STORIES OF LIMINALITY:

A NARRATIVE INQUIRY INTO

THE EXPERIENCES OF

ELEMENTARY TEACHERS

WHO TAUGHT A STUDENT

WITH A CHRONIC ILLNESS

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ABSTRACT

     This narrative inquiry explores the curriculum making experiences and stories of three teachers - Claire, an early childhood educator, Rita, a middle years teacher, and Leah, a primary grades teacher - who taught students with a chronic illness. The research wonders of this thesis asked the following questions: what does it mean to engage in the curriculum around chronic illness? How do the teachers influence such a curriculum? What is the teacher's position within it? Do they experience a shift in knowledge, awareness, perception, or practice while engaged in this curriculum making?

     Derived from individual semi-structured interviews ranging from 25 minutes to one hour, a narrative account of each teacher is presented and inquired into within the three dimensional inquiry space, defined to include temporality, sociality, and place (Clandinin & Connelly, 2000). The concept of a curriculum around chronic illness is presented. This curriculum focuses on the active construction of lives shaped by a chronic illness. In this research, the curriculum around chronic illness required the negotiation, and sometimes renegotiation, of liminal spaces (Heilbrun, 1999). Liminality, found in the making of a curriculum around chronic illness, brought the teachers of this research to the peripheries of their students' worlds, where they learned, in time, to perceive their students and themselves wholly. The three teachers, through their unique positioning of their stories to live by, created new forward-looking stories (Nelson, 1999) that guided their teaching; stories marked by inclusion, community, loving perceptions, and care.

Keywords: curriculum, narrative inquiry, liminality, playfulness, chronic illness, world-traveling

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INTRODUCTION

Following the tradition of narrative inquiry, this document opens with a narrative beginning of my experiences with chronic illness and explores ideas between and among curriculum making and chronic illness. It examines concepts and ideas relevant to this research and looks at the theoretical justification of this work. This chapter also contains a review of the literature pertaining to chronic illness in schools and details the unique positioning of this research study among the literature in this subject.

Chapter 2 examines the research methodology and methods used in this study and outlines critical narrative concepts. Chapters 3 and 4 explore the experiences of the teacher participants and draw out narrative threads from their stories. These two chapters were written as stand-alone and publishable papers intended for submission to scholarly journals. Chapter 5 offers a brief historical perspective and its relation to the ethic of care (Noddings, 2002). It also contains a summary, a reflection of my experiences in the research process, revisits key terms from the document, and returns to the research wonders of this research.

CHAPTER ONE.
SEEING REFLECTIONS: NARRATIVE BEGINNINGS AND CONTEXT

Narrative Beginnings

It was my first year on the substitute list and I was slowly getting used to the perpetual uncertainty of a life as a substitute teacher. Walking into schools with no idea of the events to come, the things I had to teach, or the people I would meet became a normal, albeit sometimes anxiety-filled, routine. One spring day, at a highschool I often worked at, we were shuffled into the gym for an assembly regarding the spring Relay for Life[1] events at the school. I stood at the back with the other teachers as a video started playing over the projector system. No one had informed me of the subject matter of the assembly until this video started. In this video sponsored by the Canadian Cancer Society, cancer survivors and family members of those affected by it were expressing their views about this illness. They spoke about the disease as if it was first person, i.e. "you destroy families, you destroyed mine" "I hate you," "you can't take away anymore," and so on. Their words froze me. I was immobilized by their stories, stories so similar to mine that I saw a reflection of myself. I was no longer the looked at, but the onlooker; a spectator to my own story. I wanted to leave, but my position as a teacher obliged me to stay. As I was fighting these rising emotions, I wondered what I was supposed to do. I was curious if the other teachers were having as many problems. I looked around and found them stoic and refined and I dolefully wondered what was wrong with me.

After the assembly ended, I again thought about what I was supposed to do next. As students slowly trickled back into my class with red, puffy eyes and some trying to hide their sniffling, I wondered where I stood. How could I deconstruct this? Should I? Can I? What do I

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[1] Relay for Life is an all-night fundraising event initiated by the Canadian Cancer Society where teams walked around a track for 12 hours. There are often events and activities leading up to the official Relay for Life walk.

say? I remember the incredible unnamed tensions I felt at the time. I was a beginning substitute teacher, with a history of chronic illness, confused and uncertain about my position with these students I did not know well. I was in the midst of a multi-layered curricular landscape that I had not anticipated. It was my intention to live out my story as a beginning teacher and survive the day as a substitute teacher; perhaps even gain some insight into the world of teaching. I was expecting some uncertainty and unfamiliarity, but I certainly did not anticipate to be confronted with this particular narrative of chronic illness and sickness in this way.

As I began to imagine my graduate work, I wondered about the teacher's position alongside a child or youth within a curriculum of chronic illness. Special events, such as this one described here, were opportunities to instill passion and increase awareness in the student body, but I began to wonder about the daily events in this curricular subject. What was the teacher's role in these daily events and regular occurrences involving chronic illness in children or youth? When teachers have a child or youth with a chronic illness in their classroom, what did they do? In my situation, I did not have the capacity and was not expected to follow up with these students. I did not know what happened after I left that day and I still wonder how the students responded. Did they go home and think about what it could be like? Did they reflect on their own experiences? I also began to wonder about the teachers. How did they manage? These powerful moments have the potential to create a space for stories to be told and heard, but how could teachers create such spaces in the day-by-day routine of the class? How could they make room for the daily curriculum around chronic illnesses?

Defining Illness

To begin, the World Health Organization defines the term chronic illness to mean a "[disease] of long duration and generally slow progression" (WHO, 2012). The specifics of

duration depend on the context and location of the individual. Much of the literature stemming from the United States specifies that a chronic illness is a condition that lasts, or is expected to last, at least 3 months (Kaffenberger, 2006; McCarthy, Williams, & Eidahl, 1996; Perrin et al., 1993; Shiu, 2001; Thies, 1999). In this document, the terms "illness" and "disease" will be used interchangeably.

It is estimated that upwards of 20% of children in school will have a chronic illness of some form based on the above definition (Hamlet, Gergar, & Schaefer, 2011; Mukherjee, Lightfoot, & Sloper, 2000; Nabors, Little, Akin-Little, & Iobst, 2008; Phelps, 2006). Chronic illnesses prevalent among children include a broad range of diseases: asthma, cystic fibrosis, and other pulmonary conditions; eczema and other skin diseases; diabetes; cancers and leukemia; arthritis; Chron's disease and other gastro-intestinal illness; sickle cell anemia; allergies; AIDS and other immunodeficiency illnesses; kidney diseases; coronary heart disease and other cardiac diseases; and cerebral palsy, epilepsy, and other neurological disorders. The most common of these found among children were found to be asthma, eczema, and diabetes (Kaffenberger, 2006; Mukherjee et al., 2000). In Canada, around 15% of children between 4 and 11 are diagnosed with asthma (Public Health Agency of Canada, 2008). Diabetes was at 0.3% among children under the age of 19 years (Public Health Agency of Canada, 2009). Certain illnesses like epilepsy, cancer, congenital heart disease, and cerebral palsy each have rates of less than 1% (Mukherjee et al., 2000). This means that most schools will have one or more students with a chronic illness of some form. Overall, the rates of chronic illness in schools are rising as advances in medical technology and treatment increases the survival rate and allows families to manage a chronic illness effectively enough to live a relatively stable life (Hamlet et al., 2011; Maslow, Haydon, McRee, Ford, & Halpern, 2011).

Curriculum Around Chronic Illness and Research Wonders

In order to expand on what it meant to engage in a curriculum around chronic illness, I drew on Clandinin and Connelly's (1992) definition of curriculum as a course of life. Curriculum in this manner is an "account of teachers' and students' lives together in schools and classrooms" (p. 392). Teachers and children embody this movement; they live out the curriculum. Curriculum is composed and embedded in the lives of those involved. It is a course of life as lives are being lived. It is a curriculum of lives, of both teacher and student (Clandinin et al., 2006).

This curriculum of lives can entail all the daily happenings in the classroom and school, the events of the near or distant past, and the prospects for the future. This curriculum entails the four curricular commonplaces described by Schwab (1973): subject matter, milieu, learner, and teacher. It can comprise the interactions between a person and the environment, between people, between subject and person, and within a particular individual.

The curriculum making found in classrooms and schools is a curriculum of lives being storied and restoried. Viewing curriculum as this course of life, composing identities and stories to live by is central to making curriculum. Curriculum making is a form of identity making; a form of creating these stories to live by (Clandinin et al., 2006). Chapter 2 explores narrative concepts, such as stories to live by, more in depth.

When this definition of curriculum as a course of life is applied to chronic illness, curriculum making is undoubtedly influenced by the presence of such an illness. This curriculum shaped by a chronic illness is founded not on illness, but rather on the rich and complex lives around it. This curriculum around chronic illness focuses on living with a chronic illness and the active construction of a life story alongside it. In other words, the curriculum

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around chronic illness is a curriculum of lives shaped by a chronic illness. Engaging in such a curriculum is to engage in a curriculum of lives - lives and identities not to be overshadowed by the chronic illness itself.   Consequently, this research revolves around lives and explores the experiences of the teachers negotiating this curriculum around chronic illness by inquiring into the following wonders: What does it mean to engage in the curriculum around chronic illness? How does the teacher influence such a curriculum? What is the teacher's position within it? Do they see themselves shifting in knowledge, awareness, perception, or practice while engaged in this curriculum making?

Theoretical Justification: The Positioning of Illness

The medical definition of a chronic illness previously mentioned referred to a disease that persists longer than three months. However, there could be other definitions of chronic illness. These definitions relate to the perceived impact; the chronicity of the disease in the person's life (Martin & Peterson, 2009). Chronicity, in this sense, refers to the extent of the illness' prevalence and persistence in one's life (Charmaz, 1991). According to Charmaz (1991), people with a chronic illness or those close to them can experience the disease in three ways: as an interruption, as an intrusion, and as an immersion. Defining illness as an interruption entails a belief of that the illness is temporary, of short duration, and will ultimately lead to recovery. Illness as an interruption is seen as a temporary obstacle or something that caused a momentary break in normal life that will shortly be resolved. As an intrusion, chronic illness is seen as demanding continued attention and time and forces the person to make accommodations and changes in routines; it threatens the perceived control the person has over her or his life (Charmaz, 1991). When people became immersed in illness, they often structure their entire life around the illness. Illness and disability are constantly at the forefront of their thoughts and

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actions and their identity and self-concept revolve around the illness or caring for such illness (Charmaz, 1991). Whether an illness is defined as an interruption, intrusion, or immersion depends on the perception of the illness's power over one's life and may not be related to the severity of the disease itself (Charmaz, 1991; Martin & Peterson, 2009). In other words, how a person perceives the impact of the disease, how she or he came to define it, and how she or he positions it in her or his life story often played a role, if not a substantial one, in its impact on that life.

The people around the student with a chronic illness, such as medical staff, parents, teachers, and other students, may also develop their own definition of the illness. These definitions, however, are not necessarily based on the actual illness as being lived by the student, but rather can emerge from previous encounters with the illness (Brook & Galili, 2000; Charmaz, 1991). Generalizations and assumptions may run rampant as stories of chronic illness emerge and the chronicity of an illness can be highly influenced by the individual's social context (Martin & Peterson, 2009). Past exposure to the illness fundamentally affects the definition one holds of that illness. The definition an individual has constructed for the illness, stemming from a variety of experiences, may have major effects on their perception, potentially causing inappropriate reactions to such an illness.

Many children or youth with a chronic illness do not want the illness to consume their lives and identity (Charmaz, 1991; Ferguson & Walker, 2012). Many struggle in silence as they try to live as normal a life as possible and celebrate the moments they achieve such normalcy (Ferguson & Walker, 2012). Others embrace illness and weave it comfortably into their daily stories (Charmaz, 1991). Concomitant with the individual's positioning of the illness, teachers are called to negotiate the tension between prioritizing the uniqueness of the student and

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recognizing the impact of the illness on him or her. They may also be called to negotiate the various levels of chronicity that others and they may construct.

Literature Review and the Educational Meaning of Chronic Illness

As mentioned previously, the curriculum around chronic illness was defined to be fundamentally based on a curriculum of lives. Although there seemed to be a growing literature focusing on the resilience of students with chronic illness, for example see Ferguson and Walker (2012), the bulk of literature relating education and chronic illness is problem-focused and centred on deficits. These problems are not the focus of this present research thesis, but warrant a discussion. Thus, the following section will be a presentation of the major educational implications found in the literature related to education and students with chronic illnesses.

Supporting Student Needs

Although all students in a classroom require individualized support, students with a chronic illness have a highly specialized and unique set of personal needs. A study by Mukherjee et al. (2000) noted that students emphasized the need for teachers to have an accurate understanding and awareness of their individual needs in order to provide appropriate help. This result was echoed in other research (Brook & Galili, 2000; Eiser, 1980; Miller, 1995; Sexson & Madan-Swain, 1993). The school can play a strong connecting and normalizing role for students experiencing the disruptions caused by chronic illness, but can also be isolating and humiliating when student's needs are unable to be met (Ferguson & Walker, 2012). Additionally, there are other specific support needs that many students with chronic illness face. Although varied, these have been listed under three major categories: absences and non-participation, knowledge and training, and communication. This has been done to echo the over-arching themes and prevalent

topic areas found in the literature and to reflect the educational considerations relevant to this particular research thesis.

Absences and Non-Participation

A major concern identified by students, teachers, and families involve absences and non-participation (Clay, Cortina, Harper, & Cocco, 2004; Eiser, 1980; McCarthy et al., 1996; Mukherjee et al., 2000; Pinquart & Teubert, 2012; Shiu, 2001; Weitzman, 1986; Wilkie & Jones, 2010). Non-participation refers to the inability to participate in daily classroom or school routines due to their condition, such as fatigue or using a wheelchair. Although many students desire to maintain academic continuity with their schools, the uncertain and complex nature of chronic illness lends itself to high rates of school absences and non-participation (Ferguson & Walker, 2012; Maslow et al., 2011; Sexson & Madan-Swain, 1993; Thies, 1999; Wilkie, 2010; Wilkie & Jones, 2010). Although these statistics may improve as management of chronic illnesses improve, students with chronic illness are at a higher risk of educational troubles or failure than their peers due to their high absence and non-participation rates (Haas & Fosse, 2008; Maslow et al., 2011; Thies, 1999).

The type of absences being experienced may influence their management. Long term absences are often easier to manage, whether expected or not, because they are harder to ignore or minimize (Thies, 1999). However, the most common type of absences, primarily brief absences of a half-day, a full day, or a few full days, are more likely to go unnoticed in the busy schedule of a classroom. These types of absences can be unpredictable and deemed inconsequential. Consequently, the pattern of absences and the availability of support will influence the success of the student living with a chronic illness.

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An additional consideration in managing absences is the availability of educational resources. Students who miss considerable portions of school usually receive assistance via special education services of some form. The teacher may provide additional help to the student during non-class time to help them catch up to their peers. However, in the student's attempt to maintain a sense of normalcy, she or he may not speak out, or have the ability to speak out, in order to receive necessary support, opting instead to remain unnoticed (Ferguson & Walker, 2012).

School refusal rates for students with chronic illness are higher than that of their healthy peers (Sexson & Madan-Swain, 1993). However, children or youth who do not return to school as soon as they are able often have more difficulties reintegrating into the school environment (Kaffenberger, 2006; Katz, Varni, Rubenstein, Blew, & Hubert, 1992; Weitzman, 1986). The support or lack of a support a student anticipates influences the willingness of the student to attend school or return after a prolonged absence.

Since schools can create a sense of normalcy in lives filled with uncertainty and chaos, regular attendance can have positive benefits for the student's and family's well-being, both physically and emotionally (Kliebenstein & Broome, 2000; Sexson & Madan-Swain, 1993, 1995). The school and classroom may be the only place where a student is treated as a person and not a patient and teachers play a significant role in this form of normalization (Mescon & Honig, 1995; Shiu, 2001).

Knowledge and Awareness

Although some research indicates that teachers receive an appropriate amount of information and are in frequent communication with parents (Eiser, 1980; Hamlet et al., 2011), there is overwhelming evidence that teachers feel uninformed and require more information. A

breadth of literature relating to students with chronic illness in schools highlight a lack of knowledge, awareness, and training on the part of the teachers and school staff (Brook & Galili, 2000, 2001; Clay et al., 2004; Eiser, 1990; Irwin & Elam, 2011; McCarthy et al., 1996; Miller, 1995; Mukherjee et al., 2000; Olson, Seidler, Goodman, Gaelic, & Nordgren, 2004; Shiu, 2001; Silver & Stein, 2001; Thies, 1999). When teachers were not well-informed or did not take the time to understand the student's needs, many serious and embarrassing issues arose, such as being refused permission to use the bathroom and being forced to participate in physical activities they felt unable to manage (Mukherjee et al., 2000). There was also a wide range of areas that teachers felt they lacked sufficient knowledge and training. These are described below.

Many teachers and other staff were often generally uninformed about the illness or had inaccurate beliefs regarding the illness (Bozkaya et al., 2009; Olson et al., 2004). Many also hold inaccurate and potential harmful ideas of first aid intervention strategies for the chronic illness, such as placing an object in the person's mouth while they are having a seizure (Bozkaya et al., 2009). Conversely, the perceived risks associated with asthma and diabetes were frequently underestimated (Clark, 2003). Overall, when a teacher or school professional had more exposure and experience with a particular illness, they were more likely to have an accurate representation of the illness (Brook & Galili, 2000; Eiser, 1980; Olson et al., 2004).

