Empowering Pediatric Sibling Hematopoietic Stem Cell Donor Voices Through Digital Storytelling

by

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Abstract

This participatory, arts-based qualitative study aimed to elucidate the sibling donor experience in pediatric hematopoietic stem cell transplant (HSCT). Six sibling donors aged 12-21 years of age who were under 18 at time of donation, participated as research partners and used digital storytelling (DS) to express their donation experiences. The United Nations Convention on the Rights of the Child (UNCRC) was employed as a framework to ensure that research partners' voices were heard. Research partners were actively involved in three research meetings (get to know you, digital storytelling workshop, data analysis), collaborating and contributing to the meeting dynamics while offering feedback on the participatory process and the creation of digital stories. During meeting three (data analysis), research partners viewed each other's digital stories and wrote words, thoughts, and ideas on Post-it notes to reflect their interpretations of the sibling donor experience. The primary researcher (AWK) conducted participatory data analysis with sibling donor research partners and six themes were identified and explored: 1) pessimism and acceptance, 2) after-procedure thoughts, 3) sibling support, 4) family experience, 5) connections, and 6) hope. Throughout the process, AWK and a secondary researcher (CHW, doctoral advisor) wrote field notes to capture the research process of using the digital storytelling method to empower pediatric sibling donors to express donation stories. Interpretive description was employed to analyze field notes and research partner meeting transcripts, leading to the identification of four themes: 1) community and connection; 2) digital storytelling - new and fresh; 3) therapeutic process; and 4) privacy. Digital storytelling is an arts-based approach that can assist sibling donors to express their donation experiences and offer support for growth and strength in the context of sibling donation and encourage children’s meaningful engagement and participation in research by exploring their HSCT donation experiences.

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Dedication

I dedicate this dissertation to my children, Syd and Nattie. Du er min grund til alt, jeg elsker dig. I want the world for you, and it is possible.

In memory of my Dad, the original Dr. Winther.

Education is for all.

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Chapter One: Introduction

Hematopoietic stem cell transplantation (HSCT) is a treatment procedure for pediatric cancers and genetic and hematological disorders (Duarte et al., 2019; Pelletier et al., 2015). Donating stem cells for an HSCT requires a compatible match determined by human leukocyte antigen loci (HLA) typing (D'Auria et al., 2015; Rinaldo et al., 2022; Weiner et al., 2019). Siblings are often compatible due to their close genetic match (l., 2015; Rinaldo et al., 2022; Weiner et al., 2019). Pediatric siblings who become stem cell donors are often thrust into a complex clinical situation, which is impacted by the weakening health of their ill sibling and the urgent need for them to be a donor for their sibling's pediatric HSCT (D'Auria et al., 2015).

Statement of Research Problem

HSCT sibling donation is a complex experience. HSCT has a high success rate, but sibling donors face psychosocial risks such as fear, anxiety, and pressure to donate, according to a previous narrative review (Winther Klippenstein et al., 2021) and established literature (D'Auria et al., 2015; Erden, Kuskonmaz et al., 2019; Gizli Coban et al., 2017; Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003; Packman et al., 1998; 2003; Pentz et al., 2012, 2014; Pot-Mees & Zeitlin, 1987; Stegenga et al., 2019; Rinaldo et al., 2022; Switzer et al., 2016; White et al.,2017; Wiener et al., 2008; Weiner et al., 2019; Wilkins & Woodgate, 2007). During HSCT, pediatric sibling donors often experience positive gains and growth such as a greater appreciation for life, increased personal strength, and closer relationships with family members (D'Auria et al., 2015; Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003; Wiener et al., 2008; Wilkins & Woodgate, 2007; Winther Klippenstein et al., 2021; Tedeschi & Calhoun, 2004).

The previous research studies exploring the experiences of pediatric siblings who become donors have favored using qualitative interviews (D'Auria et al., 2015; Hoag et al., 2018; MacLeod et al., 2003; Pentz et al., 2014; Rinaldo et al., 2019; Switzer, 2016; Wiener et al., 2008; Wilkins & Woodgate, 2007), quantitative scales, inventories, and questionnaires (Erden et al., 2019; Hutt et al., 2015; Packman et al., 1997; Pentz et al., 2014; Switzer et al., 2016; Wallace et al., 2014) to study siblings' psychosocial experiences of HSCT donation (see Table 1 for a visual of previous literature, Appendix A). These methods may not have captured an in-depth and comprehensive understanding of the psychosocial experiences or children's developmental needs to express themselves creatively through internal cues and the use of their senses (Linder et al., 2018). Further, these inquiry approaches may not have captured children's authentic voices, limiting their autonomy and ownership over their experiences and how they have been expressed.

My doctoral research adopted a participatory, arts-based research methodology guided by the United Nations Convention on the Rights of the Child (UNCRC) framework (United Nations, 1989), encouraging sibling donors' meaningful involvement (Coyne & Carter, 2018; Linder et al., 2018; Groundwater-Smith et al., 2015) and active participation in the research process. Digital storytelling (DS) was used to assist siblings in symbolically expressing their HSCT donor experience. This developmentally sensitive, artistic approach can potentially explore aspects of the sibling donation experience not accessible through words alone (Lambert, 2018). The adoption of a child rights framework is congruent with participatory research methodology, inviting a view of children as capable, competent contributors within the research process rather than passive participants (Bergold & Thomas, 2012; Christiansen & James, 2017; Coyne & Carter, 2019; Groundwater-Smith et al., 2015; Lundy et al., 2011; Hart, 1992; Hart, 2008; United

Nations, 1989). The participatory, arts-based research approach addressed the critical need for a more comprehensive understanding of the pediatric sibling donor experience by encouraging, hearing, and amplifying the voices of child donors.

Research Questions

The following research questions guided the study:

1) What are the experiences of pediatric sibling donors in hematopoietic stem cell transplant donation, as understood through digital storytelling?
2) How do pediatric siblings experience exploring their hematopoietic stem cell transplant donation through digital storytelling?
3) Do pediatric sibling donors feel that digital storytelling can help future sibling donors express their voices in a creative and participatory way?

