relevant to the study. This approach involves relatively short-term and non-continual field visits, compensated by data intensity that is often supported by the use of audio or visual data collection techniques (Knoblauch, 2005). In comparison, Wolcott (1995) defines fieldwork in conventional or traditional ethnography as a form of inquiry that entails the intensive, continual immersion of the researcher in a field setting for long periods of time to become familiar with setting’s socio-cultural dynamics, established practices and customs and built environment. Based on my experience in the hemodialysis setting, I believe that the focused ethnographies use of data intensity did not compensate for experiential intensity. Longer term continuous engagement may have facilitated a more extensive immersion in the field to capture the complexities of the mechanisms by which the children came to embody the notion of doing technological time. Given that my selected focal points of interest of time, space and technology were each, in themselves, an abstruse and dynamic feature that mutually constituted the children’s embodied situatedness, depth of exposure over the long-term may have been beneficial to capture fully their complex interconnections in the hemodialysis unit.

This study involved in-depth investigation into the experiences of a small group of children who received maintenance hemodialysis in a single hemodialysis setting located in a large urban city in Canada. The focus on a specific localized study sample and context offered both limitations and possibilities. Limiting the study to a single unit was due, in part, to the practical logistics and feasibility of the study method that included fairly prolonged field immersion over three time periods. The benefits of conducting an ethnographic study in a single unit enabled me to be situated in the setting where the children’s everyday embodied routines and relations were performed over a duration of time (Thomas & Ahmed, 2004). However, investigating complex
phenomena in a single setting forgoes broad exploration of large numbers of participants from multiple contexts that are possible with other study designs and methods, such as multicenter studies and survey research (Brewer, 2000). There may be important differences in other pediatric hemodialysis units, such as the configuration of the physical and social spaces, time routines and practices, and the characteristics of the children, nurses and other renal care providers. This study was unable to capture these differences.

An intention I had in conducting this study was the exploration of differences and similarities among children based on their gender, age and other characteristics. The hospital unit where the study was conducted provides services to a diverse population of children, reflecting its location in a large multicultural urban centre. This hospital provides hemodialysis to children in different stages in their kidney disease and renal replacement trajectory. It also provides hemodialysis to children who are of various ages, ethnicities and socio-economic positions and who live in both urban and rural settings. Because the overarching technologically-focused care positioned the children’s identities and roles foremost as patients with similar temporal and socio-spatial routines and adaptions, differences among children were difficult to discern. Differences of experience in the timespace of the unit may not be as pronounced as I anticipated when conceiving the study. However, I also recognize that the findings may be inconclusive because of the small numbers of children who ultimately participated in the study. Furthermore, the uneven sets of data among children did not allow a more complete and comprehensive analysis of variations due to gender, age and other differences.

Generalization in qualitative research involves both “theoretical inference from data to develop concepts and connections; and empirical application of the data to a wider population” (Brewer, 2000, p. 77). In regard to empirical generalization, my investigation of the perceptions and responses of the children who received hemodialysis in a single site can provide important
information and recommendations for that site. While idiographic knowledge of the particularities of the participants’ views of the time, space and technology of the specific setting are important, the findings also may have some relevance to hemodialysis dependent children in other pediatric units. There are, undoubtedly, many similarities among pediatric hemodialysis units in North American hospitals due to typical patterns of hospital-based treatments. For example, I have emphasized the pervasiveness and dominance of hemodialysis technologies upon the lives of the children. I would expect that similar embodied consequences of technologically-focused care may be experienced by other children receiving treatments in different locales. It is anticipated that the information may be, to some extent and with appropriate modifications, relevant to other pediatric hospital-based hemodialysis units and children who receive care within them. However, this would require empirical and theoretical confirmation. The study findings would be complemented by further research in various pediatric hospital-based hemodialysis settings both nationally and internationally.

Implications for further research

My study exposes rich possibilities for further research avenues that I highlight in the following discussion. Further studies would continue to expand upon the pre-existing knowledge about the impacts of hospital-based hemodialysis for children and the limited understanding about children’s perceptions and responses to the unit itself. Knowledge of the impact of children’s differences because of gender and age may be instructive in the creation of appropriate interventions, such as play activities and entertainment or socialization opportunities, which are more individualized to each child. In addition to age and gender differences, I also was unable to witness differences in the embodied situatedness among children brought about by the congenital or acquired nature of their conditions and treatment trajectories, such as length of time on
hemodialysis. My data does not clearly indicate whether their type of renal condition impacted their sense of embodiment in and outside of the unit. Because most children with acquired kidney disease receive shorter term hemodialysis until transplantation, investigating the impacts of hospital-based hemodialysis in this cohort in regard to their overall sense of embodiment across places could lead to interesting conclusions about these children’s situations. In comparison, children with long-term congenital renal conditions have lived with multiple associated physical, mental, emotional and social problems and numerous technological and medical interventions from a young age. Because of this, I suspect that these children’s overall sense of embodiment across places may be shaped differently. Inquiries into these differences could produce better understandings of children’s situations both in and outside of the unit. The results of such studies may lead to interventions that mitigate the negative effects of hospital-based hemodialysis in cohort specific ways.

The study participants’ trajectories of receiving hospital-based hemodialysis ranged from months to years. Over the duration of the data collection periods, children entered and exited the unit depending on their need for hemodialysis. One boy entered the unit because of a newly acquired kidney disease. I also witnessed two children receive transplants that allowed them to be released from cycles of hemodialysis treatments and one boy who moved on to an adult hemodialysis setting. Disruptions in the trajectory of hemodialysis also occurred for two boys who received hemodialysis prior to transplant failures that necessitated that they return once again to the unit a number of years prior to the study. One girl entered the unit once again during the study time periods due to a recent transplant failure. As a side note, within months after I completed the data collection, three additional participants received transplants. Two of the children responded well to drug therapy and their kidneys were functioning sufficiently on their own, at least for the time being and one child transferred to peritoneal dialysis. Additional
research that is able to incorporate the phenomenon of children’s entrances to and exits from a unit and lengths of time spent receiving hemodialysis is important in two regards. First, I have argued that the children in the study perceived and responded to the unit in multiple ways. Durations of time that each participant spent in the unit may have related to his or her perceptions of the unit as a “second home” or as I have characterized it, a place of imprisonment. Research that establishes a comprehensive picture of how children relate to a pediatric unit is crucial to understand their possible range of experiences and attachments. Research in this area may result in improved knowledge of children’s complex and multiple perceptions of hospital-based hemodialysis and may point to ways to create a more positive place for children. Second, results of further studies may reveal unknown facets about the children’s everyday waiting in the short-term to be released from a treatment session and life time waiting in the long-term for total release from hemodialysis because of a transplant or other means (Felski, 2000), which I found to be a significant adaptation on the part of the children. Further identification of the impacts of children’s diverse situations may illuminate significant variations among their situatedness in the temporal, spatial and technological regimens and relations of a pediatric unit that shape their perceptions and responses.