Teachers also expressed concern about dealing with medical emergencies and provision of medical care (Kliebenstein & Broome, 2000; McCarthy et al., 1996; Mukherjee et al., 2000; Olson et al., 2004; Sexson & Madan-Swain, 1993, 1995). It was noted that the willingness of teachers to take on such responsibilities varied between and within schools, but they were overall willing to learn about the health care needs of such students (Brook & Galili, 2001). The

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reluctance of teachers to involve themselves in medical care emanated from concerns of personal liability, perceived lack of support, discouragement from other staff, perceived risk of harm to self and others, and lack of medical expertise (Mukherjee et al., 2000).

The availability of medical equipment needed by students with chronic illnesses and the appropriateness and accessibility of the school building were also noted as medical care concerns among teachers (Mukherjee et al., 2000). Teachers also may experience frustration and apprehension at their overlapping roles of educator, care-taker, and health-care provider (Clay et al., 2004; Kliebenstein & Broome, 2000).

Awareness of the impact of the illness on the student was a factor in determining the amount of support (Mukherjee et al., 2000). The level of support students received and the willingness of the staff to provide it was often related to the visibility of the chronic illness, for example, the use of wheelchairs or other physical disability (Mukherjee et al., 2000). Additionally, teachers reported concern over providing appropriate emotional support, adjusting to changes in behaviour, providing meaningful encouragement, recognizing and adjusting to learning difficulties, administering appropriate discipline, as well as, modifying classroom teachings and routines (McCarthy et al., 1996; Sexson & Madan-Swain, 1993, 1995). Opening lines of communication between schools, homes, and medical offices was recommended for assisting in educating teachers and school staff about the non-health related needs of the student (Eiser, 1980; Hamlet et al., 2011; Miller, 1995). Although it is impossible to account for every educational implication of every student with a chronic illness in school, specific training in the above areas and others during teacher education programs and teacher development programs has been recommended by teachers, administrators, researchers, nurses, parents, students, and

many others (Brook & Galili, 2000, 2001; Eiser, 1980; Kliebenstein & Broome, 2000; Mescon & Honig, 1995).

Teachers also reported concerns about the amount of personal effort required to accommodate the student. In the opinions of school professionals, chronic illnesses were perceived to have the largest impact on the teacher (Olson et al., 2004; Sexson & Madan-Swain, 1993, 1995). In one study by Olson et al. (2004), teachers expressed more concern over personal risk and liability and providing extra time and attention than the impact of the chronic illness on the academic performance and peer relationships of the student. The perceived time required varied with the type of illness. Although they had positive regard for the inclusion of students with chronic illnesses in their classroom, they reported having to take on additional workloads to help the student succeed (Brook & Galili, 2001; Olson et al., 2004). They were concerned that devoting additional time to this particular student would detract from their ability to meet the needs of other students in the classroom (Sexson & Madan-Swain, 1993).

Teachers also expressed concerns that could contribute to an overall feeling of anxiety: being overwhelmed and unable to cope with their own emotional needs; uncertainty about approaching the child or youth; tension when obtaining information from already stressed parents; distrust in such obtained information; concern over student's new vulnerability; lack of control; reactions of the student's peers; and a reluctance to challenge or discipline the student (Mukherjee et al., 2000; Sexson & Madan-Swain, 1993). Many teachers were willing to learn and participate in inservice programs designed to increase awareness of the particular chronic illness (Kliebenstein & Broome, 2000).

They also reported having lower scholastic expectations of the student and admitted to tolerating more behavioural and academic issues for this student in comparison to others (Eiser,

1980; Kliebenstein & Broome, 2000). Many teachers modified their lessons and teaching to accommodate the student quite well, while many others struggled with the balance of overprotecting and over-attending with minimizing and neglecting (Miller, 1995). Such tensions with the extent of modifications may be alleviated or exacerbated with the availability of educational resources (Sexson & Madan-Swain, 1993).

Communication

Students felt it was important that teachers and staff were in regular communication with each other in order to pass along appropriate information (Clay et al., 2004; Mescon & Honig, 1995; Mukherjee et al., 2000; Sexson & Madan-Swain, 1993, 1995; Wilkie & Jones, 2010). As mentioned previously, a lack of communication can result in many serious and/or embarrassing situations (Ferguson & Walker, 2012). Teachers and school staff may feel the need to withhold information or limit its dissemination due to privacy and confidentiality (Mukherjee et al., 2000). Further tensions regarding communication arose when the students were not with their regular teacher, such as during recesses, lunches, before school, after school, with new staff, and with substitute teachers (Miller, 1995; Mukherjee et al., 2000).

Students may feel it is important for teachers and other staff to be aware of their special needs, but may have difficulty or have an inability to explain their condition and pass along information (Brook & Galili, 2000; Mukherjee et al., 2000). Peers may ask questions of the teacher about the student living with a chronic illness (Mukherjee et al., 2000). Some students may want the teacher to explain their condition to other peers and some may not (Ferguson & Walker, 2012). The unique manner in which a student with a chronic illness interacts with others highlights the necessity for teachers to be in regular communication with the student, family,

teachers' union, and school board about issues of disclosure and privacy (Mescon & Honig, 1995).

The manner in which a teacher communicates with the student and others plays an important role in determining the impact of the chronic illness and the positioning of the student-teacher relationship (Young, Dixon-Woods, Windridge, & Heney, 2003). The school plays an immense role in normalizing and fostering the development of students with a chronic illness and teachers must negotiate tensions of finding a balance between viewing the student on the same plane as her or his peers and accounting for her or his unique circumstances (Ferguson & Walker, 2012; Miller, 1995).

Sources of Literature

The above research literature was found primarily through electronic databases such as Google Scholar, the University of Saskatchewan online library, ERIC, JSTOR, Academic Search Complete, ProQuest, and other such databases. The keywords and statements that were imputed into the search engines included a combination of the following: "chronic illness," "chronic disease," "students," "teachers," "schools," "educators," and "children." Reference lists of these articles were also used to find subsequent articles or books. Because of the overwhelming amount of literature in this field, I attempted to use peer-reviewed scholarly articles found in reputable journals. I also attempted to start with articles that proposed original data or new ideas from the past 5 years, but gave exception to seminal and other crucial articles that were referenced frequently in the literature.

Re-Envisioning Problems: The Place of this Research

Although there is a growing trend towards research that holistically focuses on the voices and experiences of their participants, most of the research mentioned above analyzes the lives of

students and teachers by asking their participants to use Likert type[2] scales and short-answer

questions. Data collection was done primarily through surveys and questionnaires. Interviews

are often highly structured. This form of data collection, although valuable for educational

research, may limit the rich and contextual nature of lives in school. It is important that teachers

and researchers consider the fullness and complexity of the lives involved in this research and in

the classroom. Negating this aspect risks taking apart these individual's experiences, reducing

their lives to lists, and generalizing complexity.

   As necessary as it may be for teachers to view students with a chronic illness as requiring

a unique set of educational considerations, it is equally as important to ensure that these

considerations do not overtake the teachers' perception of the student. Researchers and teachers

may view the student as more of a patient than a child, pathologized and problematized by the

illness. Problems experienced by chronic illnesses are important, but they are not the most

important piece. We, as teachers and researchers, recognize the diversity and difference that

exists among all students. We want students to do more than barely survive in school. We want

teachers of these students to do more than barely pull them through; to do more than teach them

a "bare bones" curriculum. Consequently, this thesis inquired into the events in the teacher

participants' past and imagined future and their interaction with their environment, leaving a

sense of openness and possibility while attempting to holistically understand lives in context. It

pushed against the grand narrative that over-prioritizes the curricular and educational problems

associated with chronic illnesses in the schools. Although such difficulties were explored, this

narrative inquiry looked at these struggles with a different lens, in a different context. This

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[2] A Likert type scale is a research format where responses are scored along a range. This range captures the intensity of the participants' feelings for the given item, for example "strongly agree" through to "strongly disagree."

present research viewed teachers and students as living through such problems and envisioned a

fuller meaning of the curriculum of lives shaped by chronic illness.

CHAPTER TWO.
METHODOLOGY AND METHODS

This study was a narrative inquiry. Using the following definition by Connelly and Clandinin (2006), this research attended to the lives, stories, and experiences of teachers who taught and lived alongside a child or youth with a chronic illness:

> People shape their daily lives by stories of who they and others are and as they interpret their past in terms of these stories. Story, in the current idiom, is a portal through which a person enters the world and by which their experience of the world is interpreted and made personally meaningful. Narrative inquiry, the study of experience as story, then, is first and foremost a way of thinking about experience. Narrative inquiry as a methodology entails a view of the phenomenon. There is a focal point, a phenomena in the present that draws our attentions, and as we open the floodgate, stories surrounding that focus become the portal to understanding that phenomena. To use narrative inquiry methodology is to adopt a particular view of experience as phenomenon under study. (p. 477)

Narrative inquiry occurs in the midst of storied lives and grounds the research in the experiences of the participants. It is the study of experience as both method and phenomena (Clandinin & Connelly, 2000). The experiences and stories of teachers who have worked alongside a child or youth with a chronic illness in their classroom were the focus of this research.

A Case for Narrative

Narrative inquiry was suited for this research because it allowed for the experiences and lives of the participants to flow naturally and holistically. In this research, lives were understood to be narratively constructed. As Bruner (2002) argues, "[w]e are a species whose main purpose is to tell each other about the expected and the surprises that upset the expected, and we do that

through the stories we tell" (p. 4). He further suggested that people become the autobiographical narratives that they tell about their lives (Bruner, 1987). People live and tell stories about their experiences. These lived, told, and talked about stories are ways in which people make meaning of and represent their experiences. Narrative captures this "inextricable tangle of necessity and freedom in human life" (Chambers & Montgomery, 1999, p. 77). We lead storied lives (Clandinin, 2006). Many psychologists, sociologists, and educators have affirmed the intimate connection between narratives and identity, with some arguing that our narratives are our identity (Alsup, 2002; Bruner, 1987; Bruner & Weisser, 1991; Gergen & Gergen, 1983; McAdams, 1993, 2001; Polkinghorne, 1991; Sfard & Prusak, 2005). In the words of King (2003), "[t]he truth about stories is that that's all we are" (p. 153).

Narratives have also become increasingly important in the study of chronic illnesses and in the medical profession in general (Charmaz, 1991, 2002; Hyden, 1997). Narratives of illness act as a means of understanding for patients and those close to them as they negotiate the tensions and disruptions in identity and meaning that chronic illness can produce (Bury, 1982; Hyden, 1997).

Narrative inquiry also exists in an open space of possibility, striving to "artfully hold open the beginning and endings of the narratives presented" (Pinnegar, 2006, p. 179). It focuses on the complexities and possibilities of the teacher participants told stories. The lives of the participants are complex and diverse and narrative inquiry allows their stories to remain open, rather than be reduced and objectified. This is an important consideration in a field of research that often itemizes and prioritizes the problems and challenges of teaching students with chronic illnesses.

Part of my work as a narrative inquirer is to describe the lives of my participants and create narratives of their experiences. This inquiry focused on the stories lived and told (Clandinin, 2006). Narrative accounts of such experiences are woven throughout this document. Although individual experiences were the starting point for this narrative inquiry process, the larger social, cultural, and institutional narratives are also considered; those that shape the way the individual experiences were constituted, expressed, and enacted (Clandinin, 2006). Using narrative inquiry allowed for an in-depth representation of the participants' experiences in order to address the research wonders of this project, primarily what did it mean to engage in the curriculum around chronic illness and what was the teacher's position within it?

Narrative inquiry also allowed a place for the experiences and lives of the researcher in collaboration with the participants. Researchers cannot remove themselves from the inquiry, but rather inquire into their experiences alongside their participants (Clandinin, 2006). As Silko (1997) reminds us, "[v]iewers are as much a part of the landscape as the boulders they stand on" (p. 27). Consequently, a brief reflection of my experience in this research process will be provided in the final chapter of this document.

Narrative Thinking

A term used for thinking about the lives of both the participants and the researcher in this research is the three dimensional narrative inquiry space (Clandinin & Connelly, 2000). Dewey's (1938) ideas of interaction, continuity, and situation provide the framework for this three dimensional space: *personal* and *social* (interaction); *past, present,* and *future* (continuity); and *place* (situation) (Clandinin & Connelly, 2000, p. 50). Using these terms, this metaphorical three dimensional inquiry space is defined to include "temporality along one dimension, the

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personal and social along a second dimension, and place along a third" (Clandinin & Connelly, 2000, p. 50).

Clandinin and Connelly also discussed the four directions of an inquiry along the dimensions of personal and social, also called sociality, and temporality to be:

> *inward* and *outward*, *backward* and *forward*. By inward, we mean toward the internal
>
> conditions, such as feelings, hopes, aesthetic reactions, and moral dispositions. By
>
> outward, we mean toward the existential conditions, that is, the environment. By
>
> backward and forward, we refer to temporality – past, present, and future. (p. 50)

To conduct research into an experience, the researcher is to "experience an experience" in each of the four directions simultaneously (p. 50). In reference to place, this last dimension referred to the dimension that "attends to the specific concrete physical and topological boundaries of inquiry landscapes" (p. 51). As a narrative inquirer, I worked in this three dimensional narrative inquiry space throughout the inquiry process. The following are some relevant narrative concepts addressed in the remaining document.

Professional Knowledge Landscape

The professional knowledge landscape has been used as a metaphor for understanding the structure and influences that shape the school. In the following passage, Connelly and Clandinin (1995) described this metaphor:

> A landscape metaphor is particularly well suited for our purpose. It allows us to talk
>
> about space, place, and time. Furthermore, it has a sense of expansiveness and the
>
> possibility of being filled with diverse people, things, and events in different
>
> relationships. Understanding professional knowledge as comprising a landscape calls for
>
> a notion of professional knowledge as composed of a wide variety of components and

influenced by a wide variety of people, places, and things. Because we see the

professional knowledge landscape as composed of relationships among people, places,

and things, we see it as both an intellectual and a moral landscape. (p. 5)

The landscape of the school can be influenced by a variety of factors in both in-classroom and

out-of-classroom places. In-classroom spaces referred to the safe places where "teachers [live]

out their stories of who they were and who they were becoming as they [interact] with children"

while out-of-classroom places were described as "prescriptive, professional places shared with

other teachers, and as places where teachers [are] expected to hold certain, expert knowledge"

(Clandinin et al., 2006, p. 6).

Teacher Identity as Stories to Live By

Thinking of curriculum making in relation to lives being storied and restoried on a

professional knowledge landscapes shapes a narrative understanding of teacher identity as

"stories to live by" (Connelly & Clandinin, 1999). Stories to live by "attend to the historical, the

temporal, the contextual, and the relational [and connects] teachers' personal practical knowledge

with their professional knowledge contexts" (Huber, Murphy, & Clandinin, 2003, p. 347). A

narrative understanding of identity as "collections of stories about persons" permits an

exploration of the rich and complex connections between experience, lived and told stories, and

identity (Sfard & Prusak, 2005, p. 16). Exploring these narrative orientations of identity allows

for a concept of teacher identity to be fluid, dynamic, ongoing, interconnected, multiple, and

complex (Alsup, 2002; Beijaard, Verloop, & Vermunt, 2000; Cooper & Olson, 1996; Day,

Kington, Stobart, & Sammons, 2006; Søreide, 2006). In this research, stories to live by remain

at the heart of making and remaking of a curriculum around chronic illness.

The stories that teachers choose or do not choose to live by are shaped by the broader cultural and epistemological contexts and consequently, teacher stories, stories of teachers, school stories, and stories of the school may exert an influence on the teacher's identity (Clandinin & Connelly, 1996). Teacher stories are the stories teachers live and tell while stories of teachers are stories told of these teachers. School stories are common stories shared amongst the school and stories of school are the broader reaching stories of that particular school (Clandinin & Connelly, 1996). Each of these stories plays a role in shaping a teacher's identity, her or his story to live by.

Personal Practical Knowledge

Teacher knowledge is a highly contextualized form of knowledge. Clandinin (1985) use the term personal practical knowledge to understand the specialized knowledge foundations of teachers. A teacher's personal practical knowledge blends the academic and theoretical understandings with her or his personal background and practical experiences (Clandinin, 1985). The personal aspect entails all that makes up the person and the knowledge component consists of the "body of convictions, conscious or unconscious, which have arisen from experience, intimate, social, and traditional, and which are expressed in a person's actions" (p. 362). Similar notions of teacher knowledge as a combination of the personal, practical, experiential, and theoretical experiences that comprised a teacher's understanding have been echoed elsewhere (Alsup, 2002; Beijaard et al., 2000; Elbaz, 1983; Yinger & Hendricks-Lee, 1993). A teacher's personal practical knowledge has a temporal experiential quality; it exists in the teacher's past experiences, in the present mind and body of the teacher, and in her or his intentions and future actions. It is "a particular way of reconstructing the past and the intentions of the future to deal with the exigencies of a present situation" (Connelly & Clandinin, 1988, p. 25).

Narrative Coherence

The effects of having a chronic illness on the school and classroom landscape may cause growth and expansion in some areas and contraction and reduction in others. The professional knowledge landscape of the teacher may become unstable, shaky, and unpredictable; its grounding may be called into question. Carr (1986) described these shifting events as distractions and disconnections in the construction of meaning for one's life; disruptions in the person's autobiographical narrative coherence. When these disruptions occur, life becomes a "constant effort, even a struggle, to maintain or restore narrative coherence in the face of an ever-threatening, impending chaos at all levels, from the smallest project to the overall 'coherence of life'" (Carr, 1986, p. 91). Carr further explained that "coherence seems to be a need imposed on us whether we seek it or not. Things need to make sense" (1986, p. 97). When we seek coherence, we are "telling and retelling, to ourselves and to others, the story of what we are about and what we are" (p. 97).