Hematopoietic Stem Cell Transplant Classifications

Hematopoietic stem cell transplant is an infusion of stem cells aimed at restoring bone marrow function and treating various diseases (Rinaldo et al., 2022; Vogel, 2011). There are multiple types of stem cell transplants, but the two main types are: *autologous transplants,* which involve using the patient's bone marrow or blood cells (Bauk et al., 2013), and *allogeneic*, which involves harvesting bone marrow or blood cells from a related or unrelated donor (Bauk et al., 2013).

Process of Hematopoietic Stem Cell Donation

Finding a compatible HSCT donor begins with collecting blood samples from family members and testing the samples to find the closest human leukocyte antigen (HLA) match (Vogel, 2011; Weiner et al., 2019). Due to the genetic similarity between siblings, there is a one

in four chance of being the same HLA type, and therefore, siblings are preferred stem cell donors as their sibling genetic compatibility decreases the chances of transplant complications (Vogel, 2011; Weiner et al., 2019). When pediatric siblings are identified as a compatible HLA match, they have blood taken and an exhaustive physical exam to ensure they are healthy enough to donate (Vogel, 2011; Weiner et al., 2019).

Once the decision is made to proceed with sibling donation, stem cells are harvested through bone marrow collection (day surgery) or peripheral blood collection via large venous catheters (American Academy of Pediatrics (AAP), 2010; Vogel, 2011; Weiner et al., 2019 (b)). Medical risks of bone marrow collection include complications from anesthesia, including nerve, bone, and tissue injury, and temporary side effects such as fatigue, pain at the donation site, headache, nausea, and difficulty sleeping (AAP, 2010; Then et al., 2018; Vogel, 2011; Weiner et al., 2019). Peripheral blood collection requires some patient preparation beforehand, including injecting a granulocyte colony-stimulating factor (G-CSF) through a daily subcutaneous injection for 4-5 days pre-donation (AAP, 2010; Vogel, 2011). Side effects of these daily G-CSF injections include bone pain and soreness at the site of injection (AAP, 2010), and research is sparse regarding the long-term health consequences of sibling donation (Bitan et al., 2016) .

Once the stem cell count has risen due to G-CSF injections, stem cells are collected through a process known as apheresis, which uses two large venous catheters to separate the stem cells from blood cells (AAP, 2010). In preparation for apheresis, many donors choose to receive conscious sedation to manage the pain related to the use of large venous catheters (AAP, 2010). Peripheral blood stem cell collection may be a better option for older pediatric patients because younger patients may experience anxiety about inserting large gauge catheters, which need to remain in place for roughly 200 minutes, or 3 hours (Putzulu et al., 2023; Then et al.,

2018). The short-term effects of this form of stem cell collection include fatigue, light-headedness, pain, and sleeping difficulty (AAP, 2010; Livingston et al., 2021).

Significance of Study

One of the critical limitations of previous sibling donor research in pediatric HSCT has been the use of data collection methods that may have limited the ability of children to voice their donation experiences fully. In this doctoral research, sibling donors were engaged as research partners throughout the inquiry process using participatory research methodology (Coyne et al., 2016; Ford et al., 2018) and the UNCRC framework (United Nations, 1989). The participatory methodological approach ensured that sibling donors maintained ownership over how they expressed their donor experiences. This was accomplished in part by creating their own digital story (Lambert, 2018) about their donation experience and contributing to the data analysis process with the primary researcher and other sibling donor partners. Digital storytelling has immense potential for use in clinical practice with families and siblings who are facing pediatric hematopoietic stem cell transplantation (HSCT) donation.

My hope is that the study will inform the development of digital storytelling interventions for sibling donors in HSCT, which could help children to express their voices more effectively throughout the HSCT process, and perhaps other medical interventions. By using digital storytelling methods, perhaps psychosocial distress could be reduced while experiences of growth and strength could be supported in the context of sibling donation.

Chapter Two: Literature Review and Conceptual Framework

The literature review in this chapter draws on a published narrative review, initially written as doctoral course work, which I (AWK) led in 2021, investigating the pediatric hematopoietic stem cell donation experience from the viewpoint of sibling donors (Winther Klippenstein et al., 2021). The goal of the narrative review was to focus on child sibling donor perspectives before, during and after pediatric HSCT, and to gain a more comprehensive understanding of children's experiences with HSCT donation. Also, we aimed to gain knowledge about the support and services needed to help children successfully navigate the challenges of the HSCT donation, while simultaneously facilitating their psychological well-being and growth. This chapter updates the narrative review by Winther Klippenstein et al. (2021) with current literature regarding the experiences of pediatric sibling donors from their perspectives (Rinaldo et al., 2022). It also includes an article exploring educational interventions aimed at better preparing siblings for the donation process (Weiner et al., 2019). To identify relevant articles, a university library search was conducted using four key concepts: HSCT, sibling donor, children, psychosocial and experiences. However, this search yielded few new results, which I then reviewed manually to filter out articles that did not specifically address the experiences of pediatric sibling stem cell donors from their own perspective. Ultimately, only Rinaldo et al. (2022) met the inclusion criteria, while Weiner et al. (2019) provided valuable insights into educational interventions for potential sibling donors regarding the procedure.

Becoming a Pediatric Sibling Donor

Psychosocial Risks. Although the success rate of HSCT is high, a small but growing body of literature suggests that there are significant but overlooked psychosocial risks for pediatric sibling donors before, during, and after the treatment process (D'Auria et al., 2015; Erden et al., 2019; Gizli et al., 2017; Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003;

Packman et al., 1997a, 1997b; Pelletier et al., 2015; Pentz et al., 2012, 2014; Pot-Mees & Zeitlin, 1987; Stegenga et al., 2019; Switzer et al., White et al., 2017; Wiener et al., 2008; Wilkins & Woodgate, 2007; Zajac-Spychala et al., 2020). The literature points to four distinct themes or groupings specific to the psychosocial risks associated with the pediatric sibling donor experience: Distress and anxiety related to the medical aspects of HSCT donation, absence of autonomy over the decision to donate, lack of understanding about HSCT and the expected recovery timeline, and feeling physical and emotional isolation from parents following donation. These four themes charted closely to the hematopoietic stem cell donation timeline, beginning with blood testing to find the closest HLA match, learning siblings were an HLA match, making the decision to donate, becoming a patient themselves, and waiting to find out if the transplant was successful (Winther Klippenstein et. al., 2021).