Finally, exploring and comparing different sites of hemodialysis provision may determine better methods of treatment service that are more suited to children’s overall life routines and places. Children with ESRD experience temporal disruptions and socio-spatial dislocations in their overall childhood routines and places because of their dependency on hospital-based hemodialysis for as long as it is necessary. In Canada, most pediatric hemodialysis is received in hospital-based settings (Canadian Institute for Health Information, 2011). However, there is movement towards the development of home-based pediatric hemodialysis in Canada as exemplified by the developing program located at the hospital where the study was conducted.
Alternative health care delivery systems that merge aspects of the time, space and technology of hemodialysis into home settings may alleviate some of the temporal and socio-spatial burdens for those children who are medically able to receive home-based hemodialysis. I am aware, however, that life-sustaining health care technologies located in the home have potential to dramatically alter the time and space of the home with negative consequence for children and families. For example, Heaton et al. (2005) demonstrate that the time routines of technologically-focused care in the home interfere with home routines and children’s other social and school routines. Because of this, the time and place effects of home-based hemodialysis would need to be studied very carefully rather than considering it a panacea to the problems of hospital-based hemodialysis for children. However, research that compares differences between home-based and hospital-based hemodialysis settings may prove to be highly useful in pointing out the benefits and detriments of emerging directions for the design and place of pediatric hemodialysis.

**Conclusion**

In this study, I explored the children’s embodied perceptions of and responses to the interrelations in the temporal, spatial and technological aspects of the pediatric hemodialysis unit. The dominant theme emerging from the findings is the notion of the children doing technological time. Deeply embedded throughout all unit routines and relations, the hemodialysis technologies drove the unit’s timespace that included the children’s situated embodiment. Because the children’s time was dominated by receiving hemodialysis in this specialized high-tech environment, the findings suggested that crucial changes in practices and policies are essential to envision ways to create with children an overall positive place that merges and balances their technological care with child focused care.
References


Casey, E. S. (2002). From space to place in contemporary health care. Social Science & Medicine, 56 (11), 2245-2247.


Appendix A: Recruitment Tools

A1: Staff study information

Study Information
The purpose of this study is to find out how children and adolescents experience hemodialysis in a pediatric hospital unit and how they fit hemodialysis into their lives. Although children spend significant amounts of time in the hemodialysis unit, little is known about how they view this experience because no research has focused explicitly their perspectives and responses.

Children’s criteria to participate:
Between 4-18 years of age, English-speaking, and who visit the unit for maintenance/chronic hemodialysis treatments.

Study time frames:
There are three separate periods of data collection. Each period will be three weeks in duration, and approximately 4 to 6 weeks apart.
1st time frame: Monday December 18th to Saturday January 5th 2006
2nd time frame: Dates not yet determined
3rd time frame: Dates not yet determined

Recruitment procedures:
As per [the hospital policy], initial recruitment must be initiated by a nurse or other staff member. Because staff nurses have experience working with the children and the legal ability to assess capacity to consent, they will determine whether to first directly approach the child (ie. able to provide consent) and/or the child’s parent or guardian. For children, the study will be introduced and information provided when they having hemodialysis in the unit. Parents/Guardians can be introduced to the study when they are in the unit or information will be mailed to them. Please see the attached recruitment script for introducing the study to children and/or their parents/guardians.

Consent procedures:
If the child and/or parent guardian would like more information to decide if they would like to participate, I (Hilde) will meet with them to talk about the study and consent procedures. Each child’s capacity to consent will be determined by myself and the nurses. If the child can give consent, he/she will be asked to sign the consent form. If the child can not consent, one parent or
legal guardian first will be asked to sign the consent form and then the child will be asked to sign the assent form.

Study activities:
I (Hilde) will spend time with a group of kids when they are having hemodialysis in the unit. I will observe them while they are having treatments and informally talk with them about what they think about having hemodialysis and invite them to participate in 4 optional activities. The children’s care, school work, or other activities will not be interrupted. I will not read any child’s hospital chart or observe any confidential or staff meeting.

Contact Information:
Please contact Hilde as above
[Hospital] Principal Investigator: Annette Vigneux, CNS/NP, Nephrology Department, (XXX- XXXX)
A2: Nurses’ recruitment script

Nurses’ Recruitment Script

Study information letters/reply cards are in the white envelopes marked to be given to 1) kids or 2) parents/guardians in the unit.

1) For children approached in the unit:

Please introduce the study when the child is scheduled for hemodialysis, give him/her an information letter/reply card and state the following:

“A study is currently being carried out to find out what it is like for children and adolescents to have hemodialysis at the hospital. This letter tells you more about the study. If you would like to talk to the researcher, Hilde Zitzelsberger, to decide if you would like to participate, please fill out the reply card. The reply card will tell Hilde when you want her to visit you in the unit. After you fill it out, return it to me and I will give the card to her. If you want, I can help you fill out the reply card.”

After the child has filled out and returned the reply card to you, please put it in the white envelope marked for reply cards.

2) For parents or guardians approached in the unit:

Please give the parent/guardian an information letter/reply card (with a stamped, addressed envelope) and state the following:

“A study is currently being carried out to find out what it is like for children and adolescents to have hemodialysis at the hospital. This letter tells you more about the study. If you are willing to be contacted by the researcher, Hilde Zitzelsberger, to decide if you would like your child to participate and if your child would like to participate in the study, please fill out the reply card. The reply card will tell Hilde when and how you want her to contact you. You can return the reply card to me and I will give it to Hilde or you can mail it to her using the stamped addressed envelope. Her contact information is on the letter and you also can contact her directly by telephone or email.”

If parents/guardians fill out and return the reply card to you, please put the card in the white envelope marked for reply cards.
3) **For parents or guardians not approached in the unit:**

The parent/guardian information letter/reply card and a stamped addressed envelope will be mailed. Parents/guardians can fill out and return the reply card to the nurse or other staff in the unit. Please put the card in the white envelope marked for reply cards. Parents/guardians also can mail the reply card to me or contact me directly by telephone or email.
A3: Parents/guardian information letter

Parent/Guardian Information Letter

Dear ______________________

There is a study currently underway to find out what it is like for children and adolescents to have hemodialysis at [the hospital]. This study is conducted by Hilde Zitzelsberger, who is a nurse and a doctoral student in the Faculty of Nursing at the University of Toronto. This study is supervised by Dr. Patricia McKeever in the Faculty of Nursing. The [hospital] principal investigator is Ms. Annette Vigneux, Clinical Nurse Specialist/Nurse Practitioner in the Nephrology Department.

