

“They Just Don’t Get It”: Snapshots from Siblings of Children with Life Limiting Conditions

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## **Abstract**

Using photovoice, this thesis investigates the lived experiences of siblings of children with life limiting conditions (LLCs). Using the participant-produced photos to guide the thesis, I present their stories in a way that will allow readers to visually understand what it means to be a sibling to a child with an LLC. This thesis dissects the various emotions that are experienced by these siblings every day and discusses their importance. It also examines the daily lives of these siblings and how they care for their brothers and sisters. This thesis challenges previous beliefs that having a sibling with a disability is always detrimental to the siblings' well-being. Additionally, I will challenge my own use of photovoice and discuss complications with the method. This thesis fills a gap in existing literature while showcasing the beautiful snapshots of these siblings' lives while challenging ableist narratives of sibling relationships.

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## **Chapter 1 : Introduction**

The death of a child is somewhat unnatural and adds to the sorrow of death while having a devastating impact on mothers, fathers, brothers, sisters and extended family and friends. The grieving process for the loss of a child can begin far before their physical death. Families of children with life limiting conditions (LLCs) experience extreme highs and lows as the child's health often 'yo-yos'. Some of the most affected family members are siblings. Siblings are often left out of bereavement conversations and frequently do not have support systems to rely on while they are caring for their sibling. It can be difficult for siblings to find others who share the same experiences as them, and who understand the complexities of having a sibling who is terminally ill. Siblings in this study challenge the idea that they are suffering and struggling because of their siblings with an LLC. This thesis will reveal snapshots into the lived experiences of siblings of children with LLCs. More specifically, the research investigated the lives of siblings of patients from Roger Neilson House, a children's hospice in Ottawa. Roger Neilson House offers a Spectacular Incredible Brave Siblings (SIBS) program that allows siblings a moment away from family and siblings to be with other siblings of end of life paediatric patients. This SIBS group learns and shares about each other's experiences through games and activities, while leaving room for open conversations about death and illnesses. Children and youth who attend this group were invited to participate in this study, in hopes that outsiders could gain a better understanding of what it means to be a sibling of a child with an LLC.

Along with a unique participant population, this study used a child friendly method called photovoice. Photovoice was brought to popularity as a research method by Caroline Wang and Mary Ann Burris (Wang & Burris 1997). This method has its roots in visual anthropology and

has been used to collaborate with participants in a visual way. Three of the signature requirements of photovoice are as follows: community generated photos, elicited narratives that engage and describe the photos, and a focus on the participant's voice (Gubrium, 2013).

Photovoice is a popular method for use with children because it allows the researcher to get a better and more in-depth understanding of the child's experience. This research method is especially helpful in promoting empowerment, and decision making among research participants about how to communicate their concerns (Freeman & Mathison, 2009). This is particularly significant for work with children because in the past, children were often used as research 'subjects' rather than active participants. Photovoice is a method that allows children to be active participants in the research process.

This thesis will add to existing literature about the importance of inclusion of children in research and the significance of child friendly methods. As well, this thesis will examine ways that medical communities, families, and social circles can support siblings of children with an LLC. Currently, most of the literature available about how to support siblings is viewed through an ableist and medical lens, suggesting that having a sibling with a disability and/or LLC can only be a negative experience. For example, a systematic review of support interventions for siblings found, "several reviews suggest that some siblings exhibit symptoms of anxiety, depression, posttraumatic stress; lower quality of life and healthcare utilization; and disruption to academic and social functioning" (Gerhardt, Lehmann, Long, & Alderfer, 2015, p 751). This thesis will disrupt this notion and bring in a critical disability studies perspective, suggesting that having a sibling with an LLC is a complex and unique experience. My participants' narratives complicate this assumption that the experience is detrimental to sibling well-being. At the same

time, the thesis will describe the worries and fears of siblings, and shed light on the importance of having a support system available for siblings.

My main goal was to explore what it means to be a sibling of a child who is categorized as palliative or as having an LLC. While I did not conduct participant-observation in their daily lives, I was able to investigate their lived experiences through the use of participant-produced photos and interviews. By using this child friendly method, I was able to better understand what life was like for these siblings from their perspective. The intended outcome of this project is to help medical staff, parents, families, and the general public better understand the ways that we can help children with their experience of having a sibling with an LLC.

My use of the term ‘snapshots’ to describe the portraits of these siblings’ lives provided in this thesis encompasses two definitions. On the one hand, these children are sharing actual snapshots of their lives in the form of photos. Secondly, these photos and the participants’ discussions of them are a way for me as the researcher to see a snapshot of their lives, a moment, a capture in time. While these snapshots do not tell me everything about their lives, they offer something worth looking at and something to investigate further. These snapshots also reveal important aspects of their lives that may be overlooked, and they are taken from their own perspectives, allowing us into their world momentarily. While these snapshots may be limiting, as they do not offer a whole understanding of the complexity of their lives, they are important nonetheless in understanding and viewing what it means to be a sibling of a child with an LLC, through their eyes.

## **Research setting, and the ethnographic method**

This study took place at Roger Neilson House in Ottawa, Ontario, one of Canada's few free-standing children's hospices. A free-standing children's hospice includes everything that a hospice normally provides, but in a more home-like environment that is physically separate from a hospital. Roger Neilson House operates as an inpatient and outpatient hospice. Each family that is referred to Roger Neilson House, most often by the palliative care team, is given 72 days of respite stay per year. On top of this, patients and families can stay at Roger Neilson House after treatment, or to learn how to use a new medication or device. Roger Neilson House also offers stays for patients for pain and symptom management as well. Free standing hospices aim to provide children and families a home-like environment for children who are at an increased risk of dying before adulthood. These locations are staffed with teams of doctors, social workers, nurses, and a palliative care team. Many of the hospices are also equipped with a team of volunteers that provide respite care for families and nurses (Davies, Collins, Steele, Cook, Brenner & Smith, 2005). These care teams offer support groups as well as bereavement groups available to families and caregivers. Of particular interest to this study are sibling support groups. Roger Neilson House's sibling support group, called SIBS, is run by a recreational therapist and operates through the fall and winter every year, providing monthly SIBS group meetings where siblings get together to play therapeutic games and have discussions about what it means to be a sibling. More detail about SIBS group will be provided in Chapter 2.

My personal connection to this hospice began in 2014 when I first became a volunteer at Roger Neilson House. I was a Play and Learn volunteer for three years. I would provide respite care for the nurses and play with the children who were at the house. During my time as a volunteer, I was able to develop relationships with staff members including the recreational

therapist, whom I worked very closely with. Working with the recreational therapist was beneficial as we often discussed the importance of siblings' experiences in hospice care. Through my years as a volunteer, I was able to secure relationships that later allowed me access to this unique population.

Prior to starting this researcher project, I was just a volunteer. As my research began to take shape, my role changed as I moved towards becoming a participant observer. As a volunteer I was already an insider in the house and when my research began, I was observing and recording aspects of these siblings' lives. Roger Neilson House was a place where I had become an insider; now, it was becoming my field for research. Since I had been a volunteer for so many years, many siblings recognized me as did their parents, and this helped build trust with participants (Bernard, 2018). My role as a volunteer helped me navigate this niche community as I had already picked up on terms and lingo that were used in the house and even the SIBS group. As Bernard notes in his discussion of ethnographic methods in anthropology, "Presence builds trust. Trust lowers reactivity. Lower reactivity means higher validity of data" (Bernard, 2018, p. 266). My involvement in the culture and community helped to validate my data as there was little reactivity to my presence. However, there is no way to know if participants in this study hid or censored certain feelings or emotions from the group; furthermore, while my data may be more valid as a result of the trust and rapport that was built prior to the study, this does not preclude the possibility that what participants presented when interviewed was selective and partial. Research needs to be done within the context of relationships, especially with vulnerable populations (Wilson, 2008). Building relationships and becoming a participant observer was crucial to my research at Roger Neilson House.

My academic connection to hospice care for children began during my final year of my undergraduate degree in Child Studies. My honours thesis, titled “Comfort While Dying: A Transnational History of Paediatric Palliative Care,” explored the question: What is hospice and end of life care like for children? There has been minimal research done about children in end of life due to the topic’s sensitive nature. My goal was to inform the public, and especially, doctors, nurses, families, and care teams, of an under discussed but important topic in paediatric medicine. My past thesis helped to create a base of knowledge for this field work, as I was much better prepared for understanding complex worries that were brought up by siblings. While I was prepared for some of the worries brought up by siblings in this study, this project also surprised me in a number of ways.

Prior to this study I was not aware of how little research has been done on siblings’ of children in pediatric palliative care, therefore it was difficult for me to predict what emotions and discussions would come up. As will be discussed in the literature review, many studies used ableist assumptions about childhood and sibling relationships; because of this I was determined to show these siblings lives in a way that was not ableist and instead in an empowering way. Yet, going into this project, I had assumptions of what would be brought up by participants: feelings of jealousy, sadness, and loss; instead, mixed in with those emotions were happiness, and pride which I found challenged my ideas of what life would be like with a sibling with an LLC. Additionally, some of the most surprising findings were the complex emotions, feelings of isolation from peers, fear of their sibling being in pain, and what the care of their sibling actually looks and feels like.

## Literature review

This thesis is informed by six key areas of literature, five of which will be discussed here. The sixth, literature on photovoice as a research method, will be discussed in Chapter Two, the chapter on methodology. The five areas of literature that will be discussed concurrently here include research on sibling relationships, life course theory, child-centered studies literature, critical disabilities studies, and research on sibling effects of disability. This literature is useful for understanding and situating my research. The literature presented here will help readers better understand how past research has tended to show sibling relationships where one has a disability through an ableist lens.

Siblings are important to family structure and their relationships have implications for how the family functions. Sibling relationships are influenced by individual, family and extrafamilial connections. As evidenced by many other studies, no two sibling relationships are alike, and they vary across time and location. In depth research on sibling relationships is lacking, as many past studies have focused on parent-child relationship or only interviewed one sibling (McHale, Updegraff, & Whiteman, 2012). While sibling relationships are different when one sibling has a disability, it is important to understand why siblings are so important for children. This research will fill a gap in sibling literature, as this study included no data from the parent's perspective and solely relied on the sibling relationships to guide the research.

McHale et al (2012) offer an extensive literature review on available discourses of siblinghood. The article emphasizes that there has been a lack of research done in this area and that there is a need to fill gaps in the research. My goal for this project is to fill a gap in the literature by including siblings of children with LLCs' experiences from their perspective. The importance of siblings is made clear throughout the work by McHale and colleagues, as the

authors break down every aspect of sibling relationships. The research summarizes siblings' roles as central to the family dynamic, and how sibling relationships are varied.

Siblings are most often each other's longest standing relationships, and they have unique implications for child well-being and growth (Kim, McHale, Wayne Osgood, & Crouter, 2006). Siblings can shape the way a child experiences and understands the world. It is clear that siblings are crucial to a child's social and psychological development. Siblings fulfill different needs throughout childhood and adolescence compared to relationships with parents and peers. Some of these needs include learning behaviours (Boer & Dunn, 1992). Siblings are able to prepare each other for the social world and can help shape their behaviours with others. In this way, it is clear why siblings are so important for children's social development. However, it is also important to note that the above-cited studies investigate siblings in the context of particular samples of nuclear families, and to recognize that sibling relationships vary in different sociocultural and historical contexts.

Woodgate et al. (2016) hoped to illustrate how siblings perceive participation in the everyday lives of their disabled siblings. This study used ethnography to engage with siblings and learn about their experiences with their siblings with complex care needs (CCN). They found that siblings prioritized their relationships with siblings and cherished them deeply. It was also found that these siblings felt special because they had a sibling with CCN. The study made sure to include challenges that these siblings face. The study also encouraged clinicians to take into consideration siblings' emotions and their relationships and include them in health care communication and information. This study does an excellent job of showcasing lived experiences of siblings of children with CCN. It emphasized the desires of siblings in day to day life.

Current literature has shown that having a sibling with an LLC or disability is often negative and can have lifelong financial, emotional, and physical impacts (Steele & Davies, 2006). Similar to Woodgate and colleagues' work, my data disrupts these notions. My data showcases snapshots of these siblings' lives and explores the complexities of life with a sibling with an LLC. One reason that most past research focuses on such negative impacts is the methods used in the studies. Many studies that investigate the lives of siblings use quantitative methods such as surveys and questionnaires. This can lead to generalizations and statistical findings rather than seeking a deeper understanding of life experiences (Neely-Barnes & Graff, 2011). Many of the studies that use quantitative methods seek to compare a sibling of a child with an LLC to a sibling of a child with no disability, and rely on frequency or absence of specific emotions to demonstrate that having a sibling with an LLC is damaging.

Much of the available literature uses the presence or absence of certain traits to determine if the siblings' relationship is 'normative' (Metzler, 2018). Metzler explains that studies have revealed that sibling relationships where one sibling has a disability are less warm, reciprocal, and more rivalrous. This is problematic because no two sibling relationships are the same regardless of whether there is an LLC present or not. Using measurements of warmth and reciprocity are a limited indicator of a "good" sibling relationship (especially where one child has a disability and may be, for example, non-verbal, such that reciprocity is hard to measure). Part of this normative view of siblinghood and childhood stems from social views on disability. From an ableist perspective, disability is viewed as a problem or flaw that needs to be fixed. This can lead to a focus on the tragic side of their disability instead of focusing on the actual child (Curran & Runswick-Cole, 2014). This can result in negative societal views of sibling

relationships; if the child with the disability is labeled as ‘tragic,’ then people tend to view the siblings’ experience as negative.

