

Searching for a Good Grief?
Meaning Making Through an ESRD Illness Narrative

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ABSTRACT**Searching for a Good Grief? Meaning Making Through an End Stage Renal Disease Illness Narrative**

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This study is an autoethnographic, Arts Based exploration of the grief of illness. Making use of 'I' perspective, subjective methodologies, I have explored my experiences of End Stage Renal Disease (ESRD), kidney transplant loss and the self-administering of my hemodialysis treatments in my home. I present the psychological ESRD-dialysis experience as akin one of grief. I have made use of Neimeyer's Meaning Reconstruction Model, a narrative meaning-centered model typically used in bereavement circles. At the heart of this model is the concept that it is necessary to apply a coherent perceived meaning to loss experience in order to process grief well. This study applies the MRM to the psychology of transplant loss and dialysis, stating that the psychology of transplant loss and dialysis is, for me, akin to complex grief. Therefore, it will not likely be fully assimilated as is the case with anticipated loss. Rather, illness like ESRD, for me, is likelier to be accommodated, where complex loss requires locating *coherence, points of change* and *new plots* within lived experience in order to provide new and helpful perceptions of meaning. I have disseminated outcomes from my own narratives, interviews with family, friends and other patients who've experienced this illness, into two forms; the first, a written dissertation that presents theory and arts based narratives commenting on that theory. The second, Arts Based outcome, is in the form of a short film, entitled *Good Grief*.

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Autoethnography is hard. It's exhausting. It loses and regains momentum - often. Because this study was about the lived experience of chronic illness, I've discovered that this illness marks not only me but also those around me.

There are so many people to acknowledge for their support throughout the writing of this dissertation. In fact, I feel in many ways that the process was carried by the people in my life.

That said, first and foremost I thank my parents, whose concern for me and my health has been noticeably balanced with their ongoing support of my work. 'Keep doing', they'd say. 'If you keep doing, life will have value'. This is a mantra that I've learned from them. My brothers, Philip and John (and Madeleine), who appear in this dissertation more than once, accepted the challenge of having a sister with End Stage Renal Disease and stepped forward along with my other siblings; Mary, Stephen and Peter. It is no coincidence that this work consistently includes my family. Family is a huge variable in how illness is accommodated and normalized. In my case, anyway.

My friends, too, are an important part of this fabric. Robert, Willow, Diana, thank you for your words. Flora, thank you for long-distance printing. Andy and Terry, thank you for your challenges and for reading the multiple versions of my work and for walks in the woods.

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DEDICATION

*To my parents, John and Noreen Lewis,
who taught me to keep my feet on the ground
and reminded me that I am but one of many*



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Chapter One Forward: Grieving Felicia

My Narrative: It looks as though the time has come, my doctor uttered as he studied my blood results on the screen in front of him, his back facing my gowned exhausted figure two feet away, socked feet dangling. Silence.

Your GFR and creatinine, coupled with your volume tolerance... yes, and given you report feeling so poorly... you'll have a port inserted tomorrow and start dialysis the next day. Take some time off work too.

He swivels to face me. His white lab coat done neatly up to his tie in its usual way, but says nothing. Instead, Deborah, the transplant nurse - who I've called Debbie for years - appears, alert, in the door.

Please book Leah in day surgery tomorrow for a port insertion and schedule her for dialysis Wednesday morning.

More silence. An awkward, even clumsy bedside manner, one that has frustrated my mother for years, causing her to explode at him once in anger to my ten-year old amazement. But today, two and a half decades later, he tries his best. I think this to myself as he finally speaks to me.

Twenty three years is a long time for a kidney to last. You should be glad. Do you have a ride home?



I began this investigation, or rather was drawn into it, when I found myself grieving the loss of my kidney. Having End Stage Renal Disease (ESRD), defined as the inability of the kidneys to function well enough to sustain life - usually diagnosed when renal functioning is at 15% (CIHI, 2012), I experienced the loss of my transplant eight months prior to beginning my

doctorate. Though this loss was somewhat anticipated, gradually occurring symptomatically over a period of eighteen months and culminating with the scene described above, I still felt it as an acute, dramatic and debilitating grief. The loss of my kidney triggered a string of life changing experiences that occurred so quickly that I barely kept up; the almost-unexpected news that a port insertion, or neck catheter for high volume blood access necessary for treatment, would take place within twenty-four hours, and dialysis in 48, the unplanned hiatus from work. Dialysis. Overnight, literally, it became a forefront presence in my life's schedule, dictating what I could eat, where I could go and how my body would feel. Remaining alive. Oh yeah, it dictated that too.

The changes had everything to do with my body's adjustment to the re-emergence of this illness, ESRD. For years, I had known the relative normal health of having a working kidney transplant. Overnight, my life had dramatically changed. It now entailed routine dialysis treatments, the symptoms that accompany it of my body responding to its blood being vacuumed out, cleaned and pumped back in, all in three and a half hours, traveling continuously (it seemed) back and forth from the hospital, three times a week.

As I struggled to compartmentalize this illness narrative, I was continuously met with an inability to separate the daily-lived experience of dialysis and its accompanying ambiguous symptoms: exhaustion, sleeplessness, weight loss and emotional vulnerability. My struggle included separating these daily symptoms from my work as a researcher and student, from my personal and social life. I was chronically symptomatic due to my dialysis treatments and processing the psychological complexities of having lost my transplant of 23 years (Chih-Ken et al., 2010; Charmaz, 1997; Chilcot et al., 2008; Cohen et al., 2002; Devins, 1981,1983, 1997;

Ferru & Pruchno, 2009; Feroze et al., 2010; Franke et al., 2003; Griva et al., 2009; Grootenhuis et al., 2006; Grudex, 1995).

My life had changed shape; my schedule was not my own. My sense of being 'other' in the world was huge and I found myself comparing myself to every 'healthy' person I encountered, envying them. It was not unlike Kubler Ross's (1969) concept of bargaining, the sense that 'if only' I had made different choices, things would have turned out differently, that I had some say or control in this experience.

Or the otherness identity that Richards (2008) talks about in relation to ESRD, feeling inside a bubble of separateness and difference when it came to my physical health and survival - something that others around me play no part in. The disease had become present in my life once again and was affecting my everyday functioning, both physically and emotionally. I was forced, as a point of survival perhaps, to find meaning and motivation in a place that seemed meaningless.

There was also a need to connect my body's chronic and daily experience of illness and all that it entailed, to my scholarly work. But beyond that, there was a need to revisit, yet again, as ESRD ebbs and flows like all chronic illness, what the meaning of my life was. Failing to locate that meaning, which at the time seemed entirely possible, I felt I was going to have to intentionally create meaning out of this experience that had so affected my perceived sense of living a good and richly filled life.

The need was urgent. I was suffering psychologically, feeling sad daily, not interested in seeing friends or taking the energy to get to them physically, and instead opting for solitariness because it did not require as much energy, or reporting on 'how I was doing'. I found myself wondering if perhaps my own death were closer because of this depleted health situation of

having lost my transplant. According to the Beck's Depression Inventory (1988), I was depressed and my ability to see positive times in my future had waned dramatically.

Illness interrupts the life narratives of those living with illness as well as those witnessing it, shaping memory, what gets remembered and what gets discarded, what our cognition chooses to save and what it shelves away (Charmaz, 1997; Frank, 1995). Similarly, Kleinman's (1988, 1992) work presents the notion that new stories contribute to the evolution and reconstruction of new perceptions, when relating to the world and the people within it. When my transplant failed, flashbacks of my twelfth year, the last time I knew dialysis, hit me like bullets. The taste of the post treatment vitamins, the muscle aches from the pulling of fluid from my body and waiting at the hospital entrance for a pick up for home – leaning on the glass door in order to keep myself standing due to my low blood pressure. I somehow went back to that schoolgirl year, before my transplant, when dialysis was a routine of my week, something that at the time I wonder if I took for granted. At 35, I was definitely not so resilient. My 'life narrative' (Charmaz, 1997; Frank, 1995; Kleinman, 1988), a term used by both illness and grief scholars describing the self story I had come to know of who I was and what I was becoming, how I wanted to be perceived, was shifting in a direction that was both confusing and frightening and definitely not according to plan. It was an experience to which I could not apply meaning.

Connecting Loss in End Stage Renal Disease to Grief

I've known for a while about Frank's (1995) sociological analyses of illness, that he presents that the body is frequently perceived as object via the modern medical model. His work positions the body as central to one's identity, the 'home base' of our presence in the world, playing a central role to the 'life narrative' of the individual. The notion of the 'self story' is discussed as being affected by the body's experiences in the world and that stories of illness are

told via a wounded body, ultimately affecting perceptions of self as wounded as a result. Life narratives, even everyday stories, are informed by the body's lived experience of illness, passed and anticipated. This notion of a wounded body felt accurate and went, as I think Frank meant it to, beyond my physical disease. My life narrative, though it had always been informed by ESRD, this time was dramatically interrupted. With age, the disease had persisted. With age, my perspective and handling of it had shifted, in my mind had weakened. With age, the meaning of it had evolved. As I understood its effect on my physiology, it also coloured my psychology. However, this thought, this envisioning of myself as a wounded storyteller, somehow provided some patience and nurturance with which I could begin to understand myself as wounded, affected by my illness identity, yet containing a potential story. A containment of sorts began to occur, as I somehow began to normalize the incoherence of my experience. The thought that I was grieving made sense. It seemed a first step to investigating the meaning that being a person with ESRD had in my life.

I found myself grieving where I had been health-wise only a couple of years before; my kidney was working well, my blood chemistry was normal, iron levels controlled and hemoglobin barely noticed. Over the years I had come to find a balance between seriously appreciating the gift of this transplant and also taking it for granted, even playfully naming 'her' Felicia, as though my transplanted kidney were an entity onto itself, a person. Deep down I also understood that Felicia's 'life' was temporary. I had hiked, swum and kayaked with friends. I had felt energy surging through my body that was hungry for ideas and thought. It was an alert energy, anticipating more, planning for goals. It was the energy of a healthy body, a healthy narrative (Frank, 1995). It was an energy that was nowhere to be found now, however. More than that, I found myself, because of this illness, in a place of existential sadness, incapable of

picturing the future (Charmaz, 1997; Kleinman, 1988). Felicia had done her job as best she could, but had ultimately grown too tired to continue. As I grieved Felicia's 'death', my sense of meaningfulness in my life plummeted because my body was no longer working, no longer healthy. I was associating, as most do, physical health with life value (Frank, 1995). I began to wonder if the best of my life were over? I wondered too if it was now necessary to modify my plans, slow things down, scratch things off of my list of life goals. I wondered if I would ever experience that energy again.

The grieving of Felicia initially came to light during a Creative Arts Therapies elective class at Concordia University. Its focus was the use of therapeutic metaphor via creative process of story (Silverman, 2010). In it, I engaged deeply with my grief through the metaphor of *The Tale of Peter Rabbit*. I came face to face with my deep feelings of sadness, loss and aloneness that were ever present for me. More than that, somehow, similarly to how Peter experienced a transformation in the face of death in Farmer McGregor's vegetable garden, so did I experience something of an epiphany, a 'dropping in' that connected me to my own grief (Bochner, 1997). It surfaced at multiple times throughout the process, through my written narratives. It was, however, profoundly triggered when I presented my journey to the class as my final assignment.

My writing began to expand following this course as I moved towards autoethnographic, performance-based research. My theoretical knowledge of the therapeutic value of autobiographical performance (Emunah, 1994) in Drama Therapy began to overlap with meaning-driven components of autoethnography and the embodied, lived, data of autoethnographic performance (Spry, 2001, 2006, 2011).

Engaging with I-perspective research about my illness brought about something of a feeling of clumsy peace as I disengaged with objectivist, arms-length deductive approaches to

research - exhaled - and instead began to engage critically with my lived experience of illness, looking it in the face and presenting it to others, outside of myself. It was difficult. It was existentially big, as I also engaged with learning about the modified life span of people with ESRD (Christensen et al., 1989; Coelho-Marques et al., 2006; Feroze et al., 2010), forcing me to consider my own death.

Part of that painful peace involved sharing early bits of my research in front of my observing students, colleagues and supervisors. The externalizing, the sharing of the narrative, similar to my previous experience with the creative process course, brought with it a meaning, thereby validating it through the participatory engagement of my audience, their reaction, their reciprocity of experience. Applying Neimeyer's (2000, 2002, 2010) meaning centered model of grief only made sense to autoethnography. Ellis et al.'s (2008) concept of 'epiphany' comes to mind again, as a dropping in of knowledge occurred and I began to piece together my fragmented reality, leaving me with the beginnings of an ability to draw meaning from illness experience. The fragments of my narrative included the ways in which the features of my disease affected me as a person and how I presented myself to the world, including low iron causing lack of focus, listlessness and disinterest, sometimes requiring transfusions that, in turn, cause high antibodies, limiting my chances for a transplant and causing resentment within me and marking my interactions with my medical team. Chronically low blood pressure at times caused dizziness and fainting. Other fragments were about my family and how my disease affected them and the emotional difficulties this presented me. My relationships with my brothers, my sister, my parents were changing because of it. My fragile health became a central issue in their lives too, causing distraction, guilt, anger, and pain for them, interrupting and informing their own self-stories. By solidifying and sharing these fragmented narratives, I began

to build an understanding of my grieving. The weight of this loss on my life, above and beyond my physical state, was becoming clear.

I found myself in a stronger position to negotiate the dark spaces my mind had been visiting. Little had I been aware that my quest for value in this experience of loss was to become the sounding board for reconstructing the meaning of what my life had been to what it was to become. At some point minuscule changes began to occur. Whereas I had been seeing myself dictated by this illness, I was now beginning to experience small moments of being a normal, breathing walking woman... who happened to have kidney disease, who happened to have lost her kidney transplant and who was on dialysis. The element of Neimeyer's Meaning Reconstruction Model (2000, 2001, 2002) being an 'active' process, involving choice in grief, was gaining momentum for how I might perceive my pain.

Re-Shaping Perception

This work represents the last four years of my life, following the failure of my kidney transplant of twenty-three years. It seeks to connect the physiology of ESRD, to its psychological outcomes through a lived experience, meaning-driven, grief informed, and multi-voiced inquiry.

Chapters one through five provide a theoretical foundation to subsequent chapters, including a layout of this inquiry. It consists of an overview of the research areas that have come together to create this doctoral inquiry. Chapter three shares what is known about the quality of life (QOL) of ESRD dialysis patients, outlining a relationship between the perceived quality of one's life and the rationale for meaning-driven research. Chapter four discusses the role that patient perspective research, or illness autoethnography, can play in health-related knowledge translation (KT). This chapter refers specifically to the role that the patient voice has in the

Knowledge-To-Action (KTA) framework, and the guiding of health-related outcomes to patient understanding and behaviour. It also considers the role of lived experience data of disease as relevant to how health outcomes are translated into action. Chapter five illustrates the importance of patient perspective research, or illness autoethnography, as methodologically relevant to the QoL and grief psychology of the ESRD patient. Chapter 6, noticeably longer, presents Arts Based narrative outcomes. Selected narratives from these outcomes are also included as text in the performance outcome film *Good Grief*.

My desire for this project included wanting an arts based outcome that was performance-influenced and that was accessible to the viewer. Knowing well that Arts Based Research (ABR) is an emergent process for the researcher (McNiff, 1998) and being drawn to performance in qualitative inquiry as being a body-centered process, I found myself negotiating how a performance would emerge from personal material. An additional desire involved wanting to create a performance that was removed from myself. Not a live performance involving my body and voice and potentially placing me smack into a place of vulnerability. Rather, the use of film allowed for an objectification of this data. One that could invite critical discourse.

My Narrative: I've been thinking this past week about shaping my methodologies. Last week's article by Ellis (2011) outlined methods for approaching autoethnographic studies and it has me thinking... visualizing this project, coming in and out of being excited about it and being intimidated by the work of it, then back to a feeling of excitement about creating a visceral and accessible piece of research. I am aware and conscious of a desire to avoid saccharine writing, writing that reads as narcissistic and over emphasizing me, who I am, my life, my experiences when others experience the same and worse... I think of my high school friend in BC, and her

daily facebook postings about her cancer treatments. She's reaching out and I feel small because of it.

... that piece I read in ethnographically speaking (Bochner & Ellis [eds.], 2003) by that woman who wrote about her hatred of her abusive father (p.95)... the work was so angry, full of victimized thought, exhausting to read and feeling too single minded even though it was a personal story, frightening me to a degree as I saw an approach that I did not want to use. She meant it as an example, I know. Even so, this is not it, I thought. This is not how I want to represent this work... the 'woe is me' mentality that I spoke of last week in my pseudo focus group with D and C,... I spoke at length of being concerned about that, about this project becoming a means for my healing, for making sense of my life as it feels as though it has unraveled. "Yes," D said after I described what I wanted to avoid... "yes", like she knew what I was talking about. I was aware of the recording machine and somehow wasn't able to question her further on that... Though the thought flew through my mind nonetheless, Was I already doing that? Was I narcissistic in this work? Is this narcissism? Am I seeking attention? No. I don't want attention, not in that sense of the word. If anything, I want to neutralize my experience, the attention that comes my way because of illness, the behavioural pattern that I've developed of associating too much of my identity to my illness, using it as a means to connect with people when I feel empty-handed and unable to reach out. I want to describe the feeling, I want this work to speak to the process of grieving, I want to explore the narrative element of grief that Neimeyer (2000, 2001, 2001, 2010) talks about and translate it so that its experience is accessible. I want what I write to be accessible to others, to be helpful to/in research, to stretch and add to what already exists on kidney disease and depression.



Kiesinger (2009), talks about taking your topic and observing it from the outside, creating other perspective of it, open it up, aim at empowering themes rather than themes that sit sadly without moving. That said, however, I feel there is necessity in exploring the visceral experience of sadness as it relates to illness, the existential elements of that sadness.

Chapter Two

An Introduction to This Inquiry

Project Overview

This autoethnographic study investigates the lived-experience of ESRD in order to shed light on the psychology of illness-related loss as akin to the psychology of complex grief. Autoethnography is a form of research that stems from the researcher and seeks to explore personal lived experience towards furthering a greater understanding of cultural context (Ellis et al., 2011). Illness autoethnography combines autobiography with ethnography in order to present illness as a cultured experience. Ellis (2011) describes this as being both ‘process’ and ‘product’ occurring simultaneously. In the case of this inquiry, it seeks to provide a deep and rich understanding of the inner and lived psychological workings of what it means to lose a transplanted kidney of 23 years, and to re engage with hemodialysis as a life-maintaining treatment. Theoretical and methodological frameworks include Neimeyer’s Meaning Reconstruction Model (MRM) (2000, 2010), Illness autoethnography (Ellis, 1999) and Arts Based dissemination (Leavy, 2009; McNiff, 1998). These frameworks were chosen for this inquiry because of their central component of meaning-driven narrative investigation. The author’s illness narrative of renal transplant loss is layered, using multiple relationships and perspectives to the author; interviews from three family system relationships, three social system relationships, three patient cohorts and one patient focus group. This study is explored through a multi-voiced investigation in order to observe how the experience not only impacts the individual, but also how it might resonate with her family and social relationships. Family, friends and patient cohorts were interviewed about grief and meaning experience of ESRD and the existence of illness in relationship. Analyses were via an autoethnographic lens and was

emergent according to themes that resonated with the researcher using Leavy's (2009) narrative components for emerging meaning as a guide. These three components include the emergence of meaning according to a clearer *coherence*, the appearance of *turning points* and the surfacing of new plots to the story, or *replottings*.

Leavy (2009) talks about the concept of coherence as representing the way in which a narrative is communicated, its detail, what takes focus and how it feels to tell. Difficult narratives, such as narratives of grief or trauma, are incoherent and frenetic at first and are often difficult to share. Coherence emerges over repeated exploration of narratives, creating sense, definition and perspective. This is attained via facets of narrative engagement; words used, tone, presence of humour or other forms of emoting and change of tense.

The turning point in a narrative is the point at which a narrative changes direction (2009). This occurs via changes in perception and mindset and what roles the teller represents. For example, by using illness focused contexts the perception of passive patient may become one of agency. Consequently, due to changed mindsets, new directions emerge within the narrative.

The last component, re-plotting's, also referred to by Leavy as 'restoryings' (2009), refers to the emergence of reframing process within the narrative. A teller begins to redefine, reframe and reposition herself within her lived context and the relationships within that context.

This inquiry was inspired by a combination of events and concepts. First, the author's own experience of transplant loss prior to beginning her doctorate. The subsequent and dramatic loss of life quality that she experienced drove home her own lived experience of what the QoL and organ availability research about ESRD describes. Secondly, when Neimeyer's Meaning Reconstruction Model (2000, 2010) for grief processing was explored deep parallels were drawn between it and ESRD QoL. This model has yet to be applied to the ongoing processes of illness

related loss. As a meaning-driven model, in an inquiry where meaning was being sought, autoethnographic methodologies were found to be a sound compliment. Autoethnographic studies produce accessible, emotionally rich, deep and descriptive data (Ellis, 1999; Ellis et al., 2011). The element of patient's perceived meaning making of the proposed study is largely a missing component of current QoL investigations. This method is a complement for both patient and professional healthcare education and will enrich current data on this population. Outcomes are anticipated to be relevant to program content and delivery of psychological health services for ESRD patients. Dissemination has occurred via the creation of meaning themed narratives, coupled with the creation of an arts based psycho educational film entitled Seeking a Good Grief: A Patient Perspective Account of Renal Transplant Loss and Dialysis; a patient perspective performance about the lived experience of renal transplant loss, dialysis and the psychological grief that such an experience produces.

Participants

It is recognized that this is an autoethnographic study and that the author's experience represents that of the ESRD population with whom she shares the experience of undergoing regular life maintaining hemodialysis blood cleansing treatments and who have experienced kidney-transplant loss. Because of focusing on this particular phenomenon, patients themselves were contacted who had experienced the same health phenomenon as the researcher. Both individual interviews as well as one focus group were conducted, using semi structured interviewing about grief and the identification of meaning via the experience of ESRD and transplant loss. In addition, because this study was looking at where meaning emerges through grief and narrative-driven processes, and knowing that narrative is inherent within relationship, a cross section of

family and friend relationships were recruited for one-on-one interviews focusing on how illness-related meaning emerges and evolves in the context of their shared relationship.

Context

The content of this inquiry represents a subsection of the author's health narrative that occurred between January 2009 - when the author's kidney transplant was deemed no longer viable and hemodialysis treatments were restarted - up to present day. Typical of hemodialysis patient experience, numerous comorbid conditions surfaced, resulting in multiple necessary medical procedures and hospitalization. During the timeframe of interest the following medical events occurred. Roughly five dialysis access site procedures (the injection site, via either arm or neck catheter, used for dialysis treatment) were required, one surgical, four angioplasties, one of which was urgent, occurring outside of regular hospital hours and without sedation. Two surgeries took place for joint replacement of the hip and knee, required because of osteoporosis (avascular necrosis) due to years of steroid use during transplant years. The onset of dialysis perpetuated gynecological symptoms, revealing an adenoma, or benign uterine tumour, which entailed an overnight in ER with a hemoglobin blood level of 60 and was surgically removed two weeks prior to beginning of the doctorate. In the summer of 2010 the author experienced a systemic blood infection, which very nearly resulted in a withdrawal from her doctoral program. Dialysis was also linked to a systemic ductal infection, resulting in a bilateral mastectomy in early 2013. The author also underwent a clinical depression with suicidal components throughout 2009-2010 and again during the winter of 2013 for which she was successfully treated. Again, it is important to note that the above list of comorbid conditions and necessary medical intervention is very typical for most dialysis patients and is not unique to the author's experience. Finally, a notable component of this study is the author's combined professional

roles of academic-in-training, psychologist and artist, coupled with her life-long experiences as an ESRD patient. This combination of researcher positioning provides a uniquely ideal context for a study of this nature.

Validity, Reliability and Generalizability in Autoethnographic Inquiry

Ellis, Bochner and Adams (2011) have presented models for valid and reliable autoethnographic research. Of importance to these is the inherent understanding that within the use of narrative and the exploration of event and experience, that stories will change and evolve each time they are told, by whom, and the context in which they are told. They describe validity for autoethnography as meaning that "...work seeks verisimilitude; it evokes in readers a feeling that the experience described is lifelike, believable, and possible, a feeling that what has been represented could be true. The story is coherent. It connects readers to writers and provides continuity in their lives" (p.10). Reliability is seen differently among autoethnographers than standard qualitative scholars, though the achieving of it is likely similar to other methods in qualitative inquiry because of its dependence on components like narrative layering, rich description and continuous reflexivity. Reliability in autoethnography assesses the narrator as a primary reliable source; is the experience factual? Has poetic license been taken? Is there continuity within the research?

Generalizability in autoethnography speaks to how accessible the material is to its readers. This occurs via a process whereby thorough comparison of experience can take place, acknowledging similarity and difference (Ellis et al., 2011). Spry (2010) also presents this notion as the transformation of the 'I' to 'we' through reader accessibility, and that the achievement of this accessibility reflects the generalizability of the work.

Tracy (2010) provides eight succinct criteria for qualitative research that fit nicely with the autoethnographic and ABR contexts, ensuring richly reflexive, valid and creatively generalizable investigation. These are rich rigor; the investigation makes use of enough and appropriate theoretical frameworks, repeated reflexivity, sufficient and diverse data, sufficient and diverse contexts. This inquiry makes use of three theoretically complimentary frameworks; the meaning reconstruction model, autoethnographic inquiry and arts based narrative meaning-driven dissemination of the data from a multiple voiced data source. Other considerations from Tracy (2010) that have informed this methodology in terms of researcher involvement are sincerity (rich reflexivity regarding transparency, biases and assumptions regarding ESRD psychology, her lived experiences versus others), credibility (through multiple voices, the description and factual detail, showing rather than telling depth through layering of an illness narrative of ESRD with family and friend relationships as well as other patients who've experienced the same phenomenon), resonance (in addition to researcher resonance, material resonates with readers as true, evocative). Hunter et al. (2002) say that ABR consists of components such as rich description and meaning making methodologies, that it is an iterative process and that these are necessary subjective elements of qualitative health research.