The title of the study is: Time, Space and Technology: Children’s Perceptions of and Responses to a Pediatric Hemodialysis Unit or the Kids’ Dialysis Unit Study (KDU Study).

The purpose of the study is to find out how children and adolescents perceive and respond to hemodialysis in a pediatric hospital unit and how they fit hemodialysis into their lives. Little is known about how children view this experience because no one has asked children themselves. It is important to know their views of hospital-based hemodialysis for three reasons. First, kids have important things to say about their health care. Second, health care workers and planners need information from kids to be sure that the unit and care are the best possible they can be. Third, there may be things that could be changed about the unit to make it better for children.

Because your child has hemodialysis at [the hospital], we are inviting him/her to participate in this study. Hilde will spend three weeks with a group of kids when they are having hemodialysis. She will talk with him/her about what it is like to have hemodialysis and what he/she thinks about the unit and will invite your child to participate in 4 optional activities. Your child’s care and procedures will not be interrupted.

It is the choice of you and your child to take part in this study. You can take your child out of the study at any time and your child can stop at any time without explanation. The care that your child receives at [the Hospital] will NOT be affected in any way by whether or not your child takes part in this study. Everything your child does or says will be kept confidential and his/her name will not be in anything written or talked about the study.
If you are interested in learning more:
To decide if you would like your child to participate, please fill out the reply card to tell Hilde when and how you would like her to contact you. You can give this card to a nurse in the hemodialysis unit or mail it to Hilde using the stamped addressed envelope.

If you like, you can contact Hilde Zitzelsberger at XXX-XXX (if long distance, please call collect).
Kids’ Dialysis Unit Study (KDU Study)

Reply Card for Parents/Guardians

I am interested in learning more about the Kids’ Dialysis Unit Study (Time, Space and Technology: Children’s Perceptions of and Responses to a Pediatric Hemodialysis Unit).

My name: ____________________________________________

1) Please contact me in the hemodialysis unit:

I would like Hilde Zitzelsberger to visit me in the unit on ____________________________ and between the times of ____________________________.

2) Please contact me by telephone:

I would like Hilde Zitzelsberger to telephone me on ____________________________ and between the times of ____________________________.

Phone Number: ______________________________________
Dear ______________________

A study about what it is like for children and adolescents to have hemodialysis at [the hospital] is being carried out by Hilde Zitzelsberger. Hilde is a nurse and a student in the Faculty of Nursing at the University of Toronto. This study is supervised by Dr. Patricia McKeever in the Faculty of Nursing. Ms. Annette Vigneux, Clinical Nurse Specialist/Nurse Practitioner in the Nephrology Department, is the [the hospital’s] principal investigator.

The study title is: Time, Space and Technology: Children’s Perceptions of and Responses to a Pediatric Hemodialysis Unit or the Kids’ Dialysis Unit Study (KDU Study). The purpose is to find out what it is like for children and adolescents to have hemodialysis at [the hospital] and how they fit hemodialysis into their lives. We do not really know what it is like for kids because no one has asked them. It is important to know children’s and adolescents’ views of hemodialysis at [the hospital] for three reasons. First, kids have important things to say about their health care. Second, health care workers and planners need information from kids to be sure that the unit and care are the best possible they can be. Third, there may be things that could be changed about the unit to make it better for children.

Because you have hemodialysis at [the hospital], we are inviting you to participate in this study. Hilde will spent three weeks with a group of kids when they are having hemodialysis. She will talk with you about what it is like to have hemodialysis and what you think about the unit and will invite you to participate in 4 optional activities. Your treatments and care will not be interrupted.

It is your choice to take part in this study. You can stop at any time without explanation. The care that you get at [the hospital] will NOT be affected in any way by whether or not you take part in this study. What you say and do will be kept secret and your name will not be in anything written or talked about the study.

If you are interested in learning more: Please fill out the reply card with your name and when you would like Hilde to visit you in the unit to talk more about the study. Then, please give it to a nurse in the hemodialysis unit. If you want, a nurse can help you fill out the form.
Kids’ Dialysis Unit Study (KDU Study)

Reply Card for Participants

I am interested in learning more about the Kids’ Dialysis Unit Study:

Name: __________________________________________

Please contact me in the hemodialysis unit:

I would like Hilde to visit me in the unit on __________________________
and between the times of __________________________.

Appendix B: Consent and Assent Forms

B1: Parent/guardian consent form

Parent/Guardian Consent Form

Title of Research Project:
Time, Space and Technology: Children’s Perceptions of and Responses to a Pediatric Hemodialysis Unit.
Short Title: Kids’ Dialysis Unit Study (KDU Study)

Investigator(s):
Hilde Zitzelsberger, RN, PhD Candidate, Faculty of Nursing, University of Toronto (XXX-XXXX)
Annette Vigneux, MHSc, Clinical Nurse Specialist/Nurse Practitioner, Nephrology Department, [The Hospital] (XXX-XXXX)
Patricia McKeever, RN, PhD, Professor, Faculty of Nursing, University of Toronto; (XXX-XXXX)
Adrienne Chambon, PhD, Faculty of Social Work, University of Toronto
Kathryn Morgan, PhD, Department of Philosophy and Institute for Women’s Studies and Gender Studies, University of Toronto

Purpose of the Research:
The purpose of this research is to find out how children and adolescents perceive and respond to hemodialysis in a pediatric hospital unit and how they fit hemodialysis into their lives. Little is known about how children view this experience because no one has asked children themselves. I (Hilde Zitzelsberger) will spend 3 weeks with a group of kids when they are having hemodialysis at [the hospital]. I will talk with kids what they think about having hemodialysis and invite them to participate in 4 optional activities. It is important to know children’s views of hemodialysis for three reasons. First, kids have important things to say about their health care. Second, health care workers and planners need information from children to be sure that the unit and care are the best possible they can be. Third, there may be things that could be changed about the unit to make it better for children. Your child’s care and procedures will not be interrupted. I will not read your child’s hospital chart or observe any confidential or staff meeting.