Disability has long been seen as a flaw and something needing to be fixed. In children this is even more present. In *Brilliant Imperfections*, author Eli Clare (2017) takes readers through his life as a person with disabilities. Clare describes the view that able-bodied individuals have of disabled bodies, through their emphasis on hopes of a ‘cure’. As the author states, most able-bodied individuals view people with disabilities as a burden on society. As in the examples above, articles about disability are written from an abled body perspective and omit their privilege as such.

When a child is disabled, people tend to feel sorry for them or want to fix the child instead of realizing the potential that this child will bring to the world. Past research has shown when a child is diagnosed with a disability, the family experiences shame and embarrassment. While there will be challenges and obstacles that an able-bodied child would not have to encounter, Clare challenges the normative narrative that disabled bodies are lacking and in need of fixing (Wendell, 1996). This is important in the context of sibling relationships. If the broader culture is deeming your sibling as a source of embarrassment or shame and research is reinforcing this, it can be challenging to perceive that relationships as positive. This research will uncover what it means to be a sibling to a child with an LLC and how it may have its challenges, but it can also create deep and meaningful sibling relationships.

Research that offers alternative ways of looking at different types of sibling relationships is lacking. There are many complexities that are missed in ableist research methods. Siblings of children with disabilities have been found to be more tolerant of differences, have higher levels of empathy, have an increased sense of maturity and responsibility, and often have stronger

bonds with their siblings than those of able-bodied siblings (Powell & Gallagher, 1993).

Understanding that there are different types of sibling relationship and showing the positive outcomes of these siblinghoods is important, and hopefully will be further elucidated as more and more researchers become interested in these unique groups.

Much of the existing research is adamant that having a sibling with a disability negatively impacts a child's life. Research that compares siblings in families with a disability present to those without show two patterns: Firstly, families with a child with a disability show more warmth than those families without disability present. Secondly, siblings in families with disabilities have slightly higher risk of adjustment problems (McHale et al, 2012). However, when reading through the data and understanding the samples in such research, it is clear that a normative view of childhood was used for comparison. Rather than interviewing children, parents were often interviewed using a survey, rather than an open-ended interview, which could lead to more positive responses to having a disabled child. By using surveys, researchers produced ableist narratives about what it means to have a "good" childhood, one free from any disability in the home. Future research in this area should push for giving voice to children and even their siblings.

It is also important that all types of disabilities are included in research. It is clear that many researchers choose to interview families that have children with Autism Spectrum Disorder or Down Syndrome. Even with these groups, there are never accounts of the disabled sibling's point of view. While this is extremely problematic, it points back to the societal idea that disabled bodies are not active participants in their lives with their own agency. My research used methods that are accessible in order to bring forward voices that have been written about extensively, but never included in research that directly affects them. By using child-centered

and accessible methods, researchers can better understand and access the needs of siblings and children with disabilities.

It is understandable that family life is different for children and youth in families where one child has a disability. These challenges include disruptions to family times or routines as some of the most affected areas of everyday life (Giallo, Gavidia-Payne, Minett, & Kapoor, 2011). While these issues are not exclusive to families with a child with a disability, research has shown that these concerns are amplified when there is a child with a disability. Examining family quality of life is important as it is used to better investigate family cohesiveness.

Family quality of life is an under-discussed topic, as quality of life studies are usually only concerned with the ‘sick’ member of the family. A family quality of life perspective looks at the family as a unit and looks at siblings’ opinions as just as valuable as the parents’ opinions. Family quality of life is often judged based on parents’ perspectives, however, a study done by Moyson & Roeyers (2012) investigated siblings’ opinions of their family’s quality of life. This study found that siblings’ and parents’ definition of quality of life is different. Siblings look more closely at their relationship with their disabled siblings rather than looking at the family as a whole. Through this lens, researchers found that siblings enjoyed their quality of life with their disabled sibling and specifically enjoyed joint activities, experiences dealing with the outside world, private time, and mutual understanding. My research will reflect this perspective, examining the experience of having a sibling with an LLC fully from the perspective of the sibling, rather than their parents’ perspective.

Eaton Russell et al’s (2017) research used open ended interviews and ethnographic research over two years to understand the perspectives of siblings of disabled children with complex care needs. This study was different from others as it took place over a long period of

time and some of the siblings with complex care needs died during the study. They recruited siblings of children that were expected to not live longer than a year. This research highlighted the needs that siblings have before and after the death of their siblings, which provides valuable insight to the field. This research is crucial for understand siblings' roles when one sibling has an LLC. The study found that siblings fell into three main rolls as a sibling to a child with an LLC: playmates, companions, and helpers (Eaton Russell et al, 2017). Siblings were seen as playmates when they entertained, sang, and read to their sibling and engaged in activities to make them happy. The companion role was seen as 'being there,' and just being present with their sibling. Lastly, the helper role was defined as taking on direct physical care of their sibling. These three roles are important as they show how sibling relationships are different when one sibling has a disability or LLC. In most sibling relationships children and youth most often would just interact with the playmate role and possibly companion role. This study offers a glimpse into what life is like for these siblings. This research complements my thesis well, as it offers insight into these siblings' roles in their family. As will be shown later in this thesis, these three roles are present, as siblings in my study play, care, and provide company for their sibling with an LLC in the same way that siblings in Eaton Russell et al's study did.

Life course theory (LCT), made famous by Glen Elder Jr., is useful for studies involving families, especially sibling studies (Elder, 1998). As Hutchinson describes it, "LCT seeks to understand how chronological age, life transitions, relationships, life events, change, and human agency shape people's life from birth to death" (Hutchinson, 2011, p. 1587). By using this theory as a framework, researchers can gain a better understanding of how siblings' interactions can affect children's lives long term. When examining siblings' relationships, it is important to not only view their relationships at that moment, but how their relationship has shaped the

children's understanding of the world and their future perceptions. LCT is especially relevant when using photovoice as it can help researchers better understand the points of view the child may have of the world. By understanding LCT, the researcher can help children articulate and gain a deeper understanding of the photos that the child has taken. LCT is guided by five main concepts: cohorts, transitions, trajectories, life events, and turning points. By focusing on life events, such as having a sibling with an LLC, researchers can examine how children adapt and manage stress (Hutchinson, 2011). Additionally, using photovoice, researchers can visually examine these life events and turning points in children and youth's lives.

Recent discourses of childhood studies have pushed for more child-friendly and child-centered research. Rather than viewing the child as in development passing through childhood, researchers now view the child as an individual who is able to think freely and make decisions that directly impact them. There is also an important distinction that should be made between research about children, research on children and research with children. Research about children seeks to understand the child but is lacking their perspective, most often done without any involvement of children. Research on children involves them but does not seek to understand what the child thinks. This could include family surveys, or outsiders thoughts on the child; it is mainly focused on behaviour. Research with children attempts to include children in research by using child friendly methods so that their voice can be the most present in the research (McNamee, 2016). This thesis aims to do research with children and youth, as I tried to capture the participants' lived experiences as much as possible in order for them to express their emotions and tell their stories.

Anthropology offers literature that challenges ideas of normative and universal child development. In an article titled "Why Don't Anthropologists Like Children?", author

Hirschfeld (2002) discusses how historically, anthropology has tended to avoid including children in research. Hirschfeld notes that children have been underappreciated for their added value in research, and there has been a lack of understanding of children's culture and its importance. Since this article was published, many anthropologists have explored childhood experiences and challenged normative views of childhood and childhood agency. James (2007) explains how important it is that anthropologists view children as their own social actors in their lives. Children are no longer viewed through a lens of vulnerability and are now seen as active social agents in their own lives. Anthropologists have given children a platform for their agency, voice and opinions. James goes on to say how important it is that children share their own views of their lives in matters that are unique to them. For example, in Myra Bluebond-Langner's (1978) work with dying children, children are seen as social being rather than only ones in development. Anthropological studies of children and childhood offer unique perspectives, as they recognize attributes of childhood occur in different places, moments in time, and conditions (Bluebond-Langner & Korbin, 2007). This thesis is well situated in these works as it offers children and youths' perspectives through snapshots of their lives during a specific period of time.

This work lies at the intersection of child studies, family studies, critical disability studies and anthropology. This thesis offers a unique perspective into the lives of siblings of children with LLCs by using a critical disability lens, participatory action research methods, as well as examining children and youth's roles as siblings. This thesis will fill gaps in these discourses and bring together these disciplines in a new way. This thesis used child friendly anthropological methods, while also noticing my place as a researcher as described in Bernard (2018). Additionally, this thesis uses both Woodgate et al (2016) and Eaton Russell et al (2017)

as a starting point for understanding sibling relationships. These articles were used to guide my understanding of siblings' roles in families as well as in their personal sibling relationships.

## **Outline of thesis**

This thesis will explore the complicated emotions that come with having a sibling with an LLC, the pragmatics of daily life for these siblings, their worries and fears, and the special bonds they feel with their siblings. It will also reflect on photovoice as a method, including its advantages and limitations. This thesis is made up of five chapters. This introduction has served as a road map and background on the setting of the research, a brief introduction to its methods, and a discussion of the relevant academic literature.

Chapter 2 is the methodology chapter and will examine the use of photovoice as a participatory action research method and will offer a personal reflection on the method. This chapter will assist readers in understanding why visual methods were used and how they helped capture the main goal of this study, which was to understand: What are the lived experiences of siblings of children with LLCs? This chapter also includes the study structure and protocol. This will help readers understand timelines and details of the study.

Chapter 3, titled "Sibling Relationships and Care Work" offers readers a means of viewing these siblings' everyday experiences. This chapter shows the challenges as well as positive experiences that are associated with having a sibling with an LLC. Beginning with some background on sibling relationships, readers will be able to understand how siblings in this study have unique lived experiences. In this chapter we see how siblings fall into roles as care givers and receivers of care. This chapter also uncovers fears of loss and death and examines more closely the tight bonds that are formed between these siblings.

Chapter 4, titled “ ‘You Can Grow Stronger by Hearing About It’: The Complicated Emotions of Siblings”, will begin to explore what emotions are being held by siblings of children with LLCs. This chapter will help readers understand the very complex worries and fears that these siblings experience daily as well as stressors that they carry with them through life. Everyday stressors will be revealed in this chapter. Lastly, the frustrations that these siblings feel towards their peers, family, and outsiders will be explored in this chapter.

Finally, the conclusion will connect all points of inquiry and discuss final thoughts and key takeaways. Key findings will be revealed alongside the importance of this project and its academic and practical significance. I will again revisit the use of photovoice in this project and discuss the pros and cons of this method in the context of my work. Lastly, this chapter will also offer future directions for research in this area as well as pitfalls in this project that should be considered for future research with this population.

## **Conclusion**

In the chapters below, the photos and participants’ discussions of them will demonstrate the following perspectives: From a critical disability studies perspective, the thesis will reveal how disability should not be viewed through an ableist lens. From a child centred studies perspective, it will reveal how children and youth should be included in research and actively engaged in the research process, which begins by selecting a method that is both engaging and exciting. From the perspective of sibling relationship and family studies, it will be made clear the importance of strong sibling relationships for children’s development and wellbeing. It will show how life course theory can help us better understand the stages that children may go through and show how photos can help us visually understand them. Lastly, from an

anthropological perspective, this thesis will better situate how society views ideal childhood as socially constructed and will challenge normative assumptions brought forward by other disciplines.

The following chapters will present the lived experiences of siblings, as well as their photos. While the stories presented here are unique to the individuals interviewed, they do a good job of giving medical care teams and families a look into the lives of siblings of children with LLCs. Understanding what it's like to have a sibling who is dying is difficult for much of the population to grasp. The images and interviews described in the following chapters will help to paint a picture of what it means to be a young caregiver for one's sibling. Throughout this thesis, there will be stories that may be challenging for some to read--stories of loss, worries, and tough situations. While these stories may be difficult, they are important reflections of the lived experiences of siblings of children with life-limiting conditions.

## **Chapter 2 : Methodology**

### **Introduction**

This was a qualitative study that used photovoice combined with semi-structured interviews as the primary data collection tool. Photovoice involves participants taking photos of their lives and sharing them a group-based setting. After photos are taken the participants meet with the researchers to better explain the photos taken, and what the photos mean to them. In this way the researcher is no longer the main driving force of the research, but rather the co-participant. The participant is able to direct the understanding of the photo and therefore the research. This method is particularly useful for participants that are uncomfortable with other methods, or situations where other methods (such as surveys) have been used in ways that misinterpret or under-represent their experience. This chapter will explore the ways that photovoice is a particularly beneficial method for understanding children and youth's lived experiences. In this chapter I will also challenge my preconceived beliefs about photovoice that I held prior to starting this research.

### **Description of photovoice as a research method**

The process of photovoice research in general will be outlined here. Photovoice begins like most other research projects by recruiting participants, usually in a community-based setting. Once the participants are selected, it is important that the researcher gains consent—in the case of working with children and youth, consent comes from the child or youth directly, and the parent. If the parent signs the consent form but the child or youth verbally acknowledges that they do not want to participate, it is advised that the researcher not include them in the study. This is important for maintaining positive power dynamics within the research. This also

acknowledges that the child has agency and the ability to make choices about their own life without parental involvement (Freeman & Mathison, 2009).