Hesse-Biber & Leavy's (2011) considerations for achieving validity and reliability in qualitative ABR include placing interpretations against pre-existing knowledge, in this case what is widely known and questioned about the QoL of people with ESRD who have experienced transplant loss and who are on life maintaining dialysis treatments. This is achieved by identifying the relationship between findings and what is known, as well as by placing interpretations against pre-existing knowledge. This inquiry has examined the relationship between empirical medical research and lived-experience autoethnographic data from the

perspective of a patient researcher with this illness. Hesse-Biber & Leavy ask: does the inquiry theoretically make sense, does it resonate with the researcher, are major ideas and themes linked, do legitimate knowers in the field acknowledge this work as needed and relevant. The processes for achieving validity for this inquiry include knowing that the Meaning Reconstruction Model, autoethnography and ABR as theoretical frameworks make sense for a meaning-driven narrative inquiry in that the models allow for the material to resonate for the author. Themes that arose through the narratives, such as a need for normalcy and the consideration that meaning emerges from a co-occurrence of suffering and joy, are linked to ESRD QoL outcomes and components of meaning reconstruction. Patients who participated and nephrologists who supervised the data collection supported and encouraged the need and relevance of this kind of inquiry.

ABR researchers require the skills of symbolic thought, metaphorical lens of analysis and understanding, observation, conceptual thought, flexibility, intuition. Patient perspective inquiry creates a new lens of knowledge of disease and disease experience and symptomology. What traditional qualitative methods fail to 'get at' is the issue of interest, in this case the patient's lived experience of ESRD and dialysis psychology. These facets also entail lived experience of illness, loss due to illness, suffering due to illness, suffering due to medical procedure and procedural pain, suffering due to experiencing comorbid illness (heart or bone disease).

Ethical Considerations within Autoethnographic Inquiry

There is ongoing debate within the field of autoethnography as to how ethical concerns in this type of research are approached (Ellis, 2008; Ellis et al., 2011; Spry, 2002). Many autoethnographers state that, because the method is researcher-centered, that consent is the primary decision of the author (Ellis et al., 1999; Ellis, 2008). That said, because this study used layering of the narrative from a cross section of the author's social, patient and family system, all

participants were made aware of how their input was to be collected and used in the study and were provided description of the study overview. As required through Concordia University as well as Eastern Health and Memorial University's protocol, all participants signed consent forms. Due to the fact that close and intimate relationships are part of this investigation, anonymity was not guaranteed in those cases. Anonymity was provided for patient participants. A list of support resources was provided to participants in the case that they experienced residual reaction to the sensitive subject matter. The ethical risks related primarily to participants from the author's family and social systems, given the topic dealt with intimate and potentially challenging elements of the relationship and family history, including reviving memory of health emergencies experienced during childhood. Hence, participants were permitted to omit questions or suspend the interview without consequence. This risk was considered minimal due in part to the author's extensive professional experience in dealing with sensitive subject matter due to her graduate training as a counselling psychologist. Additional risk associated with involving family and friend relationship in autoethnographic inquiry is the risk of content inciting negatively surprising outcomes, such as feelings of blame or betrayal. This inquiry's goal is to facilitate the researcher's own understanding of grief in illness for purpose of generalizing this type of methodology. Its intention is to advance learning for health practitioners, patients and caregivers. Making use of Tracy's (2010) criteria for ethical use of personal material in qualitative research, procedural, situational and relational consideration was taken when collecting interviews and membership checks were conducted with family and friends in order to mitigate risk.

Chapter 3

Quality of Life of the End Stage Renal Disease Dialysis Patient

My Narrative: *I'm thinking now of yesterday and waking in a panic to the sensation of a blocked dialysis access; the pulsing blood flow in my arm had fallen silent. Instead, it felt hard, tender to the touch. Something was wrong. Last night's treatment didn't work and I'd opted to sleep instead and try again tomorrow... I could feel the emotion simmering. Keeping it at bay, I had to move, do something, be sensible. Rushing to my brother's, tears of panic close to the surface but not yet visible, my niece in her riding gear, ready to go the barn to visit her horse, Mad and Elsa arriving back from Saturday's piano lesson. Walking in to a normal weekend morning, un-showered in my blue fleece and jeans, spiraling internally, working hard at being gathered, appearing together. Not doing a great job. If this site stops working, they won't find another one. My veins are too small. They're small. They're small and 'wispy', I've been told. I wouldn't make a good maple tree, I've been told.*

I can't go back to the dialysis unit... I can't. Push that thought away, to the back of my mind, file it in that cabinet in the back of the room. It's the one that holds other similar files, all labeled with questions; File #1: will I be on dialysis for the rest of my life?, File #2: Will a transplant come?, File #3: When will I travel again?, File #4: Will I die before my siblings? My friends? #5: Will I have to take steroids again? Will they change my appearance again? File #6: Is the best of my life over?... File #108: Does losing my fistula somehow mean I have failed at self administering my treatments? Have I failed?



Introduction

ESRD is a growing condition in Canada, the prevalence of which increases dramatically each year, with dialysis and transplant being the only methods for controlling health (Kidney Foundation of Canada, 2012). With transplant availability on the decrease, dialysis has become the primary source for treating ESRD, largely via outpatient units where patients undergo three to four treatments per week, at 3-5 hours each time. QoL studies have begun to touch on how the evolution of ESRD affects psychological health and perceived life meaning in its patients. It is noted that this area is relatively uninvestigated, that no clear diagnostic criteria exist, and that further research is needed (Burton et al., 1988; Chih-Ken et al., 2010; Chilcot et al., 2008; Cohen et al., 2002; Devins, 1981,1983, 1997; Ferri & Pruchno, 2009; Feroze et al., 2010; Franke et al., 2003; Griva et al., 2009; Grootenhuis et al., 2006; Grudex, 1995). Within the QoL literature, outcomes also indicate that the experience of the physical presenting symptoms of ESRD requires further understanding as there is a growing body of evidence connecting the adverse accompanying effects and symptoms of ESRD with major depression and suicidal thinking. These studies describe a serious impact on perceived life value, the ability to see good in life and daily activity, work and social engagement (Watnick, 2007). Studies that offer patients' perspectives of living with chronic illness provide us with data that assist in deciphering a more holistic understanding of embodied presence of illness. A deeper understanding of the *lived experience* of these conditions in the form of patient-perspective research contributes towards a fuller defining of the effects of the disease and will be relevant towards formulating psychological approaches to wellness (Hutchison, 2005; Philips, 1998; Richards, 2008).

Dialysis systems continue to be the primary treatment plan for ESRD patients, extending life expectancy of individuals awaiting transplant, although renal transplant remains the preferred

treatment for ESRD because of improved QoL and extended life span (Kidney Foundation of Canada, 2012). Additionally, immunosuppressive treatment of transplants has improved in the past three decades, providing multiple pharmaceutical options for transplant patients, extending how long a transplanted kidney functions (Canadian Institute for Health Information, 2012; Kidney Foundation of Canada, 2012). That said, prevalence of ESRD continues to increase in Canada at a steady and dramatic rate, tripling in the last two decades (Canadian Institute for Health Information, 2011). The Canadian Institution for Health Information (CIHI) (2011) reported a 500% increase in the prevalence of the disease between 1990 and 2009. Multiple factors have contributed to this statistic, including an aging population, who make up a fifth of that figure. Diabetes, prolific in Canada, is a leading cause of ESRD and a condition for which prevalence increases with age, and which is also found to be more common now in relationship to poor health and related variables, such as obesity. At any one time in Canada, there are over four thousand individuals awaiting an organ, eighty percent of whom are ESRD patients awaiting a kidney transplant (Canadian Institute for Health Information, 2009; Canadian Institute for Health Information, 2012). What is also known is that, as the prevalence of ESRD increases in Canada, the availability of kidneys for transplantation has decreased, making for longer wait times using dialysis, and increased need for associated medical procedure for site maintenance and hospitalization (Kidney Foundation of Canada, 2012; Canadian Institutes for Health Research, 2012).

What is End Stage Renal Disease

ESRD is defined as the inability of the kidneys to function well enough to sustain life. This diagnosis usually occurs when renal function reduces to 15% (Trachy, 1987). Symptoms of early renal failure are often ambiguous, making for a slow diagnosis and producing an ongoing

and chronic list of depression-inducing symptoms such as lethargy, nausea, insomnia, muscle aches, affected hormonal levels leading to reduced sexual functioning and reduced social engagement and general diagnostically nonspecific malaise (Feroze et al., 2010; Yazici et al., 2009; Yong et al., 2009).

Nephrology teams are well equipped to medically care for patients with ESRD, having developed over the past thirty years a specialized medical treatment protocol that oversees all phases and states of the disease. Dialysis systems, both peritoneal and hemodialysis are continually developing in efficacy and accessibility (Kidney Foundation of Canada, 2012). Many Canadian nephrology centres now offer nocturnal hemodialysis programs whereby patients can train to self-administer their hemodialysis treatments at night at home.

As part of furthering research in ESRD, nephrology teams seem to be recognizing a developing need towards acknowledging care for the psychological toll of chronic adjustment that ESRD and dialysis forces on the patient (Chilcot et al., 2008; Feroze et al., 2010; Franke et al., 2003). This is largely due to a couple of factors. Firstly, ESRD as a chronic illness is progressive. Patients necessarily face repeated medical procedures due to the chronically evolving needs to treat the illness and maintain life: creation and maintenance of a dialysis site, often including repeated port insertions or angioplasty procedures, chronic hypo or hyper tension, dietary restriction, vascular thinning, restless legs, sleeplessness, lack of focus, reduced cognitive functioning and overall modified life span. All of these factors require a constant adjustment on the part of the patient. Such constancy becomes psychologically exhausting in many ESRD patients (Burton et al., 1988; Chen et al., 2010; Chih-Ken et al., 2010; Chilcot et al., 2008; Cohen et al., 2002; Craven et al., 1987; Devins, 1981, 1983, 1997; Ferri & Pruchno, 2009; Feroze et al., 2010; Franke et al., 2003; Griva et al., 2009; Grootenhuis et al., 2006; Grudex,

1995). Secondly, the issue of mental health diagnosis among these patients is challenging, made more confusing due to the overlapping and similarity of symptoms that look like psychological conditions such as clinical depression. Symptoms like lethargy, lack of focus or motivation, social withdrawal, reduced energy and sexual interest, are all symptoms that reflect poor kidney health. These symptoms possess what clinicians have found to be a confusing similarity to major depression (Blake, 2000; Burton et al., 1988; Danquah et al., 2010; Davison, 2007; Merkus, 1997, Yazici et al., 2009; Yong et al., 2009).

The Lived Experience of the End Stage Renal Disease Patient: Depleted Quality of Life

Renal failure can be present asymptotically for lengthy periods of time. Symptoms occur as a result of improper filtration of body impurities, creating toxicity within the body that triggers a rash of symptoms. These symptoms can differ from patient to patient, often including anemia or low iron, edema of the skin and other organs, reduced calcium absorption and bone softening, hyper or hypo tension, nausea, generalized soreness, insomnia, restless legs and poor focus (Chi-Ken et al., 2010; Cohen et al., 2002; Feroze et al., 2011). It is a 'difficult' area to research as it progresses at different rates in different patients. Even though it is suspected to be quite prevalent, much depression in ESRD patients still goes undiagnosed and anxiety is virtually unexplored. According to QoL studies on this population, depression is likely the most common psychological diagnosis among ESRD patients. QoL is impacted, affecting motivation, often including health affecting behaviours like non adherence to the dietary requirements stipulated by dialysis dietitians, restricting potassium and phosphorus. Khalil & Frazier (2010) found an association between diet adherence and depression, where lack of appetite and reduced motivation to eat were connected to a patient's health and energy level. Overall, studies focusing on QoL of this patient population produced significant outcomes on the prevalence of depression

(and anxiety) and their impact on life meaning. They outline the continued impact of ESRD on life meaning, yet continue to identify the psychological damage, including suicide, of this patient group as an unexplored area needing further research (Feroze et al., 2011; Chih Ken et al., 2010; Kring & Crane, 2009; McCauley, 1997; Moreno, 1996).

The ESRD population is highly prone to clinical depression and anxiety; symptoms significantly correlated with suicidal ideation (Chen et al., 2010; Chih Ken et al., 2010; Craven et al., 1987; Feroze et al., 2010; Guzman et al., 2003). Interestingly, patients with a low BMI (body mass index) have been shown to have an increased likelihood of experiencing diagnosed depression, suicidal ideation and completion than patients with higher BMIs (Chen et al., 2010; Liu, et al., 2006).

Merkus et al. (1997) produced findings similar to other research, with outcomes that indicate that QoL is significantly impaired in this population and that impairments are influenced and increased by the adverse accompanying effects of the disease; namely consistently low hemoglobin, affecting oxygen efficiency in the body, thereby significantly affecting muscle function, energy and motivation. The study concludes that these adverse accompanying effects not only impact QoL, but also are similar to depressive symptoms, making the diagnosis of depression often difficult or ambiguous. Improvement of hemoglobin levels and anemia has been linked to improvements in energy, though not always with feelings of a better life quality. In fact, even with improvements in blood chemistry, ESRD patients, when assessed, often report lack of interest or pleasure in most activities, most of the time (Watnick, 2007). Level of life quality experience is ultimately seen to be a result of a complex interaction of multiple factors; the disease itself and its adverse accompanying effects, in addition to personal traits, such as coping behaviour, social support and quality of care received (Blake, 2000; Burton et al., 1988;

Christensen et al., 1989; Danquah et al., 2010; Davison, 2007; De Vecchi et al., 1994; Devins et al., 1997). One might extrapolate that a deeper understanding of one's condition in terms of how it interacts with how one feels would also contribute to how life quality is perceived.

Depression in this population interferes with decision-making capacities regarding life perception, a factor that ought to be considered with treatment resistant patients as possibly contributing to their desire to suspend treatment. More current literature continually indicates higher instances of depression and suicidal ideation and behaviour within the ESRD population. Feroze et al. (2011) identify depression and anxiety as the most comorbid mental health diagnosis in this population (Blake et al., 2000; Chen et al., 2010; Craven et al., 1987; DeOreo, 1997; Devins et al., 1997; Franke et al., 2000, 2003; Fukuhara et al., 2003).

Suicide. In terms of suicidal ideation and completion, the kidney hemodialysis population represents four times that of the general population (Chen et al., 2010; Chih-Ken et al., 2010; Danquah et al., 2010; Feroze et al., 2010; Hakim et al., 1994). Arguably relevant is the effect that depression has on the interest to self-care, seek regular engagement with maintenance health services, compliance in taking medication, disclosure and actively reporting illness related issues (Chilcot et al., 2008). Known psychological factors of ESRD that may be influencing such outcomes include affected social disengagement due to reduced functioning and increased feelings of hopelessness and existential failure, perceived loss or lack of life control, decreased or missing sexual well being, job loss, negatively altered family and social relationships and overall inability to find pleasure in most daily roles and activities (Chih-Ken et al., 2010; Christensen, 1989; Coelho-Marques, 2006; Devins et al., 1981; Devins et al., 1997; Devins et al., 1983-84). The multiple interventions, such as procedures and hospitalization required by ESRD and health challenges of patients with ESRD increase the likelihood of a depression diagnosis

(Chen et al., 2010; Chih-Ken et al., 2010; Guzman et al., 2003). Chih-Ken et al. (2010) produced findings that presented the ESRD population as four times likelier to commit suicide in comparison with the non-diagnosed healthy population. Anxiety is less studied, but is also thought to be very common with patients on maintenance dialysis (the term used to refer to life-maintaining dialysis). Psychosocial elements such self-esteem and confidence are associated with independence of home self-administered hemodialysis (referred to as 'nocturnal' dialysis) is noted regarding improvement in QoL (Guzman et al., 2003; Wong et al., 2009), though few of the patient population seem able to engage with the responsibility of self administering their treatments. Patients on nocturnal dialysis experience higher rates of life quality associated both with social factors, such as flexible personal time, as well as improved blood chemistry allowing for a more flexible dietary plan and improved energy (Guzman et al., 2003; Wong et al., 2009). However, as mentioned earlier, improved energy does not necessarily mean there is an improved QoL or the absence of depression or depressive symptoms. Resistance to nocturnal dialysis is associated with anxiety and confidence and feelings of being overwhelmed at the responsibility associated with self-administering dialysis treatments (Wong et al., 2009). Improved QoL is also correlated with raised self-esteem and independence (Chih-Ken et al., 2010). High suicide rates are correlated with patients' QoL, fatigue or lethargy and their correlation to reduced social functioning.

Kurella et al. (2005) report different suicide figures between the USA and Canada, with US rates being higher and associated with access to medical care. It is noted that Canadian outcomes will differ in data related to access to medical service, given the differing medical systems in both countries. Few systemic studies specifically on suicide have been produced for the ESRD population. Rather suicide information that is available is in connection to feelings of

hopelessness and helplessness, with, little experience of pleasure and value in life and thoughts of death being an option of escape (Chen et al., 2010; Cohen et al., 2002).

This study also attempts to differentiate between withdrawal from treatment and suicide (Feroze et al., 2010). As a result of this differentiation, it presents potentially confusing results, stating that the rate of suicide among the ESRD population is only modestly higher than the general population. However, the rate of withdrawal from treatment is very common, a hundred times more common than suicide. This component may also be related to the age of groups studied, where focus on end of life care differs in context and experience from suicidal thinking in early to middle life. Other variables influencing suicide were comorbidity of heart disease, peripheral vascular disease, cancer, chronic obstructive pulmonary disease, alcohol or drug dependence, serum albumin level at less than 3.5 and relatively recent hospitalization where mental health diagnosis increased suicide risk by five times in this ESRD population (DeOreo, 1997; Hedayati et al., 2011; Kring et al., 2009; Kurella et al., 2005; Martin et al., 2004).

The likelihood of suicide is highest during the first three months after initiation or re-initiation of dialysis treatments. These findings are likely due to the steep adjustment curve that is associated with engaging with dialysis as an outpatient (Tsay, 2005). Likelihood of dialysis withdrawal is relatively high for the first year of dialysis and lessened afterwards. Observations suggest “[...] that ESRD acts to exacerbate a preexisting vulnerability or tendency toward suicidal behaviour among certain high risk groups [...]” (p. 246). Others surmise the combination of acute change in life pattern and physical adverse effects provide such a dramatic adjustment that foreseeing improvement is next to impossible for some individuals.

Valderrabano et al. (2001) discuss quality of care and social support as an important indicator of QoL improvement in ESRD patients. The presence of personal or familial support

also seems to be connected to life quality perception. There is also some thought that these factors influence manifestations of the disease itself, where support influences likelihood of maintained self care, such as non adherence to prescribed diet or inconsistency with clinic visits (Kalsouda et al., 2011; Khalil & Frazier, 2010; Kimmel, 2001). Additionally, it's known that impaired physical ability and mobility, in combination with affected mental health, is also linked to hospitalization, repeated procedures and morbidity (Lopes et al., 2002). In other words, the presence of physical ability and mobility is correlated with improved mental health and interest in life engagement.

Withdrawal from treatment. Cohen et al. (2002) investigated dialysis withdrawal or treatment refusal, producing findings that state that one in four patients withdraw from treatment before death, taking again into account that ESRD is a condition that at some point becomes terminal, when dialysis or transplant are no longer an option. Consequently, investigations of this phenomenon among the ESRD population differentiate between treatment withdrawal and suicide, this differentiation postulating that the decision to terminate treatment is often (but not always) a life ending decision in terminally ill ESRD patients where care becomes palliative. The concerns that do arise with respect to the issue of treatment withdrawal surface in relation to mid life patients whose prognosis is not terminal, where dialysis is a primary source of life maintenance. This discourse speaks again to the difficulty faced when diagnosing major depression and suicidal thinking in this population. Little empirical work has been done on the relationship between depression to treatment withdrawal due to the underreporting of depression in this population. Drayer et al. (2006) found that patients diagnosed with both ESRD and depression have four times the mortality rate of patients who do not have depression and that patients diagnosed with depression are likelier to withdraw from treatment. Lopes et al. (2002)

support this finding, stating that depressed patients are more likely to withdraw from treatment. Consequently, one postulates that depressive conditions are also under-treated.

Conclusion

QoL findings of the ESRD population have provided a sound foundation, which reveals a need for further investigation to provide a greater and more holistic understanding of the lived experience of this patient group. QoL studies run in Taiwan (2010), United Kingdom (2008), Iran (2010), and the United States all outline the above themes; that the ESRD population suffers from depression and suicidal thinking at higher rates than the general population, with figures suggesting somewhere around 20% of patients with depression as compared to 5% of the general population (Chen et al., 2010; Chih-Ken et al., 2010; Chilcot et al., 2008; Cohen et al., 2002; Devins, 1981, 1983, 1997; Ferru & Pruchno, 2009; Feroze et al., 2010; Franke et al., 2003; Griva et al., 2009; Grootenhuis et al., 2006; Gudex, 1995; Poppe et al.; 2012; Watnick, 2007). In addition to a clear need for further clarifying research on this, there exists a noticeable lack of patient-produced studies investigating the patient's first hand experience of ESRD (Hutchison, 2005; Philips, 1998; Richards, 2008). This study is rooted in a call for a more subjective investigation that focuses on patient experience of ESRD and its symptoms. Patient perspective investigation will add to current findings by providing firsthand patient experience of the symptoms of the disease and associated psychological responses. The literature investigating the ESRD population has largely been published by nephrology and psychiatry professionals, and is framed through a medical framework. The value of these investigations is that they consistently report high depression rates, suicidal behaviour and generalized anxiety as likely prominent features of this population and connected to hospitalization and survival (Davison et al., 2007; DeOreo, 1997; Fukuhara, 2003; Guzman, 2003; Hakim, 1994; Held, 1991). They also report a

relationship between QoL to frequency of hospitalization and mortality (Owen, 1993; Woods, 1996; Wong et al., 2009). These conditions seriously affect life quality, the ability to perceive life positively and relationship quality and engagement. Very few qualitative studies have been found that investigate data of lived-experience. Further investigation from a lived experience perspective will greatly compliment current QoL research on the ESRD population.

Chapter Four

Health-Related Knowledge Translation and the Role of Patient Perspective in End Stage Renal Disease Research

My Narrative: *Dialysis cessation and suicide...good lord. What a mouthful.*

Reading these articles on suicide on dialysis is draining. Physically draining. I'm trying to grapple with where the difference sits between suiciding and stopping dialysis treatments (Cohen et. al, 2002). Death occurring between 1-46 days after the last treatment...these rates hit me in my gut and I've been finding myself losing motivation, I think, as a result.



Introduction

KT has become a prominent feature of health research in Canada. The clear dissemination of evidence-based discovered knowledge can be challenging, meeting numerous barriers on its way to becoming action (Davis et al., 2003; Gillard et al., 2012; Graham et al., 2006; Land & Flagg, 2010; Woolf, 2008). In the field of health research, KT scholars know that most researched knowledge does not adequately make its way to the 'floor'. In most cases, new knowledge is either insufficiently or improperly applied, making for negatively affected health outcomes. The involvement of multiple stakeholder groups, including patients, in health care is an essential feature of the KTA process. Specifically focusing on QoL evidence in ESRD research, this dissertation considers the potential role that patient perspective, illness autoethnography, plays in translating the knowledge that is known about the psychological health of this patient population.

KT has been a visible player in how research is disseminated in the field of health inquiry from both the qualitative and quantitative lenses (Graham et al., 2006). KT includes within its

processes, multiple stakeholders. Primary care physicians, specialists, managers and policy-makers within health care are mentioned consistently within KT discourse as primary stakeholders involved in the implementation of health intervention and policy (Davis et al., 2003; Gillard et al., 2012; Straus et al., 2009; Woolf, 2008). Generally speaking, KT has been consistently considered to be an important and growing component of health research and as such, is a prominently featured part of agency mandates, such as the Canadian Institutes for Health Research (CIHR) and the CIHI. Both agencies include KT within their official granting mandates, positioning it as a central framework through which medical and health research reaches the ‘floor’, infiltrating treatment plans and application. The provision of findings from medical research is known to be insufficient, at times never making its way into policy and patient-related practice. Most evidence-based discovery does not adequately make its way to the ‘floor’. To ensure the provision of ‘... optimal care delivery’, KT, and within it, the KTA cycle, Straus et al. (2009) call for a sound framework towards optimally implementing new knowledge practices in health care servicing.

KT became a research discipline within medical services when it was found that researched knowledge was not adequately making its way into health care practice (Gillard et al., 2012; Graham et al., 2006; Straus et al., 2009). Insufficiency is known to exist at all levels of health care, with little difference between the developing and first worlds, in fact “globally, health systems fail to use evidence (based knowledge) optimally” (Strauss et. al, 2009, p. 165). In short, this assessment means that, though medical sciences certainly produce sound outcomes towards optimal health intervention, such discovery is often either improperly, or insufficiently implemented (Graham et al. 2006; Straus et al., 2009; Woolf, 2008). Strauss et al. (2009) also view KT as the method used for ‘closing the gaps’ between this knowledge creation and practice

as it relates to health outcomes. Yet, the means by which new knowledge is implemented efficaciously has yet to be truly understood and identified.

Part of this confusion regarding knowledge dissemination is perhaps the multitude of terms and understandings of KT that exist within the field that seeks to translate new health care knowledge to practice (Davis et al., 2003). Knowledge Exchange, Knowledge Transfer, Research Utilization, Dissemination of Research findings, Knowledge dissemination are only some of the terms – often used interchangeably – within this research field (Graham et al., 2009). Graham et al. (2009) have identified this confusing feature of KT inquiry, fundamentally calling for a common language and definition of KT to be identified.

Additionally, knowledge translators in health care have identified many barriers. These include a basic understanding that changing systemic behaviour is difficult (Straus et al., 2009) consequently a fundamental challenge in effecting behavioural change at all levels of health servicing is identified. The known relevance of the necessary inclusion of all pertinent stakeholders in change is often overlooked or inadequately applied. This is presumably due to the time and human resource challenges faced in coordinating multi-disciplinary involvement in new practice implementation (Davis et al., 2003; Gillard et al., 2012; Straus et al., 2009; Woolf, 2008). The accumulation of all these barriers, and the problems known within them, result in a depletion of what it ‘actually takes’ to disseminate research to the floor. Also, time is a necessary resource needed for consistent multi-disciplinary investment in KT in health care. Time is most often a resource that health care cannot afford. Consequently, clarity remains out of reach. That said, promising frameworks that seem to consider the complex systemic features of knowledge implementation, have been developed, such as the KTA framework (Graham et al., 2006; Lane & Flagg, 2010; Straus et al., 2009).