Distress and Anxiety Related to the Medical Aspects of Donation. Learning that the ill child needs HSCT treatment signals the beginning of a distressing period for the entire family (D'Auria et al., 2015). At this time, family members undergo blood tests to determine if they are an HLA match to donate stem cells. The HLA testing process creates stress for siblings: many children express fear and anxiety about the needles used to draw blood (D'Auria et al., 2015; Pot-Mees & Zeitlin, 1987; Wilkins & Woodgate, 2007). In one study that used retrospective, structured interviews with adults, 64% of donors stated, regardless of their age at the time of donation, that needle pokes were their primary concern (Weiner et al., 2008). After the HLA test, siblings report high anxiety while waiting to find out if they are the best match (Hoag et al., 2018). For example, a sibling shared that they felt pressure to be the match:

> When they took my blood I was so scared I passed out. I mean I was so terrified because the pressure was just so overwhelming (D'Auria et al., 2015, p. 449).

Once the decision to donate is made, siblings experience fear and anxiety about the actual donation procedure, specifically around the physical pain they might experience (Hoag et al., 2018; MacLeod et al., 2003; Packman et al., 1997a, 1997b; Wiener et al., 2008; Wilkins & Woodgate, 2007). An 8-year-old sibling described their emotional state the day of donation:

> When I entered the hospital, I was so scared…I didn't want to die or anything. I was so nervous, I thought I was going to get sick (Packman et al., 1998, p. 182).

Similarly, an adolescent sibling indicated they felt their body was "violated" during blood draws and other medical procedures (Packman et al., 1997a, p. 251). This literature reflects the fear sibling donors experience when they become a patient themselves.

Absence of Autonomy over the Decision to Donate. Once identified as the most appropriate HLA match for donation, siblings feel pressure and responsibility to go through with the procedure. Their decision to donate tends to be predominantly made from an obligation to their family, and siblings do not always feel they have a voice in the decision-making process (Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003; Packman et al., 1997a, 1998; Pentz et al., 2014; Rinaldo et al., 2022; Stegenga et al., 2019).

Pentz and colleagues (2014) interviewed parents of pediatric HSCT patients to explore the family decision-making processes. They found that an overwhelming majority of parents (77%) felt that there was "no choice" in the decision about whether siblings would donate (Pentz et al., 2014, p. e1156). From the same study sample, 31% of sibling donors felt there was no choice regarding donation, they were expected to donate (Pentz et al., 2012). Moreover, even if siblings were offered a choice, many still felt pressured by their parents to donate (Hutt et al., 2015; Pentz et al., 2014). One sibling remembered their father telling them that if they did not donate it would result in horrible consequences:

> My dad came to me and said, 'you're doing this'. I told him I didn't want to. He said 'Fine then, he'll die'…so it wasn't my choice (Packman et al., 1998, p. 180).

A separate sibling echoed a similar memory recalling that:

> You do have a choice but it's really either you do it or something really bad is going to happen (D'Auria et al., 2015, p. 449).

Furthermore, siblings still feel pressured to donate even if they are given the option to do so by their parents (Pentz et al., 2014). One sibling shared:

> There are fears and memories, it was traumatic because of the pressure. The donation was forced because of the situation (Hutt et al., 2015, p. 1339).

If the HSCT treatment was unsuccessful, and their brother or sister died, sibling donors felt guilt and blame (MacLeod et al., 2003; Packman et al., 1997a, 1997b). A 14-year-old donor sibling believed it would be their fault if something went wrong with the transplant (Wallace et al., 2014). According to MacLeod et al. (2003), children's feelings intensified over time, especially when they did not have the chance to speak with someone about the unsuccessful HSCT and the subsequent death of a sibling. One sibling recalled:

> I knew that was the last chance and knowing that it didn't work, I felt guilty… It was something that built up and nobody probably even realized that I felt that way (MacLeod et al., 2003, p. 228).

Sibling donors often felt overwhelming pressure and responsibility to save their ill siblings' lives (D'Auria et al., 2015; MacLeod et al., 2003). This pressure was described by one sibling as follows:

> I hope I'm not the one to do my brother in…it would have killed me (D'Auria et al., 2015, p. 450).

Lack of Understanding about HSCT and the Expected Recovery Timeline.

Furthermore, the siblings were under the impression that their donation would have an immediate effect; however, they did not understand that it would take several weeks or even months for their ill sibling to recover from the HSCT treatment (D'Auria et al., 2015; Rinaldo et al., 2022). Perhaps this misunderstanding was due to a lack of fully grasping the medical process of stem cell donation and transplant. Rinaldo et al. (2022) found that though siblings reported they had received medical information about the procedure, they were still unclear about the donation process. One sibling donor (age 11) reflected:

> I understood, well, that they would, sort of, take that syringe and that you would give blood to another, kind of, so that you change the blood. I understood that later, so I almost did not understand how it would go then. Otherwise, I knew what it was (Rinaldo et al., 2022, p. 4).

Another sibling donor in this study explained the frustration they still felt after the donation:

> I understood that he would get my bone marrow, but then I did not know if it would help or not, or what would happen after that. I was still very frustrated that we did not know what would happen. Because, yes, it is very reasonable that, when your brother becomes so seriously ill, that you want to make sure that he gets well, too (Rinaldo et al., 2022, pp. 3-4).