Following this, participants are usually given training on how to use the cameras given to them. This is essential when working with children, as many children may not understand how to use a digital camera. After this, participants are given the camera to take photos in relation to the theme of the research. It is important to select a number of assigned photos low enough to not burden the participants or overwhelm them (Tishelman, Linqvust, Hajdarevic, Rasmussen & Gliath, 2016). Past research has suggested that it is preferable to assign participants to take three photos for each data collection period. There are usually a number of data collection periods and following each, there is a debriefing where participants are able to describe what is in each photo and what each photo means (Tishelman et al, 2016), for example, through a semi-structured interview about the photos. This is a key component of a photovoice project because it allows the participants to take control of the conversation, rather than allowing the researcher to determine the meaning of the photos.

It should be noted that photovoice is also a lengthy process as it requires the researcher to participate in the co-creation of knowledge and be actively engaged in the research process (Sitter, 2017). In photovoice, researchers are actively engaged in the research process as they must show the participants how to use the cameras, as well go through each participant's photos and conduct an interview at the same time. This process is very different from research methods such as surveys or questionnaire that require little interaction with the participant. This time for knowledge and learning is important for participants and researchers to build rapport. Photovoice usually takes place over the course of multiple workshops, as the participants are usually given a number of days or weeks to take the photographs.

## Children as participants

When engaging in research with children and youth it is important to find ways to keep them excited and eager to continue in the research project. Often times surveys and quantitative studies can be challenging for children and youth to get excited about. It can be easier to keep children and youth engaged by using methods that provide them with a challenge, while also making it fun. Throughout the thesis planning phase, it was important that I found ways to keep the participants engaged. My first task was showing the participants how to use the tool they would need for the rest of the study, a camera.

In order to prepare the participants for this study, we practiced two exercises to get them comfortable with the camera functions. By using games, we were able to have the participants remain engaged and excited to learn how to take photos. One example of these exercises was to show the participants how to use the camera to focus on objects or people so that their photos would come out clear. In order to do so, we first had participants get into teams. We had each team set up a hula-hoop with an object inside, then we would yell “bug’s eye view” and the participants would race to take a picture from bug’s eye view (Figure 1.1). Then we would yell “bird’s eye view” and participants would take a photo from a bird’s eye view (Figure 1.2). This not only taught them how to focus their cameras, it also allowed them to see things from different points of view.



*Figure 2.1: A water gun inside a hula-hoop*



*Figure 2.2: A child standing inside a hula-hoop*

Throughout this thesis, it is clear that working with children and youth as participants has its challenges, however it was well worth it.

### **Benefits of the method**

Photography is beneficial to use with children and youth as it can be sometimes difficult for children and youth to express their experiences verbally, and it allows them to share the complexities of their lives in a creative way (Croghan, Griffin, Hunter, & Phoenix, 2008). In this study, it was clear that the children and youth were enjoying taking photos and sharing their photos each week, as a form of art. The discussions that came from the photos were not ones that would have come up in other interviews.



*Figure 2.3: Flowers that represent death*

For example, one participant shared a photo of flowers and described that they reminded her of flowers that would be placed on a grave (Figure 2.3). Because of this photo, it became clear that there were triggers in her everyday life that caused her to think about death and they were triggers that would not be obvious or clear to most people. Photos can reveal unique aspects only relevant to that specific child's life, as exemplified here (Boomer & Frost, 2011). For this participant, flowers are a dark reminder of her sibling's mortality.

Photovoice can also be very beneficial as a form of therapy for children and youth. Siblings of children with life limiting conditions often internalize many feelings about their ill sibling, and this group work offers a chance for them to see that others share similar experiences. Photovoice can be a therapeutic way for children and youth not ready to share or vocalize their thoughts or worries to express themselves. Photovoice provides participants with a skill that leaves them feeling empowered and heard. Through photovoice, children and youth are able to see that their work and opinions are valued and respected.

Not only does photovoice allow for youth and vulnerable populations to have a voice in research, it also can be used to inform policy. Photovoice is also known to foster social change;

the photos can be used to engage community members, policymakers, and leaders (Findholt, Michael & Davis, 2010). The resulting photos can be used to promote discussions about issues in communities as well. In the past, photovoice has been used to show policymakers issues of concern from a homeless community. It has also been used to help immigrant Latino men to show the need for improvement for community HIV prevention programming (Findholt et al, 2010). In the case of my research, allowing children and youth to be part of a research project that has the ability to change the community they are from is a tremendous asset. For this project, participant produced photos will be used to spread awareness of the experiences of siblings of children with life limiting conditions. This project was used as a vehicle for children and youth to express themselves and visually show their experiences as a sibling to a child with an LLC. These photos will be displayed at the Children's Hospital of Eastern Ontario along with excerpts from the interviews.

### **Limitations of photovoice**

While photovoice can prove to be a very beneficial and useful method for engaging children and youth in research, it is not without its pitfalls. Using this research methods as a form of art therapy can also have its challenges. While I am not a therapist, this method has been shown to have therapeutic benefits. Participants are often confronted with emotions that may come from their photos. As a researcher, there is an ethical obligation to find ways to alleviate some of this emotional distress. Some possible solutions are as follows. The researcher can offer a debriefing session in order to discuss some feelings or emotions that were triggered by the process, or by holding post interview debriefings. A debriefing may also not be enough; a researcher may need to have other supports available to the participants including social workers

or counseling services. It is important for researchers to remember that with vulnerable populations models of service, hours, location, and physical barriers of such services need to be considered (Liamputtng, 2007).

As photovoice only requires a camera or cell phone, some researchers may see it as an easy method to use. Unfortunately, some researchers may overestimate the user friendliness of this research method, and that can lead to photos that have fingers in the lens or photos of the floor (Gubrium & Harper, 2013). It is important for researchers to hold a training session with the participants of the study in order for the participants to feel comfortable with the cameras. By not giving the participants at least an introduction to the technical side of photography, participants may feel embarrassed or ashamed when they see their blurry photos next to the other participants' clear and crisp photos (Gubrium & Harper, 2013).

Another complication is the ethics behind location. If the participants are given cameras to document their experiences, chances are some of the photos will be taken outside of the home, in community spaces. This can be a challenge for ethical consideration as taking photos of other individuals, without consent, is not allowed. This can be a difficult message for children to understand and complications may arise when reviewing their photos. Space is also something to consider when using photovoice as the chosen research method. The reason behind the concern is that the participants may never enter or exit the 'field.' The word 'field' usually means a place separate from the researcher's home, or urban environment (Gupta & Ferguson, 1997). The field is difficult to specify in photovoice because the participants dictate what their personal field is. The participant's field may be the place where they currently live, somewhere in their neighborhood or their school. This can also be especially challenging as ethics protocols outline specific places and things that cannot be photographed.

A final complication with using visual methods is ownership. Once the project is complete, who owns the photos? The participants who took the photos? The researcher? Or the institutions involved? It is important to make a clear distinction prior to beginning a visual project, as to who owns the material (Pink, 2007). This can be particularly important when working with youth and vulnerable populations as their work is often not regarded as their own, or their ownership is not considered.

## **Study Structure**

### *Setting*

This research was conducted at Roger Neilson House (RNH). Roger Neilson House is one of Canada's four free standing children's hospices. It serves as a space for families of children with life limiting conditions and can be both a place for end of life care services and respite care. Roger Neilson House offers families respite care in their hospice. This is a crucial service that allows a family the time they need to rest so they can better care for their medically sick child. At Roger Neilson House each family is offered up to 28 days of scheduled respite care and 72 hours of emergency respite care per year free of charge (Roger Neilson House, 2018).

The social work team at Roger Neilson House provides a variety of support and bereavement groups for families such as a perinatal support group, infant loss group, and most recently added, a grandparent support group. These bereavement groups mostly run for six-week sessions by two registered staff members (Roger Neilson House, 2018). Roger Neilson House also offers something special for siblings who are grieving or supporting their siblings near their

end of life: a SIBS (Spectacular Incredible Brave Siblings) program that allows siblings a moment away from family and siblings to be with other siblings of end of life paediatric patients.

#### *SIBS group*

The SIBS group at Roger Neilson House is a group run by the recreational therapist. The group normally runs once a month for about 2-3 hours and allows siblings of children with life limiting conditions to discuss what it is like to have a sibling with complex care needs. Often times the group will engage in games or arts and crafts that will get them talking about their worries, fear or joys. Beginning in August 2019, siblings were recruited from the SIBS group to be part of this study.

Since many of the children and youth in the group have been attending for many years, many of them were very open discussing all emotions tied to being a sibling of a child with a life limiting condition. The group at RNH was created by the recreational therapist as a way to help connect children and youth who were going through similar experiences. The group runs almost year-round with a break for holidays and some summer break as well. There is no fee to attend SIBS group and it operates as an open invite to any sibling at any time. There are some regulars to SIBS group who attend each meeting, but there are also children and youth who only attend once or twice. In order to be eligible to attend SIBS, the child or youth's sibling must be living and currently accessing services through RNH. When a new ill-child is admitted to RNH the recreational therapist will make an effort to meet every member of the family and always ask the sibling to join in on SIBS if they feel comfortable. Often times if an ill-child is admitted on a Saturday, the day of SIBS, and there is a sibling with them, they may attend SIBS just as a way for the parents and family members to have time with their ill-child.

The structure of the SIBS group remains the same each month, however each meeting has a different theme in order to get the children and youth to talk about different complicated

emotions that may arise from being a sibling of a child with a life limiting condition. The SIBS group schedule, as exemplified in Appendix A, begins with an introduction game, then leads to each sibling discussing the differences and similarities between each other's siblings. This helps to build companionship between the SIBS and creates a sense of comfort and safety. Each SIBS group ends with a game where a bowl of tin foil balls is passed around. Inside the tin foil ball is a piece of candy and a question. This is most of the children and youth's favorite part of SIBS group. The questions are often not simple yes or no questions but are usually meant to spark a discussion and have others join in as well. During the course of this study the questions were always geared towards the following week's photovoice themes. The recreational therapist adapted the SIBS group and the exercises to support my research project's themes. Some of the questions included: What is the best part about having a sibling with a life limiting condition? What is the scariest part of having a sibling with a life limiting condition? What are your favorite things to do with your sibling? Each child and youth was allowed to answer one question, however, many of the participants ask to go again. For this particular study, the 'tin foil' questions were designed to engage them and get them excited for the following theme of the research project.

#### *Inclusion & Exclusion Criteria*

Children and youth who are referred to the SIBS group who currently have a sibling who is accessing services at Roger Neilson house were recruited for this study. The SIBS group services children aged six to twelve years old. A teen youth sample group was also included in this study and involved youth thirteen to sixteen years of age. The SIBS group is only accessible to siblings of children who are currently accessing services; siblings of children who have passed away were not allowed to participate in the SIBS group. Youth (13-18) with a

sibling accessing palliative care who are ineligible for SIBS because of age were also eligible to participate in this study, by forming a separate, temporary group. It was not necessary to be present at all sessions to participate in this study. Individual follow up was given as an option for missed sessions. Children and youth whose siblings had passed away were excluded. Children and youth whose siblings were not currently accessing palliative care services at CHEO were excluded, as were children under age 6 and adults over age 18. A breakdown of each participant's data and information can be found in Appendix C. In total, there were 11 participants in this study, including 7 girls and 4 boys, ranging in age from 6 to 16.

#### *Study protocol*

The study design and protocol were designed with the recreational therapist and a palliative care doctor at Roger Neilson House. As I was not directly in the sibling's circle of care, it was challenging to find ways that I could gain access to the group. Through speaking with CHEO's Research Ethics Board I found that the only way to access the group was through the recreational therapist. An email was circulated inviting siblings to be part of the research study. Signs were also posted throughout Roger Neilson House with my contact information so that participants who were interested could contact me directly.

When participants arrived for the first session, they were given the option, if over 8 years old, to read or sign the consent form on their own. Many of the parents were surprised that this was an option as normally children and youth are not able to consent on their own. During the Research Ethics Board process, I made it clear that I wanted to give participants the option to consent on their own without parental involvement if they were competent to do so.

After gaining consent from the children and youth, either on their own or with their parents' help, they filled out a data collection form which was used to better understand the

sibling's family (see Appendix B for the data collection form). This form asked siblings about their ill siblings' diagnostic category as well as how many sick siblings were in their family. These questions were selected with the aid of the recreational therapist as well as a palliative care doctor at Roger Neilson House. The diagnostic categories were important because many of the studies done on siblings fail to disclose their sibling's diagnostic category. Some studies that had interviewed siblings of children with LLCs all had siblings with the same diagnostic category. By including diagnostic categories, it is possible to examine similarities of emotions felt by siblings of children with the same diagnostic category. These categories can be seen on the data collection form in Appendix B. Understanding how many siblings are in one family is also helpful to understand how many sick siblings one family has. After the study, I noted that something that should have been included is number of siblings that had died, as some of the siblings in this study had living sick siblings but also had siblings that had died prior to the study.

This study took place over the course of 3 months from August 2019-October 2019. Participant recruitment began in August 2019. The participants met for the first time in August when they were given a camera and a tutorial on how to use it. At each group meeting the participants were presented with a theme and instructed to take pictures relating to that theme. An interview on the previous theme was completed before the next topic was assigned later in the same meeting. Interviews were offered individually or in small groups if the participant did not feel comfortable being interviewed alone. The final meeting took place in October and was used to discuss the photos from the third and final theme.