In a landscape shaped by chronic illness, an individual's narrative coherence is prone to disruptions. Chronic illness can be seen as a biographically disruptive event (Bury, 1982). The experience of temporal continuity and inner coherence can come into question (Hyden, 1997). Those with or around a chronic illness must navigate or find a new coherence of life, perhaps even renegotiating a new identity (Hyden, 1997). Even without a presence of a chronic illness, we work throughout our lives, with varying levels of success, to maintain our personal sense of narrative coherence (Carr, 1986; McAdams, 2001). This coherence and other narrative concepts mentioned previously are important considerations when negotiating a curriculum around chronic illness.

The Research Process

This research project was a narrative inquiry that took place outside a western Canadian city. Below is an explanation of the research process for this project starting from finding research participants to composing a final research text. I will also discuss the ethical considerations of this project.

The Research Participants

The participants in this study were three elementary certified teachers that taught or were teaching a student with a chronic illness in their classroom. Pseudonyms for people and places were used to protect the confidentiality of those involved. Claire was an early childhood education teacher (pre-Kindergarten and Kindergarten), Leah was a primary grade teacher (Grades 1-3), and Rita was a middle years teacher (Grades 4-6). All three women worked at East Willows Elementary School. The primary method of inviting these teachers to participate was through contacts made by the itinerant school nurse at their school.

Composing Field Texts

Over the course of this proposed study, I listened and attended to the stories and experiences of the teacher participants through semi-structured interviews in their classroom. These conversations took place after school hours without the presence of students. I recorded each conversation and personally transcribed them. I entered each conversation with questions and topics drawn out from previous conversations or from the literature on this research topic. However, I ensured that I remained open to the possible directions each conversation took and attempted to ask questions or bring up ideas based on the teacher participant's told stories.

After each conversation, I created extensive field notes and field texts from our dialogue and from observations I made of their classroom spaces, the school, the school's atmosphere, and

their demeanour. I recorded my own thoughts and feelings before and after each conversation. In a journal-style document, I wrote extensively regarding my personal experiences and observations made during the interview. I also created interim field notes (Clandinin & Connelly, 2000) from some of the stories they told, for example, the opening narratives of Chapters 3 and 4 in this document.

Each teacher met with me three times over the span of four months. The shortest time between conversations was one week and the longest was four weeks. The conversations ranged from 25 minutes to 1 hour. Each teacher was asked to bring in artefacts, photographs, documents, etc. to facilitate conversations. The recorded interviews and voice notes, as well as the transcriptions of the interviews were password protected on the computer to ensure confidentiality was maintained.

From Field Texts to Research Texts

Using narrative inquiry allowed me to construct narratives of these teachers experience that helped to map out what it meant to engage in a curriculum around chronic illness. In this research, the curriculum around chronic illness focused on living with a chronic illness and the active construction of a life story alongside it. The research texts were derived from the narrative accounts, field notes, field texts, and transcribed conversations and were placed within the three dimensional narrative inquiry space. These narrative accounts are found in Chapters 3 and 4 of this document.

The narrative accounts and other research texts were given to the teacher participants for approval prior to publication and/or thesis defense. Few adjustments were required and each teacher was grateful to be able to relive and discuss their teaching experiences. Any journal submissions from this research will be given to the participants for approval prior to submission.

In the Midst

An important consideration regarding engaging in this narrative inquiry was the understanding that stories were always in the midst (Clandinin & Connelly, 2000). The inquiry process began and ended in the middle of a story already in progress. It captured a small and partial picture of the complex lives involved in the inquiry process. The stories of the participants are positioned in this document as ongoing and dynamic. Many of these stories occurred in the past, but they are continuously being lived and told, retold, and relived in the participants' internal or external dialogue and actions (Clandinin et al., 2006). As a narrative inquirer, I entered into a midst of multiple stories for each participant, positioned somewhere along the dimensions of temporality, sociality, and place. Being in this midst required a negotiation of relationships, purposes, transitions, and usefulness and was different for every relationship I formed with the teacher participants (Clandinin & Connelly, 2000).

Ethics

Relational ethics was central to this narrative inquiry and was an ongoing and dynamic process. The foundation of my work with these teachers was the establishment of a relationship with them. Building a solid relationship with my participants meant I was constantly attentive to the ethical concerns and relational responsibilities of my work. I felt it was my obligation to care for their stories. I was constantly aware of personal and professional ethical concerns and ensured that each teacher participant was fully aware of my intentions and research ideas. As King (2003) reminds us, "[o]nce a story is told, it cannot be called back. Once told, it is loose in the world. So you have to be careful with stories that you tell. And you have to watch out for the stories that you are told" (p. 10). Each teacher participant was given a copy of their

narrative account and the analysis of their narrative for approval prior to finalizing this document.

In this work, I used pseudonyms for names and places to protect anonymity of the participants, the student(s), and the school. Field notes, texts, and narrative accounts were shared with the participants for ongoing communication and member checking. All of these details pertaining to the research procedure were shared with the participants at the start of the project through written and verbal communications, consent letters, and regular meetings. I was highly sensitive to both the physical and psychological demands that are placed on these teachers during this process and remained open in terms of scheduling. I also attempted to listen carefully to the stories they shared and lived with respect and gratitude.

Institutional research ethics was obtained August 2012 from the University of Saskatchewan's ethics review committee. A copy of the ethics approval, consent letters, and transcript release forms is included in the appendices of this document. Research ethics was also obtained September 2012 by the school board with whom this research took place. To protect confidentiality, this was not included in the appendices. All institutional ethics were obtained prior to initiating the research process.

Transitioning to Chapter 3

The previous chapters explored personal, theoretical, social, and methodological justification. It overviewed critical narrative concepts and research pertaining to narrative inquiry, chronic illness, and education. The following chapter explores the experiences of Claire, an early childhood educator, who taught a young girl with Turner's Syndrome named Madeline. Her experiences were explored separately from the other teacher participants in order to examine the unique placement of chronic illness in a pre-Kindergarten classroom based on play and exploration. The following chapter has been submitted for publication review to the journal *Teachers and Teaching*. The subsequent chapter is an extended version of this paper.

CHAPTER THREE.
PLAYING WITH MOON SAND: A NARRATIVE INQUIRY INTO ONE TEACHER'S EXPERIENCES TEACHING ALONGSIDE A STUDENT WITH A CHRONIC ILLNESS

Claire's early-childhood classroom is a treasure trove of play things hidden away throughout the room. Thick rounded letters are arranged on the walls to tell simple messages about love and family. Artwork is speckled throughout the room, highlighting each student's interests and seasonal creativity. There is very little open wall space. A few books and pillows are nestled inside a tiny teepee, seeming to act as a boundary between the carpeted area and the tiled floor with a painted hopscotch. There are two tables standing in the tiled area. Inside one of the tables was a sandy mixture called Moon Sand. Although commercially made Moon Sand is available for purchase, Claire opted to make her own. With a simple combination of flour and baby oil, Claire created a moldable and constructible mixture used for playing and creating. Moon Sand, in the same way as beach sand and water, takes and maintains the shape of whatever container it is placed into, such as a bucket or plastic starfish, but can be instantly remolded based on the creator's desire. Claire's Moon Sand mixture, because of the baby oil, does not dry up as quickly as beach sand and water or other Moon Sand recipes. Claire's students, although messy at times, thoroughly enjoy their time playing in this fine sandy mixture, imagining new stories and new never-ending possibilities. (Interim research text from field notes, 2013)

Claire's Moon Sand mixture is an apt metaphor for her pre-Kindergarten classroom. Her class is structured by pre-established routines and expectations of childcare and child safety recognized by the local school board. Claire had the opportunity to help mold her students in particular ways using the tools she has as an early childhood educator while still allowing them

to take on the forms of their desire. Claire lives alongside her diverse pre-Kindergarten children, shaping their lives as she is in turn shaped by them. In the paper that follows, this relational shaping structures an understanding of curriculum as in the making (Clandinin & Connelly, 1992).

Curriculum Making and Chronic Illness

This paper grew out of research that focused on the experiences of teachers who taught and lived alongside a child in their classrooms with a chronic illness and what it means to co-compose a curriculum shaped around a chronic illness. Our view of curriculum making comes from the work of Clandinin and Connelly (1992) who suggested that curriculum "might be viewed as an account of teachers' and students' lives together in schools and classrooms... [In this view of curriculum making] the teacher is seen as an integral part of the curricular process ... in which teacher, learners, subject matter, and milieu are in dynamic interaction" (p. 392). Curriculum is composed and embedded in the lives of those involved. We share their "vision of curriculum as a course of life" as lives are being lived (Clandinin & Connelly, 1992, p. 393). Both teacher and student live out diverse narratives of experiences in and out of the classroom (Clandinin et al., 2006). Considering the nestedness of classrooms within larger epistemological, cultural, social, and political contexts, the curriculum making in the classroom is also shaped by teachers' stories, stories of teachers, school stories, and stories of school (Clandinin & Connelly, 1996).

Using this definition of curriculum as a course of life in relation to the presence of illness in the schools, students and their teachers can be seen as engaging in a curriculum that is shaped by the presence of illness. This curriculum, a curriculum around chronic illness, entails more than a study of illness and its biological or scientific implications and its potential effects on the

implementation of government subject matter documents. It is more than a focus on symptoms, treatments, and educational problems associated with illness in schools. Although such aspects are important considerations, the curriculum around chronic illness focuses on living, and in that living attending to being chronically ill, and the active construction of a life story alongside a chronic illness. The curriculum around chronic illness is a curriculum of lives shaped by a chronic illness. Attending to the nested set of stories within the school context and their relationship to the curriculum around chronic illness allowed us to recognize the moments of bumping up of the dominant stories of school and society with the stories that the teacher and children were living, telling, retelling, and reliving (Connelly & Clandinin, 1990) in the curriculum making of an elementary classroom.

Thinking of curriculum making in relation to lives being storied and restoried shape a narrative understanding of teacher identity as "stories to live by" (Connelly & Clandinin, 1999). Stories to live by "attend to the historical, the temporal, the contextual, and the relational [and] interconnect teachers' personal practical knowledge with their professional knowledge contexts" (Huber et al., 2003, p. 347). Personal practical knowledge is a term used to understand the specialized knowledge foundations of teachers. It is "a moral, affective, and aesthetic way of knowing life's educational situations" (Connelly & Clandinin, 1988, p. 59). A teacher's personal practical knowledge blends the academic and theoretical understandings with her or his personal background and practical experiences (Clandinin, 1985). A narrative understanding of curriculum and identity entails keeping stories to live by at the heart of making and remaking of a curriculum around chronic illness.

A Curriculum Around Chronic Illness: The Place of Liminality

A school landscape imbued with a chronic illness can be uncertain and dynamic. Even controlled or pre-arranged events, such as regular therapeutic sessions or medical appointments, can cause disruptions in the daily lives of those in and out of the school system. Students with chronic illness often experience a wide variety of social, academic, and physical issues while attending school (Forrest, Bevans, Riley, Crespo, & Louis, 2011). It is not uncommon for students with chronic illnesses to be absent from school, both physically and mentally (Clay et al., 2004; Eiser, 1980, 1993; Forrest et al., 2011; Gannoni & Shute, 2010; McCarthy et al., 1996; Mukherjee et al., 2000; Weitzman, 1986). It is often the case that these students require special attention, consideration, preparation, and individualized structured support systems, such as personal care and wheelchairs (Eiser, 1993; Irwin & Elam, 2011; Sexson & Madan-Swain, 1995; Shiu, 2001; Thies, 1999; Ziring, 2000). It is easy for these students to have a daily routine unlike any other in the classroom, often shifting back and forth between the classroom and a world revolving around and designed for their condition.

Teachers may view the student's world from the edges, only glimpsing at its nature from the peripheries. When the teacher does engage with the student, they enter a place between two stories, a liminal space (Heilbrun, 1999), between stories of health and stories of un-health. This state of liminality, defined by Heilbrun (1999) to mean a state "poised upon uncertain ground, to be leaving one condition or country or self and entering upon another", is characterized by "its unsteadiness, its lack of clarity about exactly where one belongs and what one should be doing, or wants to be doing" (p. 3). It is a "state of necessary in-betweenness" (Heilbrun, 1999, p. 98). In the school and classroom, these often tension-filled, but potentially educative spaces are places where teachers and students co-compose and enact their own storylines (Heilbrun, 1999).

Liminal spaces, by nature, are transitory and not meant for permanent residency. They exist between two places of actions, identities, stories, or plotlines. Teachers and students continuously negotiate their travel in and out of these spaces in their curriculum making. As we considered the experiences of teachers negotiating the curriculum around chronic illness, we began to puzzle over the place of liminality in these stories. How do these liminal spaces manifest themselves? How do teachers negotiate the liminal space between that of health and un-health, sickness and wellness, capability and desire? What moves them to step into these spaces and what pulls them outwards towards a new path?

Narrative Inquiry: Methodology and Method

This narrative inquiry (Clandinin & Connelly, 2000) took place in small town outside a western Canadian city. Using the following definition by Connelly and Clandinin (2006), this research attended to the lives, stories, and experiences of teachers with a student with a chronic illness:

> People shape their daily lives by stories of who they and others are and as they interpret their past in terms of these stories. Story, in the current idiom, is a portal through which a person enters the world and by which their experience of the world is interpreted and made personally meaningful. Narrative inquiry, the study of experience as story, then, is first and foremost a way of thinking about experience. Narrative inquiry as a methodology entails a view of the phenomenon. There is a focal point, a phenomena in the present that draws our attentions, and as we open the floodgate, stories surrounding that focus become the portal to understanding that phenomena. To use narrative inquiry methodology is to adopt a particular view of experience as phenomenon under study. (p. 477)

Narrative inquiry occurs in the midst of storied lives and grounds the research in the experiences of the participants. It is the study of experience as both method and phenomena (Clandinin & Connelly, 2000). Holding open both the beginning and the end of the inquiry process, narrative inquiry remains open for possibility (Clandinin et al., 2006). The stories heard in the research process are in the midst of a greater ever-changing parade of lives, all in the process of becoming (Clandinin & Connelly, 2000).

Narrative inquiry is, simply stated, stories lived and told and the subsequent inquiry into those stories. It attends to the complexities of experience as individuals live storied lives and travel through storied landscapes. It examines how we use stories to shape and create meaning in and of our lives. Using the act of creating stories of our lives to maintain coherence and clarity, we live as storied creatures on a storied landscape (McAdams, 1993). Bruner (2002) stated "[w]e are a species whose main purpose is to tell each other about the expected and the surprises that upset the expected, and we do that through the stories we tell" (p. 4). McAdams (1993) affirmed "[i]f you want to know me, then you must know my story, for my story defines who I am... [w]e are all tellers of tales" (p. 11). These lived, told, and talked about stories are the ways in which individuals create meaning for their experiences. We make ourselves through story. In the words of King (2003), "[t]he truth about stories is that that's all we are" (p. 153).

Understanding the importance of narratives in meaning making of lives, we can explore how narratives are created and understood within the school system. Using a view of education as a "process of living" proposed by Dewey (1929, p. 36), narrative inquiry is a research methodology well-suited for studying lives and experiences in schools. By holding open the beginning and the end of the stories told in this process, our methodology attended to the complexities of teachers teaching a student living with a chronic illness avoiding blame or

judgment. It created a safe space for the teacher participants to share their experiences teaching a student with a chronic illness. Story was a "way to reflect upon the experience of illness and to construct significance and identity" (Clark, 2003, p. 107) and narrative inquiry allowed us to explore the tensions and harmonies created by the weaving of chronic illness within the school landscapes. Our narrative inquiry existed within this open space and "artfully [held] open the beginning and endings of the narratives presented (Clandinin et al., 2006, p. 179), focusing on the complexities and possibilities of the teachers told stories.

Methods

The overall research project, from which this paper stems, traced the experiences of three elementary school teachers at East Willows Elementary School, one in pre-Kindergarten, one in primary, and one in middle years. Their personal and professional backgrounds and experiences teaching a student with a chronic illness in their classroom were explored during recorded research conversations. This paper focuses on the experiences of Claire, an early childhood educator, in order to highlight the interconnection and influence of the mandated, but malleable pre-Kindergarten curriculum on lives shaped by a chronic illness.

Research conversations over a four month time period took place with Claire in her classroom after school hours without the presence of students. Ranging from 30 minutes to one hour conversations, we discussed various aspects of her teaching, including her personal and professional background as well as her experiences teaching Madeline, a young girl with Turner's Syndrome. These conversations facilitated the creation of field texts, including transcripts from audio-taped conversations, field notes, photography, and artefact collection. Using the field texts, a narrative account was created to reflect Claire's background and experiences engaging with Madeline. These experiences are viewed and unpacked within a three

dimensional inquiry space, discussed later, as defined by Clandinin and Connelly (2000) to encompass temporality, sociality, and place in relation to experience.

Findings: Understanding Narratives of Experience

East Willows Elementary School was a large elementary school located outside a major western Canadian city. Over the past decade or so, it had nearly doubled in population and multiple portables were connected to accommodate the increase. It was an energetic school with a young staff. The school was also known for its early intervention program. The early intervention program had operated for many years and had only recently been shut down at the time of this inquiry. It provided support to students with high physical and cognitive needs prior to school entry. They had many skilled nurses, educational assistants, therapists, and teachers working in this program and as a result of their success, the program grew dramatically. Some students were bussed in from far distances to attend. There were stories of families moving to this town solely for their child to attend the program. When the program shut down, some of the staff associated with it stayed and worked at East Willows. Many of the students already in East Willows remained at the school after the program shut down. Madeline was one of these students who received special permission to stay even though she and her family lived far away. East Willows was also one of the first schools in the school board to implement a pre-Kindergarten program.