Description of the Research:
If your child chooses to participate in the study, he/she will:
1) Meet with me, Hilde Zitzelsberger, and I will tell you and your child more about the study, answer your questions, and ask you to sign this consent form. Your child will be asked to sign an assent form.
2) Your child will see me when he/she comes to the unit to have hemodialysis. He/she will be part of the group of children who have hemodialysis at the same time. When your child feels comfortable and would like to talk with me, I will ask him/her about what it is like to have hemodialysis, what he/she thinks about the unit, and how he/she spends time when being dialyzed. Periods of talking will be no longer than 20 minutes and will be stopped anytime your child chooses. Sometimes I will be writing things down so that I do not forget things that are important to describe.

3) I will give your child the opportunity to participate in 4 optional activities. These activities include 1) map and chart making about the places and time spent in his/her everyday life; 2) drawing or writing about what he/she likes or dislikes about the unit; 3) indicating how he/she feels during one hemodialysis treatment by telling me or writing down his/her thoughts; 4) taking me on a tour of the unit. The tour will take place before a hemodialysis session and be about 15 minutes long. A tiny microphone will be clipped to your child’s shirt because he/she will be asked to talk about what he/she notices and thinks about aspects of the unit, such as the hemodialysis machines and stations, the way the unit looks, and where he/she goes in the unit. Your child’s answers will be tape recorded so I don’t forget anything he/she says. There is a separate consent form for tape-recording that I will ask you to sign.

**Potential Harms:**
I know of no harms associated with participation in this study.

**Potential Discomforts or Inconvenience:**
Your child’s care and procedures will not be interrupted and he/she will not be invited to take part in the activities if he/she feels unwell. The unit tour will be 15 minutes before a hemodialysis treatment, which may cause you or your child some inconvenience. I will arrange the unit tour with you and your child in advance. Talking about kidney problems and hemodialysis may make some children uncomfortable. Your child will be encouraged to refuse to answer any question or do any activity without explanation at any time. If your child becomes upset, he/she can be referred to a staff nurse or the clinical leader of the unit or the social worker associated with the unit.

**Potential Benefits:**
Your child will not benefit directly from participating in this study. If you or your child would like to know the results of the study when it is finished, a summary will be sent to you. The results of this study will be given to people who work at [the hospital]. This information may suggest changes in the unit’s physical design, decoration, and time routines to make them more suitable for children. The results also will be given to people who work with children in other units and articles will be written for special magazines that health care providers and researchers read. We hope that what we learn will provide information about kids’ views of hemodialysis and be used to help to provide care and design units that are the best possible for children.

**Confidentiality:**
We will respect your child’s privacy. No information about who your child is will be given to anyone or be published without your permission, unless the law makes us do this. For
example, the law makes us give information about children who have been abused; people who have an illness that could spread to others; people who talk about suicide; or if the court orders us to give them the study papers. [The hospital] Clinical Research Office Monitor or the regulator of the study may see your child’s health record to check on the study. By signing this consent form, you agree to let these people look at your child’s records. We will put a copy of this research consent form in your child’s patient health records. The data produced from this study will be stored in a secure, locked location. Only members of the research team (and maybe those individuals described above) will have access to the data. Following completion of the research study the data will be kept as long as required by [the hospital] “Records Retention and Destruction” policy. The data will then be destroyed according to this same policy.

**Participation:**
It is the choice of you and your child to take part in this study. You can take your child out of the study at any time and your child can stop at any time. The care your child gets at [the hospital] will not be affected in any way by whether or not your child takes part in this study. We will give you a copy of this consent form for your records. Your signing this consent form does not interfere with your legal rights in any way nor does it relieve the researchers, sponsors, or the hospital from their legally and professionally responsibilities.

**Consent:**
By signing this form, I agree that:

1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of having my child take part in this study. I understand that I have the right to refuse to let my child take part in the study. I also have the right to take my child out of the study at any time. My decision about my child taking part in the study will not affect my child’s health care at [the hospital].
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my child’s medical records will be kept private. You will give nobody information about my child, unless the law requires you to.
6) I understand that no information about my child will be given to anyone or be published without first asking my permission.
7) I have read and understood pages 1 to 3 of this consent form. I agree, or consent, that my child__________________________ may take part in this study.

Printed Name of Parent/Legal Guardian          Signature & date
Printed Name of person who explained consent    Signature & date

Would you like to receive a copy of the final results? _____Yes _____No

If you have any questions about this study, please call Hilde Zitzelsberger at XXX-XXXX

If you have questions about your rights as a subject in a study or injuries during a study, please call the Research Ethics Manager at (XXX) XXX-XXXX.
Participant Consent Form

Title of Research Project:
Time, Space and Technology: Children’s Perceptions of and Responses to a Pediatric Hemodialysis Unit.
Short Title: Kids’ Dialysis Unit Study (KDU Study)

Investigator(s):
Hilde Zitzelsberger, RN, PhD Candidate, Faculty of Nursing, University of Toronto (XXX-XXXX)
Annette Vigneux, MHS, Clinical Nurse Specialist/Nurse Practitioner, Nephrology Department, [The Hospital] (XXX-XXXX)
Patricia McKeever, RN, PhD, Professor, Faculty of Nursing, University of Toronto; (XXX-XXXX)
Adrienne Chambon, PhD, Faculty of Social Work, University of Toronto
Kathryn Morgan, PhD, Department of Philosophy and Institute for Women’s Studies and Gender Studies, University of Toronto

Purpose of the Research:
The purpose of this research is to find out what it is like for children and adolescents to have hemodialysis in the hospital and how they fit hemodialysis into their lives. We do not really know what it is like for children because no one has asked them. I (Hilde Zitzelsberger) will spend three weeks with a group of kids when they are having hemodialysis at [the hospital]. I will talk with kids what they think about having hemodialysis and invite them to participate in 4 optional activities. It is important to do this study for three reasons. First, kids have important things to say about having hemodialysis in the hospital. Second, health care workers and planners need information from kids to be sure that the unit and care are the best possible they can be. Third, there may be things that could be changed about the unit to make it better for children. Your care and treatments will not be interrupted. I will not read your hospital chart or observe any confidential or staff meeting.

Description of the Research:
If you choose to be part of this study, you will:
1) Meet with me, Hilde Zitzelsberger in [the hospital] hemodialysis unit and I will tell you more about the study, answer your questions, and ask you to sign this consent form.

2) You will see me when you come to the unit to have hemodialysis. You will be part of the group of children who have hemodialysis at the same time. When you feel comfortable and want to talk with me, I will ask you about what it is like to have hemodialysis, what you think about the unit, and how you spend time when being dialyzed. When we talk, it will be for 20
minutes or less and we can stop anytime you want. Sometimes I will be writing things down so that I do not forget things that are important to describe.