The themes for photos were as follows: August meeting: Take photos that are about you (your life, home, hobbies, etc.). Mid-September meeting: Take photos of what is different or special about your brother or sister (with a life limiting condition). Late-September meeting:

Take photos that show what you worry about when you think about your brother or sister (with a life limiting condition). For each theme, each participant was instructed to take 5-10 photos. They returned to the next meeting with the camera and selected their favorite photos to discuss with the researcher and recreational therapist. The interview questions were: Can you describe your photo? Tell us why you took this photo? What does this photo mean to you – what is it about? These interviews were audio recorded and lasted about 5-15 minutes depending on how much the participant was willing to share. Other follow up questions were also used to better understand the reasoning behind some pictures or for background context. During each meeting there were extensive discussions about participants' emotions before, during and after each interview. During interviews I would check in with each participant and make sure that they wanted to continue after each question. The recreational therapist was also present during every meeting so that participants could privately talk with her if they needed to.

The goal of having the siblings take pictures and be interviewed about the photos was to gain a full understanding of what the photo meant to the participant. Many of the photos seemed obscure (e.g., Figure 2.2) and needed an explanation from the participant. Other photos (e.g., Figure 2.3) were much clearer, however, the interview helped to confirm what was already visually being conveyed by the photo. By using interview data and physical photo data this project was able to investigate the lived experiences and worries of siblings of children accessing pediatric palliative care services at Roger Neilson House.



*Figure 2.4: Knife*



*Figure 2.5: A section of a board game*

Teaching a group of participants to use cameras can be quite difficult especially if many are under the age of 12. Luckily, many of the participants were able to catch on quickly and only needed a few practice shots to understand how to use the camera. There were instances where videos were taken instead of photos, and these were not included in the study. While some children and youth may find photography exciting, some did not, therefore making it challenging to get them excited about this project. In order to use photovoice effectively participants need to

be motivated as it is a self-directed task. Some participants returned with very few or no photos some weeks and were only able to share thoughts without physical data.

## **Ethical considerations**

As the participants in this study had no direct circle of care, it was challenging for the Research Ethics Board at CHEO to determine best practices and ways to protect the participants from undo harm. ‘Direct circle of care’ is a term used to describe the healthcare workers that manage a patient’s care needs. In this case, the siblings do not access medical care; they are connected to the hospice and hospital, but they do not have a direct circle of care. In hospital research, the REB want to make sure that participants are being approached by members of their direct circle of care rather than the researcher themselves. One of the ways that participants were protected was, as stated above, their first encounter with the project was through a trusted source, the recreational therapist.

As cameras were being used by young participants, another ethical consideration was brought to my attention. Participants would be able to take photos of anything they wanted, which raises privacy concerns. To remedy this, strict guidelines were given to participants regarding what photos could and could not be of. I, alongside the Research Ethics Board, created a guide of what was not allowed to be photographed, that included faces, strangers, as well as any recognizable features or items that might link the photos to a specific person. These rules were put in place as many of the participants’ siblings have recognizable features due to their complex care needs. Once these rules were explained, participants had no trouble taking photos of other objects or isolated body parts in order to convey specific messages. Ownership

of photos was important for me to consider in this study. In order to solidify ownership of photos all participants kept photos on the SD card that was later gifted to them.

A final challenge that I faced was inclusion of participants throughout the entire research process. I was unable to access the siblings prior to beginning the study and therefore was unable to have input from them during the development stage of this thesis. If I was able to include siblings in the development stages of this project, I could have worked with them to create the themes for each week. This could have resulted in a much more collective research project.

## **Analysis**

Each interview was transcribed verbatim and a document was created for each interview that placed the photo that was being described in the interview next to the text. Photo content was coded for themes so that similarities could be seen across participants' photos. Once all interviews had been transcribed, they were also coded for themes. The first round of analysis included looking for similarities within the interviews and pulling out quotes or highlighting interviews that would be useful in specific chapters. A more in-depth coding structure found that the richest interviews for providing useful data were those that were done later on in the research process. In reflecting on my methodology, it would have been beneficial to have this study run for a longer time or begin with an in-depth interview with each participant so that they would feel more comfortable once they began to start taking pictures.

Having both photos and interviews was helpful as many of the children and youth took similar photos but described their meaning differently, allowing for different types of discussions to come from similar photos. Photos are also useful for disseminating data in this thesis, as they

provide physical evidence of fears, worries, or complicated emotions. Not all photos from the study could be included in this thesis, and photos that were included were selected based on their relevance to specific themes that emerged from the data.

Some of the challenges that I faced during this study were as follows. The equipment needed for photovoice projects can be difficult to acquire. For this project as per ethics protocols, phones or personal cameras were not allowed to be used in this study. For that reason, around 20 digital cameras were needed for the project. This can be challenging as digital cameras can be very expensive and finding used ones can also be difficult. For this project, I was able to source all digital cameras used from thrift stores in the Ottawa area and SD cards were either donated or purchased.

### **Photovoice reflection**

Prior to this study, in my research proposal, I argued that photovoice was one of the only productive methodologies to engage with youth in order to hear their authentic voices. After completing this study, I can see that photovoice has many more limitations than I previously assumed. In the proposal writing phase, I was quick to judge other methods for not being child-friendly enough or not providing for the ‘authentic’ voice of the child. However, I now think that even with photovoice, it is not always clear if you are getting at the full scope of participants’ feelings, as participants still may cater to what they think you want to hear. I would still argue that photovoice is a very useful method for engaging children and youth; however, I think that it is important to consider the group that you are working with. This method specifically allows children and youth to build their social and personal identities through self-reflection, along with building their abilities through the use of photography and the

opportunity to explain it (Stack, Magill, McDonagh, 2004). Children and youth are able to see the photos they produce come to life and create discussions about these images. However, it is not without flaws, and I think that I was naive to think that there would be no complications.

Power dynamics are important to consider in research and this was something that I found challenging to navigate; however, power can also be shared between the participant and the researcher. After completing this study and reflecting on the process, I found that it would be impossible to give all the power to the participants. If the participants held all the power, I would be surprised if they would continue or let alone even begin. If I were to do this project again, I would involve the participants in the entire study design process. I would want to create the themes with them and have input from them through the entire project. By doing this, I would still be guiding the research according to my own motivations, but it would be done in a way that involved the participants in joint authorship of the endeavour. There are complexities to engaging in research with children and youth as power dynamics are always present, as children and youth often trust an adult as a person in a position of authority, and there are power dynamics that are difficult to combat. At the same time, the researcher must also be sensitive to participants providing information they think you want to hear (Higgs, Titchen, Horsfall & Bridges, 2011) It is important to establish a relationship separate from the teacher-student relationship, and to find ways to prompt responses from children and youth that represent their true perspectives (Phelan & Kinsella, 2013). I found this a challenge as many times during the study I would express to the participant that they only needed to share if they wanted to. Each time they would share, it felt as though they felt some form of pressure or they felt I was in power and it was something they had to do.

When doing research with children and youth it can be difficult to assert authority while also trying to give power to these participants. This balance is a challenge I encountered each week with the participants. I would want them to feel comfortable enough to share, however if they did not want to share, I did not want them to feel obligated. However, it felt as though week after week that for some there was an invisible sense of obligation to do this activity. One reason that I felt this way was the quality of photos; while some participants really took the activity to heart and took photos over the course of two weeks, some participants took the photos in the car on the way to the meeting. While this may not have meant that they were not engaged, I took it as such. This reveals my assumption of what makes a meaningful photo; for the participants that took photos in their car, some were profound and brought a lot to the group, while others shared their photos along with jokes. Some participants asserted their agency through seeming reluctant to share. Reflecting on my method I now see that this could be a way for those participants to shield their real emotions, or the photos they wanted to take were too emotional and they were not able to take them.

My idea of photovoice and how it would play out to be the best possible method to use with children and youth was naive. While I still believe this is one of the best methods to use with children and youth, I understand why many researchers choose not to use participatory action research methods. Photovoice is a very involved method that requires a lot of time and patience. Many of the children and youth came to the group with amazing photos that seemed to hold amazing stories or meaningful memories, but sometimes the child or youth was unwilling to share those thoughts and would choose to go to the next photo. This again reveals my assumptions of what makes a photo worth explaining. Participants may not have wanted to share intimate photos of their life with me and that is okay. Both the child and youth group had

participants that did not want to share certain photos or did not bring photos to group. In situations such as these, it leaves the researcher wanting more, and even wanting to assert their power to have the participant tell them what that photo means. Such research is thus a delicate balancing act between eliciting participation, while not needlessly pressuring participants to provide information.

## **Conclusion**

I have concluded that, despite its limitations and challenges, photovoice was beneficial for understanding the lived experiences of siblings of children with LLCs. This chapter serves as a starting point for the rest of the thesis, as I have explored the method in depth as well outlined my study protocol, complications as well as a reflection on the method. The following two chapters will illustrate how this method was beneficial for this study and how participant-produced photos can help illustrate the lived experiences of siblings of children with an LLC.

### **Chapter 3 : Sibling Relationships and Care Work**

A distinct way that children with disabled siblings interact is through caregiving. Although much of the research on siblings and caregiving focuses on adolescent and adult sibling relationships, it is important to discuss young caregivers' roles. Care roles are also an interesting point of inquiry for researchers as it has been found that gender roles are loosened in homes of disabled children; brothers of children with disabilities engaged in as much caregiving as sisters in able-bodied families (White & Hughes, 2018). By involving children in their disabled siblings' care work, children have been known to form stronger bonds and feel deeply connected to their sibling. Regardless of gender, all of the siblings that took part in this study aided in the care of their sibling with a disability.

This chapter will investigate the ways in which sibling care relationships differ when one sibling has a disability. Available research that investigates the family life of disabled children often uses either surveys or interviews with parents as their main method of inquiry. While both of these methods provide large amounts of data, it is important to discuss what is missed in these accounts. By using photovoice, this study is able to provide concrete evidence of what it is like to be a sibling to a child with an LLC.

The lived experiences and pragmatics of daily life will be evident throughout this chapter as the photos and interviews shown below will demonstrate that the lives of these siblings are much more complex than many people would assume. As will be shown in Chapter 4, for several of the participants in this study, difficult emotions and worries are felt every day. Life with a sibling with an LLC has its challenges, but at the core of it is worries of loss. These siblings know that their brother or sister is deemed palliative and it is unclear how much time they will have with them. Part of their everyday life is understanding that the person they are

spending time caring for may very well not be with them in the near future. This chapter will also provide an alternative discourse to disrupt the conventional idea that having a sibling with an LLC is always detrimental to a child or youth's wellbeing. By examining participants' lived experiences of communication, fears, daily worries and stressors it will be clear how these participants view their lives with a sibling with an LLC.

### **Background on sibling relationships**

Sibling relationships in families offer children a special and dynamic bond unlike any other. Becoming a sibling can be a challenging time for a child, as it marks a shift of attention onto the new sibling. Past research has shown that there is a “dynamic change with the addition of a new child, there is a drop in parental positivity and sensitivity following the birth of a second child” (White & Hughes, 2018). This dynamic change has many forms, for example, children may receive less attention, or may find joy in the addition of the new sibling. Whatever these changes may be, they are different for every family, and families with children with disabilities may face these changes in different ways.

The study of siblings emerged as researchers realized that childhood experiences shape the way that adults interact with their environment. Sibling relationships offer children unique opportunities to learn about themselves and others (Boer & Dunn, 1992). Since these relationships can shape the way a child experiences and understands the world, they are crucial to a child's social and psychological development.

Prior to the 1980s researchers found that sibling relationships were often strained when one sibling had a disability. These strains were supposedly marked by rivalry, jealousy, displaced aggression, fear and anxiety. There was also a link made to the embarrassment that

was felt by children of siblings with a visual disability (Philp & Duckworth, 1982). What was missing from this research was a deeper understanding of how these children were feeling. Most of these studies only sampled parents rather than asking the children about their feelings directly. Children, similar to disabled and marginalized communities, are seldom given a voice in research, therefore there is less documentation of children's actual lived experiences.

Studies that investigate sibling relationships where one child has a disability often focus on negative outcomes rather than looking at the relationships more in-depth. This chapter will disrupt this ableist narrative while looking at siblings' relationships from a holistic perspective.

### **Understanding siblings' special relationships**

Because most of the research available about siblings holds an ableist view of disability, there is a perception that there is only one 'normal' way of being a sibling (Meltzer, 2018). Sibling relationships in which one sibling has a disability have been researched in specific ableist ways to ensure that the results demonstrate that having a sibling with a disability only impacts children negatively. This has been done by using a control group where none of the siblings have a disability and measuring the presence or absence of specific traits within these relationships and comparing that data to disabled sibling relationships (Meltzer, 2018). Through this lens, it is easy to see how research can be interpreted to view having a disabled sibling as negative. Most of the research that is available uses ableist methods, however, new researchers are turning away from these ableist methodologies and using methods that sample a wider range of participants by interviewing both disabled and well siblings (Meltzer, 2018). While this progress should be commended, the popular narrative around disabled siblings is still a negative one.