Claire's Narrative

Early childhood education was the next logical step for Claire. As long as she could remember, she knew she wanted to work with the pre-school and pre-Kindergarten age group. She worked as a camp counsellor, summer baby-sitter, and as a coach for a children's cheerleading group. She entered into her Bachelor of Education with a focus of Early Childhood

Education. She worked for her first year as a Grade 2 teacher on a reserve north of her home and commuted the two hours back and forth each day. The strain of the almost four hour daily commute led her to open her own pre-school in her home town. She operated this pre-school for eight years under the belief that every child deserves the chance to benefit from pre-school. Before switching to contract teaching in the local school division, her pre-school had grown upwards of twenty pre-school aged children per class.

Claire was hired by the school division to implement the pre-Kindergarten program at East Willows Elementary School. After a steep learning curve for all involved in that first year, the program started to grow in numbers. As Claire attended Professional Development opportunities and engaged in conversations with other pre-Kindergarten teachers, she began making shifts in her teaching style. She started to release some of the control over the activities the students were engaging in and began to occasionally step down as the leader of the classroom. Although she encouraged her students to discover and engage with their environment from the beginning, students began to explore in a more centre-based, independent learning classroom structure. This meant that while some students would be crafting or building, others would be painting, while still others would be playing in Moon Sand, a moldable mixture of flour and baby oil, at their own leisure.

It was after this shift that Claire first taught Madeline, a young girl with Turner's Syndrome. Turner's syndrome is a rare condition in which females are missing or have a severely malfunctioning X chromosome, resulting in a variety of physical, cognitive, and general health conditions in early childhood. When Madeline first entered Claire's classroom, she had a very small stature for her age and low physical strength, immunity, and stamina. Although Madeline could walk small distances, she required the use of a small wheelchair, similar to a

stroller, to be transported to and from the bus and through the school hallways. She also had very limited oral capabilities which meant she had reduced verbal skills and also needed to be tube-fed. Claire did not experience much nervousness or anxiety when she found out Madeline was going to be in her class that year because she had met Madeline previously via the early intervention program at the school. Claire knew her as a sweet young girl before entering her classroom.

In the months that followed, Claire noticed drastic improvements in Madeline's condition. Her verbal and oral abilities improved as a result of work from the Speech and Language therapists. Her physical strength improved from occupational therapy and also from the outdoor educational adventures of Claire's classroom. The flexibility and mandated support of pre-Kindergarten meant that Claire had the freedom to take her students out every day to explore the outdoors. From her own experiences and through Professional Development and other learning opportunities from the school board, Claire firmly supported outdoor education programs and the benefits they brought. During these outdoor adventures, Claire and her students would wander around the yard, go for hikes, climb up hills, explore the forest, and play on the playground. Whatever the students engaged in, Claire was there, acting as a guide and facilitator of learning. Other times, she acted as she sometimes felt, as a five year old playing on the swings. "Why are you swinging?" a student once asked her, to which she replied simply, "Because I like to swing!"

Multiple Storylines

Claire was an early childhood educator that was currently teaching pre-Kindergarten and Kindergarten at the time of this research. Drawing from her narrative account, we can see the multiple storylines that weave across her life. Claire was committed to early childhood education; a storyline that permeated much of her experiences. She valued and respected the

story of her own family and the stories of her students' families. She accepted changes in her teaching career and teaching practices willingly and eagerly. Claire also lived and taught the story of play and exploration and outdoor education.

Analysis: Emerging Narrative Threads from Claire's Account

A term used for thinking about attending to the lives of both the participant and the researcher is the three dimensional narrative inquiry space (Clandinin & Connelly, 2000). With Dewey's (1938) work and ideas of interaction, continuity, and situation as the ontological framework (Clandinin & Rosiek, 2006), this metaphorical three dimensional inquiry space is defined to include "temporality along one dimension, the personal and social along a second dimension, and place along a third" (Clandinin & Connelly, 2000, p. 50). Clandinin and Connelly (2000) further discussed the four directions of an inquiry along the dimensions of personal and social, also called sociality, and temporality to be:

> ... *inward* and *outward*, *backward* and *forward*. By inward, we mean toward the internal conditions, such as feelings, hopes, aesthetic reactions, and moral dispositions. By outward, we mean toward the existential conditions, that is, the environment. By backward and forward, we refer to temporality – past, present, and future. (p. 50)

The place dimension refers to the dimension that "attends to the specific concrete physical and topological boundaries of inquiry landscapes" (p. 51). Claire's experiences were understood as existing simultaneously between these three interacting dimensions and were analyzed as such within the following threads of citizenship, shared authority, and curriculum making as a counterstory.

Citizenship

Compared to the long history of schooling and education, it has only been relatively recent that students with special or exceptional needs have been included in the mainstream classroom. Examining the personal and social dimension of experience, we can see that in the past, students with chronic illnesses or disability often lived a story of segregation, either through specialized schools or institutions or segregated special education programs (Kliewer, 1998; Mukherjee et al., 2000). Although some of these pupils experienced segregation due to medical needs or concerns, others experienced it from cultural norms and expectations. Belief in the inability of these students to benefit from a mainstream education predicated their separation.

However, with shifting societal ideals and governmental mandates, the education system began to position students with a chronic illness and other special needs alongside those of full health and full ability in the mainstream classroom with the ultimate goal of full "citizenship" (Kliewer, 1998). Citizenship, as defined by Kliewer (1998) in the context of students with Down syndrome and other disabilities, means viewing those with a disability "not as social burdens but as valued human beings" and requires the "ongoing realization of each individual's value to the larger group" (p. 12). Citizenship is the assignment of equal status and worth to all individuals. As Marshall (1963) describes, citizenship entails more than a physical presence:

> I propose to divide citizenship into three parts ... I shall call these three parts, or
> elements, civil, political, and social. The civil element is composed of the rights
> necessary for individual freedom - liberty of the person, freedom of speech, thought, and
> faith, the right to own property and to conclude valid contracts, and the right to justice...
> By the political element I mean the right to participate in the exercise of political power,
> as a member of a body invested with political authority or as an elector of the members of

such a body... By the social element I mean the whole range, from the right to a

modicum of economic welfare and security to the right to share to the full in the social

heritage and to live the life of a civilized being according to the standards prevailing in

the society. (p. 30)

To achieve citizenship, then, is to have rights recognized and practiced in each of the civil,

political, and social domains of a community.

Considering this definition of citizenship within the classroom, we can see that

citizenship entails more than a physical body in a room passively participating in the classroom

activities. It is a holistic approach and requires an active and negotiated participation of both

teachers and students. Kliewer (1998) further described classroom citizenship by explaining that

"one's human development does not set the conditions for community acceptance; rather,

acceptance is the terrain on which development occurs" (p. 12). Kliewer described the person

who is overtly denied membership into a community as an "alien" and the person who exists

within the community, but only on the peripheries to be a "squatter." The squatter struggles for

citizenship, but is "stalled at the margins of the classroom community" (p. 12).

Madeline had the potential to become a squatter and to exist along the peripheries of the

classroom and the school, but Claire was able to engage Madeline, and the other children in the

classroom, into full citizenship. Using the dimensions of place and sociality proposed by

Clandinin and Connelly (2000) to understand experience, we can see that acceptance was the

terrain upon which Claire built her classroom (Kliewer, 1998). There was an inherent

connection between this sense of citizenship and both the local and larger community.

The surrounding school community undoubtedly influenced Madeline's acceptance by

telling stories of inclusion and safety. Within Madeline's local community, Claire's tiny pre-

Kindergarten classroom meant a very socially interactive atmosphere and consequently, this arrangement promoted inclusion. Madeline always had someone near her, whether it was Claire, an EA, or another student. It was nearly impossible for Madeline to be separated from her peers in this room. This aided in Madeline's citizenship as it did not require much effort for Madeline to be physically present and included in activities; the activities, more or less, all happened in the same place. She did not have move long distances between areas of the room and could gradually build up her strength in small incremental steps. Even if her movements were only two or three feet in one direction, we are left to wonder about the increasing sense of independence Madeline gained by both controlling when and where she could move and the omnipresent potential for social interaction.

Claire negotiated these tensions in citizenship between ability and inability, sickness and wellness, participation and exclusion in order to create an inclusive classroom focused on play, exploration, and fun. She used outdoor education to broaden Madeline's story of capability; she used play and exploration in an independent centre-based classroom to encourage Madeline to grow and learn at her own pace; she taught and lived by the golden rule of treating others the way one wants to be treated and by doing so, fostered an atmosphere of acceptance and kindness. Through her curriculum making, Claire was able to bring Madeline into full citizenship.

Sharing Authority: Making Room Through Play

In her privately owned pre-school, Claire interacted with her students for two hours a day three times a week. For Claire, this necessitated the creation of a highly organized and uniformed classroom routine. For example, if she planned for painting, then all her students painted at the same time before moving onto another activity. In the beginning of her career at East Willows, Claire continued to teach in the same way as her pre-school. However, the longer

half-day classes five days a week at this new school created tensions regarding the way she organized her classroom. After reflection on these tensions and after learning from other pre-Kindergarten teachers, Claire shifted her classroom pedagogy. What was once a uniformed, teacher-led classroom structure became an independent exploration of the surrounding environment.

Understanding these tensions and her shift in teaching style within the dimension of temporality, we can see Claire initially attempting to maintain a sense of coherence with her previous personal practical knowledge. There was a disconnect between Claire's teaching practice and the increasing knowledge foundation that guided it. Carr (1986) would describe these tensions as distractions and disconnections in the construction of meaning for one's life and narrative coherence. These disruptions can cause confusion in a life story until remade or restoried. Here, Claire maintained coherence by shifting her teaching practice and teaching story to accommodate her growing knowledge and awareness of pre-Kindergarten teaching.

In this new way of teaching, Claire created concurrent play-based opportunities for student learning and allowed her students to freely explore them. She began to let go of some control and found herself stepping down as leader more often and playing alongside them as equals. She realized she did not have to be the driving force behind every activity. As she did this, the students began to take more initiative in their learning and Claire noticed that they were more engaged with their environment and with each other. Her new stance in her personal practical knowledge shifted her authority in the classroom in such a way that permitted the expression of student stories alongside her own teacher stories. Claire invited her students to contribute directly to the momentum of the classroom (Oyler, 1996).

Oyler (1996) described this invitation as a sharing of authority between the students and the teacher. This sharing manifests as a shift in the manner in which authority is maintained and expressed, rather than a complete abdication or negation of teacher authority. Sharing authority allowed for Claire's students to participate in directing and co-directing their learning in the classroom. It allowed for students like Madeline, who are perhaps living in a story of mainstream incoherence, to contribute equally to the classroom knowledge and process, learning from and with her peers and teachers.

Viewing Claire's sharing of authority along two dimensions of process, such as managing classroom procedures, and content, such as validating particular knowledge contexts (Oyler, 1996), we can see some of this sharing in Claire's stories of outdoor education. Claire allowed free, but structured, access to the outdoors. Claire shared her knowledge and awareness of the outdoors with her students and arranged for her students to participate in a variety of activities, such as climbing hills and walking through forests. The students participated in Claire's activities, but also began to create their own meaning of the activities and take initiative over the direction and momentum of play. Additionally, Claire often engaged in the playful activities herself, co-constructing knowledge and meaning, and learning from and with her students in this playful curriculum making.

A Curriculum Making Counterstory: Playfulness and Play in the Classroom

Nelson (1996) described a counterstory to be a narrative whose "aim is to resist and undermine a story of domination" (p. 97/98) and to open up possibilities for different interpretations and conclusions from that of the dominant perspective. The teller of the counterstory "redescribes a dominant story, repudiates it for her- or himself, and sets a new course that commits her or him to certain values for the future" (p. 98). In order to create a

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counterstory, one must first understand the particulars of the dominant narrative. As we looked into the experiences of Claire and Madeline and their curriculum making, we began to puzzle about the nature of the dominant narrative(s) surrounding the curriculum around chronic illness. What were these narratives? How did Claire define them, if she believed in them at all?

Claire recognized that the pre-Kindergarten classroom structure was different than other classrooms:

> And I would say that another great thing about pre-[Kindergarten] is that [Madeline's] day looks the same... as everybody else's day... they're exactly the same. (Transcript from research interview, 2013)

Here and elsewhere in our research conversations, Claire acknowledged a dominant narrative. Such a dominant narrative tells stories of students positioned differently in terms of what their day looks like; transient students existing on the peripheries of the classroom community prone to academic, social, and physical limitations (Forrest et al., 2011; Pinquart & Teubert, 2012). However, Claire distinguished her pre-Kindergarten classroom and program from this dominant narrative of structure. There was no difference between Madeline's day, a day typically designed around a sickness, and the day of any other student in her class.

Claire, at the time of this research, was currently teaching a Kindergarten group as well as her regular pre-Kindergarten class, one in the morning and one in the afternoon. She was able to glimpse at and compare the effects that a higher level of structure and standards in upper grades can have on students like Madeline:

> *Beth*: Do you think ... things would have been different if ... you had taught [Madeline] in [Kindergarten?]

Claire: ... I think a little bit, because ... I still have very ... structured activities in

Kindergarten that she would've missed ... and then maybe would have missed that

building step to that next activity ... because she, obviously, was missing ... a good

portion of days from school ... especially during the winter due to illness ... so... I think

it probably would have looked a little bit different for her. (Transcript from research

interview, 2013)

Compared with the more structured and organized classroom and mandated curricular guidelines

of other Kindergarten to Grade 12 classrooms, Claire's implementation of curricular mandates

remained open and flexible. She acknowledged that a malleable classroom structure was

beneficial for Madeline. Here, Claire imagined a counterstory, a different possibility for what a

classroom could look like. She imagined a classroom not based on the typical scaffolded or

stepping block format. A classroom flexible and pliable enough to accommodate the working

ability of each student while having everyone on the same plane, none higher or further than

another, was the format for Claire and her students.

This flexibility allowed a student with a necessarily irregular day from such excursions as

physiotherapy and personal care to feel included in the ebbs and flows of a classroom. It allowed

Madeline, who was frequently absent due to illness, to rejoin the classroom after a prolonged

absence without major tensions or concerns. Instead of being part of the dominant narrative of

difference in daily structure, Madeline easily transitioned to and from Claire's room without

having to live a completely different and detached life.

In other ways, Claire and Madeline could be telling another counterstory to the dominant

or expected narratives of chronic illness. Claire never viewed Madeline as a challenge or a

burden. Claire's classroom, a small assembled community in which its members are required to

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participate, was an inclusive setting. In this "found" community (Nelson, 1995, p. 24), Madeline was never viewed as someone who was treated differently from her other peers in a significant way. The ways she was given different care, for example maintaining a communication book with Madeline's mother, was not viewed as abnormal or significant. It was part of knowing and living alongside Madeline. Although her classroom was not a "chosen" community (Nelson, 1995, p. 24), a community in which people can form based on voluntary association, Claire created an atmosphere of mutual respect where her students could benefit and gain from the community resources equally, as if they chose to be together.

However, we also puzzled about a competing dominant narrative, one which views stories of students with chronic illness as simply narratives of inclusion. If we take the inclusive narrative, often promoted by East Willows and other schools in the division, to mean that all students are included all the time regardless of ability or health and that difference is not overlooked, but added to the natural diversity of all people, Claire was no longer living or telling a counterstory. She would, instead, be in harmony with it. Here, Claire acknowledges the diversity of all students and that inclusion extends beyond those with disability or illness:

> I think [having students with chronic illness in your classroom] just reminds you that ... kids come in all different ways ... and that you need to have patience and enjoy everything about them ... and I think it's really good, it teaches me too that ... or I guess it just confirms that kids are all kids and they accept each other however they are, which I think sometimes we find difficult as adults ... I think that it ... always just gives me that joy of knowing that we're all just here together, working together, being a team together. (Transcript from research interview, 2013)

Attending to the complexities of experience of lives in schools, we can see Claire balanced between these two narratives, between these two different professional knowledge landscapes. Her story can be considered both as a counterstory and not. The lives in Claire's "found" community were inextricably woven together, moving in and out of alignment with the dominant narrative. In her curriculum making, Claire's story was both becoming and unbecoming a counterstory. As she used play and exploration to guide her teaching, she was concomitantly negotiating Madeline's passage between a world defining illness as unusual and the inclusive classroom world where difference is normal.

In defining and shaping a counterstory in Claire's narrative, the influence of play cannot be overlooked. In children's play, there is an ultimate openness, forgiveness, and creativity. Play enables the reconstruction and remaking of the past, present, and future (Clark, 2003). It allows children and adults alike to cope with extraordinary life circumstances, such as living with a chronic illness, by creating a space for meaning and understanding that perhaps could not be articulated directly (Clark, 2003). Even when in a bounded framework, there is a sense of unlimited possibilities in playfulness, transforming fear into hope and hopelessness into fearlessness (Clark, 2003). Playfulness can let a person feel "like a new being, free of destructive forces within and capable of fighting off without"(Clark, 2003, p. 112).