Along with medical and administrative stakeholders in health research, patient involvement has been supported as very relevant contributor to the dissemination, implementation and maintenance of health intervention and policy (Davis et al., 2003; Gillard et al., 2012; Straus et al., 2009). Gillard et al. (2012) coin the concept of ‘coproduction of knowledge’ as an important consideration towards the solidification of health intervention and service policy, underlining the importance of patient participation in health research dissemination and that further attention ought to be put toward the inclusion of the patient voice of experience. Perhaps relevant to clarifying the lack of understanding in areas such as behavioural change and other missing components of KT in health research, Gillard et al. provide additional patient-relevant concepts in the KT process: Increased credence is given to the ‘expertise of experience’ that is offered by patient-participation and their hands-on experience of health services, which complements the ‘expertise of profession’ offered by traditional researchers and clinicians who investigate and provide health programming. Generally, each of these spheres of experience is identified as equally valuable contributors in terms of their roles in the KT process.

My Narrative: How is it building who I am...the needle in my neck. Again. For the fourth, fifth? Fifth time this year, I think.

You have to give me your cooperation, he said in his broken English. English wasn't his first language, I could tell, but didn't give him that, wasn't flexible, did not practice tolerance.

Aren't I being cooperative, do I have a choice but to be?, I said, stiff, in a tense tone, angry, shaky, my face forced to the left, the pad of his left hand gently pressing against my temple, positioning my head so that I would not turn it or move abruptly, to give access to the vein in my neck, unable to see much beyond the sterile towels caped around my brow and chest

with, so in an effort to distract myself chose a spot to stare at; the oxygen tap on the wall, something else next to it, I don't know what that thing's for...

Aren't I being cooperative?, I said, offended.

Oh yes, yes...dat iz not what I was meaning...I mean not that...he stumbled, stammered. I knew that he wasn't being bossy, or personal, improper. I know that, quipped this snarky remark nonetheless, needed to be angry at that moment. I needed to be rude at that moment, I thought to myself, staring at the yellow cabinets in my eyes' view, with print-out labels, black letters announcing their contents...priority!, 15 gauge hickman port, temporary catheter, permanent access, sterile gauze, 2x2, 4x4, sterile drapes...18 gauge needle...in my neck



Patient involvement in dissemination phases of research takes into account multiple levels of patient experience, including context, diagnosis, language, family involvement, need for methodological flexibility and non-conventional approaches with respect to research (Gillard et al., 2012). Such considerations take into account the informal experiences of patients within health care service and policy implementation, which potentially calls for a reframing of how new knowledge is disseminated. The inclusion of patient perspective and patient participation will create a greater understanding of behaviour, comprehension and deciphering medical advice, reaction and understanding of the complexities involved in providing optimal, timely and current interventions.

Illness autoethnography (Ellis et al., 2011; Ellis & Bochner, 1999; Spry, 2006, 2011; Richards, 2008), a form of I-perspective qualitative illness research, is a viable contributor to KT processes focusing on ESRD psychological programming and treatment. It is a relevant and complementary methodology as it provides a greater reflection and defined understanding of QoL concerns faced by both ESRD dialysis patients themselves as well as ESRD QoL

researchers. This is very important, as academic literature on ESRD QoL outlines depression and suicidal thinking as more prevalent among this population, at times influencing decisions to withdraw from treatment and patients' own ability and motivation towards self care and self agency (Cohen et al., 2002; Feroze et al., 2010). Patient inclusion in knowledge dissemination and translation has been shown to produce additional, newly discovered relevancies on what is required in order to effect positive long term change in mental health servicing (Gillard, Simons, Turner & Edwards, 2012). This inquiry acknowledges the 'usefulness' of co-produced inquiry, such patient participation and potentially reframes the ways in which KT processes take place.

This dissertation makes an argument autoethnographic illness-related (or illness autoethnographies) within KT health care research. It promotes a sound agency among patients through a solidification of the lived experience of illness via the lens of 'expertise of experience' (Gillard et al., 2012). This dissertation will explore what is already known, as well as questioned, about the field of KT, including its place in ESRD QoL health research. Some of the known confusions and gaps will be outlined about what is needed in order to translate new health KTA. This chapter outlines the sometimes-overlooked role of the patient in the actual dissemination of research outcomes into action, suggesting the ongoing parallel inclusion of patient perspective analysis in all phases of the KTA framework. A side effect of this 'action' outcome, includes the patient's own agency in self-driven care and role responsibility through new behaviour that is drawn from a concrete understanding of new knowledge, ultimately affecting optimal health outcomes.

Knowledge Translation in Health Research and Implementation – Patient as Stakeholder

To begin, a clear understanding of what KT *is* within health research and ESRD psychology research is necessary. KT is defined by the CIHR as "...a dynamic and iterative

process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthen the health care system” (CIHR, 2012). This definition has been used by, and in relation to, other health agencies such as the World Health Organization (WHO) and the U.S. Centre for Dissemination of Disability Research (Straus et al., 2009). Common among these mandates is the necessity for the dissemination of health research to be informed by the multidisciplinary nature of how health intervention ought to be implemented. As such, clinicians (primary care and specialists), managers (administrators and nurse managers) and policy makers are consistently included in the ideal vision of how KT processes should proceed. Patients too are mentioned though seemingly less frequently (or with less importance) than other groups within health care. Given the acknowledgement of barriers within KT processes, and the importance of stakeholder involvement, a greater consideration of the role of the patient should be included as possessing experiential knowledge of medical practice and procedure. Patients possess varying levels of experiential knowledge that is informed by their illness experience, how long they’ve been diagnosed, as well as the degree to which they engage with the health system.

As a central part of its process, the different definitions of KT that exist consistently present the need to close of the gap between knowledge acquisition and implementation. The WHO considers important components of this definition, such as the need for ‘dynamic’ and ‘ethically sound’ exchange toward improved health servicing, ultimately toward improved quantity and quality of health (CIHR, 2012). This relates to all levels of health care servicing and includes within it technical products that improve life quality (MRI, dialysis technology for example), pharmaceutical research (drug trials) and policy toward patient management and care,

including mental health intervention (Davis et al., 2003; Land & Flagg, 2010; Straus et. al, 2009).

Some have identified the journey between research initiation and actual implementation as consisting of four phases (Straus et. al, 2009). *First*, knowledge creation, or the primary research need acknowledged by said medical or scientific discipline. *Second*, the knowledge distillation or the creation of knowledge refers to the necessary guidelines for the research process, or the data collection and analyses phases. *Third*, the knowledge dissemination phase refers to the period after the theoretical completion of research, when outcomes are made public, appear in journals, are reviewed or critiqued, typically staying within the general discipline of research. This phase may be viewed by researchers as something of a termination, identifying the completion of a given study. KT scholars acknowledge a fourth phase, though its total solidification remains unclear. This fourth and final phase refers to turning of new research findings into action; i.e. to the floor, to the patient, to the clinician's day-to-day understanding and practice. This fourth step is where KT frameworks come into play. It is a phase that is not fully understood and is a challenge to decipher in terms of what it should include. KT needs differ significantly between the multiple disciplines that exist within health research, as contexts vary, even though the pieces of it that require consideration are known and seemingly agreed upon. The known barriers within KT processes speak simultaneously to each discipline.

Known barriers exist in KT that require further investigation. *Behavioural change* is a difficult barrier. Challenges in changing behaviour based on researched evidence exist at all levels of health care servicing (clinical, managerial, administrative and patient). Each level requires a different type of change (Woolf, 2008). Exactly how behavioural change ought to be managed, monitored and sustained is a sizeable task, at times to large to contain.

Another challenge to proper KT processing is the necessary involvement of the above mentioned multiple stakeholder groups (clinicians, managers, policy makers and patients). Though the ideal KT processing involves all stakeholders, and provides a multiple lens, parallel processing, of knowledge implementation it is often the case that all groups are not adequately included. Consequently, how knowledge is absorbed by a given stakeholder is not properly or adequately represented. Additional issues amongst discipline groups include communication clashes between groups where methodological lenses and understandings differ, often significantly (Graham et al., 2006).

Though acknowledged as a necessary player in the KT process, patients and patient input has historically been either given little credence or been omitted altogether (Davis et al., 2003). As of late, the value of patient involvement in health research has increasingly been acknowledged (Gillard et al., 2012). A need for the integration of the patient-role in KT research and processes, such as addressing the lack of clarity available in outcomes involving patients, has been recognized. Consequently, there is a call for patient presence in health research and research dissemination. Qualitative research that considers such need asks for the inclusion of not only patient-participation inquiry, but acknowledges that patient-perspective inquiry is a marginally different component of the 'expertise of experience'. This type of inquiry, illness-autoethnography for example, provides additional perspective on patient experience of their health condition as well as health servicing. It includes within it lived experience of disease and the role of support networks, such as social, medical care and family systems, as relevant in the KTA framework. Even though we understand the barriers of 'what it takes' in order to translate new knowledge into practice, successful implementation often remains out of grasp.

What Patient Perspective Brings to the Knowledge-To-Action Framework

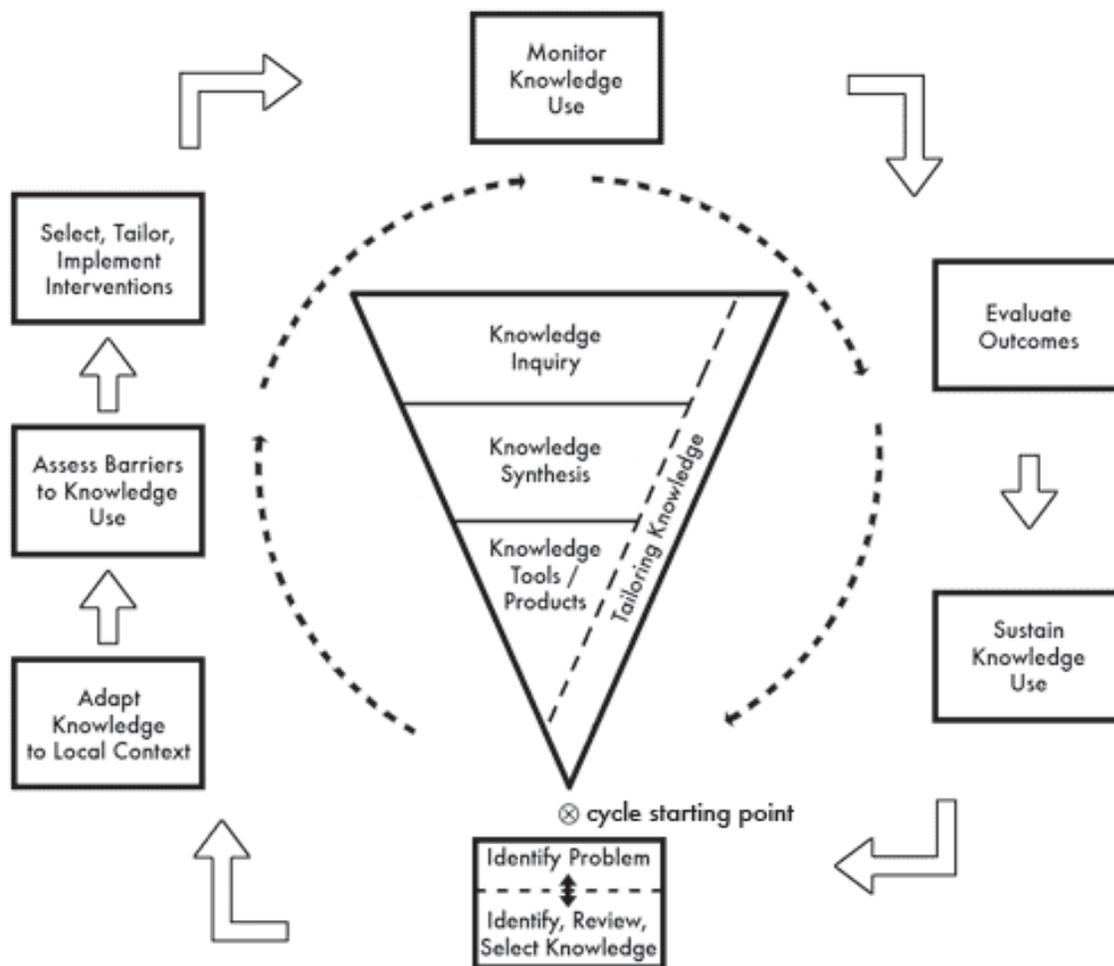
The KTA framework (see Fig. 1) is promoted by KT scholars as a means of infiltrating new knowledge into health practice. It is cyclical, yet non linear, and systemic. It promotes the initiation of KT processes at any point in the KTA cycle (Graham et al., 2006). It is also essentially adaptable to all disciplines and considers contexts within each phase for all stakeholder groups. This includes patient involvement as well as patient-driven research. ESRD QoL research consequently fits easily into the KTA framework.

The KTA framework is a cyclical implementation process that KT scholars present (Graham et al., 2006). It invites the use of lived and embodied experience research as a viable component for teaching and learning among health care providers. It contributes by shedding light on patients' day-to-day experiences of living with disease, including rationale for health impacting decision-making outside of the clinical context. Patient decision-making includes level of self-care, reporting of change, compliance regarding medication and diet. QoL ESRD research tells us that patient depression is connected to self-awareness of care and compliance behaviour. As behavioural change is a noted barrier within KT, this information is relevant. It can be linked to the known gap of behavioural change within KT and health services.

The KTA cycle outlines seven features to the KT process. Identification of problems, adapting knowledge to given context, assessment of barriers to effecting knowledge implementation, select and tailor implementations, monitor how knowledge is used and determine proper use and usefulness, evaluate outcomes and sustain use of new knowledge (Graham et al., 2006; Flagg & Lane, 2010). KT scholars have deemed this framework as a sound system towards KT processing, as it adapts to all disciplines and stake-holding groups. In

invites the parallel process of patient-perspective autoethnographic methodologies with KT in order to have clearer and reflexive understanding of the lived experience of ESRD and dialysis.

Fig. 1 The KTA Framework



Knowledge Translation and End Stage Renal Disease Quality of Life - Considering the ‘Expertise of Experience’

There exists an argument for I-perspective patient research within KT, as a greater need for subjective, patient relevance processes have been identified in order to create greater efficacy

of service in mental health programming (Davis et al., 2003; Gillard et al., 2009). Patients taking agency for their own care is an inherent consequence of developing a sound comprehension of their illness, its symptoms and its treatments. I-perspective patient research privileges experiential knowledge of illness and contributes a valuable lens for the dissemination of health research. It is a flexible and accessible methodology, suitable for all phases of medical research, as well as its transfer to action. It produces data of lived experience that seeks to translate the 'I' voice to one of 'we' (Spry, 2006), universalizing the experiences of the body and associated behaviours it engenders. It also entails active involvement of the patient as, what Gillard et al. (2012) refer to, the 'expert' source of knowledge in the experiential elements of their disease. These experiential elements include negotiating health programming, which involves patient-physician communication, liaising with specialists and the language that is used with respect to diagnosis and self care expectations. Such a dynamic should offer something of a logical lens through which patients can absorb new knowledge as it relates to diagnosis and treatment.

Disseminating ESRD QoL research outcomes to patient treatment frameworks has yet to truly occur (Craven et al., 1987; Danquah et al., 2010). Studies on QoL of renal dialysis patients report heightened statistics regarding the instances of diagnosed depression, suspected anxiety and suicidal thinking among dialysis patients (Feroze et al., 2010). While this information is known, the way in which ESRD presents as a disease (listlessness, poor appetite and weight loss, lack of motivation, reduced cognitive ability and sexual drive, to name a few) is similar to depression. As a consequence, diagnosing depression in this population remains a challenge. Consequently, the true prevalence of depression and suicidal thinking among this population might be higher than originally thought, with current figures being somewhere between 30% and

70% of ESRD patients being depressed (Cohen et al., 2002; Kimmel et al., 2001). This is in comparison to the general population.

A complex collection of factors contribute to QoL in ESRD patients, some of which are related to the disease itself and its manifestations, while others are situational or contextually related (Watnick, 2007). Patient perspective research will shed light on the intricacies of how life quality is perceived, improved or impacted by the ‘ESRD Context’. Additionally, the symptoms of ESRD, including uncertainties in diagnosing depression and suicidal tendency will acquire a new degree of clarity via a patient-as-expert lens of understanding. This type of information is highly relevant to the KT process.

Depression and anxiety are among the most comorbid psychiatric illnesses in people with ESRD (Feroze et al., 2011). Depression has been found to be the most common psychological abnormality in this population and that ESRD patients who have depression have four times the mortality rate of those who do not have depression. Depressed ESRD dialysis patients also have a higher rate of treatment withdrawal than non-depressed dialysis patients. Other ambiguities within ESRD QoL research consider the prevalence of treatment withdrawal among dialysis patients and the potential connection that such a phenomenon has with suicidal tendency (Kurella et al., 2005). Overall, the QoL of ESRD patient is substantially impaired by the symptoms and experiences of their illness (Merkus et al., 1997). Patient energy and motivation is a known component of poor QoL in ESRD patients. Some research connects the instance of anemia, low iron, hemoglobin to low energy and contextual depression with depleted QoL and treatment (Kurella et al., 2005; Merkus et al., 1997). QoL is directly linked to factors related to the disease itself, which has also been suspected as contributing to depression and possibly treatment withdrawal. Anemia (often chronic), hemoglobin level, comorbidity of other

conditions are all contributing features to life perception and opinion of the future, including the likelihood of health improvement (Valderrabano, 2001). Suicidal thinking is sometimes more prevalent in first three months of dialysis initiation (Kurella et al., 2005). Mental health diagnosis in ESRD patients increases suicidal likelihood. Depression and anxiety are among the most comorbid illnesses in people with ESRD (Feroze et al., 2011). Depression is the most common psychiatric abnormality among this population and has been recently correlated as a risk factor for mortality and morbidity. Between 1995-2001, patients with ESRD were 84% more likely to suicide (Kurella et al., 2005). It is widely known that patients who restart or newly start dialysis face a steep emotional curve of adaptation that often includes suicidal components (Cohen et al., 2002; Feroze et al., 2010; Kurella et al., Merkus et al., 1995). To date, these known psychological aspects of ESRD lack an understanding of how they manifest in day-to-day living and should be included within KT.

Little research has been done on the relationship between depression, treatment withdrawal and suicide, though the suggestion exists that the three are correlated (DeSousa, 2008). We also know that depression is under reported among this population. Depression can interfere with decision-making capabilities with respect to life perception. This ought to be considered with respect to treatment withdrawal, treatment resistance and treatment non-compliance (DeSousa, 2008; Cohen et al., 2002). Distinguishing between dialysis withdrawal, treatment refusal, treatment non-compliance and suicidal ideation have yet to be fully differentiated (DeSousa, 2008). Hence, KT requires investigating patient lived experience.

Other KT relevant factors that affect QoL in ESRD include interpersonal elements, such as family, ethnic context and the type of care received, including medical care. Support frameworks, either family or otherwise, are noted as being a significant factor to patient coping

style and outlook (Valderrabano et al., 2001). The level of patient-care received from medical staff is also relevant to patient psychological functioning. Physical and mental health functioning has also been linked to a risk for hospitalization, which itself has been link to a higher likelihood for mortality. Physical and mental health is correlated with risk for hospitalization and mortality (Valderrabano et al., 2001).

Knowledge Translation, End Stage Renal Disease and Autoethnography

Including the ESRD patient as stakeholder in ESRD KT research is encouraged by the above findings that stem from QoL studies on this patient group. Part of the gap of knowledge in ESRD QoL research is identifying what symptoms of depression look like in the day-to-day living of the ESRD dialysis patient. Furthering this knowledge involves the inclusion of patient as stakeholder, ‘holding stake’ in the creation of a deeper and more holistic understanding or how ESRD affects their life perception, relational and emotional health. A need for expanding knowledge on depression and the presence of suicidal thought among the ESRD population is evident (Feroze et al., 2010; Watnick, 2007). By including the ESRD patient perspective within KT processing, a deeper understanding of these psychological aspects will become more accessible. The addition of I-perspective approaches will add newly clarifying perspectives of these ESRD outcomes.

Given what we know about KT and patient perspective research (the gaps and identified barriers to the translation of knowledge in health research), there is a good argument for the furthering of patient perspective both in health research and KT areas. The focus on embodied and visceral data produced by this type of research has the potential for shedding light on the gaps in understanding that exist in transferring medical research outcomes to the patient-clinician experience. Arguably, patient voice has a place in all parts of the KTA cycle.

Autoethnography touches on difficult-to-decipher themes in the illness experience as it is connected to the body and the way in which behaviour and perception translates into day-to-day living and decision-making (Spry, 2001, 2006; Ellis, 2007). Dynamics, both inter and intra personal in nature, are often difficult to quantify. Yet, at the same time they are known to be very present in ESRD illness treatment and experience and often surface as central themes in ESRD QoL research (Hutchison, 2005; Watnick, 2007). Knowing this, some relevant dynamics to KT might be informed by QoL evidence. Such considerations could include patient-physician exchange, the way in which and accuracy with which diagnostic information is disseminated between specialists, how treatment intervention is decided via either primary care physicians or between specialty groups, who is involved in decision-making, how and the degree at which QoL is considered including degrees of empathy in care. Empathy in care includes within it the way in which care is received by patients from health care providers (Watnick, 2007). Other factors addressed within autoethnography include language use and clarity, and considers illness as narrative, for example how illness phase and treatment is described, how symptom is deciphered and described by both physician and patient.

Autoethnography Illuminates Patient Perspective

Illness autoethnography provides patient-as-expert perspective of the health system, its interpersonal and procedural processes. Its methodological frame privileges the individual's perspective of illness and illness treatment. Additionally, it provides data of the lived experience of disease, both socially and physiologically (Ellis, 2009). Its methodological outcomes are accessible, are most often non-didactic in presentation; scholars and non-scholars alike easily understand it. Illness autoethnography is a significantly evolving and visible methodology for researching health phenomena and it provides a different perspective of the lived experience of

illness and treatment, such as ESRD. Spry (2006) promotes autoethnography as a methodology that is centered within the body's lived experiences; that vital learning exists within visceral and non-linear data that the body, and embodied experience, produces. There is a sense-making component to autoethnographic processes, where scholarship is combined with features often excluded from objectivist investigation, coining the concept of a 'critical empathetic epistemology', making room for subjectivity in health research. It acknowledges diverse representations of lived experience, bridging the 'I' with a 'we' lens of understanding and application.

ESRD QoL scholars have identified the need for including the patient experience as pertinent to treatment, as is laid out in the themes below. These themes are linked to the ways in which patient and patient support groups disseminate health knowledge as well as sustain necessary behaviours vital to maintaining health outcomes:

- Decision-making regarding treatment intervention relevant to QoL concerns; i.e. combining QoL treatment concerns with medical/procedural intervention concerns
- Reciprocity as feature of KT processing; i.e. patient assessment, language, methodology, context – in reciprocal exchange with clinician's assessment/language/methodology/context – as a considered dynamic within KT of ESRD QoL research
- Building self-agency in patients regarding self management of depression-inducing symptoms
- Building self-knowledge regarding awareness of the relationship between ESRD as disease and how it manifests depressively, including why patients withdraw, refuse and resist treatment.

Conclusion

KT impacts many discipline groups within health care research. It acknowledges the necessary input of four main stake-holding groups within health care: clinicians (primary care and specialists, nurses, nurse practitioners and doctors), managerial staff (administrators as well as nurse managers and other clinician-come-managers), policy makers (who often have little to no contact with the 'floor', patients, etc.). The final group, patients are presented in some of the literature as central to this process (Gillard et al., 2012). Others mention them as marginal. The need for multidisciplinary and multi-level involvement seems clear, yet exactly what is expected of each group, both within each subgroup, as well as between, is consistently unclear.

Given what we know about the barriers that exist within disseminating research into practice, the inclusion of patient-perspective research, seen ever-so-slightly differently from patient-participant research (Gillard et al., 2009), potentially plays an important contributing role within medical KT processes given its emphasis on subjective learning and the way in which medical knowledge is absorbed.

What is known about the QoL of ESRD patients tells us that this patient group suffers with increased levels of depression, anxiety and even suicidal tendency (Chen et al., 2010; Cohen et al., 2002; Kurella et al., 2005). We also know that these psychological states might affect treatment withdrawal, refusal and resistance. Knowing this information calls for further dissemination and understanding that behooves patient involvement towards a clearer understanding of the manifestations of these conditions in the day-to-day functioning of ESRD patients.

Further patient-perspective of ESRD experiences would inform health-related behaviour, such as the maintenance of self-care and deciphering why patients withdraw from treatment.

Autoethnographic investigation of ESRD is a complimentary research lens for the dissemination of evidence-based findings on how psychological features of ESRD manifest themselves within the lived experience of the patient.

The inclusion of patient as ‘experiential expert’ within all phases of the KTA framework contributes, in a systemic way, to the patients own assimilation of evidence-based knowledge as it will influence how they think about, and take action regarding their own health. Notably, the cyclical nature of the KTA framework also repeatedly exposes healthcare professionals to the patient experiential voice. By presenting the patients’ own current and defined experience, as well as comprehension of their diagnosis, reciprocity between patient and the health system (clinicians, nurses) will be further informed and, by consequence, enriched.