3) I will ask you if you would like to participate in 4 activities. You can choose whether or not you would like to do these activities. These activities are: 1) map and chart making of places where you go and spend time; 2) drawing or writing about what you like or dislike about the unit; 3) telling me or writing down how you feel during one hemodialysis treatment; and 4) taking me on a tour of the unit. The tour will take place before a hemodialysis session and be about 15 minutes long. A tiny microphone will be clipped to your shirt because I will ask you what you notice and think about aspects of the unit, such as the hemodialysis machines and stations, the way the unit looks, and where you go in the unit. Your answers will be tape recorded so I don’t forget anything you say. There is a separate consent form for tape-recording that I will ask you to sign.

**Potential Harms:**
I know of no harms that taking part in this study could cause you.

**Potential Discomforts or Inconvenience:**
Your hemodialysis treatments and care will not be interrupted and you will not be invited to take part in the activities if you feel unwell. The unit tour will be 15 minutes before a hemodialysis treatment, which may cause you some inconvenience. I will arrange the unit tour with you in advance. Talking about kidney problems and hemodialysis may make some children uncomfortable. You can refuse to answer any question or do any activity without explanation at any time. If you become upset, you can be referred to a staff nurse or the clinical leader of the unit or social worker associated with the unit.

**Potential Benefits:**
You will not benefit directly from participating in this study. If you would like to know the results of the study when it is finished, a summary will be sent to you.

We will tell people who work at [the hospital] and people who work with children in other hemodialysis units what we learn from everyone who helped us with this study. Articles about the research will be written for special magazines that health care providers and researchers read. We hope that what we learn will give information about what kids’ think of hemodialysis in a hospital and be used to help to provide care and design units that are the best possible for children.

**Confidentiality:**
We will respect your privacy. No information about who you are will be given to anyone or be published without your permission, unless the law makes us do this. For example, the law makes us give information about children who have been abused; people who have an illness that could spread to others; people who talk about suicide; or if the court orders us to give them the study papers. [The hospital] Clinical Research Office Monitor or the regulator of the study may see your health record to check on the study. By signing this consent form, you agree to let these people look at your records. We will put a copy of this research consent form in your patient health records.
The data produced from this study will be stored in a secure, locked location. Only members of the research team (and maybe those individuals described above) will have access to the data. Following completion of the research study the data will be kept as long as required by [the hospital] “Records Retention and Destruction” policy. The data will then be destroyed according to this same policy.

**Participation:**
It is your choice to take part in this study. You can stop at any time. The care you get at [the hospital] will not be affected in any way by whether or not you take part in this study.

We will give you a copy of this consent form to keep. Your signing this consent form does not interfere with your legal rights in any way. The researchers, people who gave money for the study, and the hospital are still responsible, legally and professionally, for what they do.

**Consent:**
By signing this form, I agree that:
1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of taking part in this study. I understand that I have the right not to take part in the study and the right to stop at any time. My decision about taking part in the study will not affect my health care at [the hospital].
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my medical records will be kept private. You will give nobody information about me, unless the law requires you to.
6) I understand that no information about who I am will be given to anyone or be published without first asking my permission.
7) I have read and understood pages 1 to 3 of this consent form. I agree, or consent, to take part in this study.

___________________________________  ____________________________________
Printed Name of Participant & Age   Participant’s signature & date

___________________________________  ____________________________________
Printed Name of person who explained consent   Signature & date

Would you like to receive a copy of the final results?   ______ Yes ______ No

If you have any questions about this study, please call Hilde Zitzelsberger at XXX-XXXX. 
If you have questions about your rights as a subject in a study or injuries during a study, please call the Research Ethics Manager at XXX-XXXX.
**Title of Research Project:**
Time, Space and Technology: Children’s Perceptions of and Responses to a Pediatric Hemodialysis Unit.
Short Title: **Kids’ Dialysis Unit Study (KDU Study)**

**Investigator(s):**
Hilde Zitzelsberger, RN, PhD Candidate, Faculty of Nursing, University of Toronto (XXX-XXXX)
Annette Vigneux, MHSc, Clinical Nurse Specialist/Nurse Practitioner, Nephrology Department, [The Hospital] (XXX-XXXX)
Patricia McKeever, RN, PhD, Professor, Faculty of Nursing, University of Toronto; (XXX-XXXX)
Adrienne Chambon, PhD, Faculty of Social Work, University of Toronto
Kathryn Morgan, PhD, Department of Philosophy and Institute for Women’s Studies and Gender Studies, University of Toronto

**Why are we doing this study?**
We are doing this study to find out what it is like for children to have hemodialysis in the hospital. We do not really know what hemodialysis is like for kids because we have not asked them. I (Hilde Zitzelsberger) will spend three weeks in the unit when kids are having hemodialysis. I will talk with kids what they think about having hemodialysis and invite them to participate in 4 activities. Kids can choose whether they want to participate in these activities. It is important to do this study for 3 reasons. First, children have important things to say about having hemodialysis. Second, health care workers and planners need information from kids to be sure that the unit is the way children would like it to be. Third, there may be things that could be changed about the unit to make it better for children. Your care in the unit will not be affected and I will not read your hospital record or be at any meetings that are private.

**What will happen during the study?**
If you decide to join the study, you will:
1) Meet with me, Hilde Zitzelsberger. I will tell you and your parent/guardian more about the study, answer your questions, and ask you to write your name on this form. This form is called an Assent Form. If you sign the form it means you will be part of the study.
2) You will see me when you come to the unit. When you feel comfortable and want to talk with me, I will ask you about what it is like for you to have hemodialysis, what you think about the unit, and how you spend time when being dialyzed. When we talk, it will be for 20 minutes or less and we can stop anytime you want. Sometimes I will be writing things down so that I do not forget things that are important to describe.
3) I will ask you if you would like to participate in 4 activities. It is up to you if you want to do these activities. These activities are: 1) map and chart making of places where you go and spend time; 2) drawing or writing about what you like or dislike; 3) telling me or writing down how you feel during one hemodialysis treatment; and 4) taking me on a tour of the unit. The tour will take about 15 minutes. I will ask you to talk about what you notice and think about the unit, such as the hemodialysis machines and stations, the way the unit looks, and where you go in the unit. So I don’t forget anything you say, a tiny microphone will be clipped to your shirt which will record your answers.

**Are there good things and bad things about the study?**
The bad thing about the study is that some children may feel uncomfortable talking about kidney problems and hemodialysis. You can stop answering questions or doing any activity at any time without telling anyone why.
The good thing is that your ideas may help adults understand what it is like to have hemodialysis in a hospital. This might help health care workers and planners make the unit more the way children would like it to be.