In psychological terms, playfulness is a psychological trait characterized by internal motivation, orientation toward process, attributing one's own meanings to objects or behaviours, focusing on pretend and nonliterality, seeking freedom from externally imposed rules, and being actively involved (Rubin, Fein, & Vandenberg, 1983). Using Lugones (1987) idea of playfulness, it is the internal state of mind, the underlying attitude that one holds, that defines an action as play. Play is not playful if the individual is not of a playful spirit, but such a spirit can

transform any activity into play, mundane or otherwise (Lugones, 1987). A playful attitude is not bound by externally imposed rules or expectations, but rather remains open to surprise and uncertainty, open to creativity and possibilities, open to re-defining one's construction of oneself, and openness to being a fool (Lugones, 1987). Playfulness is characterized by "uncertainty, lack of self-importance, absence of rules or a not taking rules as sacred, a not worrying about competence and a lack of abandonment to a particular construction of oneself, others and one's relations to them" (Lugones, 1987, p. 17).

The playful attitude described here is not agonistic. A playful spirit is not worried about competence and living up to norms; it is not self-important and finds delight in ambiguity (Lugones, 1987). In a school world often dominated by agonistic stories of play, where the antecedent of winning is losing and the presence of a loser validates the winner's accomplishment, competence-based standards and outcomes can impose stories of what it means to be successful in school. This common school story, for example, views a student who consistently achieves 5 out of 5 as more successful in school than a student consistently achieving a 3 out of 5. Adopting a non-agonistic playfulness and a playful attitude in curriculum making may not be an easy task for teachers working in schools and societies dominated by agonistic stories of play. However, in Claire's classroom, these stories were re-positioned. There was no loser in the play in Claire's classroom. All worked together and delightfully existed in ambiguity to be successful together. Claire created a safe space for Madeline to grow and explore her capabilities without concern of having to perform for evaluative purposes. Through play and exploration, Claire was able to engage in meaningful curriculum making with Madeline and with her other students.

It was also in Claire's playful attitude, characterized by an openness and adaptability, that Madeline's position as a possible squatter was shifted within the classroom into full citizenship (Kliewer, 1998). The mandated support and inherent flexibility in the pre-Kindergarten program of this Canadian province meant Claire was free to create educative experiences for her students of her own desire. This freedom meant that Claire could adopt a post-planning curricular agenda which based the "curriculum-as-planned" on the "curriculum-as-lived-experiences" of that day instead of the typically found vice versa (Aoki, 1986/1991, p. 159). Aoki (1986/1991) described this curriculum-as-planned to entail mandated and often positivist curricular objectives that teachers are asked to teach. These are imbued with societal orientations and ideas and the creators, the curriculum planners, are "condemned to plan for faceless people, students shorn of their uniqueness or for all teachers, who becomes generalized entities often defined in terms of generalized performance roles" (Aoki, 1986/1991, p. 160). Claire was highly aware of the increased rigidity of the curriculum teachers are asked to teach in other grades.

On the other hand, the curriculum-as-lived-experiences, also called the lived curriculum, was described to be different in kind than that of the curriculum-as-planned (Aoki, 1986/1991). The lived curriculum was a plan lived out with face-to-face interactions disturbing "the traditional landscape, with its single privileged curriculum-as-planned awaiting implementation" as teachers and students live and compose individual narratives of their experiences" (Aoki, 1993, p. 204). Claire found a place in the midst, between and among these two curricula worlds; however, this space was not a space of tension for Claire. The mandated pre-Kindergarten curriculum of Claire's classroom seemed to hold open the curricular landscape. The pre-Kindergarten curriculum of this province allowed for the juxtaposition of freedom and possibility alongside that of mandated standards and expectations. In Claire's post-planning curricular

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story, she imagined another possibility for her classroom and the curriculum around chronic illness became indistinguishable from that of the curriculum of the class and the curriculum of all.

Claire's playfulness can be seen as shifting her stories of academic success for her and her students and shifting the way in which she planned her daily routines, living and telling a playful counterstory in her curriculum making. It was through this playful curriculum making that Claire was able to disrupt Madeline's expected narrative of physical and verbal limitations as a result of living with Turner's Syndrome. It was through play that Claire sought and reframed meaning from their experiences, meaning that chronic illness frequently disrupts (Clark, 2003). Claire entered a liminal space between wellness and sickness and through play, a playful personality, outdoor education, and the recreational therapies of the school, Madeline experienced much growth in her physical and cognitive realms. By the end of the year, Madeline rarely used her wheelchair and participated more fully in the activities of the classroom.

Playing in Curriculum: Remaining Open for Possibilities

With this openness to possibility and with a playful attitude, Claire was able to fully integrate Madeline into the classroom activities with ease. Madeline could have lived a story of incoherence, of being perceived arrogantly as different, separate, and failed, a story found in many experiences of those living with a chronic illness. But it was through play and a playful attitude that Claire disrupted these narratives. She was able to adopt a "loving perception" and playfully and lovingly travel to and from Madeline's world (Lugones, 1987, p. 18). These worlds, as defined by Lugones (1987), are constructions of life and descriptions of experience. Small or large, full or incomplete, these worlds must be inhabited by people or constructed

images of people. The people it encompasses may not understand how they are constructed within it or may not hold themselves to such constructions.

We cannot know for sure how Madeline constructed or viewed herself within the school world, but with the adoption of a "loving perception" and a playful attitude, Claire entered the liminal spaces between the multiple boundaries of health and created a new forward-looking story with Madeline (Nelson, 1999); one of understanding, play, acceptance, coherence, care, and one of universal success and accomplishment.

Other liminal spaces manifested themselves in the daily transitioning to and from Claire's classroom, through Madeline's frequent absences and re-entry due to sickness, through the space between the lived and planned curriculum, through the juxtaposition of a rigid school bound story of expectations and the freedom of play. Claire was moved to step into liminal spaces by her desire to create a safe and fun environment for all her students. She entered this liminal place in order to connect with Madeline and understand her world. We can see Claire negotiate these in-between stories of health and un-health, illness and wellness, capability and desire, citizenship and segregation through her playfulness in her teaching and the curriculum of play.

Claire's playfulness had the capacity to see the past, present, and future while also imagining and believing in an alternative. This playfulness amongst a discomfort of chronic illness created a forward-looking story (Nelson, 1999) for Claire and Madeline; new identities and stories to live by pulled outwards from this place of liminality by a mutual playfulness in curriculum making. This making of a new curriculum, a curriculum perhaps defined more by the attitude of its foundation rather than subject at the centre, allowed easy travel through worlds defined by illness. This playful curriculum, this curriculum of play, could be the negotiated story to live by for Claire and Madeline at East Willows Elementary School.

Final Words: The Ones Who Play

It is estimated that upwards of 20% of children in schools will have a chronic illness of some form[3] and the prevalence rates continue to rise as medical care improves (Hamlet et al., 2011; Mukherjee et al., 2000; Shaw & McCabe, 2008). As these advances in medical technology allow students living with a chronic illness to better manage their condition and attend school regularly, there is a growing need for teachers and school staff to be aware of and respond to these students in meaningful ways. Claire showed us how a playful attitude and a play-based curriculum can naturally and delightfully accommodate the ambiguities of students who have a chronic illness living alongside students of full health. This curriculum of play shifts these ambiguities found in the curriculum of chronic illness into a place of curiousity and potential. The curriculum of play does not overlook student need or difference, but seems to accept students as they come; it does not assume children are inadequate and consequently require fixing. It assumes children come complete, that they are adequate, and can participate fully as equal citizens in the classroom dynamic.

This playful curriculum allowed Claire to share her authority in the classroom. Play repositioned authority in the classroom. It positioned Claire and her students as knowledgeable citizens of their own domains. The one who plays is an expert, all-knowing creator of worlds, who is, at once, a supreme leader, a follower, a lion, a magician, a superhero, a villain, and more. The one who plays with a playful attitude encounters few obstacles that cannot easily be overcome. The one who plays transforms those with her into characters of a continuous story, to

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[3] The World Health Organization (2012) defines a chronic illness as a disease of long duration and slow progression. The specifics of duration will depend on the location of the individual. Literature pertaining to this subject, mostly stemming from the United States, defines a chronic illness to be a health condition that lasts, or is expected to last, at least 3 months (Kaffenberger, 2006; McCarthy et al., 1996; Perrin et al., 1993; Shiu, 2001; Thies, 1999).

be lived and re-lived, told and re-told many times over, each character defined and re-defined for a potentially new adventure. We can see Claire playing in her curriculum making, imagining and re-imagining possibilities, rethinking her character in the classroom, existing in a liminal space of dreams and potential, where, in a traditionally bounded environment, she creates her own version of Moon Sand.

Transitioning to Chapter 4

The previous chapter explored how a curriculum of play naturally and delightfully accommodated the tensions created by the presence of a chronic illness. It showed how a playful attitude towards teaching and learning can negotiate liminal spaces into a new forward-looking story of acceptance and belonging.

The following chapter explores the experiences of Leah and Rita as they enter the liminal spaces in curriculum making created by encountering a chronic illness. As they used their relational knowing of their students, they lovingly travelled to their students' worlds and negotiated their unique forward-looking story. This chapter is an exact version of a paper that will be submitted for publication.

CHAPTER FOUR.
NEGOTIATING LIMINALITY: THE EXPERIENCES OF TWO ELEMENTARY
TEACHERS WHO TAUGHT A STUDENT WITH A CHRONIC ILLNESS

Molly[4] and Jacob were working together on the computer, finishing up a video project for

Rita's middle years class. Jacob was patient and understanding as he diligently asked

Molly if she liked or disliked every edit he made to the video. Molly, a young girl with

cerebral palsy, pressed her communication switch accordingly. Rita watched as the two

of them finished the project. After Jacob pressed play, Rita heard Molly laugh like never

before. It was infectious. It seemed every student looked towards the pair and started to

smile. Many joined in with the laughter. Confused, but delighted, the other students

were curious as to what was happening with Molly. When the video ended, Molly got

upset and started to cry. The students, quite concerned, tried to console her and prompted

Jacob to play the video again. Molly's bellowed laugh began once more and the smiles

on Rita's students' faces quickly returned. (Field text created from interview, 2013)

The above narrative describes a moment Rita noticed, and subsequently talked about in a

research conversation, her class acting as a caring community; a community she strove for

diligently in her classroom. Rita, an experienced middle years teacher at East Willows

Elementary School, proudly told stories like this one to highlight the moments where Molly,

profoundly disabled because of her chronic illness,[5] was treated with respect and kindness and

where Rita saw one of her dreams of an inclusive classroom, built on caring relationships, being

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[4] All names and locations in this paper are pseudonyms.
[5] The World Health Organization (2012) defines a chronic illness as a disease of long duration and generally slow progression. The specifics will depend on the location of the individual. Literature pertaining to this subject, mostly stemming from the United States, defines a chronic illness to be a health condition that lasts, or is expected to last, at least 3 months (Kaffenberger, 2006; McCarthy et al., 1996; Perrin et al., 1993; Shiu, 2001; Thies, 1999).

fulfilled. These small moments were happy moments for Rita as she looked back on teaching this young girl with a chronic illness.

Such small moments are often overlooked against the backdrop of educational problems and concerns associated with chronic illnesses in the schools. The above narrative shows a moment where the richness and complexity of human experience shown by the simple act of laughter repositioned illness as a secondary consideration. What follows is an inquiry into the experiences of two elementary teachers, Rita and Leah, as they negotiated teaching and living alongside a student with a chronic illness.

Chronic Illness and Liminal Spaces

Due to the incredible variance within and among chronic illnesses and the increasingly available mis/information around it, people involved with illness may form different views of its impact, also called its chronicity (Charmaz, 1991). Chronicity, here, refers to the prevalence and persistence of an illness in a person's life (Charmaz, 1991). How a person defines the impact of the condition will vary based on previous experience and current knowledge foundations.

According to Charmaz (1991), people around a chronic illness may define its chronicity in one of three ways: as an interruption, as an intrusion, and as an immersion. People may frequently shift between these perspectives based on their experience. Defining an illness as an interruption refers to a perspective that the illness is temporary, of short duration, and a recovery is imminent. As an intrusion, illness is seen to demand continual attention, time, and moderate accommodations and therefore, threaten the perceived control a person has over her or his life. As an immersion, illness and disability are constantly at the forefront of decisions, actions, and interactions. The individual's identity and self-concept revolve around the illness and its implications (Charmaz, 1991).

How a person defines the chronicity of the disease may not be related to the actual impact of the disease; rather, it may depend upon the person's perception of the illness' power over her or his life and may be based on previous experience with illness instead of the actual current illness (Charmaz, 1991; Martin & Peterson, 2009). For example, many teachers reported inaccurate beliefs regarding students living with epilepsy and congenital heart disease and frequently overestimated the risks involved with such conditions (Bozkaya et al., 2009; McCarthy et al., 1996) while others underestimated the impact of more common diseases, such as diabetes and asthma, on the lives of their students (Clark, 2003; Olson et al., 2004). People will ultimately shift and redefine their perspectives of illness as they gain more experience and knowledge of the illness.

The disruptions caused by a chronic illness on the school landscape may be small or large, inconsequential or severely profound. At the most basic level, the illness may cause a teacher to pause and reconsider an action. These moments when the presence of a chronic illness leads to tension for the self may bring teachers into a place of difference; a place between their old knowledge and ways of thinking and a new place of shifted cognition, where the impact of an illness is acknowledged, but perhaps not yet fully defined. This place of difference is a liminal space (Heilbrun, 1999). A limen is a threshold between two places or rooms and by extending this into metaphor, liminal spaces can be considered spaces where a person is "betwixt and between, neither altogether here nor there, not one kind of person or another, not this, not that" (Heilbrun, 1999, p. 8). To be in a state of liminality is to be uncertainly positioned between two states, leaving one condition or self and entering into another.

When a teacher encounters a student with a chronic illness in their classroom, they enter a place of liminality. Their knowledge of how to respond appropriately to the student and her or

his needs may come into question. This paper explores the experiences of two elementary teachers, one in primary years and one in middle years, as they taught students with high needs chronic illness. It inquires into the following questions: how did these teachers recognize and negotiate these liminal spaces in their curriculum making with their students? How did these spaces shift their trajectory of their stories to live by and personal practical knowledge? These questions, which shape this paper, are derived from a larger wonder of an overall research project. The larger wonder inquires into the meaning and positioning of three elementary teachers in the curriculum around chronic illness, specifically, what does it mean to engage in a curriculum around chronic illness and how are the teachers positioned and shaped by it?

The Students

The students, Jeremy, Chris, and Molly who were taught by the teachers in this research, were profoundly disabled due to cerebral palsy. All three had limited control over their body and limbs, required the use of a wheelchair for mobility, and were transferred to and from school separately on a specialized school bus. All three had extremely low oral and verbal ability and they had to be tube-fed as a result. None could speak or communicate complex thoughts with words, but they could smile, laugh, and cry depending on how they felt. Molly and Jeremy also had access to a button system in which they could use a button or switch to communicate basic messages, such as yes or no and other choice based options. Molly and Jeremy were also around the same age as their peers. Chris was in his late teens when he first entered Rita's classroom. These students also required highly individualized care and were frequently taken in and out of the classroom for personal care, therapy, and specialized education.

Rita's Narrative

Rita's family was a close-knit and busy family full of sports, music, dance, and trips to their cabin on the lake. Her mother worked as a nurse and eventually as the director of care at a neighbouring community's nursing home for the elderly, and some individuals with special needs. She would often tell stories to Rita and the rest of the family of her frustration with having to remind the nurses that their patients still had a voice and deserved the right to make their own choices. Her parents did not prioritize high grades, but rather focused on the effort behind it. Rita described herself as a "real kid... very practical" and stated with emphasis that she "wasn't a bookworm keener" (Transcript from research interview, 2012).

Her teaching career began with much bed-jumping excitement on a spring day in May. She was hired on as a full time middle years teacher at East Willows Elementary School. Her summer was spent in anticipation and in arm-tingling excitement of the months and years to come. She felt confident; she felt great going into September. She lived and breathed school that year and loved every minute. This tight-knit school of no more than 300 students felt like a great match to her.

Rita learned much in the years to come and continued to enjoy her time at this growing school. She approached each challenge as an opportunity for new learning. A few years[6] went by and she encountered her first high needs student, Chris, a young man in his late teens with cerebral palsy. Rita, with a sense of nervous excitement and despite have no forewarning of his arrival, looked upon Chris's placement in her class as an opportunity for growth and learning. She did not know him and neither did her other students. As a result, some students were hesitant towards Chris. She understood how they felt, having little experience with high need

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[6] Rita taught Chris prior to this research thesis.

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illnesses or disabilities herself. In her mind, it was alright to feel uncomfortable with unfamiliar situations, but she expected herself and her students to push themselves and expand their comfort levels.

Although Chris' Educational Assistant [EA][7] was able to maintain Chris' day without much disruption to the whole class dynamic, Rita felt that Chris should be involved more. She knew he had potential. After she initiated meetings with the itinerant nurse, Chris' mother, the EA, and the people in Special Education, she made steps to fully integrate Chris into her classroom. In her mind, Chris was to be more than a mere presence, more than a "bump on a log" (Transcript from research interview, 2013). They got to know him more and as the months rolled by, a shift in her teaching occurred. In her mind, inclusion was no longer about Chris. Inclusion was about everyone.

At the time of this research, she had a family of her own, was completing a Masters of Education, and was currently teaching another student with cerebral palsy named Molly. This time, however, she found out in June that young Molly was going to be in her classroom in September. With the same excitement and eagerness as before, but with more experience behind her, she started to plan for Molly. She pushed to observe Molly in her old classroom before the year ended, but the busyness of middle years teaching and demands of the end of school year took hold and interfered with her plans.