Chapter 5

End Stage Renal Disease: Finding Value in an I-Perspective Arts Based Methodology

My Narrative: *So, it's been slow. Slow getting motivated. Slow getting to feeling good. Slow to feeling happy. Slow to feeling energetic. Slow to doing things, slow to wanting to do things. Slow to getting to a place of feeling like I'm living a life, rather than dealing with an interim situation until my real life reboots itself. It's a thick, viscous slowness, difficult to apply a meaning to.*



My Narrative: *Perhaps it's the prednisone, which I keep telling myself. Coming off of 23 years of steroids is hard on a body and can't be done overnight. I'm told I might feel sore, angry, tearful. Perhaps it's dialysis in general. It's been ten months now and I'm told, I've read, it can induce depression. Perhaps, like John said the other night as I cried over a cold piece of apple pie that'd been saved for me while I was at treatment, perhaps it's just the whole picture. Having two major surgeries in the last three months is a lot. Then there was the blocked access and the two angio procedures...*



Introduction

As presented in chapter two's literature review, the field of research that focuses on QoL of ESRD patients consistently puts forth the need for further inquiry in the area of psychological health of this patient group. Medically driven studies have produced valuable data on the prevalence of depression and suicidal behaviour among the ESRD hemodialysis population. The data directly connects these symptoms with life meaning. Almost no attention is given to the

perspective of patients' lived experience and what it means to negotiate the physiological and emotional impact of ESRD (Hutchison, 2005; Richards, 2008). This chapter discusses the application of autoethnography as methodologically relevant to the study of the psychology of ESRD, and hence the central framework used in this doctoral project. Autoethnography, due to its focus on lived experience, provides a deeper and richer understanding of how the illness is experienced by the living body. Because of this focus on the patient, it is a timely and complimentary methodology to current QoL studies. Its potential is to provide access to greater agency for this growing patient population, adding a highly relevant deeply described understanding of the manifestations of the disease. It is a methodology that plays an active and applicable role in KT, the synthesizing of lived experience and theory and inclusion of the body and embodied experience in health research. The view that adjusting to chronic illness is a psychological experiencing and re-experiencing of loss and identity (re)formation is not a new one. Over the last three decades the work of Charmaz (1997) and Frank (1995) into the sociological dynamic of chronic illness describes this repeated encountering of the ebbing and flowing of the lived experience of chronic illness as highly significant to identity formation and akin to the recycling of loss experience. They describe this process as a forced mini-grieving experience each time illness is revisited. Frank (1995) states that the 'life narratives' of the chronically ill are persistently informed, shaped and affected by the ongoing presence of illness in the body, metaphorically coining this experience as that of a 'wounded storyteller'. Charmaz focuses on the persistent modification of self that occurs and reoccurs as a result of the evolving and revolving experience of chronic illness (1997). This chapter extrapolates these central concepts on loss and identity modification through the illness experience of ESRD exploring psychological health factors and subsequent perceptions of identity.

Loss and identity interruption is a central theme in QoL literature on ESRD (Chan, Erlich, Chow & Suranya, 2009). As a chronic and prevalent illness, ESRD is slow to diagnose and presents a complex layering of physiological problems that change and worsen over time. As the disease progresses, it brings with it repeated adjustment on the part of the individual, which triggers the redefining of life meaning. This adjustment affects both physiological and psychological perspectives and experiences. QoL studies about ESRD patients illustrate the pervasive impact of the disease on the psychology of day-to-day living, suggesting the existence of depression and suicidal thinking and behaviour at levels significantly above what is known in the general population (Chen et al., 2010; Chih Ken et al., 2010; Craven et al., 1987; Feroze et al., 2010). In addition, there is strong suspicion that this group has significantly higher levels of anxiety and lack of self-care behaviours. These symptoms can also have an impact on decisions about treatment withdrawal (Chilcot et. al, 2008).

Ongoing research has medical teams calling for further clarification of the psychological impact of these losses on the ESRD patient, seeking a deeper understanding of what informs their mental and emotional health (Chen et al., 2010; Chih-Ken et al., 2010; Chilcot et al., 2008; Cohen et al., 2002; Devins, 1981,1983, 1997; Ferru & Pruchno, 2009; Feroze et al., 2010; Franke et al., 2003; Garcia, 1985; Griva et al., 2009; Grootenhuis et al., 2006; Grudex, 1995; Liu et al., 2006). These studies shed light upon the phenomenon, and yet also indicate a profound need for greater understanding of how ESRD affects the patient's psychology, including decision-making, behaviour and perceptions of life meaning.

Autoethnography is a research methodology that investigates the lived and cultured experience of a given phenomenon (Denzin, 2006; Ellis & Bochner, 2006, 1996; Ellis, 2008). It operates by emphasizing the visceral, inconsistent and subjective nature of difficult life

transitions, including illness, with the aim of applying meaning and understanding to themes of grief and loss. The primary aim of illness autoethnography is to invest in the discovery and understanding of the evocative, emotional and embodied experience of loss relating to illness, towards a richer reflexive understanding of what the day-to-day, minute-to-minute, lived experience is on the part of those living it and, in doing so, to contribute to the KT of the nature and psychology of illness such as ESRD, as it is experienced by the body.

This chapter puts forth autoethnography and its sub field of performance autoethnography (Denzin, 2007; Pollock, 2006; Spry, 2001, 2006) as a relevant methodology for exploring the psychological experience of ESRD, in the belief that this will further enhance our understanding of grief and loss of life meaning in ESRD research. It connects the need for a greater agency among the ESRD patient population through the researching of lived experience in order to formulate an understood relationship between the physical manifestations of the disease and the psychological health and related health maintaining behaviours and life quality of its patients.

End Stage Renal Disease: Connecting Quality of Life Literature to Grief and Loss of Meaning

ESRD is defined as the inability of the kidneys to function well enough to sustain life. Diagnosis is often slow, usually occurring when renal function (the ability of the kidneys to filter protein, potassium and phosphorous from the body) reduces to 15% (Trachy, 1986). The symptoms of this disease are many and often ambiguous; fluid retention putting pressure on the heart and breathing, lethargy, poor motivation, insomnia, generalized itching, nausea, hormonal abnormality and affected cognition. Though much advancement has been made in researching the medical components of the disease, the psychological affects require further investigation

(Chih-Ken et al., 2010; Chilcot et al., 2008; Cohen et al., 2002; Devins, 1981,1983, 1997; Ferru & Pruchno, 2009; Feroze et al., 2010; Franke et al., 2003; Griva et al., 2009; Grootenhuis et al., 2006; Grudex, 1995).

ESRD literature on QoL touches on themes of the modified identity and perceived life meaning as a grieving process. Chan, Erlich, Chow & Suranyi (2009) describe the losses that ESRD patients face as “[...] both tangible and symbolic [...] loss of physical strengths, freedom, employment, and social life, resulting in grief throughout the course of ESRD and dialysis” (p.2).

All presenting literature on the psychology of ESRD underlines the psychological weight that multiple losses bring to ESRD dialysis patients’ experience, as well as the uncertainty that renal specialists face when dealing with the psychological consequences of the disease. These health challenges include the ebbing and flowing of changing blood chemistry, secondary conditions due to poor vasculature and blood pressure, reduced appetite, as well as other physiological and hormonal functioning, such as reproductive and sexual engagement (Chin-Ken et al., 2010; Coelho-Marques, 2006). These health losses touch all corners of identity, as they influence the individuals’ experiences of living. Their social circle and family identities also shift and are affected. The reduction of capacities in areas such as decreased energy, weight loss, affected psychomotor ability, the diminishing of interest and ability to take pleasure from most activities most of the time, such as work, parenting and social engagement is dramatic (Watnick, 2007). Accessing day-to-day pleasure is reduced and the patient’s self-perception is altered with each depleting phase of the illness.

My Narrative: Yesterday, I had rushed surgery to circumvent an infection in my dialysis catheter. It had been feeling strange, pulling, got worse yesterday when I felt off, weak and light headed, something in my chest wasn't right. The nurse put pressure on it and it hurt, expelling

puss. (Gross.) She shook her head and turned and walked away from the curtained dialysis chair where I lay, feet up. Dr. Gagnon decided quickly that it needed to be sent to procedure asap and I had to put a stop to my day, make calls to John and Mad - 'they're keeping me here. I have an infection in my port. Can someone walk Fogo?'. John called Philip and he came to the hospital, was sitting in the chair outside the procedure room when they wheeled me out afterwards, after the procedure that was supposed to take a half hour, but took an hour and a half instead, probably because it was the radiology resident's first insertion, pushing and pulling, tight lipped and staring at the monitor depicting the vein in my neck and the fine dark line moving within it. He was not able to insert it. This was a learning moment for him. Shaky, quipping a 'no thanks, I'm fine' at the offer of assistance - a sudden juxtaposition occurred to me. This is probably an exciting challenge for this resident; something he has to master. He wants to be able to say he didn't ask for assistance. Of course, I want him to. I want him to be impeccable at inserting neck catheters into arteries. But six inches away, my experience is otherworldly. And I realize that it has to be. I have to be my own container. I feel my emotion separate and don't wish this doctor to see it.

I was so tired and feeble I couldn't hold back the tears and cried at the sight of Philip; at feeling pathetic and small, like a child...was momentarily back at sick kids and eleven years old, waking in pain and frightened, my breathing shallow; my parents in yellow icu gowns looking down at me. There were tears in his eyes too, which made me sadder. I hate being this person in my family's life.



Research on the psychological health of ESRD patients reports high levels of depression, feelings of loss and sadness, with some studies suggesting a level of roughly 30% of the ESRD population as being very depressed (Chen et al, 2010). Other reports range from 40% (Kimmel

et. al., 2000), to as high as 70% of this population struggling with depression. The actual statistical prevalence of depression, though likely high, among this population is unclear due to the symptomatic similarity between ESRD and depression. In addition, there is lack of agreement on an approach to assessing depression for diagnosis (Chilcot, Wellsted, De Silva-Gane & Farrington, 2008). The presence of depression has the potential to further influence health maintaining behaviours, affecting food and dietary adherence requirements, compliance regarding medication, proper maintenance of health procedures and general care management, including disclosure and reporting of illness change or other relevant symptoms (Chilcot et al., 2008). While debate continues regarding clearly diagnosing depression in this population, it is universally agreed that further inquiry is needed for a greater understanding of depression, anxiety and related psychology among people with ESRD (Chih-Ken et al., 2010; Chilcot et al., 2008; Cohen et al., 2002; Devins, 1981,1983, 1997; Ferru & Pruchno, 2009; Feroze et al., 2010; Franke et al., 2003; Griva et al., 2009; Grootenhuis et al., 2006; Grudex, 1995).

Charmaz (1997), Kleinman (1988, 1992), and Frank (1995) provide a deeper perspective of the QoL literature by discussing the impact of chronic illness on identity perception. They discuss the experience of chronic illness as a series of loss experiences, negatively influencing psychological well-being via repeated changes in physical health that affect identity, modifying and redefining one's place in the world and how to function interpersonally within it. Illness experience shapes human psychology, standing out in life recollections due to the often vivid experiences that it brings with it; medical procedures, hospitalization and the physical and acute experience of pain. The vivid nature of illness related memory causes such memory to sit at the forefront of development, overtaking other experience. Ultimately, it occupies a dominant portion of the lens through which one understands identity formation. Chronic illness, in this

instance ESRD and transplant loss, influences life narratives, informing and defining memory and self-perspective.

Applying the above concepts to the relationship between illness and identity formation, we can begin to understand how the chronic and pervasive nature of ESRD informs physical functioning and interpersonal presence. The recycling of symptoms as a result of ESRD accumulates and redefines the perception that the patient has of his or her 'life narrative', including planned goals and accomplishments, both personal and professional (Charmaz, 1997; Kleinman, 1992). Life plans are modified as chronic illness becomes more and more of a player, which has an impact on ability and energy and capacity for self-agency.

Although combining the above bodies of literature clearly assists in gaining greater understanding of ESRD patients psychologically, studies rarely include patient accounts of their experiences of the physical and psychological manifestations the disease (Richards, 2008). Nor do they consider the inherent presence of grief as part of individual lived experience; how chronic illness evolves in the body, affecting one's functioning and engagement with the world. ESRD patients' firsthand accounts contribute valuable and relevant understanding of the lived psychology of ESRD. A synthesis of what is known medically about the disease juxtaposed with how patients themselves live the embodied experience of it invites patients to become part of and strengthen existing ESRD research leading to more comprehensive treatment plans that are psychologically activating. But how to disseminate for accessibility beyond the field of medicine is the question.

Arts Based Analyses and Patient Perspective Inquiry

ABR emerged as a postmodern response that sought creativity in research investigation (Denzin & Lincoln, 2005; Hesse-Biber & Leavy, 2011; Leavy, 2009; McNiff, 2009). Leavy

calls ABR a new(ish) methodological stance within the qualitative paradigm (2009). It stems from a need for a different type of investigation that seeks an alternative stance to positivism. The positivist realm assumes an objectivist lens, or research that is based on an ‘arms length’ or ‘outside of’ perspective, that purports a clean and unbiased vision. ABR intentionally moves away from a belief in a positivist paradigm, where neutrality and purely objectivist ‘truth’ is seen as unattainable. Rather, it believes that all researchers are not only not neutral, but they cannot ever achieve neutrality, that all research is biased, rooted in the purview, culture and context of the researcher. Also, ABR roots itself within transparency and subjectivity as ways of acknowledging bias in research. Bias, instead, is engaged with and embraced. Transparency is acknowledged and provided with a role where it contributes to validity (Leavy, 2009; McNiff, 1998). This inquiry makes use of transparency and subjectivity in its depiction of lived experience of ESRD, kidney transplant loss and dialysis. The researcher makes honest use of bias and transparency in order to unearth the fragments of experience that make up illness experience.

McNiff (1998) describes the ABR process as ‘emergent’, where collection and dissemination almost co-occurs, with outcomes presenting over time in fits-and-starts. The method itself emerges by interacting with the phenomenon, in this case ESRD and dialysis. It seeks new forms of and lenses of discovery, the emergence of new and different voices, in this case the voice of the patient’s lived experience of disease, in research where process shapes content.

ABR is reliant on methods chosen and on researcher positioning as innovative and unique and distinctive. This study marries the researcher’s roles of counselling psychologist, Creative Arts Therapist and artist with her lived experience position of someone with ESRD. Ideas

emerge from this method, subsequently 'relaxing' within the process, allowing for incubation. McNiff (1998) guides us by stating that "[...] the method carries us. In this respect, the way of conducting research corresponds to the workings of the artistic process in which the use of media affects the final outcome" (p. 147). Theoretical engagement and relationship happens gradually via the evolving illness narrative from multiple voice perspectives. The environment, in this case the data coupled with the intentional considerations of grief and meaning, continuously act upon the researcher and shapes ideas and outcomes. Meaning and perceived meaning here is shaped by narratives that have emerged from relationships connected to the researcher.

Temporality, Disruption, Discomfort

Another element that connects ABR to patient perspective inquiry is its consideration that much knowledge is dynamic and subjective, even temporary, and it is comfortable with the concept that knowledge is iterative and evolving (Leavy, 2009). ABR's evolution is dependent on interruption and questioning. Leavy (2009) promotes debate around knowledge and its changing traits, stating that debate incites new knowledge. Some qualitative researchers perceive ABR as 'disruptive' to traditional qualitative research. This dynamic, this disruption of comfort, of familiar process, is not only encouraged in ABR, but is also deemed 'useful' and 'necessary' to discovery and the emergence of new and valuable discourse. Additionally, ABR embraces the subjective lens, transparency in research and discomfort. It acknowledges bias and the disruption of previous knowledge. All these facets are central to this grief inquiry, as grief narratives change and evolve and are different for all who experience grief; whether that grief is illness or bereavement.

Understanding the Lived Experience of End Stage Renal Disease Through an I-Perspective Empathetic Epistemology

Autoethnography saved my life. I make this statement to my friend in the midst of discussion on how I might formulate my latest essay assignment explaining why autoethnography is relevant to ESRD. Okay fine, at the risk of coming across as too dramatic, perhaps not saved my life. But saved my ‘academic life’, my ability to engage creatively and viscerally with my research. Without it, I as ‘academic’ would not have existed. We are discussing my work, we are venting about our disdain for positivist frameworks. I recall Spry’s (2001) words, describing autoethnography’s origins as emerging out of a ‘resistance’ to positivist studies. This alone draws me in. Further, Spry describes the positivist framework as a ‘façade’ that ‘decontextualizes subjects and searches for singular truth’ (2001, p. 701). Singular truth, I thought, how could that be even possible? How can the multi-layered, complex emotionally charged, individually different yet similar, lived experience of ESRD be reduced to one single truth? My answer: it can’t. Again, the methodological literature jumped into my head, that autoethnography works because it brings a kind of rootedness and coherence to the incoherence and confusion of illness experience (Ellis, 2009; Ellis et al., 2008; Ellis & Bochner, 2006; Denzin, 2006; Spry; 2001, 2011A).

I had adopted the I-perspective methodology of autoethnography in order to explore my ESRD diagnosis and current state of having lost my kidney transplant of nearly 23 years. My health had changed dramatically; my perception of myself had become sadly confused, at times incoherent. I was grappling at finding pride and meaning in my identity. I related to Charmaz’s (1997) discussions about the interrupted identity and the abandoning of a ‘preferred self’ in exchange for a modified version because of illness. I was in constant negotiations with dialysis,

a process that was slowly changing who I was and how I presented myself to the world. Dialysis, multiple treatment-site procedures, fluctuating blood chemistry; these were a never-ending arm wrestle and I was constantly the loser. These symptoms translated into my day-to-day life in the form of chronic lethargy, low blood pressure and lightheadedness, nausea, weight loss, muscle aching and a relatively constant state of vulnerability and loss (Frank, 1995, 2000; Kleinman, 1988). I know that I was grieving. I felt, as Richards (2008) put it, a feeling of ‘otherness’ from most people around me, and a constant state of difference and feeling helpless and frustrated because of it, as if a plate glass wall were separating us. My body’s ability to ‘do’, to function in ways that kept me part of the crowd, had failed.

I was not good at objective interpretation. I liked Denzin’s (1992) word, that autoethnography ‘privileges’ the researcher and method, over subject matter, resisting objectivism and engaging with the subjective experience. My need, rather, was to engage with ESRD as a disease in order to draw attention to the multiple ‘micro-experiences’ that were defining my life and hijacking my body; inability to walk any distance and the guilt it brought with it when my dog wanted a walk, the breathlessness following my dialysis treatments, the muscle aching and depleted focus from having my blood vacuumed out and pumped back in during my three and a half hour treatment. This exhaustion would often interrupt my day, keeping me from my research work, because I needed to sleep it off. It felt like, as my physician brother commented, I had been ‘hit by a mac truck’. ‘It’s a sort of violence. It’s really hard on your body’, he stated. There was a need to translate this lived experience into scholarship.

Autoethnography presented me with a lived-experience model that began to shed light on what was happening. It seemed not only theoretically relevant to ESRD, due to the implicit connections it drew to loss and grief in illness (Charmaz, 1997; Devins et al., 1991; Ellis, 2008;

Ellis et al., 2011; Frank, 1995; Spry, 2001), it seemed to me to be also medically relevant to patient experience, due to its deep exploration of the embodied experience of illness and its associated symptomology. There was an opportunity to translate the didactic medicalized version of ESRD into a living and breathing entity.

This lived experience model focuses largely on the visceral and detailed nature of illness, loss and life transition (Ellis, 2009; Ellis et al., 2008; Ellis & Bochner, 2006, 1996). It makes use of thick and rich description and persuasive logic; what I like to refer to as ‘objectivity within subjectivity’. It facilitates learning about lived, often unquantifiable, human experiences (Ellis, 1991, 2004, 2005). My work, this work, immediately became an illness autoethnography that delved into the uniquely narrated experience of ESRD. Before this, I had included myself in the group of people with ‘chronic illness’. The literature on illness describes this group as a single unit (Charmaz, 1997; Frank, 1995, 2000; Kleinman, 1988, 1992) even though every experience of chronic illness, each disease, is individually different (Richards, 2008). I needed to engage creatively with my unique experience, create an aesthetic representation of ESRD. I needed to access healing through engaging with detailed description (Ellis and Bochner, 1999; Frank, 2000). I needed to engage with the unique and ‘fragmented’ narratives of my disease (Richards, 2008; Spry, 2006), narratives which seemed to have no place in my nephrology appointments that focused on my blood results and whether my treatment site was working, quantifying my disease and categorizing my body accordingly (Richards, 2008). Nor was there a place for illness as narrative in my review of literature describing the QoL of renal patients, that describes how dialysis patients are highly prone to depression and suicidal thinking (Chen et al., 2010; Chih-Ken et al., 2010; Chilcot et al., 2008; Cohen et al., 2002; Devins, 1981, 1983, 1997; Ferru & Pruchno, 2009; Feroze et al., 2010; Franke et al., 2003; Griva et al., 2009; Grootenhuis et al.,

2006; Grudex, 1995), yet fails to describe how this fact is rooted in a multitude of micro experiences that interrupt my clumsy attempt at maintaining a normal life. My illness was depleting me in more ways than my physiology. Because of this depletion, I was falling away from finding pleasure in my daily living, my relationships, lovely moments like watching thunderstorms and blossoming magnolia trees in the spring (Watnick, 2007). I needed to rediscover, perhaps reconstruct, meaningfulness (Neimeyer, 2000), and where and how it existed within this ESRD experience. I needed to engage, from a lived experience perspective, with Bochner's (1997) concept of 'epiphany', the 'dropping in' of acute and individual understanding of my illness and to extrapolate from it. Somehow, this element of meaningfulness to me was connected to this research being meaningful to and for others.

Autoethnography, as described by Ellis contains within it healing elements (Ellis, 2004, 2005, 2008), rendering scholarship through the subjectivity of a simmering vulnerability. Healing for me was triggered when I presented my work to a roomful of people such as friends, my doctoral committee, my students, my colleagues and, perhaps most importantly, my family. This cross-section of relationships uniquely represented simultaneously the multiple roles I play in my life, similar again to Charmaz's (1997) discourse on identity, Landy's (1986) on role: sister, friend, teacher, daughter, researcher and student. This witnessing ignited a reciprocity where individuals fed back how my narratives, the fragments (Spry, 2001) of my lived experience of ESRD offered some coherence. These fragments were recognizable to their own living, their own illnesses, their work and their experience of illness in others. This witnessing also introduced new information, new dynamics to my intimate relationships with my friends and family. New information surfaced for them, shedding light, not only on who I was and how ESRD had shaped me as a person, but also on what ESRD is as a disease. My physician brother

has shared with me many times since how autoethnography has triggered pieces of information that inform his role as a doctor and his relationship with his patients. This methodology allowed this group to bear witness to this story, validate and generalize it according to their personal absorption of its truth. At some point along the way, my 'I' experience as researcher, as individual with ESRD, transformed into a 'we' experience for those taking it in. The lived individual narrative became a universally accessed understanding of illness in a framed moment (Ellis, 2008, 2009; Spry, 2006). My experiences, as author, were critically being made known so as to be understood by a broader population (Denzin, 2006, 2007).

Conclusion

Spry's (2001) evaluative standards for autoethnography seek to bring rigour and depth to this highly reflective form of research, and include elements such as 'rich description', the 'translation of theory' into 'embodied experience' and vice versa, creating an intentional 'collision of experience' between didactic theory and how life is lived and reflective in a way that "critically reflects on the subjective self" (p. 713). Autoethnography and performance autoethnography must also be aesthetically accessible via emotional engagement, because aesthetic is a tool that universalizes experience, making it plausible for the observer. These qualities fit with my desire to engage with this disease in a way that sheds light on ESRD not only for me, but for others as well. Spry's description of the body's role in research as the "[...] site from which the story is generated, thus beginning the methodological praxis of reintegrating body and mind into scholarship" (p. 705) strikes me. These words describe the intense relationship that exists between body and knowledge discovery. They are at the heart of this inquiry whereby the externalizing of my personal and painful experience of illness might be transformed into knowledge that helps others and me

Chapter 6

Arts Based Research Outcomes:

Autoethnographic Narratives About End Stage Renal Disease

Introduction

Neimeyer's Meaning Reconstruction Model (2000, 2010) is a grief construct that states that grief healing occurs via an active choice-forming externalizing of the narrative of grief whereby new understandings, perceptions and meanings are constructed out of the loss experience, thereby contributing to an assimilation of the loss in the case of anticipated loss or an accommodation of the loss in the case of complex loss (Neimeyer, 2007). These refer primarily to grief as it relates to bereavement. Meaning Making facilitates the shifting of the sense and understanding that is applied to a given experience. It is either assimilated, in the case of anticipated loss, or accommodated when loss is complex. I felt my loss was ever evolving and complex. I could accommodate this illness, but would not likely be able to assimilate it.

Previous models perceive grief to be a passive process, void of choice (Bowlby, 1980; Kubler-Ross, 1969). Neimeyer (2007) stipulates that stage-based models are limiting to the human condition because they do not take into account the social factors inherent in grief processing. I related to this, recalling how the people in my life frequently witnessed my struggling, the necessity that I felt to share. This necessity was due to the sheer darkness within me brought on by repeated illness and medical procedure. It was a darkness that perceived the value of my life as little more than hopeless and helpless, empty of interested engagement with daily activity such as cooking a meal or walking in the woods. The externalizing of the grief allowed for the meaning this darkness held to be redefined. Narrative themes vary in grief, are complex and require external processing. These factors are also tied to cultural and family belief

systems that affect and inform meaning making. The 'I', lived-experience, element allowed me to engage with the narrative of my illness related grief and permitted me to be more transparent when discussing it with the people in my life. By framing it in terms of research, a certain distance and objectivity formed, inviting a furthering of the narrative that became applicable outside of me.

Kleinman (1988, 1992), Charmaz (1997), Sontag (1979), Frank (1995) and Richards (2008) all present the notion that identity formation is affected by the experiences of illness. Re-experiencing, frequent repetition of health-loss is associated with depleted outlook, depressive symptoms, social isolation, reshaping of identity and perceptions of self, such as experiences of 'otherness' via identity changing experiences relating to illness (Richards, 2008). Illness interrupts notions of identity, prodding over time towards an inevitable redefining of our individual perceptions and ideas of identity and life goals (Charmaz, 1997). Another concept explored at length in illness literature is the notion of pain experience. Pain, another interrupter of identity, existed for me on a number of levels including, for example, the immediate experience of pain, via medical procedure. Chronic experiences of pain contribute to the body's narrative of lived experience, shaping the emergence of vulnerability, which in turn shapes one's social performance and the shame or separateness one experiences (Kleinman, 1992). Included in this is the passive pain of light-headedness and nausea associated with low blood pressure, or the muscle pain that acutely occurs during dialysis treatments when muscles spasm in reaction to the removal of fluid and the generalized aching and headache that impacts functioning following a treatment. Pain, for me, was isolating and furthered my exhaustion, limiting my patience for those around me. A limited patience that may have been due to grieving health and movement and energy that others possessed, but I didn't.