Sibling relationships where one child has a disability can be viewed negatively, however, children have found ways to adapt and continuously show how these relationships are meaningful. For example, in one study, siblings reported that they maintained a strong relationship through shared activities, visiting people important to them, leisure, exercise, or visiting places together. However, in this study siblings expressed that some of the spaces they wanted to experience together were not accessible, making it difficult for them to engage in similar activities in shared spaces (Kramer, 2008). Through this lens, the limitations affecting their social interactions are imposed by a society that does not have spaces where disabled bodies and abled bodies can interact and enjoy the same activities. This is not a problem that is exclusive to siblings, this is a larger problem within society, however, it can be detrimental to young sibling relationships as it forces separation when they seek togetherness.

From the synthesis of research about siblings of children with disabilities and chronic illnesses it was found that well siblings experienced aggression, depression, anxiety, guilt, confusion, and isolation (Hartling et al, 2014). While these feelings are not exclusive to children with siblings with disabilities, it is important to understand their impact on this population. Rather than minimizing these feelings, it is important that families tend to these needs and help siblings better adjust. Research has also shown a societal view that disabled children may 'ruin' the family dynamic. In contrast to these more negative perspectives, research by Skotko, Levine, S., & Goldstein (2011) sought to counter this societal misconception of purely negative sibling experiences, by interviewing children about their experiences of being a sibling to a child with a disability. The study found that these children were generally positive about their family life, and most often felt love and pride towards their disabled sibling.

## Life with a disabled sibling

Siblings in this study expressed that having a sibling with a disability has its challenges, however, they recognized that they did not know anything different so they could not imagine what life would be like without their sibling. The following images depict pieces of what life is like with a disabled sibling. When interviewing Lydia about what makes her sibling different or special, she showed me this photo (Figure 3.1). Lydia is a nine-year-old girl with two siblings, one with an LLC. Her sibling's diagnostic category is neurodegenerative and he has cerebral palsy. She had never attended a siblings group before. In describing this photo, she noted:

*He's had a bunch of surgeries, so he has a bunch of scars and that's another scar, big scars and there's one on his waist.*



*Figure 3.1: Lydia's brother's chest that shows multiple scars*

Lydia explained how these scars make her sibling different because not many people she knows have this many scars. Many children with LLCs have endured multiple surgeries since birth. This photo is meant to represent the life of a child with an LLC and the pain and suffering that may be attached to their disability. This also represents the physical side to the sibling

relationships; their relationships are not formed simply around emotional connections, but can be experienced through physical experiences with the disabled sibling's body, such as these scars that serve as tangible representations of illness.

The following photo (Figure 3.2) was taken by Rebecca, a six-year-old girl who has two siblings with a life limiting condition. Up until now, she had never participated in the SIBS group. She has a sibling with a neurodegenerative condition who is also diagnosed with cerebral palsy. She spoke about the van that her family uses:

Emilie: Can you tell me about this one?

*Rebecca: Yeah, I took this one because that's the only vehicle that can take my brother to school and my dad had to take the picture because I was already buckled.*

Emilie: Do you also go in this car?

*Rebecca: Yeah, I have a seat in there for me.*

Emilie: Okay, why does this show that your brother is different or special?

*Rebecca: Because it's the only vehicle that he can go in.*



Figure 3.2: Accessible wheelchair van

This photo shows how a family's life is affected by their child with an LLC. The family can only use this car to transport their child with an LLC. This van is a visual reminder and cue for those around them that they have a child with a disability. When families must travel in a specific car in order to transport the sibling, it reinforces that they are different. For a sibling this can be very challenging, as it continues to be a reminder that they are different from their peers. Rebecca, however, did not say that this van was a source of stress for her; she seems to know only this reality and was happy to show this photo.

These images show the realities of life with a sibling with an LLC. To many, these photos may be sobering and bring thoughts of sadness and guilt, however, this is daily life for these children and youth. They know no other reality and are happy and proud of their life with a sibling with an LLC. The photos above were meant to show how their lives may be different or special, and both examples show how their siblings lives are different from most.

## **Communication**

In addition to having strong attachments to their parents, children view their siblings as attachment figures (Dupond & Renaud, 2012). In this way, it is possible to see siblings as a crucial part of a child's development. Looking at a sibling's relationship from a social development perspective, it is clear that siblings can have an instrumental part in shaping a child's social world and development. The social learning framework would predict that children learn behaviors and attitudes from family relationships and display and use these as guides for relationships outside of their family (Boer & Dunn, 1992). By learning social cues and understanding how to interact with a sibling, children may become better equipped to handle social situations outside of the home. Having a disabled sibling allows children and youth to

learn social cues that may not be verbal or obvious. Using alternative types of communication is common with children with disabilities. Because of this, siblings are well versed in multiple different forms of communication and socialization.

Participants in this study described the ways that they were able to communicate nonverbally with their siblings. During an interview about what makes their sibling different or special, I spoke with Rebecca, a six-year-old girl, who shared a photo of her brother's smile (Figure 3.3). She commented:

*Rebecca: This makes my brother special because he smiles when he loves.*

Emilie: How do you show love to him?

*Rebecca: By smiling back.*



*Figure 3.3: A smile as a form of communication*

For Rebecca, nonverbal communication is important for her sibling relationship. Her brother is able to show his love for her by smiling. Rebecca finds meaning in her relationship with her brother by smiling and knowing that he loves her. Her brother is nonverbal and smiling may not clearly indicate that he is showing love, but to her it is a sign of love, and that allows her to bond with him more deeply.

Catherine is a sixteen-year-old girl. She has four siblings, one with a life limiting condition with a diagnostic category of neurodegenerative, respiratory, and gastrointestinal issues. She has attended SIBS prior to this study. She shared a photo (Figure 3.4) of her brother's stomach with a feeding tube, and told me:

*(My sibling) wasn't too happy about (me taking this photo) because I had to pop open his shirt and he didn't like that. It was really cold and he didn't like that and was kind of upset. He got over it though.*



*Figure 3.4: A child's stomach with a G-tube*

This illustrates how siblings who are deeply interconnected through care work can understand each other without words. Her brother is non-verbal and is able to express to her his discomfort nonverbally. Catherine has been caring for her sibling since his birth and has played an important role in his caregiving. She explained that she can always tell how he feels just by looking at him. It is also important to note the power dynamic here; the older sibling is caring

for her younger sibling that is non-verbal and therefore was most likely unable to consent to this photo. As a reader, you may be uncomfortable seeing a photo like this of a child that is non-verbal and unable to communicate wants and needs easily, but is nevertheless communicating some discomfort with his participation in this study on some level. However, when this photo was shared it was also clear how much these siblings love each other. Their bond is very special and close; while this sibling was unable to consent to this photo, his sister made it clear that they have a two-way care relationship. Catherine and her brother have a close loving relationship and although her intentions may have been ‘good’ in showing what her life is like, readers may see this as her asserting her power as a caregiver and asserting her power over him. While we had consent from the children and youth in this study to use their photos, there was no way for us to know if consent was given from the child or subject in the photo. As many of the siblings with LLCs in this study were nonverbal it is likely that consent was not granted. This raises the issue of ‘consent’ in a photovoice project: Whose consent is needed, only that of the participant, or the consent of the sibling whose picture is being taken? And what if they are not capable of consenting? This will be discussed further in the conclusion to this thesis.

These two photos show the ways the siblings can communicate or understand each other non-verbally. By learning non-verbal cues and different ways of understanding their sibling, these children and youth may be better equipped for social situations as they get older. Although my participants did not explicitly state that they have improved communication skills as a result of having a sibling with an LLC, we can consider that siblings develop ways to communicate together that may exceed normative modes of communication, and this is something that could be an area for future research. Communication is crucial for siblings to care for each other, however, many of the siblings in this study are non-verbal which can sometimes complicate care.

## Care work

Children with LLCs often have very complex medical conditions and care needs. For this reason, many families must become experts on devices and treatments. One example of this is the gastronomy tube or G-tube. A G-tube is a device that is inserted into the stomach. A G-tube can deliver food, supplementary nutrition, fluids, or medications for children who cannot feed by mouth (G Tube Program). These medical devices are part of many of the participants' daily lives. Some siblings knew and understood what specific medical devices were and how to use them, while others still feared them. Here are some of those examples illustrated.

The two following examples were presented by Rebecca, a six-year-old girl. She first shared a photo of her brother's G-tube (Figure 3.5) followed by a photo of his medicine (Figure 3.6). She explained:

*I took this photo of his mikey (G-tube) because it helps him stay alive with his medical stuff, his food, his medicine, and the stuff he needs to eat.*



Figure 3.5: A child's stomach with a G-tube up close

Emilie: And what about this one?

*Rebecca: His medical stuff.*

Emilie: So, what's different or special about this?

*Rebecca: Because he uses it to stay alive.*

Emilie: How does that make you feel when you see this?

*Rebecca: Nothing.*

Emilie: You don't worry?

*Rebecca: I sometimes do. I only know how to use the venting stuff; sometimes I do it.*



*Figure 3.6: A drawer full of medical equipment*

Rebecca shows how unique her life experience is compared to most six-year-olds. She is able to help with her sibling's care and understands that these medications keep him alive. In this image, we see how different life can be for siblings of children with LLCs. The fear of medical devices is often remedied with knowledge. The photos of the medical equipment and

devices needed to keep these siblings alive is important in understanding the lived experiences of these siblings.

When investigating what is different or special about her sibling, Catherine shared a photo of her sibling's oxygen monitor (Figure 3.7). Catherine is a sixteen-year-old girl, and she shared the following:

*And then I took a picture of his monitor, but like when it always beeps I'm like the first person there because I always get worried about his numbers. He doesn't really tell us how he feels so the numbers are a way for us to know how he's doing so I get really worried when his numbers are down and I get really angry with him and I talk to him about it.*



Figure 3.7: Catherine's sibling's oxygen monitor

This illustrates how Catherine interacts with her brother using her knowledge of his condition and medical equipment. Her sibling is non-verbal, so the numbers are used as queues to help her understand how he is feeling. This also illustrates how Catherine cares for her

sibling. She actively monitors his oxygen levels, the way a parent would. As a sixteen-year-old she is taking on this responsibility and actively caring for his health and wellbeing. This caregiving role can be very alienating for teens, as their peers often are not responsible for their siblings' health in the same way. Discussions of alienation will be addressed in the following chapter.

### **Disrupting ideas of care**

Sibling care has many forms. In addition to medical care, many participants expressed that they care for their sibling by spending time with them. This may include playing games or engaging in activities they enjoy. Max shared a photo of a TV screen of him and his sibling bowling (Figure 3.8). Max is an eleven-year-old boy with two siblings, one with a life limiting condition. His sibling's diagnostic category is neurodegenerative, and he has attended SIBS before as well as another siblings group outside of Roger Neilson House.

Emilie: Is this Wii bowling?

*Max: Yeah.*

Emilie: So why did you take this picture, were you playing?

*Max: Because, yeah, we were playing.*

Emilie: Is this your family? (pointing at the picture of Wii family)

*Max: Yeah.*

Emilie: Your whole family is bowling?

*Max: Well no, just me and Henry are playing (sick sibling); that's just other people.*

Emilie: And so why do you like to play bowling on Wii?

*Max: Umm...because it's fun and it makes my brother laugh.*

Emilie: Oh yeah! Do you guys play it together?

Max: Yeah.



Figure 3.8: TV Screen of Wii bowling

Playing games is a form of care for this sibling. Sharing laughs and enjoying time together is a way that these siblings care for each other. Care is a part of these siblings' daily lives and allows them to interact with their siblings in a loving way. Care can also go both ways. Many siblings noted that their sibling cares for them as well, although it may not be verbal. Something as small as smiling represents how their sibling cares for them in return.

As illustrated below, care can also be shown through patience and understanding. Melissa is a sixteen-year-old girl with two siblings, one with a life limiting condition. Her sibling's diagnostic category is neurodegenerative, and she has attended a different siblings group before. She shared the following image of her sibling's favorite toy (Figure 3.9), and commented:

*That's (my sibling's) piano. It plays Christmas music. It goes off every hour until he decides he's done with it, but it doesn't turn off on its own, it just keeps playing. We hear*

*a lot of Christmas music. He really likes it; sometimes if we have him on the floor and he has bowling, or his iPad and he decides he's done with that he will crawl over and turn it on.*

Emilie: So, what made you take this photo?

*Melissa: Because it's different, like, I don't know any other kids that love Christmas piano as much as he does. Fun fact: if you get him any other type of piano he will hate it.*



*Figure 3.9: Piano toy*

For Melissa, knowing his likes and dislikes and exhibiting patience when she has heard the same songs over and over, is a form of care. There are many different ways to care for someone and these siblings show that.

## **Loss**

Part of these siblings' unique lived experiences is knowing that their sibling will not be with them forever. Some of the siblings in this study have multiple siblings with similar LLCs, or have deceased siblings. Wade shared the following anecdote. Wade is a sixteen-year-old boy

with three siblings, one with a life limiting condition. His sibling's diagnostic category is metabolic and he has attended SIBS before. He talks about what it was like when his sister was dying:

*When my sister was dying and was very close (to death), I wasn't allowed to go in. I was feeling anger because a) it's family and b) I should be able to see my own sister on her death bed. That's when I was a kid, so I felt like I wanted to be there to see her for the last time.*

For many of these siblings, the fear of being excluded from what adults deem as difficult situations is very traumatic. Wade was taken away from his sister's last moments because the family had decided he should not be present. However, from his statement, it is clear that he wanted to be there. Perceived childhood innocence hinders many families from being open and honest with children and youth in difficult times.