**Who will know about what I did in the study?**
Only Hilde Zitzelsberger will know what you do and say. Your answers, charts, maps, drawings, and writing will be mixed with other children’s and no name will be on them. Your name will not be printed on or used in anything that is written or said about this study. The only time we would tell anyone what you did or said would be if we thought your health was in danger. If this happened, we would tell a nurse or doctor.

**Can I decide if I want to be in the study?**
Yes. It is up to you. Nobody will be angry or upset if you do not want to be in the study. If you say yes now and change your mind later, that will be OK. Hilde Zitzelsberger will talk to your parent/guardian about the study. You should talk to them about it too.

**Assent:**
I was present when ____________________________ read this form and said that he or she agreed, or assented, to take part in this study”.
Name of participant: ____________________________
Participant’s signature: ____________________________

________________________  __________________________
Printed Name of person who obtained assent    Signature & Date
B4: Parent/guardian consent for audiotape recording

Consent for Audio-Tape Recording
Parents/Legal Guardians

Title of Research Project:
Time, Space and Technology: Children’s Perceptions of and Responses to a Pediatric Hemodialysis Unit.
Short Title: Kids’ Dialysis Unit Study (KDU Study)

Investigator(s):
Hilde Zitzelsberger, RN, PhD Candidate, Faculty of Nursing, University of Toronto (XXX-XXXX)
Annette Vigneux, MHSc, Clinical Nurse Specialist/Nurse Practitioner, Nephrology Department, [The Hospital] (XXX-XXXX)
Patricia McKeever, RN, PhD, Professor, Faculty of Nursing, University of Toronto; (XXX-XXXX)
Adrienne Chambon, PhD, Faculty of Social Work, University of Toronto
Kathryn Morgan, PhD, Department of Philosophy and Institute for Women’s Studies and Gender Studies, University of Toronto

I hereby consent to my child being audiotaped during participation in this research project. These tapes will be used to ensure that the researchers have an accurate record of what my child has said during the tour of the unit. All information collected during this study will be kept confidential and secured by the researcher, Hilde Zitzelsberger. Audiotape recordings will be stored in a locked cabinet by Hilde Zitzelsberger and the tapes destroyed upon completion of the project. I understand that I have am free to withdraw this consent for audiotaping at any time without penalty.

In addition, I give consent for my child’s audiotape to be used for:
1. Other studies on the same topic Yes No
2. Teaching and demonstration at [the hospital] Yes No
3. Teaching and demonstration at meetings outside [the hospital] Yes No

I understand that I am free to withdraw my permission for these additional uses of my child’s audiotapes at any time.

_________________________________________  ______________________________
Printed Name of Parent/Legal Guardian   Signature & date

__________________________________________ ______________________________
Printed Name of person who explained consent  Signature & date

The person who may be contacted about the research is: Hilde Zitzelsberger XXX-XXXX
B5: Participant consent for audiotape recording

Consent for Audiotape Recording
Participants

Title of Research Project:
Time, Space and Technology: Children’s Perceptions of and Responses to a Pediatric Hemodialysis Unit.
Short Title: Kids’ Dialysis Unit Study (KDU Study)

Investigator(s):
Hilde Zitzelsberger, RN, PhD Candidate, Faculty of Nursing, University of Toronto
(XXX-XXXX)

Annette Vigneux, MHSc, Clinical Nurse Specialist/Nurse Practitioner, Nephrology Department, [The Hospital] (XXX-XXXX)

Patricia McKeever, RN, PhD, Professor, Faculty of Nursing, University of Toronto;
(XXX-XXXX)

Adrienne Chambon, PhD, Faculty of Social Work, University of Toronto

Kathryn Morgan, PhD, Department of Philosophy and Institute for Women’s Studies and Gender Studies, University of Toronto

I hereby consent to being audiotaped during participation in this research project. These tapes will be used to ensure that the researchers have an accurate record of what I have said during the tour of the unit. All information collected during this study will be kept confidential and secured by the researcher, Hilde Zitzelsberger. Audiotape recordings will be stored in a locked cabinet by Hilde Zitzelsberger and the tapes destroyed upon completion of the project. I understand that I have am free to withdraw this consent for audiotaping at any time without penalty.

In addition, I give consent for my audiotape to be used for:
1. Other studies on the same topic       Yes    No
2. Teaching and demonstration at [the hospital]       Yes    No
3. Teaching and demonstration at meetings outside [the hospital]       Yes    No

I understand that I am free to withdraw my permission for these additional uses of my audiotapes at any time.

Printed Name of Participant & Age                     Participant’s signature & date

Printed Name of person who explained consent       Signature & date

The person who may be contacted about the research is: Hilde Zitzelsberger XXX-XXXX
Appendix C: Data Collection Tools

C1: Schedule for participant observation

Schedule for the 3 data collection time frames (each 3 weeks in length)

Week 1:
- Meet the children, nurses, and other staff in the hemodialysis unit
- Describe and map the physical, spatial, and social layouts and aesthetic and architectural details (1\textsuperscript{st} time frame) and record changes over time (2\textsuperscript{nd} and 3\textsuperscript{rd} time frame)
- Visual recording of the unoccupied unit through digital photographs (1\textsuperscript{st} time frame) and record significant changes over time (2\textsuperscript{nd} and 3\textsuperscript{rd} time frame)
- Observe and document the physical and social spaces, temporal routines, and technological aspects of the unit (i.e. hemodialysis stations, toys, games, aesthetics, ambience, who predominantly occupies the unit and their characteristics and roles, patterns of activity)
- Child-initiated focused interactions
- Guided activities: 1) charts and maps

Weeks 2
- Structured observation and fieldnotes of the unit’s physical and social spaces, spatial-temporal routines and events, and technological relations, focused on the children’s perceptions, behaviours, and interactions
- Child-initiated focused interactions
- Guided activities: 2) ‘draw and write’ activities

Week 3
- Structured observation and fieldnotes of the unit’s physical and social spaces, spatial-temporal routines and events, and technological relations, focused on the children’s perceptions, behaviours, and interactions
- Child-initiated focused interactions
- Guided activities: 3) unit tour
C2: Structured observation criteria guide

To address the research questions, the following categories and types of observations will be conducted and documented:

1) **Physical and social spaces**
   - Map and description of the physical, spatial, and social layout and aesthetic and architectural details
   - Description of the unit’s general ambience (i.e. sights, smells, sounds, touch, comfort, functions, appeal)
   - Visual recording: To document the physical setting and significant changes (i.e. paintings, wall colours) over the time frames of participant observation, photographs of the unoccupied unit will be taken
   - Noise level ratings: To gather information about ambient noise, the sounds of the occupied unit will be recorded, read, and compared to standardized norms
   - Who predominantly occupies the unit (i.e. nurses, teachers, other staff, children) and where and how they occupy the unit
   - How being a child or adolescent is viewed and talked about by children
   - How being a boy or girl is viewed and talked about by children
   - Material and discursive symbols and practices related to childhood, age and gender

   The children’s perceptions and occupation of the physical and social spaces
   - How children move around, use, and create the unit’s physical spaces
   - Physical spaces that the children predominantly occupy
   - The children’s arrangements of their hemodialysis space
   - Frequency and types of the children’s interactions with each other
   - Frequency and types of the children’s interactions with nurses and other staff members
   - How the children speak about being in the unit – what does it look, feel, smell like, what do they like/dislike, etc.
   - How the children view and interact with me during data collection time frames
   - Difference and similarities among the boys and girls

2) **Temporal-spatial routines and events**
   - Major renal care patterns - daily, weekly, monthly
   - Patterns and duration of hemodialysis treatments
   - The children’s daily and weekly hemodialysis routines
   - Seasonal influences on the unit’s regimens (i.e. school year, holidays)
   - Disciplinary/professional routines and practices, such as medicine, nursing, education, and recreation pertaining to children’s care
   - Merging of various routines/places that usually are separate, for example school work or recreational/social activities while receiving health care treatments, or receiving health care treatments in a ‘public’ space
   - Technologies and material objects that mark or alter passages or senses of time (i.e. clocks, time counter on hemodialysis machines, TV’s, VCR/DVDs)
The children’s perceptions and uses of time
How the children spend time during hemodialysis
How the children talk about the care routines in the unit
Activities imposed on the children and by whom
Choices made by the children about how they spend their time
How the children talk about time in the unit
How the children talk about how time in the unit connects to their everyday lives and ways of accommodating and negotiating hemodialysis
How the children talk about how their bodily rhythms and cycles of disease symptoms are connected to hemodialysis
Difference and similarities among the boys and girls

3) Human-technological relations
The influence of the hemodialysis machines on the physical, social, and temporal aspects of the setting
The impact of the physical, social, and temporal setting on the placement and use of the hemodialysis machines
How the children interact with the nurses and other staff while they receive hemodialysis
How the hemodialysis machines’ assessment and recordings impact understandings and of the children’s bodies

The children’s perceptions of the hemodialysis machine and associated treatments
How the children interact with the hemodialysis machines
How the children speak about the machines and being connected to them
How do the children speak about the site accesses to the hemodialysis machines on their bodies and how this influences their feelings and behave towards their bodies
How do the children behave toward the hemodialysis machines
Physical symptoms of disease/illness during hemodialysis treatments and how this impacts their perceptions of and care in the unit
How the children interpret and describe his/her understandings of his/her body in light of the monitors and recordings
Other technologies in the unit that the children significantly interact with, i.e. weight scale, fridge/ice machine, TV and VCR/DVD players and how children relate to them
Difference and similarities among the boys and girls
C3: Focused interactions guide

Topic areas are based on the research questions and examples of what will be raised with children in focused interactions. All topics and associated questions will be modified for the age and/or capacities of each child. They will be reflected upon after participant observations sessions and modified as needed, based on the children’s responses.

How do the children perceive and occupy their embodied positions in the physical and social space?

Physical spaces
What does each child notice most in the unit, in a good way or in a bad way? How come?
What things do each child like or dislike in the unit?
What does the unit look, smell, sound like?
How does the unit make him/her feel inside?
What does he/she like or dislike about the place/station where they have hemodialysis, i.e. the chair, TV, friend sitting nearby? Does he/she do anything to make this spot special or more comfortable?
If he/she were to describe the unit to a friend who has never seen it, what would he/she say?
If he/she had a magic wand, what would he/she change?

Social spaces
Who does each child see or talk to in the unit? (i.e. nurses, other children, doctors, etc.) Who does he/she talk to the most? The least?
Who does each child like to see the most? How come? Who does each child like to see the least? How come?
Is there anyone who makes him/her feel comfortable? How so? Is there anyone who make him/her feel uncomfortable? How so? What does he/she do in response?
What does he/she feel inside when talking to the nurses? doctors? social worker? volunteers? teachers?

How do the children perceive and embody various senses of time?

What does each child like to do the most when having hemodialysis? What does each child like to do the least?
If they chose an activity, i.e. watching TV, talking to a friend, reading, why did they choose that activity?
Does he/she tell nurses or other staff what activities he/she prefers?
Is there anything he/she would like to do but are not or cannot? Why not? What would help to do this?
Do the things he/she does in the unit change, for example, during seasons, holidays, or the school year?
Is he/she aware of time when having hemodialysis? If so, what makes him/her aware of it?
How does time feel, for example, does it feel restful, boring, fast or slow or do the treatments seem long or short? Does anything change how time feels, for example, watching TV, talking to someone?
How do the children perceive and respond to their technological embodiment?

What does he/she think about the hemodialysis machine, for example, what is it for, what does it do, how does it work?
Does he/she notice the machine? What does he/she notice the most? The least?
What does he/she think about having treatments, for example, are they difficult, boring, no bother?
How does hemodialysis affect how each child feels in a physical way, for example, does he/she feel better or worse before a treatment? Better or worse after a treatment? Does how this affect the things he/she does in or outside the unit?
In what ways does each child describe his/her understandings of his/her body in light of the monitors and recordings?
Are there other technologies with which he/she also significantly interacts with, such as the weight scale, fridge/ice machines, or TV and VCR/DVD players? How does he/she relate to and make meanings of these technologies?

How do the children accommodate and negotiate their hemodialysis regimens in their everyday lives?

How does each child feel about coming to the unit, for example, is it no bother, boring, fun? Has this changed since he/she first came to the unit?
How much time does each child feel that hemodialysis takes in his/her life, i.e. a lot of time, a little time?
What bothers each child the most about coming to the unit? What bothers him/her the least?
How does hemodialysis affect each child’s daily activities, for example, day care, school, seeing friends, being at home, playing sports or games, etc.? Are there things he/she cannot do at all or very often? If he/she was not having hemodialysis, what would he/she like to be doing?
How does each child fit hemodialysis into his/her life? Is there anything he/she does that makes it easier? Is there anything that he/she does that makes it harder?
Are there periods when he/she does not want to come to the unit? What does he/she do in response?
How would each child prepare another child for hemodialysis in this unit? What does he/she think would be important to know about?
C4: Demographic information form

Demographic Information Form
(to be completed by the researcher with input from a parent/guardian or staff if necessary)

Pseudonym: ______________________________________________
Gender: ______________________________________________

What is your age?