To me, the psychological literature of illness and identity formation sounded a lot like meaning reconstruction, though presented more passively on the part of the individual experiencing illness. Otherness, described by Richards (2008), was something that ‘happened’ to her during her own experience of ESRD and transplantation. Identity modification, the abandoning of the preferred person, described by Charmaz (1997), is also potentially a passive experience. Illness stands out in our life recollections because it often presents us with vivid experiences, not unlike experiences of trauma, ultimately integrating into development, personality, life choices and relationships (Frank, 1995). Life narratives experience ‘interruption’ by illness sub-stories. Procedures, comorbid conditions, medical crises that evolve and arise from chronic illness and pain experience all form these sub stories (Charmaz, 1997; Frank, 1995; Kleinman, 1988). When combined with meaning reconstruction, however, I wonder if new reconstructed perspectives of otherness and identity can be built by engaging with the illness narrative.

In discussing meaning reconstructing in grief, it seems also relevant to consider the importance of cultural and individual family systems in how grief is understood and processed (Fiorini et al., 2006; Lister et al., 2008; Maciejewski et al., 2007; Somary et al., 1991; Stroebe & Schute, 1999; Whiting & James, 2006). There is a need to familiarize with a sub culture of a group or family when assessing their grief experiences. Behaviour is linked to loss and how loss is processed, no matter how the loss occurred. This research draws parallels to illness-related loss and the systemic factors that interplay within the patients’ social system. It additionally has a place in how meaning reconstruction is shaped according to individual life maps and cultural identities.

Other theories are also rooted in the notion of meaning. The dual process model seeks to integrate what already exists in the field of grief psychology (Stroebe & Schute, 1999) towards an understanding and integration of loss. The Apperception Theory (Watson, 2004), similar to the Meaning Reconstruction Model, focuses on a need to make sense of loss. It describes the loss experience as complex and requiring effort to contend with, affecting self-esteem, self-image, identity and relationships. By adding meaning reconstruction to my illness narrative, there emerged a strange richness within my suffering that I knew, from somewhere deep inside me. Spry (2011) describes this experience as a necessary part of autoethnographic investigation. The engagement with the emotional pain of illness is difficult, yet the externalizing of it through the containment of autoethnography can be enhancing, even healing (Ellis, 1991, 2004). It had a place in my work and contained something important within it that would inform not only how the medical world cared for ESRD patients, but also how ESRD patients might care for themselves.

Some of my exploration of grief was dedicated to the questioning of stage theories. I certainly had experienced elements of what stage theories presented. I had experienced phases of anger, that was for sure (Kubler Ross, 1969). I had yearned for my past life, my childhood, times of physical health (Bowlby, 1980). It seemed to me that, though all psychological states of stage theories are certainly experienced, that my grief as a psychological process, was an active, interpersonal and fluid process (Kubler-Ross, 1970, Lister et al., 2008; Attig, 1991; Neimeyer et al., 2007; Neimeyer, 2000, 2002, 2010). My intentional engagement with my illness-related grief, allowed for the consideration of self-driven components, such as choice of how I was going to discuss and analyze my thoughts, and with whom. Neimeyer (2000, 2002, 2010) notes that an expanded conception of meaning in relationship to grief and loss is necessary in order to

process grief well. He developed the Meaning Reconstruction Model as one that is inherent to humans as meaning-makers who invariably “give thematic significance to the plot structures of their lives” (Neimeyer, p. 28, 2010). Timing of grief processing will differ according to the individual, type of loss, nature of the loss and culture of the individual (family and ethnic). This inherent feature is the sense making need that I ultimately experienced in the grief I had in relation to my ESRD diagnosis, the loss of ‘Felicia’ and the life maintaining necessity of dialysis treatments. The emergence of the subsequent narrative that was associated with my loss was and is unique to me, my life, and my relationships (Neimeyer, 2000). By externalizing the narrative, its uniqueness waned, becoming less of a ‘me’ context, and more of a sharable and accessible ‘we’ one.

This chapter consists of narratives that have been developed with in-depth reference to interviews and focus groups that investigated End Stage Renal Disease and kidney transplant loss as a grief experience, where perceived meaning of one's life becomes depleted due to illness. I conducted nine interviews in all. Three of these were with family relationships, three were with close social or friend relationships who know my illness experience well, three were with patients from a dialysis unit that I’ve attended and who have experienced the loss of a kidney transplant subsequent hemodialysis treatments. Lastly, I also conducted one patient focus group that explored kidney transplant loss and being a dialysis patient from a meaning-driven grief perspective.

Making use of these meaning-driven processes, three predominant areas of meaning-emergence became apparent. Meaning for me, surfaced out of an intentional objectifying of my own lived experience of ESRD. Using Leavy's (2009) three components of meaning emergence in narrative methodologies as a guide, analyses involved working with interview and focus group

data via seeking a clearer coherence of my understanding of my illness narrative from an I-perspective lens. This was accessed via engaging with this illness narrative as not just mine, but as a narrative that has also informed and defined my family, my mother, my siblings as well as my friend relationships. Part of this coherence is the reminder that illness infiltrates not just the individual who carries the diagnosis, but also marks those that surround her. A second shifting of meaning occurred through identifying turning points within my narrative where new or different explanations of illness surfaced in friendship, family development and parental relationship. Lastly, illness narrative consists of new plots, or re-plottings, that influence perceived meaning, such as the presence of immunosuppressive treatment like prednisone and its subsequent influence on development, self esteem, sibling perception and comorbid conditions like avascular necrosis of the joints (Watnick, 2007).

This chapter relays the lived, day-to-day, experience of ESRD and dialysis. It illustrates how meaning is informed by daily presence of illness. Secondly, it outlines how meaning emerges via the consideration of multiple mini narratives, or as Spry (2006) describes them, 'fragments' of lived reality, often gone unnoticed unless intentionally acknowledged. These 'fragmented' narratives take center stage in this investigation, accumulating towards a broader, inclusive, representation of the lived experience of this disease. Lastly, I consider Neimeyer's concept of accommodation (2000, 2002, 2010) as part of complex grief. Complex illness is presented as akin to complex grief, and therefore not likely something that can be assimilated into daily living, but rather something that requires revisiting, reframing and accommodation. The following 3 thematic groups that emerged from the data will be explored in narrative form in this chapter:

1. The Lived Experience of End Stage Renal Disease;

2. Where Meaning Emerges within the End Stage Renal Disease Experience;
3. Reframing, Accommodation and End Stage Renal Disease.

Each of the individual narratives is preceded by quotes from the data and the literature that act as jumping-off points for the narrative that follows.

Theme 1: The Lived Experience of End Stage Renal Disease

The first five narratives presented in this thematic group (see below) describe my lived experience of ESRD. The beginnings of my autoethnographic explorations consisted of making use of this methodology in order to assist myself in understanding my embodied experiences of this disease, in building a 'coherence' for myself. Some of the sub themes presented here were about the embodiment of procedure and negotiating the medical elements of disease, such as in the narrative Broken English, depicting an invasive procedure necessary for dialysis maintenance, experienced by all dialysis patients at one time or another, often repeatedly.

Other themes involve the impact of diagnosis and medication on those around me, as is explored in the narrative Prednisone, written in reaction to data that came from interviewing two of my siblings. The final two narratives, Royal Vic and Killaloe, present themes of social and day-to-day logistics of illness; hospital visits and notions of limited freedom. These were written in reaction to data that came from friends and other dialysis patients.

Broken English

Oh my god, that's right. I'll never forget that morning on Hamilton Avenue. When you had a seizure. I guess that was when you were rejecting your first kidney. It must have been. I think so. I think those series of seizures ended in that kidney going. And I remember saying, 'we have to get an ambulance,' and dad saying 'no no we'll drive her'. And me arguing with him saying, 'no, get an ambulance!'. I actually can't remember if we did get an ambulance or not. It

was the morning. Yeah, we were on our way to school. Yeah. Yeah, I think you were in your school clothes. And we ended up at the hospital instead. I guess I was in university at the time. I must have been. And we went with you to the hospital instead. I can't remember if we took an ambulance or not... (Sister interview)



My site stopped working a lot of times. But you know what you're going to have to go through. You go in to get it de-clotted [if they can], to get it working again. For however long. Then it'll work again for a while, then you['ll] have to go back in... Yeah, it can be very frustrating. (Patient interview)



...Pressure, pushing the line down my chest. I exhale audibly to help myself through the painful sensation. Strength, I think.

De prezzure it will be uncomfortable for this minute. Broken English. Paged in on a Saturday. Was at his son's ball game...something like that, or a family event of some kind, I overheard him tell the assistant something like that, chit chatting as she tied the back neck of his sterile green gown while I waited ten feet away staring at the broken tiles in the ceiling.

We don't administer pain medication with procedures like this one.

How is it building who I am...the needle in my neck. Again. For the fourth, fifth? Fifth time this year, I think. You have to give me your cooperation, he said in his broken English. English wasn't his first language, I could tell, but didn't give him that, wasn't flexible, did not practice tolerance.

Aren't I being cooperative, do I have a choice *but* to be?, I said, stiff, in a tense tone, angry, shaky, my face forced to the left, the pad of his left hand gently pressing against my temple, positioning my head so that I would not turn it or move abruptly, to give access to the

vein in my neck, unable to see much beyond the sterile towels caped around my brow and chest with, so in an effort to distract myself chose a spot to stare at; the oxygen tap on the wall, something else next to it, I don't know what that thing's for...

Aren't I being cooperative? I said, offended.

Oh yes, yes...dat iz not what I was meaning...I mean not that...he stumbled, stammered. I knew that he wasn't being bossy, or personal, improper. I know that, quipped this snarky remark nonetheless, needed to be angry at that moment. I needed to be rude at that moment, I thought to myself, staring at the yellow cabinets in my eyes' view, with print-out labels, black letters announcing their contents...priority!, 15 gauge hickman port, temporary catheter, permanent access, sterile gauze, 2x2, 4x4, sterile drapes...18 gauge needle...in my neck.

Tell me if you feel somet'ing strange of your heart, he said. Tell me az zoon az if you feel strange in your heart. You tell me.

Strange in my heart? What do you mean 'strange in my heart'?

Oh, yes...there it is. My heart. Something just touched it. Slid next to it. Interrupted it. A popping feeling...something's just touched my heart.

I feel it, I said...extra beats. Hard to fill my lungs, can't breathe. Should I be having difficulty breathing? I ask, trying to be patient...

J'ou cannot breathe? He asked, uncertainty in his tone...no...j'ou be breathing now?

Ok. Maybe I'm just panicking, I say. Maybe panicking...

Oh, I feel it again, I say. My heart popping. Bouncing. Skipping beats.

And again...

Again. I just felt it ag...

And again. What's happening to my heart?

And again. There it is again. I felt it again.

I wonder. A quick flashing thought. Will this procedure damage my heart? Will it stop it? Maybe these yellow doors, these yellow laminate hospital cabinets in this procedure room at 2pm on a Saturday in March...maybe this will be the last thing I see...I thought, one of many crazy thoughts that flew through my head. A quick zip of a thought, along with others. My nephew Felix's tangled blond curls, his dirty nose, his odd socks and plaid pants, the dead shrew my cat left at the bottom of the steps at our cottage last summer, the slush underfoot at the summit trail on Friday when I went for a walk with my dog, the scallops in my pasta at supper that same night, my telephone chat with Terry, chocolate, the coffee crisp bars on the shelf at the dollarama, the half dozen oranges on my kitchen table bought on special as Esposito during last week's rain storm, my dog asleep on his blue checked dog bed in my brother's living room, a half chewed rawhide bone nearby...many images, many thoughts snapped through my mind, including whether or not the popping sensation in my heart that made this doctor nervous, including whether this popping was something big. Bigger than me.

Prednisone

But I, I remember Mom saying to me, 'don't say anything to her. It'll hurt her feelings,'. I was so shocked. I guess I was so shocked. I must have said something like, 'you look so different', or something like that. And mom shutting me up, you know, 'Mary!'. And of course it would have hurt your feelings... I remember you coming up to me and saying, 'hi Mary'. So sweet. And honestly, I didn't know who you were until you spoke to me [because of the prednisone]. (Sister interview)



“ESRD patients experience multiple losses, both tangible and symbolic; for example, loss of physical strengths, freedom, employment, and social life, resulting in grief throughout the course of ESRD and dialysis” (Chan, Erlich, Chow & Suranyi, 2009, p.2).



Well, we can't be sure. Everyone is different. My transplant doctor is informing me of the likelihood of my having to take steroids, in the event of a transplant... which is unlikely at the moment due to my high antibody levels.

But we must still be prepared, she quips. I've told her, clearly and concisely, possibly even rudely, that I don't wish to take steroids... in the 'unlikely' event that I'll even have to consider it, I add. That I've heard there's a large group of immunosuppressive treatments that are possible these days, unlike when I was a child and prednisone was the best option.

I want to hear about these new meds, I say, I've heard they're just as good or better. They have their own set of side effects, I assume to myself. Nothing comes without a trade in this world of tricking the body into not rejecting a transplant.

Prednisone. A trigger of gross sadness flies through me at the mention of its presence in my life, in who I've become even, what I look like, how I move... in some ways, because of it, what's it's done to me, my shape, my face, my skeleton. This has always been the case for me, ever since my first transplant at Toronto's Hospital for Sick Children when I was six and a half. Prednisone, I learned alongside my parents, from the Toronto-based transplant team, has hundreds of side effects, some of which would affect me, some not. I could experience a change in appearance. My face might balloon out, become puffy, a 'moon face' was the happy term my doctor used; a face like a full moon. Prednisone restricts calcium absorption, causing bones and joints to soften in response. Prednisone causes 'prednisone rages' or random feelings of violent

anger, something that when I consider it now, I think, yeah, of course. It definitely pissed me off. It raises cholesterol, it increases susceptibility to different kinds of cancer, to warts, to the shakes and to nightmares, it causes giggle-fits and deep sadnesses minutes apart, it causes excess hair growth, softened finger nails and yellowed teeth ...but it keeps a kidney working. That's what matters, my transplant nephrologists would chime when I'd request a reduction to my dosage.

What really matters is your kidney. We don't want to play around with that. Do we? No, I guess not.

Prednisone softened my bones, caused me three years of pain between 12 and 15. We can't really do anything right now, my doctor would drone. The words frustrated me and I resisted them. I'd have pain. A pain that infiltrated my identity, a pain that filled my dreams, dreams that permitted painless joy, the ability to run timeless distances or permit flight over my home where I'd spot the head-tops of friends and my parents in the garden, going about their lives while I watched from the sky above. Painless flight without wings, where I could uplift myself via thought alone. No wings necessary.

Prior to that first kidney transplant, I'd been a slight, thin, imp of a child. I'd fit easily in groups of same-aged children. I didn't stand out or look different. I'd been like everybody else. I was normal. Prior to that surgery, my siblings knew me as that small gangly, dark-haired kid. The one who got underfoot when their teenage friends came over, who bugged for attention, followed them around the house and sat quietly in the corner, just to be around them. The very kid whose potential I wonder about now, years later, were it not for...

After the transplant surgery though, when my appearance was so different that they didn't even know who I was when I stepped off the air plane. Excited to be home, my seven-year old mind couldn't wait to see my sister, whom I adored. Their expectations of greeting me upon my

return at the airport where shattered, instead not recognizing my seven year old newly transplanted face and body. Someone they didn't know, could not find in a crowd. I didn't know who you were, they tell me now years later in response to my questions about illness in our family, now that my transplant's are over and gone. Now that my appearance has morphed yet again, I've lost a fair amount of weight. My face no longer that of a person on steroids, though I had grown so used to it I don't see the difference and rely instead on others' perspectives, my brother and sister. I didn't know you, I kept looking for you in the airport and mom said, ssh ssh, don't say anything, don't let her know you're surprised, don't let her know you're shocked. I was shocked, my sister said as she described her first sight of me. You came to me, she described. You knew. You came to me, 'hi Mary'. So sweet, so little, standing at my feet in the airport when you came home. I was lost and confused, but you seemed to understand that.

Hi Mary. It's me. It's Leah. I bit my tongue and fought the tears of shock that were whirring in my gut, she said. What had they done to you? What had they done to my little sister?

Royal Vic

"In particular, a good deal of evidence supports the view that the ability to find meaning in experiences of loss predicts positive adaptation, whereas a persistent and unsuccessful struggle for meaning is associated with intense, chronic and complicated forms of grief" (Neimeyer, 2005, p.28).



Yeah, and the first day that I went into the dialysis unit with you. That was...it just hit home, you know? 'Cause you'd described it. And I was like, oh yeah it must be bad. Then I went in and it was like, ugh. Seriously? It was like a warehouse. Housing 'hooked up' people. Yeah. Like a movie. (Friend interview)



Let me sleep in the arms... of my beautiful one. My friend Sean's words ring through my iPhone earbuds. Sitting in a narrow hospital hallway, with music in my ears, in an attempt to bring on patience with tolerance, the familiar sensation of an oversized gown around my shoulders. This morning was long, it was mundane, it was a morning like many. I'm revisiting an arms length list of tests in order to make my way back on the transplant list, known now as the 't-list' in text messages to my friends. My status that allowed me to have a transplant had been suspended due to a systemic infection. A year and traumatic surgery later that interrupted my thesis work for weeks, I'm here again and my name will be back on the list by next week. I feel as if I've been in this room many times before. I feel ambivalent and unresponsive to being back on the list. I feel it's good to feel this way. I stare at the wall and count the dirt spots in front of me.

An EKG, a chest X-ray, an abdominal ultrasound, the by-route 'no there's no chance that I'm pregnant' statement before the question's even presented. Ah, you've been here before. A smiling technician retorts. Yes, once or twice I think.

Yes, I've been here many times before. The Royal Victoria Hospital, or the 'Vic' as its known in Montreal patient circles, is located on top of a hill, which is itself on top of a hill, then up a set of stairs and along a walkway. To reach the main entrance. To get to the transplant clinic, I take the elevator, located at the end of a LONG hallway, to the 8 th floor of the main pavilion, then walk a quarter of a mile along a rounded unending hallway, dodging floor polishing machines and jogging residents in scrubs and sneakers, to the Ross pavilion. Then take the second set of elevators up two more floors, walk through three corridors to another set of elevators, which will deliver me to my final destination a floor away. Today, thanks goodness, I only had to go to radiology, conveniently located neatly on the 4th floor of the main pavilion.

Any stress associated with a medical appointment, I realize, is connected to where it's located in this hospital, which I've nicknamed Hogwarts, the convoluted mystical castle from the Harry Potter novels, where stairs appear and disappear or turn upside down and doors to rooms are invisible, appearing only with the uttering of special magical words.

A heart test, abdominal ultrasound chest X-ray later, I make my way back to the car, through redirected roadwork traffic, sending most unsuspecting hospital-goers back downtown twice before they clumsily realize that parking is only available on that hill twenty minutes away. That's where I parked today.

Oh my, I think, as I spy an older woman shuffling down Ave des Pins, probably close to eighty, though she could be younger. She's using a cane and moving about a tenth of the speed I am. She stops and gazes up the hill towards her destination, exhales, and continues. Where has she come from? Where is she going? How on earth will she get there? My own anxiety returns as I recall three hours earlier and sitting outside a friend's apartment. We had planned for her to drop me off and take my car this morning. I quickly realized she'd forgotten after a call and two texts, shit I'm going to have to take on the Vic by myself today, I thought to myself. A foreboding feeling of anxiety infiltrated my body, started in the middle of my gut and moved into my throat, cancelling out the hunger I'd been feeling.

The hospital that houses one of the best transplant programs in the country feels simultaneously impossible to access if you're a patient, a child a senior with mobility problems, a senior without mobility problems, require assistance of any kind, have to rest to catch your breath, are in an emergency, can't read, are in a wheelchair, feel weak, have little money, have no one to bring you, want to visit someone in hospital, are using a cane or crutches...

I don't fall into any of these categories today. Today, I'm visiting this hospital for the twelfth time this year. It's a routine visit. It's one that is necessary, because without it I'll not be eligible for the transplant list. Yes, it's routine. But it's important. You have to have these tests done by the 15th of the month, the transplant coordinator informed me on my cell three days ago. That was the 9th. Today's the twelfth. If you don't get them done, you'll not be included in the database this time. So do your best, okay?

This is Depression

"[...]instead, the intimate details of people's stories of loss suggest a complex process of adaptation to a changed reality, a process that is at the same time immensely personal, intricately relational and inevitably cultural" (Neimeyer, 1999).



... if there's a tension between us... especially last year. There's times when I've had to go, like, okay is this a friendship thing or is this an impact of the disease thing?... like, I think for a while there... it was starting to get really hard [for me]. Because... that anger that you had? Sometimes I absorb what people are putting out... so for me in that place I was like, okay she needs to be angry. I'm here. That's what I can do right now... but then, of course, you can only do that for so long... [before backing away]... generally it's not the physical stuff that I worry about. I worry about your soul. That's where my hurt for you comes from. (Friend interview)



This is what darkness looks like, what the depression statistics in the literature feels like in a moment of lived experience. It's a place that we don't speak much about outside of numbers representing people who go through it, because we're afraid of what it means, or the sheer size of it. And let's face it; depression is hard to diagnose when dialysis taps your energy and motivation and depletes your hemoglobin levels, affecting oxygen in the blood.

It's a place that's frightening to hear about for loved ones, one that incites an urgent feeling in the gut and rushing to a phone for lack of anything else to do. It's also a feeling that co exists silently, when there's enough energy and recognition nearby for appreciation for people, oddly with positiveness, for working at being noticeable and not burdensome to those around me. Sometimes that energy gets used up and a different kind of truth takes its place.

This darkness, this darkness is rooted in a feeling of being trapped, by illness, by the dialysis machine in my room, by the inability to get even the tiniest of tasks done; washing the floor, making myself a nutritious meal, calling a friend to talk, maintaining the conversation itself, walking through the park. I feel trapped inside a place that is limited in terms of how far I can go; standing on the edge of a cliff while others fly off to Europe and Mexico and Cuba. Only so far, and then my leash, my bunji, pulls me back again; to this machine. This place is about feeling angry and resentful, resisting spending time with others who have, what seems like, it all. This is a darkness that chips a distance between family who are well and active, and those who are not. This place is a place of resentment, disliking children because they have full lives ahead of them, resenting mothers who are nurturers and are present for their toddlers who trip and fall while they learn to walk. This is a place where memories of childhood - of pure joy, swimming pools and play, family walks in the woods, grandmothers and spontaneous laughter from the gut void of hesitation - sit stagnant as something that is over and will never return. This is a place where the worried voice of my mom on the phone is becoming too common, where I can't find a happy medium between white-lying my way through emotional turmoil to help her, or to be transparent about this helplessness in the hopes of emptying my heart and feeling better as a result.

This place is a place of wondering if I should stop dialysis. Not now. Not today. But in time - years away. If I should write down these wishes. If I should walk away, knowing that another transplant is unlikely and that an existence of being connected to a machine in order to stay this much alive is not how I want to live. I want to live the way I've lived before, with energy in my veins and plans and goals in my thoughts. With a vision on the horizon of what's to come, with the ability to sit contentedly in a moment and love it for what it is. I've had that ability, honed it clearly, sat in a moment of an early morning walk, the excited sight of a bright red cardinal in a city park, the taste of strong hot coffee beside a kitchen window. These were moments I could at one time engage with. Right now, though... right now, the spring awakens around me and I'm not present. My dog waits by the door and I can't bring myself together to take him out.

I woke last night, in the empty space of this apartment, the dialysis machine's whirring a constant white noise inches away, alarming every few minutes when I moved my arm, causing me to think that perhaps my access needs to be reassessed. Having begun the treatment early, to get it over with - I hadn't considered how much thinking time I'd forced upon myself. Fell into a deep dark space where nothing seemed possible, do-able or relevant. Where concrete goals seem meaningless, where I no longer care about finishing this phd even though I'm so close, yet am still full of anxiety over it. Where the thought of my parents dying, my dog no longer being asleep at the foot of my bed, events that aren't that too far away, events that might be too big, too much to push through. Events that seem, somehow, huge and insurmountable markers in my life. An urgent need for escape yet encountering blocks at every option; can't travel, can't visit Killaloe because dialysis can't be planned, can't visit Newfoundland because the dialysis unit is too full, can't leave this apartment because it holds my machine. Can't. Go. Anywhere.

I'm tangibly aware of how difficult this energy is for others to take in, to understand, to tolerate. I can almost feel their sense of helplessness, of not knowing what to do. Instead, attempts at helping come in the forms of nail painting outings and Sunday brunches. There are times when such events help, for a moment. There are times, however, when events like these feed my anger, my sadness, my ever-present boredom. Conversation is a burden, painting nails is stupid and time-wasting.

Right now, twelve hours later. My treatment is over and I'm sitting at my computer - the radio playing nearby. It's a sunny, early spring, warm day. It's a kind of day where, in another's world, would be full of anticipation and energy, excitement at the prospect of summer. I've felt that before. But not today. Today, I grocery-list my thinking. I'm feeling listless because my machine backed up as I was taking myself off this morning. My machine stopped and, even though I tried to manually push saline through tubing containing 300ml of my blood back into my body, I couldn't manage. Using all my might, hurting in my arms... it took so much energy I didn't have, it became emotional. So I feel half alive today. I remind myself that my hemoglobin is likely in my boots, along with my blood pressure. Too low to look at, a nurse in Newfoundland once joked. That's one on my list. Number two is that I'm in a large apartment, all by myself. I'm by myself, not that I feel like talking. But someone reading in a nearby room makes a difference somehow. Being alone pushes me into an existential place of feeling alone in a big, drop-in-a-bucket way, like I've not succeeded in life, like I've made bad choices, that the choices I've made have been about proving myself as a functional and smart human being. These are the things that can grey the darkness, can introduce a little night-light in the corner.

Killaloe

Freedom is what I struggle with. The lack of freedom. My friends go off on vacations together, all-inclusives or whatever...it feels like their lives are fuller than mine and I don't know what to do about that sometimes (Patient interview)



“End-stage renal disease (ESRD) imposes additional constraints due to the vital need for regular sessions of renal dialysis. On these grounds...ESRD have been defined as provoking a state of prolonged distress (limiting freedom)” (Kaltsouda et al., 2011).