And another sibling added:

> Uhm, yes, but it was a bit like this, if, if the transplant had not worked, it would have felt very hard personally, that I was not good enough, sort of. That it did not work as it was supposed to do (Rinaldo et al., 2022, p. 4).

The need for a deeper understanding of the medical aspects of the HSCT process and recovery was the focus of a pilot study by Weiner et al. (2019). This study aimed to create educational tools for pediatric sibling donors to increase their knowledge and understanding of donation and transplant procedures (Weiner et al., 2019). The goal of the study was to assess and compare pediatric sibling donors' knowledge of HSCT at three-time points (through a brief quiz): 1) when they were identified as a donor, 2) after meeting with health care professionals, and 3) after educational tool interventions (Weiner et al., 2019). There were two educational tools: a board game for children ages 10-15 and a written workbook for young adults and adults ages 16-25, which were completed with a study investigator (Weiner et al., 2019). "ShopTalk" (Weiner et al., 2019, p. 2) was a previously created board game adapted for this study with questions exploring facts and information about HSCT and sibling donors' thoughts and feelings around their donation. The written workbook, *Being a stem cell donor* (Weiner et al., 2019, p. 3), provided information about both bone marrow and peripheral blood donation through activities and visuals to encourage active engagement. After each time point, sibling donors were quizzed about their knowledge (Weiner et al., 2019). Seventeen sibling donors ranging from 10-25 years of age participated, and results found that knowledge scores increased from "59.6% to 68.8%" after meeting with healthcare professionals and further to "88.5%" after educational intervention tools were implemented (Weiner et al., 2019, p. 1). The authors concluded that based on these results, these educational tool interventions increased sibling donors' knowledge of HSCT and provided an opportunity for sibling donors to explore the psychosocial aspects of donation (Weiner et al., 2019). The authors also noted that the educational tools' creative, active, and interactive aspects were especially impactful (Weiner et al., 2019). Given the findings that many pediatric sibling donors relay feelings of worry and a lack of understanding of the HSCT process

and recovery, these findings are poignant and provide support for the use of actively engaging mediums that are developmentally sensitive with sibling donors.

Feeling Physical and Emotional Isolation from Parents. When interviewed about issues they faced and concerns they had during their brother or sister's HSCT process, donor siblings have reported "feeling negative effects of separation from the parent and caregiver" (White et al., 2017, p. 4). Packman et al. (1997a) asked both donor and nondonor siblings of the HSCT recipient to complete three self-report measures during hospital follow-up visits or in their homes. These measures included an anxiety scale (Reynolds & Richmond, 1985), a traumatic stress symptom scale (Frederick et al., 1992), and a self-esteem scale for children aged 12 years and older only (Rosenberg, 1965). Donor siblings' scores reported significantly higher anxiety and lower self-esteem than their nondonor siblings. Furthermore, donor and nondonor siblings reported moderate-to-severe levels of posttraumatic stress reaction following the HSCT procedure (Packman et al., 1997a). Additionally, Gizli et al. (2017) retrospectively compared the PTSD scores of siblings of pediatric bone marrow transplant (BMT) survivors, including sibling donors, to a healthy control group. A child psychiatrist administered the Child PTSD Reaction Index (Pynoos et al., 1987) to 35 siblings aged 5-18 years of age and their healthy peers, which revealed that siblings of BMT survivors experience significantly higher levels of PTSD (Gizli et al., 2017).

Interestingly, when comparing the scores of donors to those of nondonor siblings, the nondonor siblings' scores were higher (Gizli et al., 2017). Donor siblings may experience anxiety as they prepare for and anticipate donation, while nondonor siblings may be grappling with the emotional stress of not only having a seriously ill sibling but also seeing another sibling become a patient through the donation process (Gizli et al., 2017; Packman et al., 1997a). Packman et al.

(1997a) attributed the lower self-esteem scores reported by sibling donors to the physical and emotional isolation they experienced once the focus returned to the patient after completing the HSCT donation procedure.

According to Rinaldo et al. (2022), sibling donors reported that they had to mature quickly and become self-sufficient because their parents were at the hospital caring for their sick sibling. However, they also acknowledged that it made sense that their parents' focus at that time was on their ill sibling (Rinaldo et al., 2022).

After their ill sibling's health improved and their parents were home more often, sibling donors reported finding it difficult to open up emotionally to their parents. For some adolescent sibling donors who had withdrawn emotionally, the return home of the patient and other family members was a stressful experience (Packman et al., 1997a). Sibling donors have indicated that neither their parents nor clinicians had asked about their psychosocial well-being post-donation (Packman et al., 1997a). In an interview with a researcher, one donor sibling revealed:

> No one really asked me…I didn't have anyone to talk to about it. In fact, you are the first person I've talked to about this (Packman et al., 1997a, p. 251).

Similarly, Hoag et al. (2018) found that 40% of sibling donors felt they needed to be provided with support post-donation. Studies have also emphasized the importance of emotional support during and after HSCT (D'Auria et al., 2015; Pentz et al., 2014; Wilkins & Woodgate, 2007; Zajac-Spychala et al., 2020). Interestingly, Rinaldo et al. (2022) found that though all thirteen sibling donor research participants in their study were offered an opportunity to talk to a psychologist or social worker, they all declined. Instead, they chose to speak with parents, grandparents, friends and neighbours (Rinaldo et al., 2022).

Positive Gains and Growth for Sibling Donors

The literature highlights the complex nature of the HSCT process for sibling donors. In addition to the psychosocial risks they experience, sibling donors also report personal growth and gains post-donation. However, the possibility of post-traumatic growth for sibling donors has not been extensively researched. The term "posttraumatic growth" (PTG) refers to the psychological change that occurs when individuals are faced with highly challenging circumstances (Tedeschi & Calhoun, 2004). These experiences of growth were categorized as posttraumatic growth, which encompassed an augmented “appreciation for life”, “closer relationships with others”, “gains in personal growth and strength”, and “spiritual growth” (Tedeschi & Calhoun, 2004, p.6).