After the students were gone for the summer, Rita was in her classroom as Molly's EA from the previous year started to bring in Molly's equipment. Molly had separate tables, a separate desk platform, and a separate box of supplies; the traditional equipment for high needs

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[7] An Educational Assistant [EA] is an individual assigned to support students in multiple ways depending on the needs of children or a classroom. In this research they were assigned specifically to the individual children with expectations of helping the rest of the class as well.

students at the school. Rita knew her own tables were adequate for her other students and would be fine for Molly as well. In her usual straightforward manner, she asked the custodian to adjust her tables so that Molly could sit, in her wheelchair, anywhere in the room. Rita, again with very little hesitation, got rid of Molly's desk.

At the beginning of the year, both Molly's EA and Rita were still unfamiliar with Molly and the necessities of her care. After a few weeks of feeling like they were floundering, Rita and her EA actively sought out people for help. Rita, a now highly experienced teacher at East Willows, went out of her way to express her frustrations to pivotal people in the school.

Molly was also part of the school system since the age of three and was able to grow up with a stable set of peers since Kindergarten. As a result of this familiarity, Rita noticed that the other students often forgot about her. Whereas a verbal student would have the ability to speak up to be included, Molly had to be a conscious inclusive effort. It became as important as ever to make inclusion an expectation of everyone. Although Molly's parents had expressed that Molly was having the best year in school she had ever had, Rita knew that there were so many more ways to be meeting Molly's needs and she was still passionately seeking them out at the time of this research.

Leah's Narrative

Leah has always believed that she has the power and the ability to control her destiny and travel down any path in whatever way she wants. She grew up in a small town in the northern part of a western Canadian province. She played soccer and softball and took horseback riding lessons, an activity she continued into her university years. In her post-secondary years, she had moved to many cities across Canada and had also taken time off to ride horses, volunteer in schools, and travel to Europe to volunteer at an orphanage.

After graduation, she moved to the United Kingdom and worked as a supply teacher for a few months. Free from concern about making mistakes, free from worrying over her reputation, she thoroughly enjoyed her stay there. After moving back to Canada, she started to work as a substitute teacher and found a part-time position at East Willows Elementary School working as a classroom support. One day, she was offered a full-time position as a primary years teacher at another school. Although initially she was upset to leave East Willows, she found her new school to be well-suited for her needs. After a few years of shifting between teaching Grades 1 and 3 at this school, she was offered a full-time position as a primary grades teacher at East Willows. For a variety of reasons, she moved back to this new and upcoming school.

Leah's first year at East Willows was tough for her. East Willows was larger and structured differently than her previous school. The first thing she noticed was the lack of desks and tables in the hallway for students to work independently, a feature that was valued by Leah and the staff at her old school. She immediately felt it was her job to keep the students in the class despite feeling tensions about it. Though subsequent years have been an improvement, she found it difficult to seek support during this time, partly due to being a new teacher in a large school and partly due to her perception of what it meant to be a good teacher at this school.

At the time of this research, Jeremy, a small young boy with cerebral palsy, was in her classroom at East Willows. Leah had never taught a student with as high physical needs as Jeremy before. She was overwhelmed with information regarding the technological systems available for Jeremy at the beginning of the school year. Jeremy's previous teacher, although positive and encouraging, could not provide constructive advice for including Jeremy in the classroom. She had said that Jeremy was very sweet and quiet and that his EA did most of the work. The classroom EAs who were currently taking on the majority of Jeremy's care, one in the

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morning and one in the afternoon, were highly experienced with a long history in the school. They spent most of their day with him. Jeremy spent surprisingly little time in the classroom without an EA by his side.

Jeremy was frequently taken in and out of the classroom for various care and therapies throughout the day. Leah often noticed how this transient and isolated daily structure contributed to a perception of Jeremy as a plus 1 in a class of 25. Although 26 students were enrolled in her classroom, Leah was displeased about the positioning of her students as "25 plus 1" (Transcript from research interview, 2013) rather than an integrated population of 26.

Leah also noticed her students and EAs sometimes treating this tiny young boy like a baby or toddler, often cooing and cuddling him. She wanted him to be treated like any other student, with the same freedom, respect, and dignity afforded to any other. She wanted to be more involved with his life and certainly wanted Jeremy to be more involved with the classroom, but expressed some uncertainty about which direction to take. Despite this doubt, at the time of this research, Leah, who had placed a table and chair in the hallway, was pursuing opportunities to evoke a positive shift in her students and her EAs perspective of Jeremy.

Curriculum Making and the Curriculum Around Chronic Illness

This paper grew out of research that focused on the experiences of teachers, described above, who taught a child or youth in their classrooms with a chronic illness and what it meant to co-compose a curriculum shaped around a chronic illness. This view of curriculum making comes from the work of Clandinin and Connelly (1992) who suggested that curriculum "might be viewed as an account of teachers' and students' lives together in schools and classrooms... [In this view of curriculum making] the teacher is seen as an integral part of the curricular process ... in which teacher, learners, subject matter, and milieu are in dynamic interaction" (p. 392).

Sharing the "vision of curriculum as a course of life," curriculum is seen as composed and embedded in the lives of those involved (Clandinin & Connelly, 1992, p. 393). It is a curriculum of lives. Considering broader epistemological, cultural, social, and political contexts, curriculum making in the classroom is shaped by teachers' stories, stories of teachers, school stories, and stories of school (Clandinin & Connelly, 1996).

Using this definition of curriculum as a course of life in relation to the presence of illness in the schools, students and their teachers can be seen as engaging in a curriculum that is shaped by the presence of illness. This curriculum, a curriculum around chronic illness, focuses on living and in that living attending to being chronically ill. It focuses on the active construction of a life story alongside a chronic illness. The curriculum around chronic illness is a curriculum of lives shaped by a chronic illness. This paper attends to the bumps in the navigation of such a curriculum and focuses on the stories that two elementary teachers were living, telling, retelling, and reliving (Connelly & Clandinin, 1990) in relation to teaching a student with a chronic illness.

Thinking of curriculum making in relation to lives being storied and restoried shapes a narrative understanding of teacher identity as stories to live by (Connelly & Clandinin, 1999). Stories to live by "attend to the historical, the temporal, the contextual, and the relational [and] interconnect teachers' personal practical knowledge with their professional knowledge contexts" (Huber et al., 2003, p. 347). Personal practical knowledge is a term used to understand the specialized knowledge foundations of teachers as "a moral, affective, and aesthetic way of knowing life's educational situations" (Connelly & Clandinin, 1988, p. 59). A teacher's personal practical knowledge blends the academic and theoretical understandings with her or his personal background and practical experiences (Clandinin, 1985). Attending to teacher identity narratively permits an understanding of teacher identity as "collections of stories about persons"

and explores the richness and complexity of the connection between experience, lived and told stories, and identity (Sfard & Prusak, 2005, p. 16). A narrative understanding of curriculum and identity requires keeping stories to live by at the heart of making and remaking of a curriculum around chronic illness.

Narrative Coherence and Dis-Ease: Shifting Stories of Inclusion

Leah and Rita were confronted with tensions as their stories of what it meant to be good teachers who practice inclusive education bumped up against the events of their classroom being lived out in relation to Jeremy, Chris, and Molly. Leah and Rita did not have extensive backgrounds with such high needs students and had very little experience with chronic illness in general. Although both teachers had a few years of teaching background before encountering these students, each teacher, in her own way, had to confront the reality of not being the knowledgeable leader of the classroom and not being aware of which action or pathway would be the most suitable for these students in order to create an inclusive setting. Both Rita and Leah expressed considerable states of indecision, doubt, questioning, and uncertainty during our conversations regarding their approach to teaching these students. However, they never seemed to lose confidence in themselves. They always knew there was a way; they just had to find it.

Both teachers experienced a tension in their story of themselves as teachers, their story to live by. In a narrative understanding of lives, this tension is understood as a disruption in their narrative coherence (Carr, 1986). Maintaining narrative coherence is not an easy task and at different times, a person's life may exhibit more or less coherence. A gap can form between the stories of one's perceived self and the lived and told stories of oneself and others (Sfard & Prusak, 2005). According to Carr (1986), when we struggle for unity and continuity, "[w]hat we are doing is telling and retelling, to ourselves and to others, the story of what we are about and

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what we are" (p. 97). Carr continued by saying that coherence "seems to be a need imposed on us whether we seek it or not. Things need to make sense" (p. 97). Leah and Rita told stories to and of themselves of being competent knowledgeable teachers with inclusive educational practices. Each aimed to create a classroom community and such an aim was part of their story to live by, their storied teacher identity. When the unity of their stories to live by was interrupted because of new experiences teaching a student with a high needs chronic illness, they looked for and anticipated ways in which these new stories belonged. They worked to restore their narrative coherence when it seemed lost or misplaced by seeking out and imagining new opportunities and new realities (Carr, 1986).

Rita: Rediscovering Coherence

In Rita's narrative, the struggle to find ways to include Chris into her classroom can be seen as an act to restore her coherence as an inclusive teacher. Her prior ways of teaching worked well with her previous students, but it seemed she needed to do more with Chris in order to foster inclusion. She relied heavily on the EA, but also worked to maintain coherence by diligently seeking information, guidance, and advice from other members of the school staff. She asked many questions of the special education staff and nursing staff and invited Chris' mother to come into talk with her and the class. She strongly encouraged, if not mandated, that Chris, and later Molly, were part of all classroom activities and that her other students were to include them as they would others. Rita sought ways to foster an inclusive setting for her students despite being in a situation she had never found herself before and consequently sought coherence with her identity of herself as an inclusive educator.

However, it was in this struggle to maintain her first story of inclusion with Chris, a narrative that shaped her story to live by, that her ideas of what it meant to be an inclusive

educator began to shift. In this struggle, she came to a new understanding of her practice. In her

attempt to maintain coherence by externally negotiating her classroom, she was shifting her

internal state and her personal practical knowledge. From working outwards to change her

external environment and create a safe place for Chris, Rita ventured inward to find a new story

to live by. She learned that inclusion was more than simply including students with special

needs in her classroom:

> When I first ... had the opportunity to teach students with special needs, I came at it from
>
> [thinking] inclusion meant they became a part of my classroom and then as that idea
>
> evolved ... inclusion became about everybody ... because inclusion was socially about
>
> the shy girl who's afraid to ask to sit with the other girls ... inclusion is about that athletic
>
> boy who passes the basketball to the boy who can't dribble the ball, inclusion is about ...
>
> everyone all the time, it's not [just] about taking time to include [people with special
>
> needs]. (Transcript from research interview, 2013)
>
> It's not just the expectation for [Chris] ... it's the expectation for everyone. (Transcript
>
> from research interview, 2013)

She learned from Chris that inclusion was for all students, regardless of ability or health, and she

maintained this new story to live by in her teaching practices with Molly and her other students

at the time of this research.

When she found out that Molly was going to be in her classroom, she was eager to

engage in the rich educative learning experiences brought about by the presence of a visibly

diverse child. Because she knew of the promise from such students, she became frustrated when

Molly's potential was not being met in the first few weeks of class. She felt that Molly, Molly's

EA, and she were floundering during this time. She did not have the answers, but knew they

existed. Rita had to work hard and persist in order to seek resources and knowledgeable people to help her through this struggle. In this, she actively sought ways to maintain a coherent sense of inclusion in her classroom.

Leah: Negotiating Coherence

Leah also worked to maintain coherence in her stories of what it meant to be a good teacher with inclusive educational philosophies and practices. She worked to maintain this perception of herself and her practices in a school that adhered to different values and beliefs. In her teaching, Leah worked towards an inclusive setting by creating safe places for children to work together and talk to one another; safe places emotionally, physically, and intellectually. She strove to interact with each student every day and to listen genuinely to them in order to foster meaningful relationships. Jeremy was Leah's first very high needs student in this capacity. When he entered her classroom, Leah's personal practical knowledge of how to create an inclusive setting built upon relationships was brought into a place of tension. She found it challenging to form a meaningful relationship with Jeremy due to his inability to communicate and she found herself, to her dismay, sometimes forgetting about this very quiet young boy amid the busyness of a primary grade classroom. During our conversations, Leah would express how she felt unable to include him in the daily classroom routines. This created tension in Leah's story to live by and interrupted her narrative coherence.

Throughout our conversations, Leah grew in her commitment to create opportunities for her classroom and EAs to learn how to interact with Jeremy as an equal. She was planning to ask Jeremy's family and siblings to come into her classroom and talk about how they interact with him in order to demonstrate to the class that Jeremy can and should be treated as an equal. Here, Leah was in the midst of seeking ways to maintain coherence of herself as an inclusive

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educator by actively pursuing opportunities for classroom growth and learning. One is left to wonder how this quest and its outcomes will shift her teaching stories to live by.

Making Meaning from Liminal Spaces

As each teacher struggled to find and maintain narrative coherence in their inclusive curriculum making amidst an environment disrupted by a chronic illness, they were negotiating their travel into and out of liminal spaces. Rita and Leah were brought into a liminal space as they encountered Chris, Molly, and Jeremy and strove to understand and make meaning of these new relationships. Marked by uncertainty and doubt, they negotiated the liminal spaces created by chronic illness and its effects on their curriculum making and practices. Each teacher entered a liminal space in a similar manner, but upon exiting, they were able to create a new "forward-looking story" (Nelson, 2000, p. 501); a future oriented story that guides their actions. This new story held their definition of themselves in harmony with the new classroom circumstance.

Rita's narratives were riddled with stories of optimism, passion, and confidence. She used this determination to actively and persistently seek support and resources. She created learning opportunities from moments of tensions and eagerly promoted relationships within her classroom with an open mind and a kind heart. Her forward-looking story (Nelson, 2000) was marked by excitement, understanding, passion, and empathy. It became one of social justice and agency. She persisted against inequality on behalf of and for her students and fought for her students' right to make their own place in the world and control their own destiny.

Leah's narrative was permeated with freedom of place, freedom of movement, and freedom of transition. She valued her ability to choose her own place and consequently promoted this aspect in her teaching. When she noticed the perception the class and EAs were taking towards Jeremy, she felt considerable tension. She knew Jeremy had the right and

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freedom to choose his place in the classroom, to make his own decisions, and find his own destiny. This conflicted with how Jeremy was being treated, as a baby or toddler within the classroom, cooed and cuddled. Leah's tension brought her into a liminal space. She knew the way Jeremy was viewed and treated was not congruent with her perception of her students as having freedom and choice, but she was unsure of how to address the issue. She also knew she needed to do more than what she had previously done, but did not quite know what path to take.

It was in this liminal space that Leah began to imagine new, although slightly nebulous, stories to live by in her classroom (Huber et al., 2003). Leah was stepping away from a scripted story of this school in order to negotiate the curriculum around chronic illness that "fit the moment and the lives being lived there" through entering a place of liminality (Huber et al., 2003, p. 359). At the time of the research, she was negotiating this transition, this liminal space, with her new forward-looking story in the making. The beginnings of this new story were carved out by a sense of freedom in transition and place; a freedom to choose, and re-choose, one's own destiny. It will undoubtedly continue to be marked by such a freedom.

Shifting Perspectives of Chronicity: Redefining Illness Boundaries

In creating a new forward-looking story from the liminal spaces created by the chronic illnesses of the children, Leah and Rita started to look past the physical implications of the illness. Although it was clear from the beginning that Leah and Rita recognized there was more to these students than their illness, they started to weave the story of illness into their perception of the student, rather than having the illness as the most visible characteristic of their identity. They began to look past their condition and came to know the person behind the veil of illness.

In Leah's experience, such a mask was slowly being uncovered as she was working towards creating an inclusive setting. Her experiences doing so were also made more complex

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by her position as a relatively new teacher at East Willows Elementary School and by her working through a story of finding her place in this large school. It was also made more complex by her relationship with the EAs assigned to the children. The EAs had many more years of experience in education and working at this school than Leah. They had a different perspective of what was best for Jeremy which often conflicted with what Leah thought was appropriate. Leah expressed tensions regarding this situation that manifested themselves through concerns with communication, authority, and relationships that grew over the course of our conversations.

These growing tensions alluded to a shifting definition of the priority of the student(s) condition. Both Rita and Leah experienced such a shift. Their students' illnesses were impactful in the daily life and the lives of others around them; these students and the ones who cared for them were immersed in the chronic illness (Charmaz, 1991). However, over time, this immersion was woven into the story of these students. Leah, as with Rita, knew the children and youth with whom they taught were bounded by illness, but they also knew they were more than that. Both Leah and Rita realized their students would always be immersed in illness and that they would never make them able-bodied. Instead, they thought of the illness as a part of knowing and living alongside them. Rita's and Leah's physical lives were characteristic of being immersed in illness, but they lived a teaching story that believed otherwise.

World-Traveling and Relationships: Worlds and Arrogant or Loving Perception

Both Rita's and Leah's narratives were permeated with stories of trying to understand their students; a task made more challenging by the limited capacity for Molly, Chris, and Jeremy to respond back. In their attempts at understanding, Rita and Leah were travelling to the worlds of their students. Lugones (1987) argues that these efforts to identify with and know a

person of a different "world" are part of a loving perception. On the contrary, an "arrogant perception" perceives others arrogantly and fails to identify with them. A "world" is defined by Lugones (1987) to mean constructions of life and experience. Worlds must be inhabited by people or imagined people; they may be complete or incomplete; they may be part of a larger society or may be the larger society itself.

People can travel from world to world willfully or unknowingly. They may be different people in each world. A person can inhabit multiple worlds at the same time. A world may construct a person in a certain way, but she or he may not hold, adhere to, or believe the construction of him or her in that world. To understand someone else, according to Lugones (1987), is to lovingly travel to their world.