Throughout this study, it was clear that a main source of fear and worry for children and youth was knowing that their sibling was going to die, and many of them do not know exactly when this will occur. The following images (Figure 3.10 & Figure 3.11) represent these siblings' realities and the ways they perceive the fear of losing their sibling and what loss might look like to them. Both photos were taken by Melissa, a sixteen-year-old girl. She talks about death in the following interview excerpt:

Emilie: Why did you take this photo and what is this a photo of?

*Melissa: This is a picture in the garden park. I took it because it has his favorite color blue, a lot of it, and also because it almost reminds me of a gravestone.*

Emilie: It's such a hard worry to admit but it's a worry that all of us have. I understand how hard that photo was to take because like you said, with the other one, it makes your worries real. Thank you for sharing, though.



*Figure 3.10: Stepping stone interpreted as a grave stone*

With reference to the second photo (Figure 3.11), she continues on this theme of death:

*Melissa: It's kind of the same content, like, all of them are about that.*

Emilie: What was your thoughts behind the chairs?

*Melissa: They're empty.*



*Figure 3.11: Two empty chairs*

The photo of the chairs is one of the most powerful images that came out of this project. Melissa broke down while sharing what this photo meant to her. This was a challenging moment for everyone present in the room, as bringing up these emotions is difficult. This photo shows much more than two empty chairs. It represents the emptiness that will be felt when her sibling eventually passes away.

Both the above photos were taken by Melissa, who had a difficult time finding the words to explain what it meant for her to take these. After the interview she shared that taking photos for the final theme of “What are your fears that relate to your sibling with a life limiting illness?” was the most challenging. She said that by taking these photos, death became a reality for her. She was already aware that her sibling was going to die at some point in her life, but by taking these photos, it solidified her thoughts about her sibling’s mortality.

Below, Rachel also shared her worries about loss, with reference to Roger Neilson House’s ‘wall of stars’ (Figure 3.12). Rachel is an 11-year-old girl, with two siblings, one with a genetic life limiting condition, she has attended SIBS before. She shared the following:

Emilie: What is this a photo of?

*Rachel: The wall with all the stars.*

Emilie: And why did you take this photo?

*Rachel: Because I don't want him to die.*

Emilie: And what do the stars represent to you?

*Rachel: I don't know.*

Emilie: What made you associate the stars with your brother and dying?

*Rachel: Because there's names of kids who died that came here.*



*Figure 3.12: Wall of stars at Roger Neilson House*

Whether a child lives for mere moments or 18 years, they leave a legacy and the pain that parents feel is everlasting. At Roger Neilson House, this legacy is physically present in the house, by way of a star wall. This star wall illustrates the legacy that children leave behind at Roger Neilson House. When a child passes away, their name is engraved on a star that is later fixed onto the wall in the playroom, where it will stay forever. Each fall and spring, families are invited for a star ceremony to honor the children that have been lost that season. It is an emotional day when families are able to visit their child's star and take picture with it and remember their child. These stars serve as an acknowledgment to families that their child was

alive and was part of their lives no matter how short that time was. For many families, having a physical location to visit their child's legacy can be very meaningful. It can be a very emotional experience for them, but at the same time can offer a symbol of their everlasting bond. Knowing that someone cares about their child enough to memorialize them is something that many families find comfort in.

Loss and the anticipation of their sibling's death is part of the experience that these participants face every day. Their worries and fears about their sibling's death is a reflection of their close relationships that are cultivated with their siblings. These children and youth create deep and meaningful connections with their siblings, who are most often non-verbal. An ableist perspective might imagine that creating a strong sibling relationship where one sibling is non-verbal would be challenging. Yet at a young age, it is clear that these siblings have created a strong bond and that bond is reinforced through non-verbal communication and care. It is pertinent to also revisit Wade's quote from above, "*When my sister was dying and was very close (to death), I wasn't allowed to go in...*". Wade felt the need to see the relationship through to the end and be there for his sister's final moments. While his parents felt that it was in his best interest to be excluded, it might not have been as productive as they would have hoped. These siblings deeply cherish their relationships with their siblings, even if their sibling is unable to vocalize their emotions. For Wade, being in the room when his sister passed away was important to their relationship and strengthened their continuing bond.

## **Concluding thoughts**

Many of the participants in this study shared that having a sibling with an LLC can sometimes be challenging. Much of the research available that investigates the lives of siblings makes it very clear that siblings suffer when one sibling has a disability or LLC. Through these photographs and interviews, it is apparent that while having a sibling with an LLC is not a common experience, for these siblings it is an every-day reality and a relationship that they cherish. Through a critical disability studies lens, these photos can be seen as examples of what life is like for many people living with disability in their families. The participants in this study understand that their reality is not the same as most of their peers', but they are happy with their life and the experiences they get to have with their sibling who has an LLC. It is important to showcase pictures and interviews of these participants' realities so that society, medical professionals, and even their families can see life through their eyes, to understand their lived experiences.

The everyday moments shared between siblings is critical for understanding how siblings interact. For many participants, these photos are just part of their everyday experience and do not seem different or special but for most of society, these photos show a unique reality. This chapter has challenged normative and ableist assumptions about what it means to be a sibling to a child with a life limiting illness. This is important to acknowledge, as it will help to change the ways that communities view disabled siblinghood. Rather than viewing children and youth interacting with their disabled siblings as either traumatic or extraordinary, these snapshots have shown how, for these siblings, these are everyday scenes.

## **Chapter 4 : ‘You Can Grow Stronger by Hearing About It’: The Complicated Emotions of Siblings**

Siblings of children with an LLC can often feel isolated from their peers; the SIBS group can help to mitigate these feelings. SIBS is a unique place where siblings of children with an LLC can meet and discuss their feelings without any barriers. Siblings are able to realize they are not alone, and they are greeted with an opportunity to ask questions and engage in discussions without the fear of hurting or upsetting anyone, something other researchers have identified as important (Nolbris, Abrahamsson, Hellström, Olofsson, & Enskär, 2010). This study allowed for siblings to openly talk about their complex emotions that are tied to the relationships they have with their ill sibling. To date, there has been very little research on the experience of children growing up with a sibling with an LLC. These siblings face challenges in all aspects of their life and the experience of having a sibling with an LLC can impact their psychological, social, and academic functioning (Chin, Jaaniste, Trethewie, & Chin, 2018). The complicated emotions felt by the siblings in this study are made clear through the interviews and photos.

### **Fears and worries**

When asked about their fears related to their siblings, many participants shared their fears surrounding hospitals, pain, or money. Their fears were not always directly linked to their siblings dying, but rather, sometimes were about the events that might lead up to death, or the aftermath. One ten-year-old boy named Finn shared his fears about his sister going to hospital through a photo from a board game that reads ‘Hospital’ (Figure 4.1). Finn has two siblings, one

with a life limiting condition, and he has attended SIBS before. He talked about fears of the hospital:

*This is a photo of a hospital because I'm worried about her going to the hospital and her having problems and everything. (I'm worried about) her dying and, yeah, I don't like when she goes to the hospital; it makes me scared.*



*Figure 4.1: A section of a board game*

Rachel is an eleven-year-old girl. She shared a photo of an ambulance (Figure 4.2), and commented on its negative association with hospitals:

Emilie: And what's this photo of?

*Rachel: An ambulance.*

Emilie: What made you take that photo?

*Rachel: I don't want him to go in an ambulance that goes to the hospital because I don't like hospital.*



Figure 4.2: A photo of an ambulance

The fear of hospitals was a common fear that was brought up by siblings in this study. Some of their fears also stemmed from the unknown or lack of information. I spoke with Kyla, a thirteen-year-old girl with three siblings, one with a metabolic LLC, who had attended SIBS before. She shared how she would feel if her sibling was rushed to the hospital and she was not allowed to come:

*I would be disappointed because, I guess, since I feel like I know so much now about my siblings I feel like I could be in the meeting and I'm being left out, even though I know I'm old enough to understand what's going on and be able to hear it.*

A second participant, Wade, who is a fifteen-year-old boy with three siblings, one with a metabolic life limiting condition. He has attended SIBS before. He added:

*And that you can grow stronger by hearing about it.*

Knowledge is power for many of these siblings. The unknown and unanswered questions can lead to racing thoughts of 'what ifs' and misinformation. While some families and doctors believe that siblings should be left out of conversations relating to their ill sibling's health, siblings are asking to be included and feel they should be involved.

This is an example that shows that these children and youth have agency, and how normative assumptions about children as ‘not yet grown-ups’ commonly lead to considering children as vulnerable, too young or unable to understand complex topics. Family communication is very important in these relationships, as it allows siblings to minimize misunderstanding and disappointment (Chin, Jaaniste, Trethewie, 2018). In these quotes, we see how the siblings are asking to be included in difficult conversations. An important point here is the feelings that Kyla is experiencing. These siblings would prefer to know, and possibly to worry, than to imagine and feel fear while being left without knowledge of what is going on. We can see here how these siblings are challenging normative assumptions about what might worry them or their ability to worry. These examples illustrate how siblings are asking to know, they can grow through that knowledge, they can ‘take it.’ Commonly, adults want to avoid having their child worry or suffer. They may think their child is not old enough, doesn’t have the maturity to deal with complex situations and worrying about their siblings, but what the siblings are saying is that they prefer to know. The examples illustrated above challenge normative views of childhood and childhood innocence. These siblings are asking for a chance to be involved in difficult conversations that some may not deem ‘appropriate for children.’ Parents and medical professionals may have a difficult time finding a balance of when and how to include siblings in complex conversations, but it is important to note that they want to be included. They have spent their entire lives learning about their siblings and growing with them. To be included can reaffirm their identity as a sibling and an important part of the family.

Medical devices can also be a source of worry for these siblings. While most siblings understand their use, they may be unaware of how they function. This can cause worries for

some, as illustrated below. Ten-year-old Finn shared a photo of his sister's G-tube (Figure 4.3), and commented:

*This is a photo of her G-tube, G-tube makes me scared of her thing falling off or her G-tube not working well and breaking and hospital again, and yeah, I don't like it or the idea of the G-tube.*



Figure 4.3: G-tube

For Finn, the G-tube is a source of spiraling fear. In his mind, his sister's G-tube malfunctioning will bring her back to the hospital. After this interview, the recreational therapist explained to the group that most often when a G-tube malfunctions or comes loose, the parents can fix it right away and if not, they would just need to call a nurse to help them. That knowledge was helpful for Finn, and we hoped it would ease his fears and worries about his sister's G-tube.

Lydia, a nine-year-old girl, shared the following photo of her sibling's G-tube as well (Figure 4.4). Like Finn, she talked about fears around the G-tube:

Emilie: So why did you take this photo?

*Lydia: Because I'm afraid his mickey will fall out. My dog chewed at it when he was a puppy.*

Emilie: If they fall out it's pretty easy for it to go back in.

*Lydia: Because you just need to fill it with water.*



*Figure 4.4: G tube*

The photos of the G-tubes are meant to represent the siblings' fears of medical devices that are unknown or foreign to them. Many of these siblings know G-tubes' functions but may not know exactly how they work or how safe they are. This can become a big source of stress for these children and youth.

While the fears of the participants in this study related mostly to an event that might occur, like a hospitalization or their sibling's death, their daily worries and stresses manifested from their lived experiences of having a sibling with an LLC. For example, sixteen-year-old Melissa described feeling stress that was felt by her whole family due to financial concerns and the inability to afford a proper van that would make their life more manageable (Figure 4.5). She commented at length on this concern:

*Melissa: This is another wheelchair thing its partially also what I worry about because of the whole wheelchair van situation.*

Emilie: And what is that?

*Melissa: Oh, how it basically doesn't exist anymore. Okay, so we had a basically hand me down wheelchair van that we got from a friend who didn't need theirs anymore and it's basically unsafe to drive at this point; I think that's our consensus now. I think the bottom or the ramp is rusted through; the wiring is all screwed up because it's an actual van that was converted into a wheelchair van. So if we want to fix it they don't even know where to start. We've taken it to mechanics and they said it's almost worth it to get a new one, but new ones are ridiculously expensive. I can't remember how much they are. I want to say like \$25,000, actually like \$40,000 or more. So we don't have that, what we have to do now is on the car, we've attached a little trailer to the back and the wheelchair goes in that and he goes in his car seat. Which is gigantic because he's not a child, so we have to lift him in and out of the car and in and out of the seat and wheelchair in and out of the back. Which is hard because we still have to lash it down. So that's a big worry because what if something happens to the car what are we going to do? Because what if someone steals the wheelchair; it's stuff like that. Because we can't just lift him forever. We already have the lift, the ceiling lift because he's already hard to lift and he doesn't help you at all and he's really heavy.*

Emilie: Do you help your parents lift him a lot?

*Melissa: I try to. But you know, it's stressful. Also, I haven't really told my parents that I'm stressed about this because, I don't know. I had a reason but it was a dumb reason. I haven't actually told them because I think I'm like adding to their list of stresses.*

*They're already stressed with the situation. I don't want to add to that situation. Which, like, they're stressed with him, they're stressed with me to get me to do things because I don't do things very often, you know, so I don't really want to add to their list of things to be stressed about.*

Emilie: I think a lot of kids feel like that because of circumstance and they try to hide it. It's interesting that you brought up financial, because well a lot of people don't think you worry about anything or they think you're oblivious, but they go straight to medical things.