Appreciation for Life. Within the research reviewed, sibling donors describe a sense of purpose concerning what they perceived as a direct contribution to their brother/sisters' recovery (Hutt et al., 2015). Six years after the donation, one sibling commented:

> You are giving life to someone else. You are not just one of those people just standing there trying to help them, you’re actually the one who is doing it. You’re the one who is saving him (Packman et al., 1998, p. 182).

This experience was articulately described by another sibling:

> It’s not a life ending experience, it’s a life growing experience (MacLeod et al., 2003, p. 227).

Some sibling donors were confused as to why an individual would choose not to donate if they were a match and given the opportunity to save their sibling's life (D'Auria et al., 2015). Despite their concerns about the procedure and the possibility of experiencing physical pain, donors also realized how crucial their donation was to their sibling's recovery. Even after several

years had passed since the donation process, they continued to maintain this perspective. They gained a greater sense of purpose as a result of this experience (D'Auria et al., 2015).

Closer Relationships with Their Ill Siblings and Parents. Sibling donors felt their relationship with their siblings and other family members improved after HSCT (D'Auria et al., 2015; Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003; Packman et al., 1997b; Pelletier et al., 2014; Pentz et al., 2014; Wilkins & Woodgate, 2007). During semi-structured interviews, Hoag et al. (2018) found that most siblings felt closer to each other six months after the donation. Several siblings described a stronger bond with their ill sibling and a stronger sense of loyalty:

> When I say we're closer than brothers, whatever it is, if there's a word for closer than brothers, that's the word we are (D'Auria et al., 2015, p. 450).

Sibling donors expect that their ill siblings would be there for them when needed in the future (D'Auria et al., 2015). Sibling donors felt that after HSCT, the whole family became closer. The trauma of HSCT encouraged them to lean on each other for support, strengthening family bonds (Hutt et al., 2015; Weiner et al., 2007). Many sibling donors could recognize the growth their family had experienced together.

Increased Sense of Personal Strength. Several sibling donors expressed happiness and relief upon discovering that they were a match for their sick siblings and appreciated the opportunity to actively contribute to their sibling's treatment (D'Auria et al., 2015; Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003; Pentz et al., 2014; Rinaldo et al., 2022). Within the literature reviewed, only two siblings regretted their decision post-donation. One sibling donor expressed shock after their sibling died and grappled with the post-donation realization that death was possible (Hoag et al., 2018). The other sibling described the donation as "painful" (Pentz et al., 2014, e1160).

Most siblings felt proud and happy about their donation decision (Hoag et al., 2018; Packman et al., 1997b) or experienced increased self-esteem and felt good about themselves (Erden et al., 2019; Hutt et al., 2015). Three years after the donation, one sibling reported:

> I do feel like a better person after giving bone marrow to my brother and I would do it again…you can save somebody's life (Packman et al., 1998, p. 179).

In a recent study, a 15-year-old sibling shared:

> So yes, you feel more confident and then you feel proud that you have done it. Then you can sit and think that you are a good person instead of a bad person who does nothing (Rinaldo et al., 2022, p. 3).

Post-donation, siblings showed gains in their social and personal development at school. Behavioral problems and social competencies of donor siblings were assessed in a study two and a half years following donation by teachers of both donor and nondonor siblings (Packman et al., 1997a). Donor siblings scored higher in terms of adaptive skills, leadership qualities, and social skills when compared with nondonor siblings (Packman et al., 1997a). The authors hypothesized that school might provide a positive distraction for donor siblings by providing a place to practice mastery, receive support, and create distance from the trauma of their donation experience. When considering the pain experienced by their sick sibling, many siblings who donate put aside their own concerns and fears about the pain they may experience during the donation process as reported by D'Auria et al. (2015) and MacLeod et al. (2003). This act of compassion towards their sibling may also initiate a process leading to post-traumatic growth.

Spiritual Growth. The domain of spiritual growth was only mentioned in one study (Wilkins & Woodgate, 2007), where sibling donors referred to their spirituality and religious

beliefs as a coping response for HSCT. Prayer was the most common spiritual tool that helped sibling donors process their experience (Wilkins & Woodgate, 2007).

The experiences of psychosocial distress and personal growth expressed by pediatric sibling HSCT donors show how complex the donation process can be for donor siblings. They live with fear, anxiety, and isolation while also experiencing greater meaning, personal growth, and better relationships. Although this literature is small, it is growing (Rinaldo et al., 2022; Weiner et al., 2019) and highlights the need for a better understanding of the multifaceted experience of pediatric HSCT donation from the unique perspective of pediatric sibling donors themselves. By understanding these perspectives of distress and growth, it will be possible to develop support and resources that can minimize the trauma experienced and foster the potential for personal growth and meaning. To gain a comprehensive understanding of the supports and resources required for pediatric sibling donors, researchers must be mindful of the theoretical perspective that informs the research design, processes, and objectives. To create genuine, respectful, and valuable research opportunities for pediatric sibling donors to share their donation experiences, they must be empowered, invited as active participants in the research process, and recognized as competent, capable contributors. To ensure that this was possible, I adopted the United Nations Convention on the Rights of the Child theoretical framework (United Nations, 1989) with a particular focus on Article 12, for this participatory, arts-based study.

Child Rights Framework

The United Nations Convention on the Rights of the Child (UNCRC)

The United Nations Convention on the Rights of the Child (UNCRC) is a human rights treaty that upholds children's inherent rights from birth to 18 years of age (United Nations, 1989). The UNCRC allocates the responsibility for actualizing these rights to parents, legal

guardians, care providers, and government bodies (United Nations, 1989). The UNCRC has been signed by 196 nations, including Canada, although not the United States (Ford, 2017). Canada ratified the UNCRC in 1991, acknowledging that it is a moral obligation and a legal government responsibility to ensure these rights are realized for all Canadian children (Government of Canada, 2017).