This stay in Killaloe is different. This stay will be for 8 days. Not the two-day speedy overnights like before. Before I'd 'fit in' the trip and feel the sadness of a premature departure, knowing that I had to get home for dialysis, that the drive back into the city punctuated by a treatment setup as soon as I stepped into my apartment. With Kathy's efforts and a little self-motivating on my part, we've arranged for dialysis in Renfrew, the Ontario county two hours west of Ottawa. A gorgeous drive through farm land and a welcomed escape from Montreal's humidity this time of year - something that, as an east-coaster, I can't quite adapt to. The young nurses at the small unit in Renfrew seemed fascinated by a patient my age and functioning level, barely believing my knowledge of the machine and of treatment protocol because of my nocturnal dialysis training. My age; younger than most patients here, is welcomed by them I think. As they chat with me, I'm reminded that my functioning is better than most and feel proud of that fact. This thought hit me when my eyes locked with a decrepit young patient's cane-ing his way out of the unit after his treatment, pasty and pale, like so many dialysis patients I've met and known – a familiar sight, yet I never get used to it. His age is what hit me though; probably close to mine, or younger, yellowy skin and permanent sad expression... I almost

commented, but quickly realized that my guest-status here might make such a comment unwelcome, presumptuous, rude even. I kept it to myself, reminded that, even with my grocery-list of invasive medical experiences, this disease is not visible on me these days like it is on him, aside from my mother's commenting on my own pallor at times when my anemia worsens. I don't have yellow skin that puffs around my eyes making them appear as slits and hardly useful, calling attention to sickness – even if the diagnosis itself is invisible. I pull myself up after a treatment and walk away usually with a hurried step, wanting to get away I guess, reserving a collapse for home. I don't want it to be visible on me, I want to appear that I'm doing just fine, getting work done, enjoying sunny days. This is part of my engaging with normalcy, and I'm aware of it. His departure was different though. He shuffled slowly towards the door, head hanging and expressionless. The nurses called familiar, almost-loving goodbyes, possibly in an effort to support his departure, help him with his movement. I don't know. I wonder for a moment, if during my times of extreme hypotension, reduced appetite and low hemoglobin are as visible on me?

Unlike my previous in-unit treatments, this one is an hour away, interrupting the momentum of our work and time together, in order to travel the 50 (actually more like an hour and fifteen minutes) minutes to go for my treatment. Andy happily announced that 'we'd use the time for work...or not'. He wanted my dialysis to be nothing more than a pit stop. I know I don't work well on dialysis – I know this but keep it to myself as best I can, though it doesn't take a neuro scientist to figure it out. But I want to respect Andy's efforts, even though I also know that coming to Renfrew will be a big interruption in his life, his scheduled renovations. These treatments will cut into our time, will cut into Andy's life. Yesterday's travel back home after my first treatment from the hospital caught us in an immense rainstorm. Terry described

their trip to get me as frightening, that Andy had to sit uncomfortably forward on the driver's seat, eyes inches from the windshield in order to glimpse the country highway they were driving on. That's how thick the rain was falling, she described as I pulled myself into the front seat, hungry and a little grumpy (typically my post-treatment state – though I didn't indicate it to them - they probably noticed it anyway), blinded by thunder claps that seemed to be hitting farm ground as close as a mile away. The familiar feeling hit my gut of being burdensome to those around me as I listened to her energetic description of their drive to collect me, wondering if she was pushing that energy at me so that I'd not feel bad. This week will demand that they drive from an hour away four times, back and forth, in order to collect me from dialysis; instead of staying indoors, safe, locked in conversation, away from the rain.

The week was productive, yes. I wrote and gardened and laughed. I'm also quietly aware, now that I consider it over a month later, I'm aware that such a visit, where dialysis is so far away, is too much to ask of others. I'll not go again and, instead, will go back to my two-day visits, heading out at lunchtime on the second day, to get home to my machine that sits beside my bed in my Montreal apartment.

Theme 2: The Emergence of Meaning Via the End Stage Renal Disease Experience

This section presents themes that describe emerging meaning. Aided by Leavy's (2009) components of meaning emergence; *coherence*, *turning points* and *re-plotting*, I engaged with intentional 're-framings' as I progressed through the multiple voices within this narrative. Meaning emerged at numerous points for me. The use of autoethnography as a methodology proved itself to be a necessary container for meaning emergence. This necessity is explored in the first narrative *Negotiating Autoethnography as Method*. The subsequent narratives, *Epiphany* and *Good Grief?*, consider Bochner's concept of epiphany as a necessary component

of meaning emergence. The notion of epiphany is universally accessible, yet the lived experience itself is unique to the individual. This dual dynamic actively moves a narrative from ‘me’ to ‘we’, a concept from Spry (2006) that I love and return to often. The final narrative presented in this section explores the notion of otherness (Charmaz, 1997; Richards, 2008), how it applies to illness and identity formation and how otherness is also multifaceted and can be experienced by many.

As in theme 1 the 2 introductory quotes are taken both from the data and the literature represent jumping-off points from which the narratives evolved.

Negotiating Autoethnography as Method

... because I'm a medical person I do see people who encounter medical issues and then become 'disables'. And it's sometimes what happens psychologically, [is] that I think they 'give up'. They capitulate.... you know I think that the project that you're doing is a great thing. When I went to your presentation that time it was really an eye opener. Yeah, so many people need to, you know, hear about... [patient perspective of disease] (Brother interview)



“Thus, the autoethnographer not only tries to make personal experience meaningful and cultural experience engaging, but also, by producing accessible texts, she or he may be able to reach wider and more diverse mass audiences that traditional research usually disregards, a move that can make personal and social change possible for more people” (Ellis, Adams & Bochner, 2011).



I've been thinking this past week about shaping my methodologies. A recent article by Ellis (2011) outlined methods for approaching autoethnographic studies and it has me thinking... visualizing this project, coming in and out of being excited about it and being intimidated by the

work of it, then back to a feeling of excitement about creating a visceral and accessible piece of research, containing empathetic knowledge of lived experience.

I am aware and conscious of a desire to avoid saccharine writing, writing that reads as narcissistic and over emphasizing me, who I am, my life, my experiences when others experience the same and worse, material not only useless to others, but also pointless to my own methodological journey, resulting in my learning little in relationship to the lived experience of illness and how to reframe it, missing the point entirely of what this work is about (Ellis, 2011). I think of my high school friend in BC, and her daily Facebook postings about her cancer treatments for breast cancer. She's reaching out, announcing her experience in search for support, and I feel small because of it, measuring my illness experience and this work somehow against hers. Perhaps not measurable.

I've read an example of such work, work that is unfocused and inaccessible. That piece I read in ethnographically speaking (Bochner & Ellis [eds.], 2002) by that woman who wrote about her hatred of her abusive father... the work was so angry, full of victimized thought, exhausting to read and feeling too single minded even though it was a personal story, creating a hesitation within me to a degree as I saw an approach that I did not want to use. She meant it as an example, I know. Even so, this is not it, I thought. This is not how I want to represent this work...the 'woe is me' mentality that I spoke of last week in my pseudo focus group with Diana and Cherie,... I spoke at length of being concerned about that, about this project becoming a means for my healing, for making sense of my life as it felt at times as though it has unraveled, that the person I once was is no longer (Charmaz, 1997). Yes, Di said after I described what I wanted to avoid... yes, like she knew what I was talking about. I was aware of the recording machine and somehow wasn't able to question her further on that... Though the thought flew

through my mind nonetheless, Was I already doing that? Was I narcissistic in this work? Is this narcissism? Am I seeking attention? No. I don't want attention, not in that sense of the word. If anything, I want to neutralize my experience, the attention that comes my way because of illness, the behavioural pattern that I've developed of associating too much of my identity to my illness, to dialysis, to the loss of my kidney transplant and its impact on my mind and body. I fear I'm guilty of using this experience as a means to connect with people when I feel empty-handed and unable to reach out. I worry about the psychological isolation that occurs with chronic illness (Kleinman, 1988) as something that is happening to me. Rather, I want to describe the feeling, I want this work to speak to the process of grieving, I want to explore the narrative element of grief that Neimeyer (2000, 2002, 2010) talks about, that through narrative grief can be addressed, and translate it so that its experience is accessible. I want what I write to be accessible to others, to be helpful to/in research, to stretch and add to what already exists on kidney disease and depression. This transplant loss has been a grief for me that I know.

Reframing the experience. Reframing. Kiesinger (Ellis and Bochner [eds], 2003), talks about taking a painful topic and observing it from the outside, create other perspective of it, open it up, aim at empowering themes rather than themes that sit sadly without moving. That said, however, I feel there is necessity in exploring the visceral experience of sadness as it relates to illness, the existential elements of that sadness. The reality that sadness is a universally shared experience.

Epiphany

“While epiphanies are self-claimed phenomena in which one person may consider an experience transformative while another may not, these epiphanies reveal ways a person could negotiate ‘intense situations’ and ‘effects that linger-recollections, memories, images, feelings—long after a crucial incident is supposedly finished” (Ellis et al., 2011, p.3).



Sometimes I wonder if I'm a harder person to love. Because I carry a lot of 'serious' with me everywhere I go... (Patient interview)



I feel like the epiphanies that have come my way have been existential, pulling from my childhood the emotional learning that was seeded at ages six, seven, twelve and bringing it into the present where new understandings emerge. The familiarity, even comfort (oddly) that I've developed, for example, of light blue walls and plastic-covered mattresses of a typical hospital room. The routine-ness of my home dialysis treatments, needling my arm as CBC's *Ideas* plays in the background and my dog sleeps at the foot of the bed. A feeling of familiarity to something unfamiliar to most anyone.

Existential too, partly because it is about mortality, death... the dropping in of reality, a sudden realization, a fuller and rounder comprehension that death has been close on a few occasions in my life - something I believe I've compartmentalized until recently. Talking to other dialysis patients, I've learned that this is not uncommon among this group. Small things become serious quickly. An infection in an access can reach the heart within hours, can become systemic.

I think my most recent epiphany, to call it that here in the Bochner (1997) sense of the word, for the sake of it, is the comprehension too of my living grief. The trueness and

inescapability of grief for me at this point in time. The okay-ness, befriending of grief is an epiphany, in a way. It's okay that I'm grieving. It's expected that I should be. Many are, so in that sense I'm not that different. I've thought to myself often that many around me are grieving, for reasons different from mine. This particular realization makes the grief of illness instantly smaller and easier to understand. This epiphany, however, this illness narrative - though shared by many - is also unique to me. The recorded discussion, my pseudo focus group that I hosted last week, surprised me. I was surprised to hear my friend say that talking, dialoguing about illness as interruption, is a form of validation... relieving I think she said.

When we talk about this shit, Leah... Our venting conversations expel what she can't share elsewhere. When she does here, though, she realizes that the experience of illness is shared by many. My patient focus group produced in me a sense of mixed humility and empowerment. Humbled, in reaction to their medical narratives; removing of the parathyroid hormone, replacement of heart valves, inability to work. And empowered because the focus group contained seemingly no hierarchy and was engaged with ease, a place where a certain expertise of experience was more fully defined (Gillard et al., 2012).

And I had been worrying about that. I still worry that I'm too involved in this experience, that if I weren't writing about this experience, this grief, I might not see it as such. I'd worried that I was becoming tiresome, a broken record, someone my friends would no longer want to spend time with, the image of the isolated sick that Kleinman describes (1988), the abandoned identity that Charmaz (1997) presents. This relief she spoke of, this easiness, surprised me. The benefits of a dynamic, moving narrative. Our narrative is fluid and multifaceted, ever present in movement and language, my slow and careful snow walk, my curses when my heel slips... Motherfucker...! An offensive word. A harsh, almost violent word. One

that would shock my mother, my father and one that I never use. Yet appropriate to the experience, the exasperated fear of walking on ice.

That talk, that focus group became then part of this meta narrative. I enjoyed listening to it afterwards, yet another layer, to their voices, to my own voice. I thought to myself, this is good. This is interesting. I never thought other patients voices would empower me in this way - and, I suspect, me them - that their stories of suffering, similar to my own, were oddly and almost counter-intuitively a source for laughter, enhanced knowledge and accommodation.

Good Grief?

I don't feel loss. I'm not feeling loss. But I grieve your grief. [On behalf of you, or whatever?]. Yes. Yeah. Yeah. I feel that. Most definitely...I see you losing something. And that hurts. I grieve seeing your grief...and like anything that's big in a person's life, it follows me.

(Friend interview)



“The subject matter of interpretive research is meaningful biographical experience. Interpretive studies are organized in terms of a biographically meaningful event or moment in a subject's life. This event, the epiphany, how it is experienced, how it is defined, and how it is woven through the multiple strands of a person's life constitute the focus of interpretive biographical research” (Denzin, 2001).



Epiphany. Epiphany. Epiphany is a word that I have a difficult time getting my head around. It brings immediately to mind the catholic celebration, my father's voice grandly announcing, today is the feast of the epiphany!, standing in our family kitchen. The image of candle flames atop the apostles' heads in paintings from somewhere in my childhood, though I don't explicitly remember where I saw them; probably St. Theresa's church, the church I

attended regularly as a child always boasted huge felt banners behind the alter depicting a cartoon-like image of the given celebration. Certain times of the year required daily attendance, on my way to school with my father. We'd sit in the last pew, next to the lady who would bring her dog to mass and he'd lie down underneath her feet, a piece of rope for a leash around his neck. I recall her clearly, her beige spotted ratty coat and she always sported a hat, I remember hoping she'd be there as I trudged up the church steps in my school uniform holding my dad's hand; mass was more of a chore to me. Being the youngest of six, the age eventually arrived where I was the only one getting a ride to school. Dropping into to early morning mass was an easier feat for my dad with only one child, I think.

But that's not the meaning of epiphany here. Though the church meaning certainly influences my thinking around it. For me, it is shaping as a sudden realization; a self-revelatory dropping-in of knowledge. A flame atop my head that momentarily sees clearly a meaningful sense-ness to my illness experience. The privilege of having a different experience in life, one that is different from most, the gained knowledge of the medical world that so many fear, but that I have gained a patience (sort of) for. Is that epiphany? Epiphany here refers to the absorption, the realization of significance through lived experience; an event that brings about isolated significance that spills into other areas. But is epiphany revelatory? Does it produce joy? Does it produce transformation?

Denzin's (2001) description of epiphany for me weaves into Neimeyer's meaning reconstruction model (2000, 2002, 2010) and is perhaps linked to the way that grief evolves into meaningfulness and depth of lived experience. I'm thinking that exploring this story, this experience of illness, will evolve into a finding of meaningfulness. I think that meaning already exists in this experience, can feel it nearby, though not yet embodied. It may have something to

do with death, and not feeling it as a foreboding thing, understanding the reality of it, that my life span is likely to be shorter than most. I think of it, rather, as reaching rest. Sleep. Not a bad thing, an inevitable thing, something that happens to us all. I keep recalling that moment that I've mentioned before here, that moment at the cottage last summer. My mother's blank face when I spoke those words, the best of my life is over. I wonder did she think I was referring to death.

I don't feel that way anymore. At least, I don't think I do. Maybe I do feel it, somewhere deep inside. The statement, the feeling, sits in the back of my thoughts most of the time. I felt it tonight as I forced a smile while watching the slides of my brother's trip to Cuba on his new Mac computer; beaches and ocean and healthy smiles, my niece buried in sand shaped like a mermaid's tail. An emotional feeling, a lonely feeling, came over me right there in the middle of the kitchen. It surprised me, and I spent the next twenty minutes fighting with my inside self, to keep it from being visible, not even wanting to feel it. Rather, wishing for a different feeling, one of grace and even joy for them. Instead, Oh, I won't be staying for supper, I said. I have too much to do at home. This essay, Robert arrives at eight and his bed needs changing... I said this and smiled hard and felt their concern in the air. Not something one would mention. Staying for supper would have been exhausting, would have taken work, would for some reason have been a struggle. They began to feel it too, I think. It started with Madeleine's comment, You would have enjoyed it Leah. We missed having you there... My brother looked into my eyes. What do you say to that? Yes. Sure. Yes...would have loved to be there.

Meaning, defined as the possession of inner significance, possessing goal or intent, something that is conveyed or signified (Your Dictionary, 2011). I'm struck too by the ambiguity in what meaning actually is and has me jumping back to last week's article about end

stage renal disease and its role in quality of life. Quality of life. QoL. The quality of my life keeps jumping back to previous chapters, already lived, as though the quality time has already been used.

Not what's happening now. Now feels more like a search for meaning, more like Bowlby's yearning, searching (1980), a separateness from what is present and focusing on what is from another time, a time of better health, a time of activity, a time of inclusion. A search to recapture the feeling of importance, of anticipation and the feeling of being productive as an actor, a writer, a singer, a psychologist, a daughter, a sister. Meaning exists at a time that is before for me and feels as though I have lost hold of it, am not able to apply a feeling of belonging, meaning, doing, productivity in relation to what I am now. Or the feeling that I do apply is limp, lacking truth. I scratch and grab at moments of meaningfulness; doing some work, getting exercise, cooking a meal, baking banana bread from old bananas that I'd been staring at for a week and told myself, you have to use those, don't waste them. I used them, baked banana bread so lovely it could have been in a baking magazine, I told Diana on the phone. A hint of meaning in that but still difficult to touch, still can't quite define it.

This feeling of separateness has returned again, otherness and again the outside observer emerges in my mind as I compare my life to the lives of people around me; my best friend Robert who won the Governor General's award for playwriting. I attended the awards with him at Rideau Hall, wore my black cocktail dress and flat ironed my hair, wore boots instead of shoes so that I'd be more stable on my feet, my knee shaky because of the steroids. I considered the two-day visit to Ottawa a vacation, forty-eight hours away from my dialysis machine, a tour through parliament and lunch with the speaker of the house... lazed in the hotel room in my pjs instead of exploring the city while Robert was at a media event. Bought a pay per view movie

and felt a foreign feeling of relaxation sitting alone in that hotel room, more than just a hotel room. The Chateau Laurier. It is a reference point as a feeling of 'good-ness', I cannot go as far as to call it happiness in the pure sense of the word... no, not that. That was in late November and I still think of it on a semi-regular basis. I bring it up now because it somehow has meaning attached to it; meaning through the vicarious experiences of others in my life, their successes and associated pride. The epiphany in it was Robert's. Winning the Governor General's award underlined his work, gave credence to his choice to become a writer, lit in him a confidence which has been warranted for a long time, but has finally become visible. I felt pride, thrilled to be the one accompanying him. It's a big thing winning a national award. I felt that it momentarily was accessible, this kind of success. I wondered to myself, is it this kind of success I want? Is this what will bring me to a sense of meaningfulness? Because if so, that's big, perhaps too big. Is it too much of an expectation?

Meaning. It has shifted and changed for me in the past year and become something that involves contentment, the absence of illness related stress, the absence of expected urgency, the acceptance of who I am as someone with an illness and perhaps even the recognition of my uniqueness as a human being because of it, having a role to play in the lives of others; an active, present, recognized role, contributing to the lives of others. I find that my constant vacillation between other phases and stages of my life and my present-day life is where I have remained as of late. I refer to other times. I refer to my tour with Sheila's Brush theatre company way back in 2003, the fun of it, the health of it, the inclusion of it, travel signifying freedom I guess. I refer my siblings and their lives, their children, their work. I refer to my parents and my friends and their successes feel stagnant in my own life. Maybe I'm searching and yearning, as Bowlby puts

it. Yearning for lost time, searching for a replacement for it, searching for a way to bring my current self to a place of contentment, self pride, satisfaction.

Yallop's (2010) lovely article about his mother's death moved me. Though I have not experienced the loss he describes, I viscerally related to the emotion of the piece, the metaphor that is contained in home (Newfoundland, interestingly, for him as well as for me), the land, mother and the two together. The grief, the feeling of loss, though our two forms are different, was present for me. "The metaphor was my reality. And one day she will take me back, back into her arms, back into body. One day, perhaps, I will learn what Newfoundland and my mother's body were, and still are, trying to teach me" (p .5).

Trying to teach me? What is my body trying to teach me, I wonder. That life is more than a body? That identity is knowledge? That my identity is about knowledge; that's where my strength lies...? My mother is still alive and I wonder if what I grieve when I think of her has to do with the worry and grief that she feels for me, more so as of late. I am anxious about interviewing her for this study; worried as to what might surface. Worried for both myself as well as for her. Like most mothers, she takes a lot on...too much ownership over things she has not control over, had no control over.

I related to the yearning for home, and associating mother with home. I feel I'm in a similar place, but resist it. I associated my mother with my illness somehow and lately will often recall moments as a child in hospital; awaking from my transplant at age twelve in the sterile recovery area, my two masked and gowned parents hanging over me, their eyes the only part of them visible. Can I not be touched?, I thought to myself. I remember thinking this to myself. Am I contaminated? Too fragile? Breakable? What would happen if they didn't wear those masks? Those gowns? They would only stay for two days, flying home again quickly to get

back to work and responsibility. Our family friends, living in Toronto, would visit me then and I began a relationship with them that is visceral to me still today. My mother would tell me years later in the midst of a serious conversation where I claimed my multiple visits at Toronto Sick Kids were most of the time alone, I did it alone, I said... she couldn't know what it was like because she wasn't there... she told me that the nun principal of her school wouldn't give her the time off. For some reason the simple acknowledgement of it, of the fact that I had been on my own in hospital as a child, the acknowledgement of having happened the way that I said it had, helped. It's less heavy now.

Otherness...

Part of the problem was struggling with any kind of contact... with anyone. It was easier to not have contact... with anyone. I didn't have the energy. I felt so different from everyone else's life. Like it wouldn't work anyway...(Patient interview)



“‘Othering’ means turning a person into an object of some sort, such as a stereotype or even an object of study. Those whom we study are never quite on the same level as we are. And they are always ‘not us’... [othering] requires researchers to be aware of the centrality of the insider voice: The expert on the lived experience of disability or illness is not the clinician, but the person experiencing disability or illness” (Richards, 2008, p.1717).



Otherness. Who defines otherness? Me? My doctor? Those who observe me? Those who treat me? I feel a feeling of otherness in some circumstances and not in others... I don't feel other with Robert. Otherness is this diagnosis, this machine, this waiting list, this pager in my back pocket that I accidentally leave at home on the kitchen table then think to myself, oh, they'll reach me if they have to. If a kidney comes. If someone dies and a kidney comes. My

cell, My phone, my brother's number, my friend's...they have every number in the book...besides, it's not likely to happen... it won't happen. I tell myself this. This otherness is the feeling of a growing gap of functioning and life similarity from those around me, my friends, my colleagues - because of losing this transplant. I have other things on my plate now and no matter how hard I try to put it on a back shelf, on a lower priority list, in a back cupboard somewhere... it remains present, daily, stuck onto me in the form of this pager, the machine in my room, the needle in my arm.

Otherness is my six year old self fibbing about the lump in my polyester brown pants at school not quite sure how to explain the empty saline bag attached to a tube in my belly for my Peritoneal dialysis... so I fibbed a fib about taking in the newspaper that morning and forgetting to give it to my parents, so it was in a pocket inside my pants until after school... that was otherness. An otherness that I chose to address in a strange six-year-old way, because I knew (even then) that the truth was too big, was too 'other' to be understood by my six year old friends, alongside whom I wanted nothing more than to be similar, or like them... The words I uttered to my mother last august, shivering with a blood infection and not knowing what it was, wondering if it was going to end, driven to nightmares over my academics...foolish, now that I think of it. Hindsight, they say, is twenty-twenty.

I think that the healthiest part of my life is over. I have to start thinking about accommodating myself now... adjusting my goals, shortening my weeks... preparing for some sort of end. I said this to her, sitting in the light of the window. A chipmunk stealing the bird feed and the dog's eyes fixed and ready to pounce...

She said nothing at the time. I said it to the room, sitting at the breakfast table with the bird feeders swinging on the other side of the glass, my open laptop in from of me...trying to

conceive of a paper on ethics and barely able to string a sentence together, let alone one that sounded smart and important and worthy, battling an infection, in my blood... I said it out loud just because I needed to expel it, not because I needed anyone to hear. I don't think.

She brought that up again recently, months later. A year later. A day later. Over Christmas she brought that up. It frightened her, I think, when I said that... the best of my life, of my healthiness, is over. I think it's over...

I bring tears to those around me, this otherness inflicts pain on those around me. My sister's test being positive and meeting her in the foyer of the RVH, her red jacket and pink eyes, arms folded in that way of self comfort, holding something in... silence in the elevator, feeling like the other, on the other side of a thick pane of glass. The one being observed. The doctor's voice like the adult voice in the Charlie Brown cartoons, a repetitive white noise in my ears, a rush of nothing takes the place of my thoughts. This meeting was supposed to be about planning a surgery. A beautiful gift. My sister was proud and full of love over it. I was awkward, uncomfortable, felt small and dependent, yet grateful and anticipating.

Scrambling out of that fog, it took months to scramble and climb and scrape my way out of that fog of white noise, the corridor image that planted itself in my mind of what the rest of my life would entail; dialysis, steroids, wheel chairs and gurneys, shortened life span...

Create meaning. In. Through otherness. The uniqueness of skill. Yes... the skill of knowing the steps towards cleaning my blood (sure, you'll be more skilled than most nurses, my sister wrote me on Facebook when I was transitioning home after the training)... turn on the water machine, lug supplies from the supply room to my bedroom, go back and get what I forget. I always forget the little garbage bag for the bin by my bed, hang two saline bags from the iv pole. Is tonight the night I have to give myself iron? I hate the added extra steps, makes me

anxious, more anxious than normal. Test the chlorine level, make note of the conductivity... measure the saline in the ten cc syringe, ten full cc's, measure the heparin, one cc, then top with nine of saline (don't push it back into the bag. I did that the first time in the training clinic, anxious and shaky, and think of the moment each time since...), that'll be for the venous side... oh yes, remember the topical deadener for my arm... which hole tonight? Which one did I use last time? I run my finger over my arm and identify the hardened holes, squint my eyes to identify the pin-sized entrance for the needle, and fight the feeling of frustration at not having a clear view. That's the button-hole technique; the same spot each time creates a tunnel. Less malformed arms because of it, so the research says.... prepare and turn on the machine. The beep beep beep introduces the rest of the night... will I reach REM tonight? I don't think I have yet. Will need to find time to nap tomorrow...damn, tomorrow is Wednesday. Research day. I have to code, I have to keep up with the coding. It's hard to leave early with all of that work, and it doesn't move fast, coding is slow and frustrating... There is otherness in this. This is not the norm, this humming machine in my room, the venous pressure alarm beeping.... That young couple with the baby I can see from my kitchen window don't have a dialysis machine in their bedroom, the beeping, the humming, the whishing beat of the pump finding its way into their dreams...they don't have that. There's otherness here. Though, as the months pass it is slowly, clumsily, awkwardly, un-sexily, merging into something, becoming a form of norm...