*Melissa: We can't afford a new wheelchair van. We were going to set up a Go Fund Me [fundraising campaign] I think.*



*Figure 4.5: Shadow of a girl in an accessible parking spot*

This story illustrates how siblings' fears can relate to non-medical aspects of their lives. It may be that medical professionals and parents think that siblings' only stress relates to the sibling's illness, but many of the complicated emotions felt by siblings relate to their daily lives. This participant expressed how her family not having a way to transport her sibling in a practical way was a significant source of stress for her and her family. It is interesting that she did not share this worry with her family and kept it to herself. She felt that by telling her parents, it

would add more stress to their lives. By sharing this story in the SIBS group, she was able to tell the group about her worry, so she did not need to keep it to herself. Many other participants shared that they too hold in emotions and do not tell their parents about their worries and fears. Through this example, it is clear that their stresses are not just confined to worrying about their sibling's health and future death. Their fears also relate to all family concerns and practical matters. They are also emotionally burdened by their worries as they feel that they are just adding to their parents' stress. Most of these siblings turn their emotions inward and this can create an extra burden.

As Melissa illustrates, siblings of children with LLCs can have worries and complex emotions that do not only relate to their siblings' medical issues. Rather, as we see here, Melissa is expressing the societal impacts of having a sibling with a disability, and mobility impairments. Her worry stems from society's inability to provide accessible vehicles at a price that most families can afford. This example demonstrates that siblings' worries are not always related to their siblings' health, but can relate to a multitude of stressors, including structural constraints, that come with having a sibling with an LLC. This points to societal issues surrounding disability. Non-disabled people do not think about the needs of people with disabilities. Non-disabled people are most often the ones creating and designing much of the world around us and therefore are not thinking of the structural and practical needs of people with disabilities (Wendell, 1996). Melissa's example illustrates the assertion of critical disability scholars that it is not disability itself, but the structural constraints of a society that does not provide equal access for disabled bodies to everyday life, that 'construct' or create disability for people. Melissa is demonstrating this point by pointing out that the lack of access to an accessible

vehicle is a source of constraint on her family's life, and therefore a source of concern and stress for her.

A common worry among participants is their sibling feeling pain. When speaking with Lydia, she described her fear of her brother's wheelchair (Figure 4.6). Lydia, a nine-year-old girl, shared the following photo:

Emilie: So why did you take this photo?

*Lydia: Because I'm afraid of his wheelchair collapsing.*

Emilie: What do you mean by that?

*Lydia: Like a screw or bolt falls out and then the entire thing will collapse.*

Emilie: And what would happen if it collapsed?

*Lydia: He would get hurt.*



*Figure 4.6: Wheelchair*

This participant illustrates how siblings' worries can be about events that are out of their control. In this case, her worries may be remedied by someone explaining to her that it is unlikely that the wheelchair will collapse. Her fear is that the wheelchair collapsing would hurt her brother. This

photo is a good representation of fears that siblings experience as well as a good reminder that for these siblings, knowledge is comforting and can sometimes alleviate worries and stress.

Alternatively, this photo and fear can be interpreted as Lydia understanding how unpredictable and uncertain her brother's illness is. She is worried about things collapsing, as she is attuned to the nature of his illness and the uncertainties associated with it. Lydia can receive as much information as is needed, but her sibling is still dying, and she is acutely aware of this. Perhaps this image can be used as a symbol of her life, as she is worried that her life may come crashing down as a result of her sibling being hurt or dying. She may use the wheelchair as a way to express her fears of the lack of control that she has in her life. Even if the adults in her life provide her with information, this may tend to her fears and worries momentarily, but will not remove the complexities and unpredictability that comes with having a sibling with an LLC.

### **Worries as a part of everyday life**

Worries pervade these siblings' everyday lives, as the care for their siblings never stops. Many of their worries are further complicated if they feel alone in their worry and do not want to express their worries to their parents. Catherine, a sixteen-year-old girl, shared the following, as she illustrated in her photo, below (Figure 4.7):

*I did this one of the sky because I do a lot of thinking there. I look at the sky and I just worry a lot about my brother and stuff that worries me.*



*Figure 4.7: Photo of the sky*

Catherine shared her worries and explained how it takes up a lot of her time. This photo is an important representation of where siblings worry. The sky is representative of how she keeps her worries to herself. Again, we see an example of the hardships that these siblings face. For them, worries are something they may experience alone. As will be revealed below, many of these siblings have a difficult time expressing their worries to their friends and peers. This photo of a sky represents how Catherine views her worries, as something she must do alone.

During the course of the study, the recreational therapist would check in on the participants as a group to make sure they were not too upset by the themes that were being brought up. One example of this was when discussing worries:

Recreational therapist: Are the worries you took photos of a lot of the time like most days? Or do you think about it some of the times? Or did having this camera really make you think about it and it brought it up?

*Finn: Three times each week.*

*Lydia: I don't really know, middle I guess.*

*Rebecca: Every time I come to SIBS.*

While it may be difficult to discuss worries, it is important that these siblings understand that they are not alone in their worries and that other siblings are feeling the same way. Nolbris and colleagues' (2010) study showed that having a group was reassuring because children were able to listen to other stories and tell their own. The discussions that we had in the group were challenging at times, but the siblings that participated were often validated by their peers. The siblings would reassure others by saying things like "I feel like that too" and "Yeah that happens to me." By sharing their fears, although challenging, it showed the siblings that they were not alone in their emotions.

The above examples illustrate how worries seep into these siblings' everyday existence. Everyday, these siblings are thinking about their siblings and most often their siblings' health. Through the examples presented above, we can see examples of worries these siblings go through. Sometimes coming to SIBS can trigger these worries and make siblings aware of these worries. For some, SIBS offers a space where they can openly share their worries that they once kept to themselves.

## **Frustrations**

As illustrated in this chapter, being a sibling of a child with an LLC can be challenging. Siblings have complex emotions that they often face alone. One other emotion that these siblings feel is frustration. The following examples have no images as they were part of discussions in the larger group. Melissa, a sixteen-year-old girl was asked: "What is the most challenging part of being a sibling?" She responded:

*Doing things, if we have my sibling, he won't last very long, he wants to go home. So, we have trouble going places. And also, the places we go, a lot of them aren't accessible, they don't have wheelchair ramps or elevators or stuff like that. We have trouble because I don't want to go to those places because they're crowded and loud. These things make our everyday life difficult.*

For Melissa and her family, various barriers make it difficult for her family to spend time together outside of their home. This is an example of how children with disabilities are unable to enjoy the same spaces as their siblings. There are challenges and obstacles that an able-bodied child would not have to encounter, that are not a reflection of the child, but instead the society and its inability to adapt. This example illustrates how the ableist infrastructures and access issues are challenges in these siblings' lives. The ableism and inaccessible design of society is the source of their frustrations, not having a sibling with an LLC in-and-of itself.

Following the above discussion, the group was asked about the importance of SIBS. Catherine, a sixteen-year-old girl, commented on the social context of life with a disabled sibling:

Emilie: Why do you think it's important to tell the world about what it means to be a SIBS?

*Catherine: It gets kind of tiring telling people over and over about it. And they just don't get it.*

Here, we can see Catherine expressing the frustration of having to explain her situation to people. In society today, disability is so invisible that many children may not have experience with disability. For these siblings, it can be difficult to try and explain their siblings' LLC to their peers. Catherine explains she's tired of telling people when they 'just don't get it.' For

Catherine, her frustration also stems from people being curious and wanting to know all about her sibling with an LLC.

Having a sibling with a disability can be difficult, especially if the disability is visible. For many of these teens, their siblings are non-verbal and use wheelchairs. Many participants shared that they can't go anywhere without being stared at or getting looks from strangers. Throughout history, disabled bodies have been stared at and observed almost as an object for public viewing (Eisenhauer, 2007). Again, we see that having a sibling with an LLC is not the source of frustration, but rather the ableism that is so present in society that makes siblings frustrated.

Being a sibling of a child with an LLC can be isolating, because of how invisible disability is, and how difficult it may be for siblings to have to constantly be reminded that by extension, they're not considered 'normal'. For the siblings in this study, interestingly many of them do not share with their friends that they have a sibling with an LLC. And if they do, it is not something they discuss often. The following discussion included three of the teenagers, Wade, Kyla and Catherine:

Emilie: At the beginning of this study you said that a lot of your friends didn't know you had siblings with an LLC. So do you go to them with your worries?

*Wade: I tell some of them about it, but the tough thing is that they don't have the understanding. They don't understand death, you can't understand death unless you've seen it and experienced it. Which is tough, because I feel the most alone about that because people can't relate to that at all. Other emotions like fear, anxiety, depression people can relate to that. But with death it's so many [emotions] at once, that your brain is fumbled.*

*Kyla: My friends change the subject when I bring it up, because I have a lot of worries and I just don't bring them up.*

*Catherine: I have only talked to one person about it and it was recently. And the only reason I talk to him is because his mom got hit by a car, like a hit and run, and so I feel like he understands what I'm going through. But my actual friends know nothing. Like my friends might know, but I haven't told them and we don't talk about it, I think they're weirded out by it.*

This conversation is important for outsiders to understand what life is like for these young adult siblings. Their friends are not supportive, or as Wade explains, they just don't understand. Wade offers a unique perspective as he has had two siblings pass away in his lifetime. He feels that his friends may offer sympathy, but they will never really understand what his life is like. This can be very challenging for young adults who seek community and friends. One can infer that if their friends do not know about their sibling, most likely they have never been over to their house. As shown in previous chapters, LLC's require a lot of medication and equipment, making it very difficult for someone to go to that person's house and not notice it. Kyla shares a heartbreaking anecdote that her friends change the subject when her sibling is brought up. As a young adult this can be challenging. If these siblings feel that they can't go to their parents for fear of worrying them, and they can't talk to their peers, they are left to worry on their own and internalize all their problems.

Catherine adds to the discussion that none of her friends know about her sibling, unless they have found out through someone else. She explains how alienated she feels, however she has found someone she can relate to. By finding this person that she feels can relate to her situation, she is able to express feelings of worry, loss, and death. This is one of the reasons SIBS group is so important for these young adults. As illustrated above, having a SIB with an LLC is very isolating, and SIBS is a place where these siblings can come together and talk about topics that their friends may not understand. They can also be surrounded by people who understand exactly what they are going through. This information is important as it may help parents and medical professionals understand that friends may not always be there, and that a strong support group of young people going through the same situation is important for these siblings' mental health. These examples have also supported the argument that these siblings' frustration arises from the ableism so present in our society rather than the frustration stemming from having a sibling with an LLC.

### **Concluding thoughts**

While many of the emotions of these participants are felt across all ages and genders, these may not be the only worries of siblings of children with LLCs. By illustrating their complex emotions in these photos, the participants in this study were able to express fears, worries, and daily stresses in their lives in an artistic and approachable way. Discussions in the group were helpful for most participants, as we were able to talk through each emotion and find ways to remedy their worries and fears. This chapter also showcased the frustrations that these siblings feel. It is interesting to note that none of the frustrations were felt towards their siblings but were felt towards society and their social circles. This thesis challenges ableist assumptions

that siblings experience frustrations due to their siblings' LLC. This chapter has served as a way to view these frustrations as societal failure and ableism which makes disability invisible, which makes it difficult to talk to their friends and participate in family activities together.

Using photography as a way to express their complex emotions and frustrations was valuable for the participants in this study, as many of them struggled to directly speak about their emotions. The photos were used as a guide for them to express their feelings. By understanding what siblings of children with an LLC worry about, medical staff, families, and other people in their circle of care can better understand their needs. This chapter showed how siblings' worries and stresses can vary from child to child, and how their worries do not always concern the medical needs of their siblings, but are deeply rooted in the ways that their siblings and families manage their day to day lives.

## Chapter 5 : Conclusion

This thesis aims to give a glimpse into the lives of siblings of children with LLCs. This population is often forgotten, as the child with the life limiting condition is prioritized over concerns about their siblings. By showing their stories, in a visual way, and by using a method that engaged the participants in a fun and exciting way, this research has uncovered the beautiful stories of the siblings. It has also shown the importance of support; through support and SIBS group, these siblings were able to share their emotions openly with others that understood their lives. Most importantly, this work shows what it means to be a sibling to a child with an LLC.

I have explored what day-to-day life is like for these siblings, while showing that life with a sibling with an LLC can bring on many complex emotions. Additionally, the frustrations that these siblings feel are often driven by society's inability to adapt to disabilities, that is, accessibility issues are a greater source of frustration than having a disabled sibling in-and-of itself. These photos have also shown that it can be challenging to have a sibling with an LLC, but that strong bonds are formed between siblings, and they share care with one another. The photos also challenge the ableist narratives of disability by looking at these relationships from a critical disability perspective, highlighting both the structural constraints affecting families' lives, and the positive bonds of sibling love and care in these families.

I have examined the fears and worries of these siblings and given concrete evidence as to what triggers these emotions. The images presented in this thesis can help guide care teams in understanding what events or locations can cause strong emotions for these siblings. The stories that were shared in this work add to the complex narratives about what it means to have a sibling with an LLC. An important take away from this project is how important knowledge is for these

siblings. By giving them knowledge about their sibling's illness, medication, or diagnosis, they are able to regain control of their emotions.