The UNCRC consists of fifty-four articles, forty-one of which are inherent rights, and thirteen which describe how nations can implement these rights for children (United Nations, 1989). The UNCRC guarantees rights to provision, participation, and protection of all domains of children's well-being: physical, mental, emotional, social, spiritual, and cultural (United Nations, 1989). The grounding assumption of the UNCRC is that children are entitled to rights beyond basic needs such as food and shelter, that they should have opportunities for the "full and harmonious development" of their personalities and be raised within a family environment of "happiness, love and understanding" (United Nations, 1989, p. 1). A primary strength of the UNCRC is the focus on the whole child, supporting them to survive and thrive (United Nations, 1989). Particularly relevant to the experience of pediatric siblings who are presented with the decision to donate, a UNCRC aim is that children are encouraged to be vocal and feel confident to express their opinions in decision-making processes (Office of the High Commissioner, United Nations Human Rights (OHCHR), 2020).

Relevant Rights for Pediatric Sibling Stem Cell Donors. Five rights apply to the experiences of pediatric sibling donors: Articles 3, 6, 12, 13, and 24. Article 3 is the cornerstone of the UNCRC, which ensures the supreme consideration of the child's best interests (United Nations, 1989). Articles 6 and 24 directly relate to children within medical spaces, stating the protection of children's right to life and high standards of medical care (United Nations, 1989). In

addition, Articles 12 and 13 highlight children's right to share their thoughts and opinions and become informed participants in decision conversations regarding their health and well-being (United Nations, 1989). Taken together, the rights in these five articles support the need for pediatric sibling donors to hold voice within medical discussions, practice autonomy over decision-making, and feel empowered to advocate for their health and well-being (Ford, 2017; United Nations, 1989).

To narrow in on specific articles that most directly apply to the experiences of pediatric sibling donors, Articles 12 and 13 acknowledge the most relevant issues facing sibling donors: voicing their personal views, opinions, and preferences while receiving relevant information throughout the HSCT experience (United Nations, 1989).

Voice and Autonomy of Pediatric Sibling Donors. Article 12 describes the child's right to their views and opinions and the freedom to express their views regarding their health and well-being (United Nations, 1989). Article 12, complemented by Article 13, entitles children to receive information through various mediums, ensuring they feel informed to contribute input to decisions (United Nations, 1989). It is important to note that this right is not specific to the UNCRC; it is also a right awarded to adults through the Universal Declaration on Human Rights (Lundy, 2007). Article 12 does not stipulate that children must display a definite level of competence or be at a certain age to express their views, perspectives, and preferences (United Nations, 1989). Children's capacity to form views should not be determined by age but should be presumed by states (Bala & Houston, 2015). According to Bala and Houston (2015), Article 12 is "especially important since it is one of the few provisions of the CRC that children can exercise themselves, and because it provides for children's involvement in decision-making that most directly impact their lives" (p. 2). Article 12 also uses broad, general language to encourage

as few restrictions as possible on children's participation (Bala & Houston, 2015). The goal is that through Article 12, children are heard directly through their voices (Bala & Houston, 2015).

Lundy (2007) proposed four elements that should be met to fulfill children's right to Articles 12 and 13: space, voice, an audience, and that children have genuine influence. The element of "space" presents opportunities for children to express their views, "voice" encourages the actual facilitation of children expressing their views, an "audience" commands active listening by adults, and "influence" requires adults to act upon the shared views, as is fitting for the situation (p. 933). Equally, Lundy (2007) emphasized that Article 12 is a "right and not a duty" and that there may be situations where children make an individual choice not to participate at all (p. 934).

Article 12, complemented by 13, can be enacted immediately for pediatric siblings who become donors. When the need for a stem cell donation is identified, family members of the ill child begin blood testing to determine the best human leukocyte loci (HLA) match (D'Auria et al., 2015). Many siblings express fear and anxiety over blood draws, specifically around the pain of needles (D'Auria et al., 2015; Pot-Mees & Zeitlin, 1987; Wilkins & Woodgate, 2007). Article 12 would oblige health care providers to include sibling donors throughout the testing process, providing them with developmentally respectful information. In this exchange of information health care providers could use techniques such as “confirming, pointing, demonstrating, labeling, questioning and expanding on the child’s initiatives” (Coyne et al., 2016, p. 498). Furthermore, seeking their opinion on any possible decision-making (e.g., which arm to draw blood from; the use of local anesthetic cream), and providing them with the necessary time, space and support to be actively engaged (Coyne et al., 2016). In this way, siblings may feel less

like passive subjects and more like willing participants in the testing process (Coyne et al., 2016).

Within the literature, pediatric sibling donors expressed the limited autonomy they felt over the actual decision to donate, which created psychosocial distress (Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003; Packman et al., 1997a; Pentz et al., 2014; Rinaldo et al., 2022; Stegenga et al., 2019). A rights-based approach would call for conversations to begin around the concept of assent to donate, and the donation would only proceed once written and oral assent was granted from sibling donors. Though gaining assent from pediatric patients is encouraged by the Canadian Paediatric Society, it is not a legal requirement (Coughlin, 2018). In most Canadian provinces, the age of consent is 16, 18, or 19 years of age (Coughlin, 2018), and parental consent is sufficient. This can lead sibling donors to enter the donation process with a sense of helplessness, lacking trust in health care professionals, and missing the opportunity to express their feelings about donating (Pentz et al., 2014).

Ultimately, Article 12 does not stipulate that once children express their thoughts, feelings, and opinions, their decision is final (United Nations, 1989), but that through inviting pediatric siblings into a dialogue regarding donation, siblings have the opportunity for their voices to be heard and practice perspective taking and negotiating (Graham & Fitzgerald, 2011). Within this dialogue, health care professionals and parents must provide sibling donors with correct, developmentally appropriate information in various mediums, such as verbal, photos, or video, to be discussed until the sibling acknowledges understanding (United Nations, 1989).