Relational Knowing: Challenges Faced on the Peripheries of Relationships

Leah and Rita both expressed difficulties learning about their students and lovingly travel to their worlds. When these women were unable to travel into their students' worlds, they became world-observers; looking at the lives of their students from the outside. These women knew that in order to achieve their inclusive classroom community, they needed to know and understand their students; to travel to their worlds. They knew that this understanding came through relationships. They wanted to form meaningful relationships with their students, Jeremy, Chris, and Molly, but expressed that they faced many challenges brought about by the limited ability of these students to communicate. They spoke of how challenging it was learning to create and maintain a relationship differently than before.

Rita sought to form relationships with Chris and Molly from the peripheries. Rita asked many questions of their parents, siblings, other family members, and support staff who worked extensively with the students. She learned about Chris and Molly through those closest to them.

All along the way, Rita made purposeful interactions and observations of Chris and Molly in order to understand them and better meet their needs. Rita also reflected upon her experiences teaching Chris to inform some of her practices with Molly.

In Leah's classroom, Leah began to form relationships through observation and intuition. Leah empathized with Jeremy by putting herself in Jeremy's "shoes." She would try to perceive as Jeremy did and would ponder about what action she would prefer if she was in Jeremy's position. She made her decisions based on her intuition and observation. She learned to see Jeremy and his actions differently. It was through this difference she learned to read Jeremy's signals and place different meanings on his actions.

Rita and Leah learned how to make curriculum with Chris, Molly, and Jeremy through this "relational knowing" of the student (Hollingsworth, Dybdahl, & Minarik, 1993, p. 8). This relational knowing is central to teaching any child or youth. It "occurs as much in energy or intuitive perception as in either concrete or languaged form" and "evokes past memories of stored knowledge transformed into knowing through not only cognitive, but moral, spiritual, psychological, and physical responses" (Hollingsworth et al., 1993, p. 10). Undoubtedly, the way Rita and Leah grew in their relational knowing of these particular students was different than they had experienced before. Rita's and Leah's relational knowing informed their personal practical knowledge and their curriculum making with these students.

Filling in the Gaps: Shifting Perceptions

Both teachers worked to fill in the relationship gaps created by the boundary of illness and health. They were aware that the nature of their students' condition could result in an incomplete relationship. They knew that they could not have the same relationship with these students as with students of full communicative ability. Rita and Leah were required to shift the

way they learned about their students. As Bateson (1994) explains, "sometimes change is directly visible, but sometimes it is apparent only to peripheral vision, altering the meaning of the foreground" (p. 6). Leah and Rita sought to form relationships in unfamiliar ways, through ways perhaps only visible in the peripheral visions of experience (Bateson, 1994).

Rita worked from the outside in, filling in the centre of the relationship by seeking out external answers with a passionate drive. Leah worked from the inside out, filling the gaps with empathy and observation. Through patience and understanding, they learned to appreciate "doing without answers ... and making do with fragmentary ones" (Bateson, 1994, p. 9). These women learned to perceive their students lovingly and were able to playfully travel to their world. They learned how to perceive and accept the incompleteness of relationship created by high needs and non-communicative cerebral palsy. They learned to perceive lovingly while having an incomplete picture and find their coherence within this complexity and multiplicity (Bateson, 1994). As Noddings (2003) explained, "[t]o cultivate our happiness, we must enjoy situations and relationships that are less than perfect but, as we are open to them, yield moments of great joy" (p. 132).

Through this relationship building, Rita and Leah were able to shift their curriculum making from prioritizing the chronic illness to being able to weave it into knowledge of Chris, Molly, and Jeremy. They were able to shift away from an arrogant perception that saw only the overwhelming problems and troubles associated with the chronic illness. Although still recognizing such problems, they learned to perceive lovingly (Lugones, 1987). Their relational knowing of the student shifted as they learned to see past the implications, symptoms, treatments, and therapies that dominated the students' lives. Chronic illness became a part of the student's identity rather than the largest identifier.

They also learned how to perceive themselves lovingly in their recognition that they may not always know what is "best" for their students. This manifested in their curriculum making by the knowledge that students themselves could help inform decisions regarding their care and education and that the adults responsible for them should not dictate every action or decision. Leah recognized this more subtle arrogant perception in one classroom's EA. The EA, although doing what she thought was best for Jeremy, seemed to rely heavily on her previous experience to inform her decisions. Leah felt she doted on Jeremy at the expense of the rest of the class and at times, even isolated him. Leah, recognizing that she herself did not have all the answers regarding Jeremy's care either, had hoped that the EA would be more understanding towards her desires for a classroom community. In a way, Leah hoped the EA would be more open to new circumstances and opportunities in her classroom rather than relying on her experience with Jeremy from years previous.

Rita encountered another subtle arrogant perception. This perception purports that teachers should be able to "figure it out" when it comes to the unique care of students with high needs. Rita received very little training regarding accommodating health care needs. She received very little instruction regarding Molly's educational technology and asserted that such training would have been highly valuable. Rita exhibited a passionate drive in her efforts to find more information. She was also highly aware that such persistence was easier for her because of her years of experience at East Willows Elementary School.

Such arrogant perceptions work to suppress liminality. Dominant stories, such as the stories that say "the cerebral palsy kid," "you'll figure it out," and "I know what is best for him or her," halt the negotiation of meaning across difference (Huber et al., 2003). Places of liminality vanish as the dominant stories of school and illness are imposed. Moments of uncertainty,

unknowing, and unfamiliarity, necessary for curriculum making, disappear as arrogant perceptions take hold. These arrogant perceptions impose certainty and stability on a landscape full of ever-changing and complex lives; lives that enter and exit liminal spaces in dynamic relations oriented towards new forward-looking stories. Although liminal spaces can be onerous as teachers transition from certainty to uncertainty, these spaces allow teachers to imagine new possibilities and new stories to live by (Huber et al., 2003).

Social Significance and Liminality Revisited

It is estimated that upwards of 20% of students currently in schools have a chronic illness of some form and these numbers are expected to rise as medical care advances allow a child or youth and her or his family to better manage the illness (Hamlet et al., 2011; Mukherjee et al., 2000; Shaw & McCabe, 2008). Consequently, there is an increasing need for people involved in these students education to be responsive to the student's educational concerns and needs. This paper explored the experiences of two elementary teachers as they negotiated their actions and decisions on a school landscape shaped by the presence of a chronic illness.

It can be said that teachers always have an incomplete picture of their students and that they, in different ways at different times, perceive their students arrogantly. There is simply not enough time in the regular school year to know the ever-changing lives of children and youth or to account for all the varying circumstances that affect the way teachers view their students. In Leah's and Rita's experiences, their curriculum making bumped up against a landscape marked by a chronic illness. They were confronted with tensions when their hopes and aims of building a classroom community were interrupted by various arrogant perceptions suppressing places of liminality. They worked towards world-travelling and learned to perceive the incompleteness created by illness as whole. They knew the worlds of their students were complete and

integrative. Through their relational knowing of the students, they lovingly negotiated their travel to and from different worlds and places of liminality and were continuing to do so at the time of this research.

An Aside for Time

At the beginning of the school year, each teacher struggled with understanding and coping with the demands of the illness, which seemed, at the time, to be the most visible identifier of the student. The various therapies, personal care excursions, and illness symptoms seemed to dominate each teacher's pedagogical actions. Their attention was directed towards management rather than obtaining and fostering an inclusive community. As the teachers learned to perceive their relationship with the child not as different and incomplete, but as whole and full within, and learned how to manage effectively the implications of their students' illness, a key feature became apparent: time. The settling of their relationship negotiation and their curriculum making simply took time. The negotiations of liminal spaces and new forward-looking stories required time. It required time for the arrogant perception of the students as only their illness to subside and to learn to perceive lovingly. It took them time to learn how to world-travel and accept the inconclusiveness of their curriculum making in the curriculum around chronic illness; a trait undoubtedly found in all curriculum making. It took time to not only look towards their students with loving eyes, but also look towards themselves with the same loving and forgiving eyes.

Final Words

When teachers teach a child or youth with a chronic illness, when they attend to a child and her or his lived experiences, they are called into transition. Engaging in a curriculum around chronic illness called Rita and Leah to see and observe differently, to see the same story through

a different lens. Rita and Leah entered a liminal space in their curriculum making and were learning to perceive wholly as they were brought into a new forward-looking story. They entered into a place of difference, a liminal space between health and un-health, illness and wellness, capability and desire. A space created, in time, by the transitioning from a story they lived by beforehand and the story they will come to, a new story to live by. The act of curriculum making around chronic illness requires time and possibilities present in liminal spaces. It was through these teachers' relational knowing of themselves and their students in liminality, developed through patience and ingenuity, that they were able to, and were still learning to, see past the illness and perceive their students and themselves with loving eyes.

CHAPTER FIVE.
CONCLUSION

Overview of Document

Chapter 1 of this thesis opened with a narrative that highlighted a moment of tension in a teacher's curriculum making that was created by the unforeseen events in the curriculum around chronic illness. Following this narrative beginning, the chapter explored the definition of chronic illnesses, chronicity, the curriculum around chronic illness, relevant research literature, and the unique placement of this thesis in the broader research field.

Chapter 2 focused on the methodology and methods of this research. It explored narrative concepts including professional knowledge landscapes, stories to live by, personal practical knowledge, and narrative coherence. It also described the research process and detailed ethical considerations of this research.

Chapter 3 and 4 inquired into the experiences of the teacher participants. Chapter 3 explored Claire's experiences as an early childhood educator and highlighted the way Claire's playful curriculum making and playful teaching attitude naturally and delightfully negotiated the ambiguities and tensions in the curriculum around chronic illness. Chapter 4 explored the experiences of Rita and Leah as they taught students with high needs cerebral palsy. This chapter inquired into the place of liminality in the curriculum around chronic illness and explored how world-travelling and loving and arrogant perceptions can manifest on a school landscape marked by chronic illness.

This chapter details some common concerns and stories of the teacher participants that were not previously addressed directly and discusses historical perspectives of chronic illness and the ethic of care. The chapter contains a reflection of my experiences in this research

process and revisits key concepts and terms explored in this research. This chapter ends with some thoughts about the curriculum around chronic illness.

Common Concerns

Each teacher participant had a unique background, approach to teaching, and personality. However, they shared many similar concerns that were not mentioned directly in the previous chapters. Considering the complexity and importance of the lives of teachers and students in school, they warrant discussion. Some of these concerns will be addressed here.

All three women strove to create a safe place in their classroom for all their students. Although sometimes not directly naming it as such, all three teachers worked towards fostering inclusion and a sense of community in their classroom. It was apparent in our conversations, both recorded and casual, that these women cared deeply for both their students with chronic illnesses and those of full health. They genuinely wanted the best for all their students. It was clear that their students' happiness and safety were a high priority in their teaching.

All three women expressed the importance of administrative support and other support structures within the school. The support of the EAs was consistently acknowledged as invaluable and crucial for maintaining the classroom. All were appreciative of the support and guidance of the itinerant nurse working at this school, to which I am also grateful, and members of the special education department. All three teachers valued the support they did receive, but Rita and Leah expressed a desire for more consistent and easily accessible support. Claire explained that the provincial pre-Kindergarten program mandated that there must be one adult for every eight children with a maximum of 16 children per class. As a result, she felt she received considerable support.

The teachers also expressed little concern regarding taking on responsibility for the physical safety and medical care of the students. Personal liability was not alluded to or mentioned directly. They were not concerned about any physical or political harm for themselves and did not express any fear for the safety of their students in the classroom. The teachers also expressed thoughts, both positive and negative, pertaining to the large student population at East Willows Elementary School.

Rita and Leah expressed other unique concerns regarding Chris, Molly, and Jeremy. At times, they felt they did not have enough time to appropriately meet and address the student's needs. They expressed concern over how much time and attention Chris, Molly, and Jeremy were getting in comparison to the other students in the classroom. They felt that there should be a more balanced and equitable approach.

Rita and Leah did not feel that their teacher preservice programs adequately addressed the issues created by chronic illness and other high needs in the classroom. Both told stories of a sharp learning curve in their first few years of teaching and when they encountered their students with chronic illnesses. They also mentioned or alluded to their willingness to engage in additional training specific to their situation and to learn more about the student and her or his condition.

There was a common storyline pertaining to peer relationships. Both Rita and Claire explained that some of the students who exhibited physically and emotionally aggressive behaviour towards others formed caring and loving relationships with Chris, Molly, or Madeline, respectively. For example, in Claire's classroom, a young boy who exhibited aggressive and unkind behaviour towards the children in her pre-Kindergarten class would never hurt Madeline.

Claire described moments when this typically physically aggressive young boy, who practically

tackled other students in the class, would lean in and give Madeline the kindest, gentlest of hugs.

Historical Perspectives: From Segregation and Misconceptions to an Ethic of Care

There have been a wide variety of perspectives towards chronic illnesses in the past.

Shamans and healers turned to supernatural, spiritual, or intangible aspects of human existence to

understand the meaning of sickness and work towards healing (Eisenberg, 1977). Many

religious groups of the past and some in present times believed that illness was a plight or

punishment from a deity (Pargament, Smith, Koenig, & Perez, 1998). Illness was also thought to

be manifestations of psychological disturbances, such as "hysteria" (Micale, 1995). On the other

end of the spectrum, the treatment of chronic illnesses did not often consider the quality of life

for the patient, focusing on symptom diminishment rather than enjoyment of life (Cella, 1995).

Increasingly, the patient's subjective experience has become an important factor in considering

future treatments (Burckhardt, Woods, Schultz, & Ziebarth, 1989). There has been a push

towards investigating the psychological and social influences on illness, such as looking at the

effects that social support and psychological states, including high stress, negative affectivity,

depression, and emotionality, can have on body and its relationship to illness and quality of life

(Biondi & Zannino, 1997; Ostfeld, Lebovits, Shekelle, & Paul, 1964; Renn, Feliciano, & Segal,

2011; Watson & Pennebaker, 1989).

Care for those with chronic illnesses has also shifted away from a burden and loss

conceptualization towards imaging health within illness, transformation, and normality (Thorne

& Paterson, 1998). It works more towards ensuring a quality of life and a sense of normalcy for

the patients in addition to the required treatments and regimens. The mass public is also better

informed than in years previous. For example, in 1961, a survey regarding the public's opinion

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of the causes of cancer revealed that the majority of those surveyed did not know any causes of

cancer or believed that it was caused by neglect of skin bruises, irritations, infections, or sores;

the remaining believed in a wide variety of reasons including, but not limited to, poor sleep,

smoking, infections, pollution, lack of cleanliness, stress, drinking, babies, and sexual intercourse

(Toch, Allen, & Lazer, 1961). It is apparent that public knowledge of cancer, and other chronic

illnesses, has improved since this survey and are still improving.

Such conceptions and misconceptions of people living with chronic illness were based

upon their knowledge of the disease and its implications and side effects, often without

consideration of the individual behind it. The teachers involved in this research thesis, Claire,

Rita, and Leah, through their personal commitment to care and educate these students to the best

of their ability, experienced a shift in their knowledge. Their knowledge of the disease shifted

into a knowledge of the student.

This personal and professional obligation to care and learn was part of their ethic of care,

as described by Noddings (2002). Noddings (2002) advocated that the way to create a better

world is through better people. She argued for an ethic of care that is fundamentally based on

the caring relation between the carer and the cared-for. Noddings further argued that educators

abide by the obligation of genuine care of the cared-for not because of a pre-existing set of

principles or virtues, but because of a "response-ability" (Noddings, 2003, p. 35) to their

students, meaning that they willingly respond positively to their students through dialogue,

observation, and meaningful relationships (Murphy, 2013). Response-ability, accordingly, is

deeply relational (Noddings, 2003).

In contrast to response-ability, Noddings (2003) described accountability; a term

commonly used in discussions of education and standards. This term stems from the business

world and focuses on a person's vulnerability. Accountability creates a sense of worry about reputation as it forces individuals to find ways to prevent accusations or look for excuses when she or he does not fit within the imposed standards (Murphy, 2013). Although accountability is important in the school setting, for example being accountable to arrive at work on time, Noddings stressed that educators should focus on the ones they are responsible for, namely, the students (Murphy, 2013). In this research thesis, Claire, Rita, and Leah expressed a strong ethic of care and a strong desire to be response-able. They felt both a personal and a professional responsibility to provide an inclusive and meaningful education for their students and to be responsive to their needs. Such an ethic of care, in a landscape shaped by a chronic illness, focuses on the education of the child rather than a segregated management of disease.

Social Significance and Future Implications

In comparison to the long history of discrimination and segregation that children with chronic illnesses or disability have experienced, it has been relatively recent that these students have been included in mainstream education (Collins, 1995; Kliewer, 1998). Considering the unique needs of these students and the rising prevalence rates of chronic illness in the schools, it is important to explore ways to appropriately respond to the educational needs of these students.

The social significance of this research thesis was in its ability to retell the stories of the teachers who worked and lived alongside a student with a chronic illness; stories typically underrepresented in the literature of this topic. It neither reduced the complexity of the stories nor prioritized the educational problems associated with chronic illness; instead, it allowed for the complexities, both positive and negative, to exist freely without judgement or blame. It focused on the stories of these teachers, lived and told, so that others may find a reflection of themselves in them and learn from these experiences.

Given that this inquiry was a *telling* narrative inquiry (Connelly & Clandinin, 2006), meaning that the stories, experiences, and field notes were collected through interviews, future research could entail living alongside a teacher for an extended period of time as she or he teaches the student with the chronic illness. This would entail what Connelly and Clandinin (2006) call a *living* narrative inquiry. Further research in this topic includes gathering the stories from a broader range of individuals involved, such as families, peers, educational assistants, itinerant or school nurses, special education teachers, and administrators. Stories could also be gathered from the students themselves.