Lastly, I hope that I have shed light on an underdiscussed topic. My hope is that this research can be used by anyone in the lives of siblings of children with an LLC. Siblings are often overlooked and forgotten in medical settings, as they are seen as background members of the family. Through these images, it is clear that these siblings have real worries and stressors in their lives.

### **Key findings**

By using photovoice, this thesis was able to uncover the lived experience of siblings of children with life limiting illness. This research showed that siblings' lives are much more complex than researchers may believe. Their lives are also much more complex and challenging than those of their peers. Many of the siblings in this study engage in care for their sibling, either through medical care or emotional care.

Siblings in this study also expressed their fears and worries that relate to their sibling with an LLC. These fears not only related to the medical needs of their siblings, but also related to their sibling being in pain or dying, as well as financial and practical concerns of the family. This is an important distinction, as caregivers may often only think of siblings worrying about their sibling's death. This information will help those in the lives of siblings of children with LLCs be more aware of triggers and situations that could bring up strong emotions.

Another important key finding relates to knowledge. Many of these siblings expressed that with knowledge, they felt stronger. They felt that they were more comfortable and less worried about their siblings if they knew about their specific condition and medical devices.

Throughout this study, it is apparent that many of these young children know how to use complex medical equipment, however, they may be unclear on what the equipment actually does. Siblings shared that knowledge is power. Knowing as much available information as possible gave them a sense of relief. This supports the idea of inclusion. Medical professionals and families may want to exclude siblings from tough decisions and conversations; however, siblings are asking to be included. They are rejecting the notion that they are too innocent and fragile to be included in difficult conversations and moments in their siblings' lives.

The goal of this study was to investigate what life is like for a sibling of a child with an LLC. Through the interviews and photographic evidence provided in this thesis, we have been given a glimpse into the hidden lives of these young carers as they navigate their roles as siblings and caregivers.

### **Significance of the research**

Presently, there have been few photovoice projects done with siblings in medical settings. The most recent was a photovoice project with siblings of children with Down Syndrome (Rampton et al, 2017). While this study investigated siblings' relationships, the researchers suggested that future researchers examine a wider variety of siblings' disabilities or illnesses rather than focusing on only one. This research fills that gap, as this study looked at siblings with multiple different diagnostic categories--i.e., neurodegenerative, cerebral palsy, and genetic. By doing so, I was able to examine different life experiences of siblings living with children with different disabilities. For example, some siblings with LLCs were verbal and were able to give verbal consent for photos or help their siblings with ideas for photos. Other siblings with LLCs

were non-verbal and were not able to communicate with their sibling at all. These differences impact the participants differently and may be a source of strong emotions for some.

The findings from this research will contribute to disability, family studies and anthropology of children, youth and childhood. This study will provide unique perspectives from children and youth in Ottawa specifically. As much of the research emphasizes how negative life can be for these siblings, compared to families where no disability is present, this research will offer a different perspective. By challenging normative views of childhood and disability this research will add to existing anthropological literature that confronts ways of looking and questioning the world around us. This research shows the special bonds and positives that can emerge from having a sibling with a disability. This thesis can also serve as a starting point for families with children who have recently been diagnosed with an LLC.

## **Photovoice**

Through the course of this research, I have challenged my views on photovoice as a research method. Prior to starting the study, as stated in the introduction, I viewed photovoice as the best possible method to use with this population. During the planning phase of this project while I went through available literature, I found that photovoice was seen to be therapeutic for participants. I was drawn to this aspect of the method, as I wanted this project to be more than just a research project for my thesis; I wanted to engage the participants so that they felt a value to be gained from participation. When the study began, I noticed that the therapeutic aspect was not that simple, and it had effects I did not anticipate. For example, for some participants this project brought out strong emotions that caused them to break down and cry. In such moments, I felt regret for making them discuss something so difficult. There were also moments when

participants were resistant to the method. For example, some participants felt that they could not take photos of certain themes because they were too hard for them to think about, or they were just not interested. In moments like this, I felt that it was important to explain why we were doing the study and that this research would allow others to understand what life is like for them. Some participants used this knowledge to take photos and continue with that week's theme, while others turned inward and said it was too much for them and did not want to take photos. In those times again I was challenged with questioning my method and wondering if I was pushing too hard for them to take photos, or not enough? And was this method really beneficial for them and providing comfort? Or was it opening emotional wounds they never had to address before, in a way that was less than therapeutic?

From these moments, my key takeaway was that no method is perfect. Going into this project I assumed that this method was perfect and would function as such. But throughout the project I was presented with moments when I realized this method had its flaws. The benefits I saw from this method included the joy and excitement that the participants felt when they found out they were getting to use a camera of their own. Many of the participants had never used a camera before and were so excited that they got their own. The question that I think will never be answered fully is, was this method therapeutic? As I did not use pre and post surveys, it is difficult to track how therapeutic this method was. It was my bias as a researcher to assume that by talking about their fears and worries that this was a beneficial and therapeutic way to deal with participants' emotions. It is difficult to say what is therapeutic, and this was a challenge I faced throughout this project. As mentioned earlier, I never knew when to push for more information and when to pull back. As I am not a therapist it was difficult for me to navigate those moments. However, I did find that many of the participants felt proud to show off their

photos and excited to share what it meant to be a sibling. I also feel that by sharing photos about the positives of being a sibling to a child with an LLC, the participants felt joy and pride, and this in itself felt therapeutic.

As discussed in my methods chapter, this method has many ethical considerations. Figure 3.4 offers a way to examine these ethical considerations closer. Figure 3.4 was taken by Melissa and showed her brother's bare stomach with a G-tube and Melissa pointed out that he expressed some (non-verbal) objection when she lifted his shirt to take the photo. We asked participants to consent to the study but were unable to get consent from the children in the photos. In an attempt to mitigate this concern, we told the participants to not take any identifying photos of their siblings or family members and to try not to capture anyone's full face in photos. However, this does not mitigate the discomfort some might experience from having their body photographed. Is it ethical to include photos of siblings' bodies, without their explicit consent? What would consent look like for a non-verbal photographic subject? Future research could investigate ways for non-verbal siblings to give consent or find ways for participants to take photos of objects rather than of their sibling directly. These are complex issues that could not be addressed fully in this study.

There is no way that a method can be all powerful and only beneficial. Although this method provided me with the data needed for this thesis, it was not without flaws. I was naive to assume that a method could only be beneficial; this adds to the complexities of research. As noted above, for some participants it was an exciting way to engage in research, for others it was uninteresting and boring. This is something I was not ready to accept. I wanted all participants to be equally excited for this method and that is not always possible. I think that this speaks to the value of picking a method that functions for your participants. While it may not have been

the best method for all the participants, it worked well for most and provided snapshots of these siblings' lives.

Photovoice also misses a number of emotions. In these interviews and photos, many participants chose to share emotions that were, perhaps, the easier ones to discuss. Feelings of anger or jealousy can be difficult to capture in photovoice, since participants may be reluctant to take photos and initiate discussions that focus on these hard emotions. For this reason, having additional methodologies would have been beneficial for capturing these emotions. For example, having a scenario-based focus group, where participants were presented with scenarios and asked how they might feel, could reveal emotions that are not captured through the use of photovoice. Photovoice in this study also only showed us one side of the sibling relationship. We were unable to see their relationship as a whole, instead we saw how one side, the able-bodied sibling, perceived it. Lastly, using methods such as photovoice excludes participants that are uninterested in photography, or arts-based methods. In this particular study, the boys seemed less interested. Further investigation into ways of supporting boys through qualitative research would be beneficial.

### **Future research**

As my research took place in one particular SIBS group, future research in this area should use different sites to gain a better understanding of what siblings experience in different areas. Many of the families that access services at Roger Neilson House are of higher socioeconomic status. It would be interesting to see how socioeconomic factors impact care work and sibling relationships in a family.

While using photovoice seemed to be the best method for this particular study, other methods, such as other ethnographic approaches, may also be beneficial for learning about the

lived experiences of siblings of children and youth with LLCs. Since this project needed to be completed in a tight timeline, it was difficult for me to have make up interviews with anyone who missed the SIBS group that month. Unfortunately, using Skype or Zoom was not an option available to me as per my research ethics board approval, and this would be a beneficial addition to future projects to ensure all participants can share.

This research, with only eleven children and youth, was also lacking a large participant base. Future research should aim to have more siblings in the study with wider age ranges. Other research has noted that it is difficult to find sibling participants for studies, as many siblings do not access support groups and there are few support groups available for them to access (Hodapp, Glidden, Kaiser & Hodapp, 2005). Future research should also include more background about the families. My study only asked for a diagnostic category in a survey form, rather than leaving it blank for the families to fill out with specific conditions. As many of the siblings with LLCs in this study shared similar conditions, it was difficult to infer if specific feelings stemmed from specific conditions. Future research should aim to have participants write specific conditions as well any comorbid medical conditions that accompany them, so researchers can explore similarities and differences in emotions across groups.

I want to also challenge future researchers to include siblings in the entire research process. Many hospitals and other medical spaces are turning towards more patient and family engagement in research. This includes engagement in design planning, interpretation and dissemination of research findings (Carman & Workman, 2017). As this project was done in order to complete a master's degree, the timeline was limited and access to the siblings before REB approval was not allowed, therefore it was impossible for me to include siblings in the entire process. However, for medical staff that may work with these siblings often, it would be

easier to include them in the entire process. Allowing participants an active role in the research process allows for better collaborative research.

## **Final thoughts**

While this project was done in order to complete a master's degree, this project is much more than that. For these siblings, this was a chance to explore artistic abilities and uncover feelings and emotions that may have been left untouched before. During this study, this group met more frequently than normally, and this allowed for more participant bonding. At the end of the project, each participant was meant to be presented with a book of their photos at a ceremony showcasing their photos in an art gallery style. However, due to the Spring 2020 COVID-19 pandemic, this event had to be cancelled. As I finish this thesis, I have not been able to celebrate this accomplishment with them. At the last group meeting, the participants shared how sad they were that this research project was over, and how much they would miss meeting each month and sharing their photos. They all explained how much they enjoyed using their cameras and how much fun they had with them. Because of this, although not originally planned, we let all the participants keep their cameras so they could continue to take photos of their lives and experiences.

The lived experiences showcased in this thesis are an important reminder that siblings' perspectives are crucial in understanding how to help families with children with an LLC. Information and photos gained from this research will add to the discussion about siblings and shows that using photography can be a powerful tool to engage children and youth in research. My hope for this project is that it will aid others in understanding what it means to have a sibling with a life limiting condition.

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## Appendix A: Example SIBS group schedule

### Your VOTE Matters SIBS

1. Intro and questions
2. Best part about being a SIBS, --learning to take care of brother or sister, Getting to go on a wish trip
3. Most challenging part about being a SIBS-missing out of a party.  
--break into group and become artists with balls of Clay
4. What emotions do you think you feel more because of having a sibling with a life limiting illness
5. Pods
  - a. Why do you think Roger Neilson House is interested in doing research about SIBS and what do you think the benefit is?
  - b. Why do you think it might be important to tell the world about what it means to be a SIBS?
  - c. What challenges do you expect to face as your and your sibling get older.
  - d. What is something you look forward to as your get older?
  - e. If you could tell your parents one interesting thing about SIBS group, what would it be?
  - f. What do you believe is the best lesson you've learned or will learn from having a brother or sister with a life limiting illness.
  - g. What do you think makes SIBS stand out above everyone else?
6. What would you tell the world about being a SIBS  
Wordelle
  - List as many words as you can about your sibling
  - List as many words as possible that describe you relationship with your sibling
  - List as many words as possible that describe what it means to be a SIBS
7. Interview for each question

## Appendix B: Data collection form

### Case Report Form for Minimal Risk Studies

Study ID #: 9994

#### Youth Participant Information

Initials: \_\_\_\_\_

Age at the start of project: \_\_\_\_\_

#### Gender

- Male
- Female
- Non-Binary
- Prefer to self-describe \_\_\_\_\_
- Prefer not to say

Total number of siblings (Not including self): \_\_\_\_\_

Number of affected siblings: \_\_\_\_\_

#### Diagnosis categories of affected sibling

- Neurodegenerative
- Metabolic
- Cancer
- Cardiac
- Respiratory
- GI
- Genetic
- Other

Have you attended SIBS Group or another sibling support group before?

- Yes, SIBS Group
- Yes, Another Group
- No, None

Participants will be given pseudonyms for any published research

During presentation at Roger Neilson House initials will be assigned to photo

### Appendix C: A Table of Participant Data

Pseudonym	Age	Gender	Number of siblings	Number of affected siblings	Siblings diagnostic category	Attended siblings group before
Catherine	16	F	4	1	Neurodegenerative Respiratory GI	Yes SIBS
Wade	15	M	3	1	Metabolic	Yes SIBS
Kyla	13	F	3	1	Metabolic	Yes SIBS
Melissa	16	F	2	1	Neurodegenerative	Yes another group
Tommy	10	M	1	1	Other- Spinal Muscular Atrophy	Yes SIBS
Rachel	11	F	2	1	Genetic Other	Yes SIBS
Max	11	M	2	1	Neurodegenerative	Yes another group Yes SIBS
Lydia	9	F	2	1	Neurodegenerative- CP	No, None
Rebecca	6	F	2	1	Neurodegenerative- CP	no, None
Finn	10	M	2	1	Other	Yes SIBS
Elizabeth	8	F	4	1	Neurodegenerative Respiratory GI	Yes SIBS
Average	11.36	7F/ 4M	2.45	1		