To fully enact Article 12, sibling donors' views and opinions should be heard, recognized, and taken seriously by parents and health care professionals (United Nations, 1989). The case of sibling donors' opinions are merely heard and acknowledged is referred to as "tokenism" within

the child rights literature, where children's views are sought out but carry little to no weight toward the final decision (Lundy, 2018). Hart (1992) created "The Ladder of Participation" to visually depict the process of adults providing children with participatory rights in decisions that affect their health and well-being (Hart, 2008, p. 22). On the bottom three ladder rungs are labels of "non-participation," the lowest of which is manipulation, followed upward by decoration and tokenism (p. 22). Tokenism would be the most relevant level of non-participation to pediatric sibling donors, where assent/dissent to donation is best practice but may not impact the future of the donation. This is in contrast to the three highest levels on the ladder of participation, which ultimately reflect the intentions of Article 12 within the UNCRC: "adult-initiated, shared decisions with children," "child-initiated and directed" and "child-initiated, shared decisions with adults" (p. 22). These levels reach beyond simply gaining assent from a sibling donor to validating their legal, inherent rights.

Of course, there are times when legal guardians and health care professionals must recognize that medical decisions are beyond the pediatric sibling donor's cognitive abilities (Coyne et al., 2016). In upholding Article 12, the goal would be to invite pediatric sibling donors into conversations, ensuring they have the space, voice, listening audience, and some influence within decision-making (Coyne et al., 2016; Lundy, 2007; United Nations, 1989), but adults are still responsible for fulfilling Article 3, making a decision that is in the best interest of that child.

The UNCRC provides a robust and respectful framework to support pediatric sibling donors through the HSCT process and within my research as they share their donation experiences. One of the most challenging areas for improvement of the UNCRC framework is the barriers to adults implementing Articles 12 and 13. Lundy (2007) describes three barriers to adults implementing Articles 12 and 13. The first is a skepticism that children can articulate their views or process

information; the second is that if children are given control within the decision-making process, it will undermine adult authority; and the third is that these articles will require too much time and effort from adults to implement UNCRC standards (Lundy, 2007). Lundy (2007) also recognizes that many adults may not know that children have these legal rights and do not feel accountable.

Family-Centred Care vs. Child-Centred Care

Currently, Canada approaches pediatric care through a family-centred lens (Coughlin, 2018), which according to the Canadian Paediatric Society, represents a "shared decision-making model" that "best respects and supports the emerging capacity of the paediatric patient as well as parental authority and the knowledge and expertise of health care professionals" (Coughlin, 2018, p. 139). In family-centred care, healthcare decisions are made through the context of the child's family and community systems (Coyne et al., 2016). However, when family-centred care is interpreted through a child-rights lens (Coyne et al., 2016; Ford et al., 2018; United Nations, 1989), this approach to pediatric care may be seen to intensify power imbalances between caregivers and children and between health care professionals and families, when the family rather than the child is the central focus (Coyne et al., 2016). This is especially the case when young children are labeled as having not yet attained "even a very limited definition of capacity" to make medical decisions, and adolescents as having "impaired decision making" abilities (Coughlin, 2018, p. 139).

An alternative approach presented within the literature is for pediatric policies to adopt rights-based child-centred care (Coyne et al., 2016; Ford et al. et al., 2018). Child-centred-care enacts Articles 12 and 13 by tasking health care professionals to offer pediatric patients an active voice in discussing treatment options and preferences, to provide pediatric patients with

opportunities to receive factual medical information, and to create the space and time necessary for pediatric patients to process medical decisions (Coyne et al., 2016; Ford et al., 2018; Weiner et al., 2019). Parents, legal guardians, and health care professionals support and guide children throughout this process, aiming to increase the child's capacity, competence, and sense of autonomy (Coyne et al., 2016; Ford et al., 2018).

In their article, Rinaldo et al. (2022) discuss that although sibling donors in their study received information about the donation and transplant process before donation, they did not fully comprehend it. This research study took place in Sweden, which enacts UNCRC rights as part of the law, and Rinaldo et al. (2022) specifically mention Article 12 in response to this lack of understanding. Rinaldo et al. (2022) reflected that “the best decision requires complete, age adapted and correct information” adding that “as the participants felt obliged to donate, it is important to inform and discuss options with them prior to HLA typing and to ensure that potential donors are given the informed possibility to decline typing and donation” (Rinaldo et al., 2022, p. 5). Providing information is not enough. To fully implement Article 12 and 13 for pediatric sibling donors, information must be communicated in a developmentally appropriate way and health care professionals need to ensure that the information about the medical process is understood before care proceeds (Rinaldo et al., 2022; United Nations, 1989).

By adopting Article 12 as a framework for this study, children were viewed throughout the research process as capable, competent contributors who have the right to share their experiences, and these experiences are seen as valid and significant. Pediatric sibling donors received information about the research process through a variety of visual aids, written materials, and verbal communication to promote comprehension. In the present study, child and young adult participants were considered and referred to as "research partners" to acknowledge

their contributions' participatory nature (Coyne & Carter, 2018) and significance throughout the study. In my doctoral research, the principles of UNCRC were at the forefront of the inquiry process.

Chapter Summary

In this chapter, I engaged with literature exploring the pediatric sibling stem cell donor experience, from the sibling donor perspective. This literature reflected the complexity of the pediatric sibling donor experience, capturing the psychosocial risks of becoming a sibling donor and the potential growth that can occur post-donation, called posttraumatic growth (Tedeschi & Calhoun, 2004). Psychosocial risks experienced by pediatric sibling donors explored from a narrative review published by colleagues and myself included: Distress and anxiety related to the medical aspects of donation, the absence of autonomy over the decision to donate, lack of understanding about HSCT and the expected timeline for recovery, and feelings of physical and emotional isolation from parents. The literature also highlights aspects of posttraumatic growth (Tedeschi & Calhoun, 2004), which were identified as: an appreciation for life, closer relationships with their ill siblings and parents, and spiritual growth. Next, I shared the child rights framework guiding the present study, the UNCRC. The articles within the UNCRC that can apply to pediatric sibling donors included articles 3, 6, 12, 13 and 24, and the recognition of pediatric sibling donors' voices and sense of autonomy was highlighted to prepare for the next chapter, exploring the designs and method of this participatory, arts-based, qualitative research study.