Reflection on the Research Process

This research was a powerful learning experience for me as I travelled along a path that started with telling a story of a school assembly. From this single story grew research wonders that guided the process and creation of this thesis. One of the most rewarding and challenging aspects of conducting this research was listening to the stories of others who either lived through a chronic illness themselves or knew and cared for someone with one. It became apparent that many of those who I spoke with, both in and out of the research context, needed to tell these stories and needed to have them heard. It also seemed that many people, in some way, had a personal or professional connection to this topic. I found it increasingly important to listen attentively to these stories, both good and bad, in many aspects of my life. It was challenging to hear stories of shame, fear, and sadness, but it was highly rewarding to listen to stories marked by optimism, courage, healing, and friendship. It was these latter stories that encouraged me along the way as I negotiated my own personal and professional stories of chronic illness.

I was surprised and overjoyed about how open and honest the teacher participants were during our conversations. Considering the uncertain and possibly fearful nature of chronic

illness, I was expecting some hesitation or concern over sharing their experiences. Instead, these women were forthcoming and direct and were eager to share. It was a pleasure getting to know these women and listening to their stories.

Revisiting Key Terms

The following sections revisit key terms and concepts presented in this research in relation to the experiences of Claire, Rita, and Leah. These include: citizenship, sharing authority, counterstories, liminality, forward-looking stories, personal practical knowledge, stories to live by, narrative coherence, world-travelling, and arrogant and loving perceptions. It also explores some shifting peripheries from this research and revisits the curriculum around chronic illness.

Citizenship

In the past, children or youth with a chronic illness have lived a story of discrimination and segregation in their education and it has only been relatively recent that these students have been included in mainstream education (Kliewer, 1998; Mukherjee et al., 2000). With shifting societal ideals and governmental mandates, these students have been included in mainstream schools and classrooms with the goal of full citizenship. Citizenship refers to viewing those with a disability as valued human beings and recognizing their significance in the larger community (Kliewer, 1998). Working towards citizenship in the classroom requires the active and purposeful participation of all students and teachers in multiple realms. In citizenship, acceptance is the foundation for development (Kliewer, 1998).

In their curriculum making, teachers can work towards engaging students with chronic illness into full citizenship. Using a playful attitude and spirit to guide their curriculum making, as was shown in Claire's teaching, teachers can create a safe and accepting place for students like

Madeline in the classroom. Claire's playful spirit was boundless, adaptable, and open to possibilities. Adopting such a playful attitude in teaching means that teachers view the discomforts and disruptions created by a chronic illness as obstacles to overcome or, in lieu of the imaginative plotlines of young children, mighty dragons to slay. This playfulness imagines possibilities and hope where limitations and fear reside. In this curriculum of play, teachers can negotiate the tensions and ambiguities of a curriculum shaped by a chronic illness and help bring these students into full citizenship.

Sharing Authority

Oyler (1996) described a sharing authority to entail a joint construction of knowledge where students are invited and encouraged to direct their learning towards a mutually developed agenda. It is not a dismissal or negation of teacher authority, but rather a co-participation between teacher and student in directing the process and content of the classroom (Oyler, 1996). When a teacher shares her authority with her student with a chronic illness, as Claire did with her pre-Kindergarten children, it allowed for these students, who often have lives dictated by those more knowledgeable in their illness (Charmaz, 1991), to contribute equally to the classroom process, content, and learning. As Claire shared authority with her classroom, she engaged Madeline and other students into full citizenship and equal standing. This sharing of authority in the classroom allows students with a chronic illness to co-construct meaning and contribute equally to the momentum and direction of the curriculum making in a curriculum around chronic illness.

Counterstories

Nelson (1996) described a counterstory to be a narrative that resists and challenges dominant stories and stories of domination. A counterstory "redescribes a dominant story,

repudiates it for her- or himself" and opens up alternative interpretations while undermining the dominance of dominant stories (Nelson, 1996, p. 98). On a school landscape shaped by a chronic illness, many possible dominant stories exist. These stories speak of standards and expectations, rigid governmental subject matter topics, and lack of support. It also portrays students with chronic illness as transient, problematic, and existing on the peripheries of inclusion.

The teachers in this research recognized some of these dominant stories, but did not live by them; instead, these teachers repudiated them and worked towards living a counterstory of acceptance and care based on their background and personal beliefs. It was through their loving and caring curriculum making that they disrupted the expected narratives of limitations from living with a chronic illness. They sought to reframe meaning from their experiences, meaning that chronic illness frequently disrupts (Clark, 2003), by working towards a loving and caring counterstory.

Liminality and Forward-Looking Stories

Liminal spaces are transitory spaces where a person is exiting one place or condition and entering another; it is an in-between place, neither here nor there (Heilbrun, 1999). The disruptions caused by chronic illness can bring a person into this place of difference, into a liminal space. On a school landscape marked by a chronic illness, these liminal spaces can manifest when teachers negotiate the multiple boundaries of health, such as the ones between illness and wellness, capability and desire, citizenship and segregation. Liminal spaces manifest when a teacher's ideas of what it means to create meaningful and educative experiences with students bumps up against the disruptions and limitations found in dominant stories of school

and illness. Liminal spaces can manifest when there is a disconnect between identity and practice, when a teacher steps away from a previous story to live by and moves towards another.

Claire, Rita, and Leah entered a liminal space when they desired to know and understand their students with a chronic illness, students of another world (Lugones, 1987). These teachers entered liminal spaces in order to create a new forward-looking story that was based on the relational knowing of their students and themselves. They were moving away from a dominant story of what it meant to teach a student with a chronic illness; stories that portray these students as transient, isolated, on the peripheries of a classroom, and prone to academic, social, and personal problems. Instead, Claire, Rita, and Leah imaged a new forward-looking story, one that holds the definition of themselves as teachers in harmony with their new classroom circumstances.

Claire's forward-looking story was marked by a playful attitude towards teaching and life, with family and kindness at the core of her curriculum making. Rita, a dedicated middle years teacher, had a forward-looking story riddled with passion, drive, and a clear idea of what inclusion meant for her classroom. Leah's forward-looking story was in the making at the time of the research, but with her background marked by freedom, transition, and autonomy, her new forward-looking story in the making hinted at such a freedom for herself and her students. These teachers were drawn into spaces of liminality in a similar way, through their desire to create safe, meaningful, and enjoyable experiences for their students in the most appropriate ways, but they were pulled out of these liminal spaces by their unique stories to live by and personal professional knowledge.

Personal Practical Knowledge, Stories to Live By, and Narrative Coherence

Clandinin (1985) explored teachers' personal practical knowledge as the blending between the academic and theoretical underpinnings of a teacher's knowledge with their practical experiences. It has a temporal quality as it exists in the teacher's past experiences, current mind and body, and her or his intentions for the future. Stories to live by is a narrative understanding of teacher identity that attends to the historical, temporal, contextual, and relational aspects of identity (Huber et al., 2003). Stories to live by are at the heart of making and remaking a curriculum around chronic illness.

Understanding narrative as the organizing principle of experiences and actions, Carr (1986) asserted that we find meaning in our lives through a narrative coherence. He explained that to experience, act, or live, at the most basic level, is to work towards maintaining or restoring narrative coherence. Coherence, Carr (1986) stated, "seems to be a need imposed on us whether we see it or not. Things need to make sense" (p. 97). When such a coherence is lost, we experience a "lack of sense" and work towards finding it again by telling and retelling stories of who and what we are to others and to ourselves (Carr, 1986, p. 97).

Given that chronic illness has the potential to be a biographically disruptive event for both the patient and those that care for him or her (Bury, 1982), teachers negotiating the curriculum around chronic illness are also susceptible to such disruptions in their personal practical knowledge and stories to live by. Teachers can experience tensions in their narrative coherence when the idea of themselves as inclusive educators bump up with the events of their classroom being lived out in relation to students with chronic illness. They may have to confront a new storyline that positioned them not as the knowledgeable leader of the classroom; they may have to confront the reality that there was no easy answer to what path they should travel along.

In this research, the teacher participants, confident that answers did exist, sought ways to maintain a certain level of narrative coherence in their stories to live by. Rita diligently asked questions and expressed her concerns to stakeholders in the school while seeking out and creating new ways to foster inclusion, such as the buddy system[8]. Leah was looking for ways to restore her coherence at the time of the research. She was considering incorporating Jeremy's family into her curriculum making to teach the students, the EA, and herself how to include Jeremy in the everyday activities of the classroom.

World-Travelling and Arrogant and Loving Perceptions

Lugones (1987) argued that to know another is to identify with them and lovingly and playfully travel to her or his world. These worlds are constructions of life and experience; they must be inhabited by people or images of people and may be complete or incomplete. Worlds may construct their inhabitants in a particular way, even though the people may not hold to that construction. Lugones asserted that people can travel between worlds willingly or unknowingly and can inhabit multiple worlds simultaneously. To understand and identify with someone of a different world is to adopt a loving perception; on the contrary, an arrogant perception is a failure to love and a failure to identify with someone (Lugones, 1987).

Teachers of students with chronic illness may find it challenging to adopt a loving perception on a landscape often dominated with arrogant perceptions. Some of the arrogant perceptions in this research told stories of segregation and incomplete relationships; some told stories that say "you'll figure it out" or "I know what is best for her." Such arrogant perceptions suppress educative moments of transition and halt the negotiation of meaning across difference and across liminality. Arrogant perceptions work against inclusive educational efforts. On the

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[8] The buddy system assigns a specific student or students to be a helper for the student with a chronic illness. These helpers stay with the student during recesses and lunch and help them with classroom activities.

contrary, adopting a loving perception allows teachers to see past the implications, side effects, symptoms, and treatments of chronic illness. Chronic illness, seen with loving eyes, becomes a part of the student's identity and is woven into the relational knowing (Hollingsworth et al., 1993) of that student. Rita and Leah, although initially overwhelmed by the outcomes of their students' illness, learned to perceive their students and themselves lovingly and wholly.

Shifting Peripheries

The teachers in this research, Claire, Rita, and Leah, spoke of some of the challenges forming relationships with their students with chronic illnesses. Absences and excursions that took the student out of the classroom were aspects of a life with chronic illness that reduced the interactions between student and teacher. Consequently, it made it more challenging to foster relationships. The students' limited verbal ability to communicate also created obstacles in forming meaningful relationships. As a result, the teachers had to form relationships with these students in unfamiliar ways. These efforts, perhaps only visible from the peripheries, were unique to each teacher. Claire based her relationships on play, outdoor education, kindness, and unfaltering acceptance. Rita used persistence and questioning to form a relationship with Chris and Molly, pushing herself and her students to know and learn more. Leah was thoughtful and observant, relying on her intuition and empathy to guide her relational knowing of Jeremy.

However, it is in the peripheries of knowing that change is possible. These peripheral visions are liminal moments where a teacher can learn to see and hear differently, where they can learn to accept a potentially incomplete relationship created by a high needs chronic illness as whole and complete from within, and where they can learn to perceive their students and themselves with a loving perception. In these liminal moments, where a teacher's vision is

centred in the peripheries of a student's world, the teacher can learn to appreciate "doing without

answers … and making do with fragmentary ones" (Bateson, 1994, p. 9).

Curriculum Making and the Curriculum Around Chronic Illness

Drawing on Clandinin and Connelly's (1992) definition of curriculum as a course of life,

curriculum is composed and embedded in the lives of teachers and students as they live out

storied lives in and out of the school context. A narrative understanding of lives views

curriculum as a course of lives being storied and restoried on a complex and dynamic landscape

(Clandinin, 2006). Accordingly, curriculum making is a form of identity making (Clandinin et

al., 2006).

When this definition of curriculum and curriculum making is considered in terms of the

lives shaped by a chronic illness, the making of a curriculum is undoubtedly shaped by the

presence of such an illness. Although such a curriculum recognizes the significance of illness on

the lives involved, this curriculum around chronic illness is founded on the active construction of

a life story alongside the illness. The curriculum around chronic illness focuses on the rich and

complex lives shaped by a chronic illness, lives not to be overpowered by illness.

In this research, the curriculum around chronic illness required the negotiation, and

sometimes renegotiation, of liminal spaces. It brought about questions of citizenship often

answered by a playful story of the sharing of authority. It opened up potential for counterstories

and other forward-looking stories; it caused shifts in the teacher's personal practical knowledge

and in their stories to live by. The liminal spaces of the curriculum around chronic illness

created new opportunities to world-travel and to form relationships in unfamiliar ways, guiding

new ways of relational knowing. Liminality, found in the making of a curriculum around

chronic illness, brought the teachers of this research to the peripheries of their students' worlds, where they learned, in time, to perceive their students and themselves wholly.

Ending with the Research Wonders

The research wonders of this thesis asked the following questions: what did it mean to engage in the curriculum around chronic illness? How did the teachers influence such a curriculum? What was the teacher's position within it? Did they experience a shift in knowledge, awareness, perception, or practice while engaged in this curriculum making? Throughout this document, there were stories where the curriculum around chronic illness required the entering, exiting, and negotiation of liminal spaces. The three teachers, through their unique positioning of their stories to live by, created new forward-looking stories that guided their teaching; stories marked by inclusion, community, loving perceptions, and care. Their position as world-travelers in the curriculum around chronic illness necessitated a relational knowing of their students. They sought inclusion through many paths and in many forms, with some aspects of their teaching shifting while others were reaffirmed. They recognized, as Claire stated poignantly in one of our conversations (2013), that they all were there together, working and being together, "no matter how you come to school."

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APPENDIX A.
CONSENT LETTER

Project Title: A Narrative Inquiry into the Experiences of Teachers with a Student with a Chronic Illness

Researcher: Beth Davis   **Supervisor**: Shaun Murphy
M.Ed Graduate Student   Chair of Curriculum Studies
University of Saskatchewan   University of Saskatchewan
b.davis@usask.ca   shaun.murphy@usask.ca
(306) 715-0521   (306) 966-7586

Description:

   My name is _____. I agree to participate in the research study entitled "A Narrative Inquiry into the Experiences of Teachers with a Student with a Chronic Illness." I understand that the purpose of this research is to inquire into the experiences of teachers who teach or work alongside a student with a chronic illness. The study is funded by the Social Sciences and Humanities Research Council of Canada. I understand that this research will be carried out by Beth Davis, a graduate student from the Department of Curriculum Studies at the University of Saskatchewan, as part of her Masters of Education thesis. I understand that she will be working under the supervision of Dr. Shaun Murphy, Associate Professor in Curriculum Studies at the University of Saskatchewan.

   I have been informed that Beth will be engaging in conversations with me on my experiences working/ teaching a student with a chronic illness. I have been informed that she will audio-record each conversation, transcribed the dialogue, and write field notes of our conversation. I understand that there will be up to 5 or 6 conversations of approximately 1 hour each that will take place between September 2012 and April 2013. The timing, location, and duration of each individual conversation will be negotiated as the inquiry progresses. I have been informed that the transcriptions of the conversations and any research texts will be shown or given to me for approval before publications. I have been informed that there may be a risk of being identified on the basis of my experience and what is said in the final research document, but I understand that Beth will take multiple precautions to ensure my confidentiality and anonymity at all points in the research process. I have also been informed that there are no other known or anticipated risks for participating in this research and that I can request any changes to the final research document that I may feel is too revealing. The proposed research project was

reviewed and approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on August 24, 2012.

I am aware that writing based on this inquiry will be submitted for publication in journals and that presentations will be made at local, national, and international conferences. I have been informed that my anonymity, the anonymity of the student, as well as the anonymity of others and the school, will be respected. All material collected will be safeguarded to ensure confidentiality and stored securely. I understand that all identifiable information will be stored separately from the research data.

I have been given the opportunity to ask questions and to clarify concerns about this inquiry. I understand that I can contact Beth to ask questions or seek clarification at any point during the inquiry process. I know my participation is voluntary and that I can withdraw from the research process at any time for any reason without explanation or penalty of any sort. I have been informed that my right to withdraw from the study will apply until the results have been disseminated. After this time, research dissemination will have already occurred and it may not be possible to withdraw my data. Should I wish to withdraw during the process, I feel comfortable in talking with Beth about this possibility. By signing below, I acknowledge that I have read and understood the above description and consent to participate in this research project.

_____   _____

Name of Participant   Name of Researcher

_____   _____

Signature of Participant   Signature of Researcher

_____   _____

Date   Date

A copy of this consent form will be left with you and a copy will be taken by the researcher

For further information concerning the completion of this form, please contact Beth Davis, b.davis@usask.ca, (306) 715-0521

APPENDIX B.
TRANSCRIPT RELEASE FORM

Project Title: A Narrative Inquiry into the Experiences of Teachers with a Student with a Chronic Illness

Researcher: Beth Davis   **Supervisor**: Shaun Murphy
M.Ed Graduate Student   Chair of Curriculum Studies
University of Saskatchewan   University of Saskatchewan
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(306) 715-0521   (306) 966-7586

Description:

      My name is _____ and I have reviewed the complete transcript of my personal interview in this research. I have been provided with the opportunity to add, edit, and delete information from the transcript as appropriate and feel comfortable approaching Beth Davis in this matter. I acknowledge that the transcript accurately reflects what I said in my personal interview with Beth Davis. By signing this form, I hereby authorize the release of this transcript to Beth Davis to be used in the manner described in the Consent Form. I have received a copy of this Data/Transcript Release Form for my own records.

_____   _____

Name of Participant   Name of Researcher

_____   _____

Signature of Participant   Signature of Researcher

_____   _____

Date   Date

A copy of this form will be left with you and a copy will be taken by the researcher

For further information concerning the completion of this form, please contact Beth Davis, b.davis@usask.ca, (306) 715-0521