Where do you live? (i.e. city or rural, general area, major intersection)

What school do you go to? What grade are you in?

Can you tell me about your family (i.e. members of family, relationships, how often sees them)?

Can you tell me about who you live with at home? (i.e. parent(s) marital status, siblings, who lives in the house)

How do family members help you care for your kidney problem?

What language do you speak most often? Do you usually speak a different language at home?

Where were you born? Have you lived in a different place than Canada? Did your parents or grandparents live in a different place than Canada?

History of kidney disease and treatments:
When did you first find out that you had a problem with your kidneys?

How would you describe your kidney problem?

Do you have any other illnesses or disabilities? Is your kidney problem related to them? How do they impact your kidney problem?

What kinds of treatments have you had for your kidney problem before having hemodialysis (i.e. transplant, peritoneal dialysis)? How have they worked out for you?

Where else have you had treatments or care for your kidney problem?

When did you begin hemodialysis? How long have you been coming to this unit?

How would you describe why you need to have hemodialysis?

On your treatment days, do you come from and go back home or do you stay somewhere else?

Who usually comes with you to the hospital?
C5: Description of guided activities

1. Charts and maps: (adapted from Barker & Weller, 2003b; Christensen & James, 2000)
The aim of these activities is to elicit data about how children accommodate and negotiate their hemodialysis regimens in their everyday lives. The children will be invited to participate in chart and map-making to illustrate places, times, and activities in their lives. These charts and maps also will be used to engage them in discussions about how they manage hemodialysis regimens in their overall lives. They will be the first activities conducted in week 1 of the data collection time frames because they will provide a way for me to learn about the children and for them to learn about myself.

   Place and time charts:
   Children will be asked to identify and list the places that they spend time on hemodialysis days and non-hemodialysis days. Using circular white sheets of paper, they will be asked to divide the circle into different width sections that represent these places, according to amounts of time spent in the places. Materials (glittered glue, stars, non-toxic colour pencils or washable markers) will be provided so that children may colour or decorate the sections of the circle.

   Children will be asked to list the activities they typically engage in on hemodialysis days and non-hemodialysis days (i.e. eating, sleeping, school, watching TV, health care). Using circular white sheets of paper, they will be asked to divide the circle into different width sections that represent these activities, according to amounts of time spent in each activity. Materials (glittered glue, stars, non-toxic colour pencils or washable markers) will be provided so that children may colour or decorate the sections of the circle.

   During and following these activities, the children will be asked to reflect and elaborate on their places, times, and activities and how hemodialysis fits into their overall life with questions such as: ‘Is coming to the unit a long or short trip for you’, ‘What do you do in this place’?; ‘What is it like for you to be here and not at school? at home? with friends?’ ‘Are their times when you miss out on things because you have to come to the unit?’ ‘Are their times you don’t want to come to the unit and if so, what do you do about it?’

2. Drawing and/or writing exercises (adapted from Guillemin, 2004; Pridmore & Bendelow, 1995; Punch, 2002)
To elicit data about the research questions of how the children perceive and occupy physical and social spaces, perceive and spend time, perceive the hemodialysis machine and associated treatments, the children will be invited to participate in drawing and/or writing exercises which employ the ‘draw and write’ technique. These exercises will be conducted in week 2 of the data collection time frames.

   Children will be given coloured sheets of paper and with a requested topic at the top of the paper and asked to draw or write about the following topic areas:

   a) What I like the most about the hemodialysis unit?
   b) What I like the least in the hemodialysis unit?
Following each ‘draw-and-write’ exercise, the children will be asked to elaborate on their pictures and/or writing, and their choices of content and form in order to obtain their interpretations and reflections about the hemodialysis unit. To gather their own interests or concerns, they will also be asked to engage in spontaneous drawings or writing about any aspect of themselves and the unit.

*Note: This following three topics were discarded early in the data collection periods as they were not well-liked by the children and deemed not useful in gathering information.*

a) What is the best thing about being a girl/boy in the unit?
b) What is the worst thing about being a girl/boy in the unit?
c) Me and the hemodialysis machine

3. **Unit tours with children:** (adapted from Clark, 2005; McKeever, 2006)
   
   To elicit data about how the children perceive and occupy physical and social spaces and perceive and spend time in the unit, the opportunity to conduct a unit tour will be offered to each child.

   Because it is suggested that developing a rapport with children facilitates this activity (Clark, 2005), the tours will take place in week 3 of the data collection time periods. However, the children will be told about the activity in advance so they can plan the tour. Each tour will be individual, approximately 15 minutes in length, and take place immediately before hemodialysis when children tend to be waiting for their treatment. If willing, the children will be given a clip mike to record their comments which will be transcribed. Staff will be consulted about any areas or objects that are restricted.

   Issues of time, space, and social relations will be used to structure this activity. On the tour, I will ask the children to share their views about the unit, such as where and how they spend time, what they like and dislike about the unit, and with who, what, and how they interact in the unit. During the tour, children will be asked questions that include: Show me/tell me about where you go after you walk in the door? Where do you go? Where don’t you go? How long are you here? What happens when you are here? Who do you see and/or talk to? How much time do you spend in this area? To get a sense of the children’s meanings, values, and feelings about aspects of the unit, they will be asked questions that include: What is it like for you to be here? Tell me what this means to you? What do you do with this?
Appendix D: Certificate of Participation

Certificate of Participation

Kid’s Dialysis Unit Study
March 2007

with thanks!
Appendix E: Timegraph of the Participant’s Durations in the Hemodialysis Unit

<table>
<thead>
<tr>
<th>Phase 1</th>
<th>Phase 2</th>
<th>Phase 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dec 06-Jan 07</td>
<td>Feb-March 07</td>
<td>August - Sept 07</td>
</tr>
</tbody>
</table>

Dec Jan Feb March April May June July Aug Sept Oct Nov Dec

2006-------------------------------2007

A: 2000-------------------------------June 2007
B: 2006-------------------------------March 2007
C: 2001-------------------------------Feb 2007
D: 2006-------------------------------June 2007
E: 2005-------------------------------2007
F: 2008-------------------------------Feb 2007
G: 2000-------------------------------2007
H: 2006-------------------------------July 2007
I: 2006-------------------------------July 2007
K: 2007-------------------------------2007
Appendix F: Diagram of the Physical Layout of the Pediatric Hemodialysis Unit