Theme 3: Reframing, Accommodation and End Stage Renal Disease

This is the third and final section presenting the narrative outcomes of my inquiry. It presents themes of reframing and accommodation, as outlined by Neimeyer (2002, 2010). Again, the italicized portions represent quotes from both data and my literature review and are jumping-off points for the narratives that follow. The first narrative, *We're Products of*

Experience, explores themes of how illness experience marks the development of relationship and personality. The second, Illness as Culture, explores my notions of my illness as a cultured experience, possessing its own unique defining practices and rituals and relationships. The third and fourth narratives, Accommodation Begins in The Body and A Walk, illustrate how the body's accommodation of illness is a source for new knowledge. Again, the first two quotes are taken from the data and relevant literature, out of which the narrative was written. These are presented as jumping-off points for the narratives that follow.

We're Products of Our Experience

... I'll try really hard not to get upset (laughs). It's probably gonna happen. I feel that, as much as this has been a horrible thing for you...(laughing)...as much as this has been a really horrible thing for you, I think that we are a product of our experiences. So, (crying) so the you that I love is a product of that... if I could snap my fingers and make all of that go away, I totally would. But at the same time, I believe that we're a product of our experiences (Friend interview)



“[...] the therapeutic value of narrative becomes apparent each time we deconstruct debilitating life narratives and reframe them in ways that empower us, thus improving the quality of our lives [...]” (Keisinger, 2002).



There are many ideas and themes tangled up in this data, that in some ways I don't know which way to turn. The notion of 'normalcy', the need to strive towards not being much different than those around me, has been very present... for me, inevitably involving a reframing of experience in order to envision agency and positive movement.

Not so much for my friends. ESRD and dialysis infiltrates practical issues in my life; travel is difficult and limited. But emotionally. Emotionally, little is different. If anything, my emotional health has ebbed and flowed, but has also relaxed.

What to write about. My quandary is whether I should write about personal 'opinion', experience... or if I should take the words of my subjects and react to them. The point of this study is multi-faceted. One aim is to communicate the I-perspective psychology of this disease experience. Another is to communicate how illness informs others surrounding the person who is sick, in addition to that relationship. For example, these past four years have impacted the lives of those around me in different ways; my family predominantly. But my friends too.

One level of reframing involves the following. My friendships, prior to 2009, had never known me as a dialysis patient. With the exception of Flora I guess, though when I was on dialysis in grade 7, it wasn't at all visible. My school friends, of which Flora was one, were barely aware that my destination on the bus after school wasn't piano lessons or ballet or the after-school babysitter. I can't remember if I ever shared where I was going on those days; that I'd be on route 10 alongside my school friends, giggling and misbehaving, because it stopped right next to the Health Sciences Centre, the hospital that housed the only outpatient dialysis unit in the city. That I'd stay on after they got off along stops before me. They'd get off and I'd bypass home and keep going. I'd step down just outside the hospital and make my familiar way to the fourth floor unit, where I'd be expected by the nurses who over time became very familiar to me. How was school, Leah? Did your math test go well? Did you get that book report done? You're over by the window today... A familiar routine that was so much a part of my childhood, that the reminder that my current-day adult friends knew nothing of that time of my life was very surprising. Though when I give it some thought, I realize of course they don't know. Of course.

I've never known you to be sick, really, they'd say. Except for your hip surgeries... this dialysis thing was so sudden, they'd say. I thought your transplant was there for life. That it lasted forever, they thought. The experience was other-worldly, kidney disease was something that happened to old people. Illness happened to others. They'd never thought of me as anything other than normal...with the exception, again, of the joint surgery. But even that, as odd as it was for a fifteen year old to have a hip replacement, the process was temporary. I healed over the period of a few months. I graduated from crutches to a cane, from a cane to nothing. After that, the illness was once again invisible.

The loss of my transplant in 2009 in some ways marked a milestone in my close friendships. Whoa, what's this dialysis thing? You have to do it HOW often? It's life maintaining?! I didn't know dialysis was life maintaining. You can't travel? Really? In other ways, though, it made no difference at all. As much as this has sucked for you, Robert uttered halfway through out long interview, as much as this has royally sucked for you, watching movies over junk food in your room while you were on dialysis... well, those are great memories for me. Really special times. You know? Yes, I do know. They are for me too. Doing my own dialysis was new to me, mistakes were frequent. It was a point of humour rather than anxiety, when friends were nearby. Visiting to keep me company during those early treatments. Oh don't mind me, I'm just bleeding out here... tears of laughter with Di in response to forgetting to clamp my tubing with the pump running. Now there's something I'll never again forget.

Blood sprayed across the front of the machine next to my bed, a half hour of clean up with the needle in my arm, Andy nearby weak in the knees at the sight of the blood, prostrate on my bed, pale and staring at the ceiling, playing bejewelled on his iPod as a distraction, as I scrub the blood away. Nonplussed, barely affected by the experience, not fully comprehending why it

makes others nervous. Vampire and ax-murderer jokes chiming in... or, oh look, Leah's bleeding out guys, guess we've lost her. Imagine that. And we here gorging on Kitkat bars and potato chips watching like it's a movie. Waiting for me to take care of whatever treatment-related delay - an alarm, a backed up chamber, a blood bath - in order to get back to episode 8 of that british cop drama we've become temporarily obsessed by. The whirr of the machine in the background like a white noise. Cherie, a songwriter friend, now humms the musicality of the pump quietly to herself when she sits beside me, her homework on her lap, concentrating on her latest essay while I watch Netflix with earphones beside her. I can't work when I dialyze. I've accepted this and still struggle with it, feeling like I should be putting this time to better use. My mother's voice in my head tells me this. She's always been a hard worker, making use of every minute. Here, with Cherie beside me, I reject the patterned thinking and tell myself that I am working hard right now. I'm dialyzing. I've cleaned the blood off the floor. I have a needle in my arm and every bit of blood within me is being sucked out and cleaned.

Not talking. Just hanging. A normal scene, were it not for the dialysis machine beside my bed. Or maybe the machine is my normal now. Friendship that lasts through recovery rooms and medical treatments in my bedroom, inevitably goes to a more profound place.

Illness as Culture

Yes. There's something about talking about all this stuff with patients that have been there...you know? Who have had the surgeries and the site infections and fifty angios...or who know what it's like to lose a transplant after five years...huh. There's something that makes it...I dunno. You're not talkin' to some doctor who doesn't really know what it's like... (Patient interview)



“[Autoethnographers] must use personal experience to illustrate facets of cultural experience, and, in so doing, make characteristics of a culture familiar for outsiders and insiders” (Ellis et al., 2011, p. 40).



This process is big. It's large. It's rich and important... I think. I'm reminded of Ellis's (2011) words, “when researchers do autoethnography, they retrospectively and selectively write about epiphanies that stem from, or are made possible by, being part of a culture and/or by possessing a particular cultural identity” (p.4). This process, this process of autoethnography, criss-crossing my life relationships through this illness experience, has me thinking about the culture that exists within illness. I will take Ellis's (2010) word 'culture' and stretch it... as I'm sure that what she means is the culture of experience, like Sontag's (1978) illness as metaphor, how she (Sontag) talks about the world of the sick, those who've experienced illness as being other-worldly, that one cannot know the experience of serious illness until one has been part of that world, that sooner or later everyone visits, some more sooner than later.

Will it do me no favours to view this experience this way? Is it too morose of a place to delve into; illness and grief? What makes culture? How is culture defined? A shared experience, context? Shared practices and beliefs? Going to mass on Sunday? Singing songs at family gatherings? Food, fried fish and chips? I'm from Newfoundland and have never been much of a fish-eater. Had my first-ever feed of actual deep-fried, bought-around-the-bay fish and chips in the summer of 2008 and was sick a half hour later.

Culture, the experience of a shared culture is an ambiguous thing. It involves, it seems, a feeling of belonging to a group. Belonging? Can we, in this context of culture that Ellis has me wondering about, can we be part of multiple cultures? Is illness, the experience of it, the sharing of the visceral elements of it, the language of it, the other-ness of body of it... is it a culture? Is

it cultural? Because otherness is subjective. As Terry says, I belong to a group, of dialysis patients, that I spend no time with. Yet that group is so much of who I am right now, at this stage.

To me, this culture of illness involves an understanding of the medical world, waiting four and a half hours for my doctor's appointment, working on my laptop patiently because I understand and know the speed of these things, pragmatically discussing my avascular necrotic knee and accepting openly that surgery will be necessary, negotiating a date that works for my academic schedule. A business meeting. No, not before comps, I think to myself... and then say out loud - I have to get through my comprehensive exams, so can we work around that? Let me get through comps and I'll find a way to take some time. Walking the convoluted hallways of the Montreal General afterwards, I think to myself whether I should tell my family, my mother, my father. Tell John, because he's a doctor and has the language, will package it that way. It will be a practical discussion, a planning discussion, which somehow makes it much easier, much more digestible. The surgery itself, the anesthesia, the recovery room... I'll deal with on the day of. For now, I think, focus on my last course. Be aware that some of this plan may not come together, may not pan out as I've planned. I feel a sense of immediate acceptance of this surgery. I've been having knee problems for a while, associated with the steroids in my system. Another consequence. In a way, I welcome it. But it'll come out of left field for them. My news is often out of left field as of late and I struggle with censoring details for their sake. I buy a small black coffee and a four dollar crap wrap sandwich, a combination I've gotten used to and associate with this hospital, with long waits here and dialysis treatments in the unit downstairs. I'd been told, for some reason, not to eat before hand so now am starving, could eat the arse off a low-flying duck, I smile as the saying from home passes through my mind. Have

to eat and head to campus now, catch up on coding. This decision is made now so I can get stuff done.

This feels familiar. Easy. An unemotional, logical decision. Surgery after comps or before? What makes better sense?

This culture is knowing, the automatic familiarity with other patients who've been there, who know this experience, like sharing custom, ritual, symbolism. The patients I've interviewed enter my mind now as I revisit this essay, affecting my perception. My dialogue with other ESRD dialysis patients has driven this cultured experience into a normalizing direction. The validation of inclusion, of knowing an experience, an atmosphere, a feeling, the frustration of repeated medical procedure yet the ability to take it on without resistance and knowing that's easier for the psyche. The validation of detail and cultural practice, being part of a group that knows experience, feeling at home at not having to describe, to provide detail, to re-tell the story because the story is so similar that understood experience is inherent, to define the language, the obscure terms; avascular necrosis, hemoglobin and how the body feels when levels drop, creatinine, dialysate, fistula, I could go on... that feeling comes when I meet other dialysis patients my age. I feel an automatic affinity with them. It's far less work.

That man. That man who I was introduced to when I started my training back in October, I was hesitant yet certain about taking it all on. It felt big, taking this medical role on, a machine in my home, putting my own needles in my arm, the sterile surface, the supplies taking over my space... So, what's it like?, I asked while he sat in the training room, the machine whirring between us, the nurses in the office next door. I was impressed at his ability to work on his laptop with the needle in his arm, noting his site was further up the arm than mine. I won't be

able to bend my arm like he does. He looks fit, I thought. He looks like an athlete, not a normal sight here.

It's a great improvement from before. His confidence was soothing, soothing because I knew he was coming from a similar place, a place I was about to go. I felt like shit when I was going to the unit... I feel so much better now... and I can eat what I want! Had terrible phosphorus levels before...

Weeks later we meet at the monthly clinic. I was sitting in the nurses office, reporting my trouble with multiple alarms at night keeping me from sleep, how the only time it wouldn't alarm one night was when I was sitting upright on the side of the bed, in the dark of my room, my dog fast asleep on his back, paws in the air. I'd had a few nights like that, it was catching up with me. Was exhausted, heavy lids. When his head popped around the corner, I jumped to question, to compare notes, Do you have these alarms? Does it get better?

No. A prompt reply. It doesn't get better. I know what you mean, the machine is so sensitive, I feel like I can't move.

Yes!, I say, almost with exuberance. It was a relief to know someone who'd felt it, the frustration, the screaming machine at 3am. Our conversation continued, comparing notes, a feeling in the air of a shared experience, a unique and shared experience. The nurses watching blankly.

I don't even recall his name. But his words were the most helpful I've heard in a long while...

How many times did that venous pressure alarm go off last night? I thought I was going to have to disconnect again. That air detector, the feature that is supposed to keep air from being pumped into me accidentally, it confused me with its repeated alarming, every four minutes

according to the clock in the corner of the screen. I flashed back to two nights before and that mess, spraying, the arterial chamber containing my blood overflowing and spitting blood everywhere... my room was like a scene in a horror film, blood spatter specialists analyzing the crime... roommate not hearing my calls over his laptop. An ax murderer had come. Faulty tubing, I think, like when that happened before in the hospital during my training... blood spraying like a punctured vein. The nurses had no answer. Faulty tubing, I guess.

Culture. My identity (Charmaz, 1987) is shaped by this culture. These experiences.

Can I frame this role that I'm in right now as cultural? Can this lens of identity be one of kidney disease, illness and the experiences that come along with it? Is kidney disease and all that it entails a culture onto itself? Is dialysis a subculture of experience? I mean, Richards (2008) says that no two illness experiences are the same, that each one represents its own separate experience of other-ness.

Accommodation Begins in the Body

I sort of feel like, for me, I can't assimilate. Because I've always got that 'what if... when's the next problem, the next surgery?' happening, you know? I don't completely absorb it and just keeps moving ahead. Because for me, it's always going to be an accommodation. It's never...and I sort of feel like chronic illness and complex chronic illness, like what I've had, can... that's what it is. It's a complex loss... and that it's inevitable that I'm going to go through phases of tripping and stumbling, falling into dark places about it. But it also forces a negotiation of everyday experiences, so that I'm okay and accepting of who I am within those experiences. You know? (Leah)



“Autoethnography is further informed by research on oral and personal narratives in performance and communication studies, situating the socio-politically inscribed body as a central site of meaning making [...]” (Spry, 2001, p. 710).



Today, I gardened. Today, overheated in the mid-spring sun, I raked soil, turning the beige dehydrated dirt over and over, like folding meringue in a bowl; don't stir, my mother would say. Stirring will ruin the effect, will ruin the lightness of it. Fold. Fold it over itself just enough. That way it'll remain fluffy and lovely. I folded and turned the soil, making it fluffy, loosening it until it was dark brown, where the moist earth below revealed itself.

I bent at the hip and leaned into my knees, fully aware of the steel artificial joint on the right side, two years old this summer, and feeling as normal and natural as anyone's knee, as Terry's or Dad's or anyone's. Save for the mark that reminds me of that surgery, the epidural, high on morphine for three days afterwards to the amusement of my visiting brother, asking the same question three times in fifteen minutes and wondering why he was smirking. I think I'll tell others to wait to visit you. Maybe wait til you're home.

Today, though, not quite two years later, I lift my pants to bare the straight, perfect, pink scar to the sun and think to myself, like I've thought a hundred times since receiving this knee. My leg works; it bends, it holds me in place, it carries me with ease and keeps me upright. It allows me to feel good about working here today, alongside my fit and sturdy friends, though I'm fully aware that my contribution is small. I am small. My contribution is small too. Almost like that of a child assisting a parent; watering the parched beds (but only the ones I'm told to), spreading cover evenly, scooping it into a tin bowl with a painted flower on the bottom, scooping as much as it will hold and covering every corner and crevice I can bend towards without stepping on the soil and making size 6 foot prints. Intrusive, giving away the culprit among this

group of size eight-ers. Wanting to do a good job for Kathy. Wanting to do the job correctly. Wanting to be part of this year's colourful, edible, pickable harvest. The gardening gloves make me feel worthy, spreading the bark evenly over the small bed. Checking in for Kathy's approval, feeling satisfied at her, yep, that's perfect Leah. Too bad we only got one bag.

I'm aware of how small my contribution feels, the tiny child-like tasks, pulling stubborn baby weeds from between the flatrock on the path between Kathy's flowerbeds, lost in quiet thought of my mother, my niece's summer adventure in Europe, this dissertation, my dialysis treatment tomorrow afternoon and how I'll avoid too much volume gain between now and then. I raise my head every few minutes from my sitting bent position, and observe Terry and Andy's heavy work two hundred feet below me. They pull and carry and push and heave. Terry has taken off her jacket because she's worked up a fast sweat. She stands for twenty seconds with her hands on her hips, catching her breath and staring into the air, then grabs her pitchfork and bends again. They're work is big and adult. It's heaving, breathing work. They fork probably hundreds of pounds of composting hay into the back of Andy's truck, move it fifty feet, then fork it out again and form another bed for planting. They do this work in silence, conserving the energy wasted through talking, reserving words for useful things, like Terry directing the truck as close as possible to the desired location, exchanging brief plans of what the next heavy task will be. I watch from afar and am completely aware of my inability to do what they're doing. I don't have the strength they do; or the drive, for that matter. I'm aware of this fact, and I'm fine with it. I think this thought as I watch them for a minute or two more, before bending back towards the stubborn deep-rooted weed between my knees. I fight with it, call it a 'little frigger', muttering under my breath, then let out a quiet 'aha, gotcha!' to myself as it finally releases. I toss it into the growing pile two feet away and focus on a new victim. I do this repeatedly for

forty minutes until the soil between the flatrock has been cleaned completely of tiny, thick rooted, frigging weeds. I bend my legs towards me and pull myself up with ease, thinking as I almost always do when I use my legs to boost myself up, how normal and unnoticeably smoothly this knee does its job. It has walked me closer to that imaginary line only in my head, that separates me from other ‘normal’ people.

It’s a normal that is this side of the kind of normal that Terry and Andy have today; the strength of giants, I call it. It’s a normal that says I’m content with these little tasks, hoping that they’re appreciated and that they’re saving Kathy from having to do them later. She’s taller than me. Sitting on these rocks would be uncomfortable for her, I think. She’d need a stool or a rock to sit on, when I don’t. I’m small enough that sitting on the ground works for me. It’s a normal that feels okay, my cross-legged position fitting me perfectly in the pathway. It’s a normal that reminds me that not everyone can hump heavy hay... or wants to.

A Walk

That was the day they called when you were on dialysis. You went unconscious and they told me to come fast because they thought you were going to die. I remember I was making supper. (Mother interview)



“[...] personal narratives work [...] to the degree that they assist us to integrate life events into our histories so that our story is experienced as coherent, intelligible and meaningful” (Bochner, Ellis & Tillman-Healy, 1997).



A walk. A walk. A walk. It’s been some time since I’ve walked, any distance. My visit home last month, yes. I walked five km and people applauded and said wow, Leah, that’s amazing. I felt good about that, kept ahead of some. Today though, today’s walk was different.

It was through woods, pushing brush aside, avoiding nettles, getting wet in the rain, climbing over trees, a running dog flying by. Feeling like an included person, a normal person, keeping up with speed. Relative speed, and arriving back and not feeling overtired, because I have some fitness left. Normalcy has found its way back into me; even with the moments of dropped pressure and the need to hold the wall or the window or Blair's shoulder so as not to pass out, fall down, break my nose, eyes blacking out temporarily, quick thought to myself, wondering what my numbers must be with symptoms like this? My insides have changed. This conversation, for once in a long time, this conversation is bringing about a realization for me. I'm not the other here today; Michelle is the other. Andy and I have found something; a place to sit, comfort, proud of our work. The hopelessness is tactile, this hopelessness that I want to pick off of her, carry away and burn.

I grew up in hopelessness, she said minutes ago, before standing up and starting away, wanting to disengage by leaving for a cigarette. I am failure, she said. No you're not, you're not, from the outside looking in you are vibrant and contributing, I said... desperate to shift the destructive thought pattern from within her. It feels like self-hate, I think to myself, but don't say out loud. I feel self conscious about feeling good. But then again, she's seen those moments in me. My hopelessness, my sense of not being a contributor to the world, my feelings of being invalid as a person because of this illness... but something changed, changed following my port infection, my emergency surgeries, the two years of dialysis, the bloated face, the blocked fistula, the transplant that didn't happen... something has changed within me. That change is present within this moment.

Understanding our bodies: a connection to epistemology and the co-occurrence of pain and pleasure

This walk, again, is meaningful. I do my best to keep my mind clear and fluid, to let the thoughts and triggered sensations flow. My emotions ebb and flow. This knee. A small part of me, yet somehow has, in its rehabilitation, has freed my movement. The hills are still hard. I stop and turn away from Terry and Andy. I stop and take in the view, take deep breaths and count my tapping heartbeat in my ears. I'm alive, but my body falls behind. I'm alive, yay! But my body takes its time. I'm alive, yet feel weak in this group of three. I prefer the woods to the meadow, I swear quietly to myself as my foot catches a root and I lose my footing, "fuck it!". I watch for Terry and Andy, looking for their bright coloured jackets, their down vests and hooded heads. Granny smith apple green and strawberry red...moving thru the woods slowly, quickly, disappearing, the dog zipping back and forth keeping us all on track, panting with canine confusion to our having separated quietly with no words. I'm wearing black. Not as visible as them, camouflaged into the woods and I find myself wondering for a second if my movement might trigger a gunshot from a deer hunter nearby. I heard a shot this morning as I was letting the dog out for a pee. A loud crack some distance away. Terry commented on why we often hear multiple shots. If they got it, wouldn't a single shot do? A single shot this morning. I guess they got it. I keep walking. The swish of the leaves, the snapping of twigs, the prick of those tiny thorn-like things in my thighs. I prefer the woods to the meadow. There are fewer of those red twigs pricking my thighs. I make my way into the woods with Fogo in sight. I make my way and let my might flow. I feel my working body, my knee carrying me. I wonder what my orthopedic surgeon, Dr. Lenzner, is doing right at this moment? Is he in the OR? Is he anesthetizing someone through an epidural in the spine? Is he zipping around Montreal in his

new beige Fiat? I don't remember what his voice even sounds like, but I think of him now as I walk and lift my leg over a dead tree, duck under a low branch because I'm small enough to fit. I recall too, an image of that time dad and I got lost in the woods, riding on his shoulders and a branch scraped my eye. He lost our way and knocked on a stranger's door because it was snowing. I slept in a strange twin bed that night, six years old and accepting of the situation. Mrs. Hall, our babysitter, my surrogate mother, the woman who cleaned our house and baked twelve loaves of homemade bread twice a week, half of which got eaten by my hockey or basketball playing brothers after school... Mrs. Hall could barely speak when we came in the door the next day. My dad tells the story years later with giggles at the memory, resisting the idea that we were lost. Mrs. Hall, my mother, both could have killed him at the time. Taking that child out in the woods like that! When I think of it now, thirty years later, I wonder if it was dad's way of bringing me into the fold, of making me part of the outdoors, hiking, canoeing, respecting the woods-fit family that he wanted... I was fragile, unable, incapable. These twigs I catch before they scratch my cheek as a walk today trigger this memory, trigger the sensation of branches caressing my face as I bounce atop my father's shoulders in a winter storm.

Feelings of anxiety come and go as I loose myself for moments and then look up to solitariness. Terry and Andy have disappeared. The red, the green apple green is no longer visible. I listen for steps and hear nothing, only the swish of Fogo running, a different sound, less decided, lighter. I battle with frustration. I battle with a familiar feeling of being left behind, a fly back to hikes with family or friends where I struggle with keeping up, camping trips that I did not attend, 'it'll be too hard for Leah'. I fight it. I fight the nervousness and remind myself that this activity is purposeful, I remind myself that moving away from one another is good, is meditative, is not exclusionary, is not them 'walking away' from me. I fight it and begin to feel

it fall away. I see Terry's red hooded figure make its way out of a woods and across the meadow. I sit and feel peaceful and consider what to do next, where to go. I feel a responsibility to wait, know that we'll move soon into the next chapter or phase of this exercise, that we'll do it together as a group, a threesome... or foursome, as somehow the dog has earned a role in this. Perhaps in my mind only.

The embodiment for me in this exercise emerges out of pain, discomfort that lives within me most of the time, every day. It is a sensation that I know well and have come to a place of not minding so much. My pain, my discomfort is transforming into something of a strength. Rather, I'm finding a place for my mobility, ability. I'm not sure if the right word is strength; I'm finding a place for the two to co-exist. Co-exist because the weakness, the discomfort, the strange pleasurable pain in my legs as they wake up, the connection that they hold to kidney disease, the lightness in my head due to the familiar feeling of chronic low blood pressure - made worse by dialysis. Physical weakness. These will be ever present within my body. But I've identified strength somewhere in there, as I begin to anticipate finishing this walk - completing a physical task. It's not the same strength that Andy and Terry have, twirling yesterday in the meadow, I felt a tension fill my body. Don't grab me, don't include me, and put forth my humourous-grump character, relaying the message that 'I'm not doin' that...'. Don't ask me to move fluidly. I might fall. I might fall and do something. I don't know what. Look foolish? Not be able to, maybe? I don't know. Just don't do it. It's a quiet, patient strength, one that isn't about might. Rather it's about understanding this illness, what I can and cannot do to help myself, that this knowledge is translatable and provides me insight into others' experiences of illness.

This walk is enough. My body oscillates as I write, vibrating with the energy it has expended. A satisfaction moves through me for having succeeded in movement, a good movement. Not the same endurance of a fifteen mile hike like that of my father, my brothers. But one that satisfies. I have earned this rest, this hot tea, this folded futon that I'm sitting on as I write, my sheepskin slippers hugging my feet.

What's Next: Implications for This Inquiry

Patient Agency

For me, agency surfaced as a result of objectifying my diagnosis - via the ABR outcomes of narratives and, especially, the film *Good Grief*. This means that, rather than perceiving ESRD to be who I am, via this intentional engagement, ESRD became a separate entity that has happened *to* me. This dynamic speaks to Leavy's (2009) concept of 'replotting'. ESRD became an experience that was represented through the writing and the film, in which I intentionally and knowingly opted to not show my face. I wanted to represent ESRD, blurring my own identity for purposes of others accessing this experience as potentially similar to their own.

For me, agency crystallizes as one becomes more aware of the potential for self identifying from a 'passive' perspective, a perspective where illness and treatment becomes inevitable and void of choice, something that is known of dialysis patients because of their reliance on life-maintaining treatment - to an actively engaged perspective. Keisinger's (Ellis & Bochner [eds.], 2002) piece that I discuss earlier in this chapter reminds me of the victim identity that at times drives autoethnography in a direction that is inaccessible and unproductive. Rather, as we revisit our illness narratives, perceived illness identity, or choice to engage with illness, shifts and transforms.

It would be irresponsible to not add that agency comes and goes for me as an ESRD patient, is not a consistent state. Agency is tapped by illness events that occur randomly and suddenly: urgent visits to day surgery, repeated angioplasties that maintain my dialysis site, a systemic infection that suspended my transplant status for a year. Rather, I believe that *having accessed agency* - via this study, via interviewing other patients, via gaining additional knowledge on ESRD - will mark these interrupting experiences when they surface and inform how I manage them.

Relationship Between Patient Perspective Inquiry and Autoethnography to Health Related Knowledge Translation

The question has arose that the term 'knowledge translation' inadequately describes how knowledge emerges via lived experience research, and this will be considered. Rather, lived experience inquiry seems to 'synthesize' clinical knowledge into day-to-day functioning terms. The knowledge translation relevance of this inquiry has to do with behavioural change and Gillard et al.'s 'expertise of experience' (2012) that includes the patient as part of research creation, and not simply a participant. It suggests that behavioural knowledge, possessed by the patient needs to be further explored by physicians and other medical professionals. In my case, ample knowledge was synthesized with the learning about self-administering my own dialysis treatments. This type of knowledge synthesis speaks to patient and medical learning potential that exists within methodologies that are patient perspective centered.

Relevance of Drama Therapy Concepts (Autobiographical Process, Embodiment, Role and Witness) to Autoethnographic Illness Based Research

The concepts of autobiographical process, embodiment, role and witness (Emuhah, 1994; Jones, 1996; Landy, 1986) fall neatly alongside the methodological literature on autoethnography and performance autoethnography due to the common denominator of the body's role in knowledge synthesis and change. The primary goals of these concepts are therapeutically driven, at the heart of which is the knowledge that embodying new knowledge begets change, begets healing. Paralleling, similar, concepts have been presented within this inquiry as known concepts within both Neimeyer's Meaning Reconstruction Model as well as the methodological literature about the body being a central site for knowledge discovery (Neimeyer, 2001, 2002; Spry, 2001). Drama Therapy, to date, exists minimally within empirical research, yet its core concepts are shared outside of creative arts therapy parameters. Neimeyer's theory tells us that if we can apply a sense-making meaning to the pain of loss, then we can begin to heal. This study suggests that part of meaning emergence has to do with embodying what new meaning feels like, in terms of day-to-day function and interpersonal relating. There is a place for these core concepts in further qualitative health research about the lived experience of illness.

Clinical Relevance of Patient Perspective Research

This study has made use of patient perspective research and illness autoethnography in order to shed light on the lived experience of kidney transplant loss and dialysis of the ESRD patient. It has taken in and presented the quality of life literature about this population and presented data that is seen as clinically relevant to physicians attempting to decipher depression, anxiety and suicidal ideation among this patient group. Data such as the data produced here further delineates how depression surfaces, what it 'looks like', and what contributes to its

emergence. This includes that perceived meaning is associated with how suffering is experienced and dealt with, that depression is part of the psychological arc of digesting the reality of lived illness, and that interpersonal dynamic is relevant to identifying the (almost inevitable) contextual depression that accompanies the dialysis experience. It also provides an additional layer that helps us understand what depression 'looks like' and how it emerges contextually.

Infiltrating Qualitative Medical Research with Patient Perspective Using Autoethnography

Qualitative health studies often necessarily objectify patient involvement with questionnaires and surveys. While the use of objectively gathered data is certainly valuable, autoethnographic patient perspective involvement in health research, adds valuable subjective, reflective and evocative data relevant to variables such as language use and physician-patient dialogue, the relationship between space and wellness and psychological health and family involvement (Gillard et al., 2012). Health related knowledge translation, or synthesis, is reliant on changes in patient behaviours that affect health outcomes. Rethinking how qualitative health research takes place may be an important variable in patients' synthesis of such knowledge.

Conclusion - Final Words

So... are you back on the transplant list now?, my friend asks me during recent a visit home. Because now that you're finishing your PhD, she continues, you can concentrate on that, yes? I take this in as we walk on a wooded path with our dogs. It's a misty, typical Newfoundland summer day. We're in our windbreakers, but at the same time are overheated in the humidity, making for some discomfort. The dogs trot ahead and we can hear their panting as they weave on and off of the path, eagerly seeking out something to chase. I have to be at the

hospital dialysis unit for 4 for my treatment and this sits in the back of my thoughts too, keeping an eye on time.

No, I say simply, mildly irritated at the question, perhaps unwarranted. That's not how it works. Transplants don't 'just come'. My antibody level is high. I'm a difficult match.

Right, she responds quietly. Right.

I'm thinking now that I have reframed within me how I perceive the notion of a transplant. Have done my best to 'normalize' dialysis in my day to day life. To some degree, I try not to think about having a transplant - it's not something I have any control over, after all. Yet, I also know that my life-span prognosis will be greatly assisted with a transplant at the same time. To another degree, I am motivated to focus on transplant policy in Canada, to lobby for legislation that assumes donation after death. I guess this motivation has stemmed from this study, by engaging with my inevitable condition. It's a difficult negotiation, one that forces me to think about my death, if only momentarily. I realize that this fact is perhaps why I feel irritated when I'm presented with questions like this one. This moment, I think as I walk slowly beside my friend, this is a moment in which grief is present...and will always be. This moment is a concrete, lived, example of how the difficulties associated with illness co-occur within everyday life moments. It is also a reminder to me that accommodation, Neimeyer's notion of how complex grief resides within us, is also ever-present in negotiations like this one.



As I've discussed meaning, for me, emerged a number of ways. Again referring to Leavy's (2009) components for meaning emergence, I found myself intentionally making use of and analyzing data according to emergence of *coherence*, where greater clarity and understandings of my illness related life events came forth. The narratives became the first step within the ABR process and towards the ABR outcome. Focusing on the simple lived

experience of illness was part of this emergence. Focusing objectively on components like medication, prednisone and its effect on my body and emotion, accessible hospitals, limited freedom when it comes to dialysis and the darkness of depression, allowed for a deeper understanding of my own lived experience of this disease. Time and continuous reflection was necessary in order to locate objectivity within these subjective lived experiences.

Another component of meaning emergence for me was when *turning points* surfaced in the data, or new directions the narrative took that were positive or healing. My decision to pursue an autoethnographic, arts based inquiry was a radical turning point that emerged from this process. This experience has been healing, self-informing and transparent in ways that more conventional styles of inquiry would not have been.

The final component of meaning emergence occurred via the surfacing of new plots - or as Leavy puts it, *replottings* - in my narrative. One of these involved a solidifying of the reality that meaning emerges out of a co-experiencing of pain and joy. Pain and suffering crystallizes micro moments where joy and contentment can be experienced, moments that remain accessible even with the limitations of illness.

Another plot to this outcome underlines the reality that meaning in relationship is reliant on context and intimacy. My relating to other patients produced different feelings of empowerment and knowledge than did my exchanges with family and friends, for example. My narratives involving family were informative, adding coherence to my illness narrative by clarifying the story for me and confirming events that were unsure for me. They accomplished this simply by relaying their perspectives and experiences, after which it began to merge with my own. My sibling's adjustment to my dramatically changed appearance due to steroids for example or my mother's narrative of a dialysis crisis as a child, very nearly resulting in my death

and pulling her away from a normal supper time preparation. Or my brother's experience of learning more about me and my illness subsequent to my moving to Montreal and taking an apartment in his neighbourhood.

My lived experience of chronic progressive illness, ESRD, required intentional engagement with my illness narrative in order for me to access and acknowledge shifting and emerging meaning, when and how and with whom it occurred. ESRD, chronic illness, for me, is very much like complex grief, or the grief process that manifests from traumatic and unexpected loss, like homicide or suicide, never truly accepted but, rather, tolerated and incorporated into one's existence and behaviour (Neimeyer, 2010). Neimeyer's concept of accommodation rings true as the way in which I deal with my illness-related grief. Not surprisingly, I'd have chosen not to have ESRD and all that accompanies it – were it up to me. But given that I cannot change this reality, I will work at accepting that feelings of grief are ever-present - sometimes more so than others - and that I'll have to accommodate this illness into my living and my relationships. This dynamic will inevitably mark those around me, as I present them with fragments of this illness narrative. My illness presents me with contextual struggles, such as acute conditions requiring procedure that interrupt my life momentum (work, family and social roles that are unique to me). These interruptions will produce psychological distress, like depression or self-questioning of my life's value and survival. They will mark my perception of my life value. They have. Accommodation does not extinguish grief. It negotiates with it. It dances with it. Sometimes I lead the dance. Sometimes I'm led.

Lastly, I'll note that the intentional engagement with illness and the grief of illness has brought forth, for me, a degree of 'temporary' expertise in what it means to live with End Stage Renal Disease. Understanding a broader spectrum of what health outcomes mean for me,

through layering of this narrative and by intimately investigating what it means to engage with my own self care, has changed my own health behaviours, creating agency within me that marks how I deal with this life-long and complex health condition.

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Appendices

- Appendix A Study Description for focus group
- Appendix B Study description for individual interviews
- Appendix C Concordia Consent- for family and social system participants
- Appendix D Memorial University Health Research Ethics Authority Consents for patient interviews and focus group
- Appendix E Concordia Consent for Patient Participation in Research
- Appendix F Semi Structure Questions for family and friends
- Appendix G Questions for patients Questions for focus group

Appendix A

Study Description for focus groups

This study is autoethnographic. This means that it is an analysis of lived experience from the researcher's perspective. In this investigation, I'm focusing on the lived experience of End Stage Renal Disease, Hemodialysis treatment and kidney transplant loss. You have been asked to because of your first hand experience and knowledge of Kidney Disease and hemodialysis. As someone with a lived and day to day knowledge of this illness, your participation will offer a wider perspective of quality of life themes [ie. life meaning] and issues that are associated with ESRD and will contribute to the outcome of this study.

From a quality of life perspective, the intent of the study is to provide a deep and rich description of what it means to live day to day with End Stage Renal Disease. This will contribute to the understanding of psychological health among patients with this condition.

Lastly, this study will also explore ESRD as a grief experience. It will consider how perceived life meaning is affected by dialysis and transplant loss.

Your participation in this study will be kept completely confidential. This means that your identity will not be released at any point in the process and that any information that surfaces in the final outcome will not be identifiable.

Thank you for your time and contribution to this work.

Leah B. Lewis
Concordia University
School of Graduate Studies
leahbridgetlewis@gmail.com
514-293-6695

Appendix B

Study Description for individual interviews

This study is autoethnographic. This means that it is an analysis of lived experience from the researcher's perspective. In this investigation, I'm focusing on the lived experience of End Stage Renal Disease, Hemodialysis treatment and kidney transplant loss. You have been asked to take part because of your role in my life, as either a member of my family or social system. As someone with a relational understanding of this illness, your participation will offer a wider perspective of quality of life themes [ie. life meaning] and issues that are associated with ESRD and will contribute to the outcome of this study.

From a quality of life perspective, the intent of the study is to provide a deep and rich description of what it means to live day to day with End Stage Renal Disease. This will contribute to the understanding of psychological health among patients with this condition.

Lastly, this study will also explore ESRD as a grief experience. It will consider how perceived life meaning is affected by dialysis and transplant loss.

Your participation as part of this focus group will be kept confidential in the study outcome. This means that your identity will be kept private.

Thank you for your time and contribution to this work.

Leah B. Lewis
Concordia University
School of Graduate Studies
leahbridgetlewis@gmail.com
514-293-6695

Appendix C

Study Consent for family and friend participants:

CONSENT FORM TO PARTICIPATE IN RESEARCH

For individuals

CONSENT TO PARTICIPATE IN

Good Grief? Meaning making through an illness narrative A study of grief in end stage renal disease [ESRD]

I understand that I have been asked to participate in a program of research being conducted by Leah Lewis of Creative Arts Therapies and Applied Human Sciences faculties of Concordia University, leahbridgetlewis@gmail.com, 514-507-6089, Dr. Stephen Snow, Creative Arts Therapies, ssnow@alcor.concordia.ca, x4641 and Dr. Warren Linds, Applied Human Sciences, w.linds@sympatico.ca, x2203

A. PURPOSE

I have been informed that the purpose of the research is as follows:

This study is a personal story-based (autoethnographic) investigation about the lived experience of End Stage Renal Disease, losing a kidney transplant and hemodialysis treatment. It is seeking to analyze the way in which these experiences affect life meaning; in particular how the perception of life meaning is created within the context of a relationship and illness-related loss, either family or social or shared experience, such as patient-to-patient.

B. PROCEDURES

- *I understand that my participation will involve a single one on one interview in a private setting, lasting approximately one-two hour*
- *I understand that this study's aim is to look at how the experiences associated with ESRD are like grief*
- *I understand that I will be asked questions about the impact of the author's End Stage Renal Disease [ESRD] diagnosis on our relationship*
- *I understand that some of the questions may elicit emotional response, either positive or negative*
- *I understand that I may be asked for a second interview*
- *I understand that, at any point before during or after the interview, I may decide to be removed from this study*
- *I understand that my identity in the outcomes of this may not be confidential. This means that my relationship with the researcher may be recognizable in the final outcome.*
- *I understand that all material collected for this study will be destroyed after **one year***

C. RISKS AND BENEFITS

- *I understand that, given that the goal of this study includes investigating the perceived meaning associated with illness experience via relationship interaction, I may experience some topics explored as challenging or emotionally overwhelming.*

- *I understand that this exchange will be via conversational semi-structured interview about the dynamic of my relationship with the researcher, Leah Lewis.*
- *I understand that, because of the unique nature of the investigation and the small number of participants, I realize that some identifying information will be revealed in the final results of the study.*
- *It is, therefore, necessary that I understand the above risks prior to agreeing to take part in this investigation.*
- *I understand that, because of my acknowledged intimate relationship with the researcher, I know that I may encounter feelings of obligation or coercion that might impact any desire I might have to opt out of this study. Even so, I should feel comfortable choosing to opt out without consequence.*
- *This said, my experience of the interview process may also elicit a deeper or more profound experience of meaning within relationship, as well as feelings of active contribution to patient experience inquiry.*

D. CONDITIONS OF PARTICIPATION – please check box in order to indicate understanding

I understand that I am free to withdraw my consent and discontinue my participation at anytime without negative consequences.

I understand that my participation in this study is purely voluntary and that my input will be NON-CONFIDENTIAL (i.e., my identity, or elements of it, will be revealed in study results)

I understand that, even though I am agreeing to take part in this study, it is my right to choose how much I decide to disclose at any point during this interview process.

I understand that the data from this study may be published.

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS AGREEMENT. I FREELY CONSENT AND VOLUNTARILY AGREE TO PARTICIPATE IN THIS STUDY.

NAME (please print) _____

SIGNATURE _____

If at any time you have questions about the proposed research, please contact the study's Principal Investigator. If at any time you have questions about your rights as a research participant, please contact the Research Ethics and Compliance Advisor, Concordia University, 514.848.2424 ex. 7481
ethics@alcor.concordia.ca

Study contacts: Dr. Stephen Snow, C/O Creative Arts Therapies, ssnow@alcor.concordia.ca, 514-848-2424, ext. Dr. Warren Linds, Applied Human Sciences, w.linds@sympatico.ca, 514-848-2424, ext. 2203

Leah B.Lewis, Creative Arts Therapies/Applied Human Sciences, 514-507-6089

Appendix D

Study Consent for patient participants: HREA and MUN versions



CHECKLIST

*This checklist is to be completed and submitted with this consent form.
It is to be removed from the final version of the consent document.*

- X Most recent version of consent template (November 2011) has been used
- X Footer includes consent version, study name, line for patient initials
- X Font size no less than 12 [except for footer]
- X Left justification of text
- X Grade 9 or lower reading level. Assessed reading level is: _____
- X Accepted definitions for specialized terms used where applicable
- X Plain language principles used for study specific wording – no jargon, no acronyms, short words, short sentences, active voice and, where appropriate, bulleted lists

Standard, required wording (in bold type) has been used in the following sections:

	Yes	No
Introduction	X	
Benefits (Q6)	X	
Liability Statement (Q7)	X	
Privacy and confidentiality (Q8)	X	
Questions or problem (Q9)	X	
Signature page	X	
Signature page for minor/assenting participants if applicable	n/a	

If you have answered No to any of the above, please give the rationale for these changes below:

TCPS2 guidelines provide a list of the information required for informed consent. Please refer to TCPS2, Chapter 3, available at: <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-epc2/chapter3-chapitre3/>.

The HREB Policy Manual provides detailed information on specific consent issues including: consent to research in emergency health situations; the use of substitute decision makers; assent for children; research involving special populations (children, cognitively impaired); managing consent in situations of difficult power relationships; and community consent to research involving Aboriginal communities. Please refer to the HREB Policy Manual on the HREA website: www.hrea.ca

Appendix E



Consent to Take Part in Research For dialysis patients

TITLE: Good Grief? Meaning making through an illness narrative

INVESTIGATOR(S): Leah Lewis, PhD Candidate

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. You can decide not to take part in the study. If you decide to take part, you are free to leave at any time. *This will not affect your dialysis treatment.*

Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:

- discuss the study with you
- answer your questions
- keep confidential any information which could identify you personally
- be available during the study to deal with problems and answer questions

1. Introduction/Background:

You have been invited to take part in this study because you are a person with End Stage Renal Disease and you are receiving hemodialysis treatments. Following the review of other studies from around the world about kidney disease and dialysis, information regarding the quality of life and psychological health of hemo dialysis patients was discovered. Dialysis

patients experience depression and consider suicide more than the normal population. Some dialysis patients choose to withdraw from dialysis and it isn't really known if such decisions have to do with depression or not, because sometimes the symptoms of kidney disease itself look a lot like depression. This study, which is being conducted by a researcher who is also a dialysis patient, will hope to add to the information that is already known about depression, suicide and reasons for withdrawing from dialysis treatments, by making use of the patient's perspective of how kidney disease affects how you feel emotionally in your day to day life as a dialysis patient.

2. Purpose of study:

The purpose of this study is to help psychologists, kidney doctors and other patients, have a deeper understanding of the emotional and psychological experiences that accompany kidney disease, losing a transplant and hemo dialysis treatments. The researcher herself is a dialysis patient who has experienced transplant loss and this fact is central to the study

3. Description of the study procedures:

Your participation, if you choose to take part, will involve participating in a one-time focus group discussion, lasting approximately 2 hours. The discussion group will talk about the experiences of being a kidney disease patient and being on hemodialysis. Other dialysis patients will be present at the same time. The researcher conducting the study will act as moderator. The researcher who will be moderating the group is herself a hemodialysis patient who has experienced transplant loss. The researcher will guide the discussion using a loosely structured list of questions.

The discussion group will be recorded. The content of the recordings will be analyzed for themes of loss and life quality as it relates to having kidney disease and being on dialysis. The outcomes of these analyses will become part of the researchers doctoral dissertation and accompanying publications in academic journals.

No identities will be revealed and all input will be generalized in any documented outcomes of the study.

Knowing this:

- I understand that my participation will involve a single focus group [or group interview], lasting approximately two hours
- I understand that, with other kidney patients present, and because of that fact, full confidentiality may not be possible
- I understand that we will be asked questions about the impact of the End Stage Renal Disease on quality of life, relationships and feelings of loss
- I understand that some of the questions may elicit an emotional response, both positive or negative
- I understand that, even if I choose to take part in this group, I am only required to share as much as I am comfortable with
- I understand that the focus group will be recorded

- I understand that my identity will not be revealed in the final outcome of this study,
- I understand that all material collected will be destroyed after **one year**

4. Length of time:

Your participation will involve a single one-time involvement in a focus group discussion. The length of the group will be a maximum of 2 hours.

5. Possible risks and discomforts:

Some minimal risks are possible with this study:

- Because this is a study on End Stage Renal Disease, and you are being asked to take part because you are an ESRD patient, your diagnostic status will be revealed
- Because this is a study on the emotional health and psychology of ESRD, you will be asked to discuss emotional challenges and difficulties involved with ESRD and dialysis. This might be experienced as overwhelming or difficult and elicit feelings of sadness or loss
- Because the participants of this study are being recruited from the same unit, there is a strong likelihood that you will know or be familiar with others taking part in the group, which might contribute to feelings of awkwardness
- Because focus groups necessarily involve participation of others you might know, your participation cannot be fully confidential. In other words, your identity will be known to others in the group.
- Because the focus group discussion is being recorded, it will not be possible to omit your voice afterwards. That said, your contribution to the discussion will be anonymous and not identifiable in final outcomes of this study and your dialysis unit name and location will also not be identified.

If there is potential risk that a participant would be emotionally disturbed, the investigator must be qualified to deal with this situation or must describe the procedure for immediately addressing the situation. A list of professional supports is provided below in the event follow up is desired:

- Lemarchant House, Eastern Health, 777-5622
- Pat Rose Psychological Counselling and Workplace Wellness, 754-5533
- Alanna Greene, MSW, RSW, 765-6117

6. Benefits:

It is not known whether this study will benefit you.

7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. What about my privacy and confidentiality?

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However it cannot be guaranteed. For example we may be required by law to allow access to research records.

Two copies of this consent will be signed. One will be filed by the researcher and protected by key until such a time that all data pertaining to this study is destroyed on one year's time. The second copy will be yours as a record of your participation.

Regarding participating in a focus group, it is important to note that:

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However it cannot be guaranteed. Other people taking part in this focus group may know your name and hear your comments.

All members of the focus group will be reminded to:

- Respect the privacy of each member of the group
- Treat all information shared with the group as confidential

When you sign this consent form you give us permission to

- Collect information from you shared in the context of a focus group discussion
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

Use of your study information

The research team will collect and use only the information they need for this research study.

This information will include your:

- Medical conditions – Your status as an ESRD patients who has experienced transplant loss
- Information from study interviews and questionnaires – Focus group discussion of ESRD patients who have experienced renal transplant loss

Your name and contact information will be kept secure by the research team in Montreal, Qc. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

Information collected for this study will kept for five years (one year).

If you decide to withdraw from the study, the information collected will be destroyed, meaning your contributions to the focus group will be omitted.

Information collected and used by the research team will be stored in *Montreal, QC, in the primary researcher's computer, under password protection.*

Leah Lewis, PI for this study, is the person responsible for keeping it secure.

Your access to records

You may ask *Leah Lewis* to see the information that has been collected about you. Any information, or data, will be in the form of transcripts created from the discussion group.

9. Questions or problems: Principal Investigator's Name and Phone Number

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is: Leah Lewis, Concordia University School of Graduate Studies, Montreal, Qc., email: leahbridgetlewis@gmail.com, 514-293-6695 or in NL at 709-726-0834

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Ethics Office

Health Research Ethics Authority

709-777-6974 or by email at info@hrea.ca

10. Declaration of financial interest

The investigator, Leah Lewis, is receiving no financial recompense for any aspect of this study.

After signing this consent you will be given a copy.

Signature Page

Study title: *Good Grief? Meaning Making Through an Illness Narrative*

Name of principal investigator:

To be filled out and signed by the participant: Please check as appropriate:

- | | | |
|--|---------|--------|
| I have read the consent <i>and study description</i> | Yes { } | No { } |
| I have had the opportunity to ask questions/to discuss this study. | Yes { } | No { } |
| I have received satisfactory answers to all of my questions. | Yes { } | No { } |
| I have received enough information about the study. | Yes { } | No { } |
| I have spoken to <i>Leah Lewis, study PI</i> and he/she has answered my questions | Yes { } | No { } |
| I understand that my identity will remain anonymous | Yes { } | No { } |
| <ul style="list-style-type: none"> • That because my voice is being recorded in a group setting, it cannot be withdrawn afterwards • That my name will not be revealed in final outcomes • That the location of my dialysis unit will not be revealed in final outcomes | | |

I understand that it is my choice to be in the study and that I may not benefit. Yes { } No { }

I understand how my privacy is protected and my records kept confidential Yes { } No { }

I agree to be audio taped Yes { } No { }

I agree to take part in this study. Yes { } No { }

Signature of participant Name printed Year Month Day

Signature of witness (if applicable) *Name printed* *Year Month Day*

To be signed by the investigator or person obtaining consent

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of investigator Name printed Year Month Day

Telephone number: _____

If this is to be printed as a double-sided signature page, the parental consent should be on the front and the minor assent on the back.

Parental consent is NA to this study.

Appendix F

Semi-Structured Interview Guide For family and social systems

This study is autoethnographic. This means that it is an analysis of lived experience from the researcher's perspective. In this investigation, I'm focusing on the lived experience of End Stage Renal Disease, Hemodialysis treatment and kidney transplantation. You have been asked to take part because of your role in my life, as either a member of my family, or my social system.

1. What is your understanding of Kidney Disease and hemodialysis?
2. Can you describe our relationship?
3. What has your experience been of kidney disease been through your relationship with me?
4. How has the presence of kidney disease informed our relationship?
5. Can you describe any memories you might have of the presence of kidney disease in our relationship?
6. What meaning do you associate with the existence of kidney disease in our relationship?
7. How has our relationship evolved in terms of the presence of kidney disease?
8. What role might grief play in the presence of illness in our relationship, if any?
9. What challenges has the presence of illness brought to our relationship? What benefits?
10. Is there anything you'd like to add?

Appendix G

Semi Structured Questions for patient focus groups

1. We are a group of people who share the experience of End Stage Renal Disease [ESRD]. Sometimes it is referred to as Chronic Kidney Disease or Kidney Disease. We also share the experience of having lost a renal transplant and of engaging or re engaging with hemodialysis treatment. Let's begin by generally describing the experience of being an ESRD dialysis patient.
2. I am interested in life quality and life meaning as perceived by dialysis patients. In what ways does ESRD affect your quality of life?
 - a. Your day to day functioning?
 - b. Your mood?
 - c. How you perceive the future?
3. Many dialysis patients experience multiple [sometimes unplanned] medical interventions, such as angioplasty, site surgery or hospitalization.
 - a. Is this something you've experienced? If yes, what procedures?
 - b. In what ways do these experiences enhance or weaken the meaning you apply to your life?
4. In what ways have you accommodated, or made room for, dialysis in your life?

I'd like to thank you for taking part in this focus group. This discussion will contribute significantly to this study. I'll remind you again that your participation is confidential. You will not be identified in any way in the final document of this study.

If you have further inquiries, please feel free to contact me:

Leah B. Lewis

leahbridgetlewis@gmail.com
514-293-6695