Chapter Three: Methodology and Methods

Researcher Positionality

The positionality I brought to this research was unique; I am not a nurse and have never worked in pediatric hematopoietic stem cell donation or transplant. I am a child development specialist with a Master's degree in Developmental Health of Children from the Department of Family Social Sciences, University of Manitoba (2009). I have taught Early Childhood Education at Red River College Polytech for 15 years. Prior to my PhD studies, I gained research experience working with children and parents/caregivers through multiple projects. My experience includes analyzing observational data, surveys, and qualitative interviews. After mentoring Early Childhood Education students and working with children for over 20 years, I utilized my expertise to facilitate hands-on artistic activities to help children learn and express themselves in child care centres.

My interest in this research topic began with a quest to find a PhD advisor with expertise in research with children using arts-based, creative methods. I met Dr. West, an Associate Professor in Nursing, who had experience using arts-based methods while working with families who had lived the pediatric hematopoietic stem cell transplant experience (West et al., 2022; West et al., 2020). Dr. West also had experience as a pediatric hematopoietic stem cell transplant nurse and had knowledge of the medical treatment process. We concluded that our areas of expertise could complement one another, and I would focus on studying the experience of pediatric sibling stem cell donors through rights-based, participatory research (Coyne & Carter, 2018) employing the artistic medium of digital storytelling (De Vecchi et al., 2017; Lang et al., 2019).

I wrote a narrative review as a paper assignment for my first doctoral course and chose to focus on the experiences of pediatric HSCT sibling donors because it would inform my planned

thesis research. Later, in the *Journal of Child Health*, I published this narrative review in collaboration with Dr. West, Dr. Caroline Piotrowski, and Janice Winkler (Winther Klippenstein et al., 2021). I studied literature about arts-based methods (Boydell et al., 2012; Chilton & Leavy, 2014; Coemans & Hannes, 2017) and participatory research methodology (Bergold & Thomas, 2012; Coyne & Carter, 2018; Christiansen & James, 2017; Groundwater-Smith et al., 2015; Hart, 1998; Hart, 2008; Lundy et al., 2011; United Nations, 1989) in child research during my PhD studies. The framework for my thesis research is based on the UNCRC (United Nations, 1989) to uphold children's rights when working with them. One of the critical aspects of participatory methodology is the adoption of an action-based approach to meaning-making (Coyne & Carter, 2018), which favors hands-on, creative data collection opportunities found in arts-based methods (Boydell et al., 2012; Chilton & Leavy, 2014). I have been fortunate to receive guidance from members of my advisory committee, who have extensive experience and knowledge in arts-based research methods and arts-based knowledge translation (Scott & Hartling, 2023; Scott et al., 2021; West et al., 2022; West et al., 2020). Dr. Javier Mignone, another member of my advisory committee, brings expertise in participatory methodology, and the arts-based method called “life stories” (Chase, 2000; Mignone, Chase & Stieber Roger, 2019; Stewart-Tufescu et al., 2019).

In preparation to conduct my doctoral thesis research, I completed a six-week course titled *"Introduction to Digital Storytelling*" through Story Center to enhance my knowledge and understanding of digital storytelling, which is a key method in my doctoral research. This digital storytelling training included six weeks of two-hour classes that covered topics such as the definition of digital storytelling, the composition of a digital story, digital story creation, and different media platforms to use in creating a digital story (storycenter.org). I was proud of the

digital story I created during the training. In the final class, students had the opportunity to showcase their work and receive constructive feedback. I explored the philosophy of digital storytelling and created my own story (Lambert, 2018). This involved writing, selecting photos, and editing the final product. I gained a deeper appreciation of the mental and emotional effort needed for this artistic expression (Lambert, 2018).

During my thesis research, my knowledge and understanding of the UNCRC provided critical guidance. I am particularly passionate about participation rights, which invite children and young adults with opportunities to express their thoughts, feelings, and ideas in ways that are developmentally appropriate (such as creative, hands-on methods) (United Nations, 1989). I do wish I had the opportunity to design this entire research study in collaboration with children and youth. However, since I had never pursued participatory research with children and youth before, I chose to create participatory opportunities where possible. I intend to use this experience to inform future participatory research with children and youth.
Additionally, I believe that the thoughts, feelings, and ideas of children and youth should be taken seriously by adults and decision-makers (United Nations, 1989). I believe that empowering and supporting pediatric sibling donors is crucial. To achieve this, it is worth exploring the potential value of using digital storytelling (Lambert in 2018) to help children and youth express and share their experiences of pediatric HSCT sibling donation. In my doctoral thesis research, I also wanted to explore and understand the challenges of using this medium.

Philosophical Underpinnings

The aim of my thesis research was to respect and honour the unique perspectives of the sibling donor research partners, by following the guidelines of Article 12 within the UNCRC and upholding the autonomy and voices of the siblings throughout the research process. To achieve

this, I employed qualitative, participatory research methodology (Coyne & Carter, 2018) that was informed by the constructivist paradigm (Crotty, 1998) and interpretive description (Thorne, 2016).

Constructivist Epistemology. Constructivism refers to the process of individual meaning-making through actively constructing knowledge by interacting with individual social worlds (Appleton & King, 2002; Crotty, 1998). Arts-based research involves the creation of individual art, and when combined with a participatory approach, this individual endeavor is supported and further constructed within a collaborative community (Coemans & Hannes, 2012; de Jager et al., 2017; De Vecchi et al., 2017). Within arts-based research, research partners have the tools and control to construct and display their unique stories (Coemans & Hannes, 2017). In this way, these diverse interpretations represent a range of possible constructions of meaning (Appleton & King, 2002). For the present study, individual digital stories were created by sibling donor research partners. The process of co-constructing knowledge involved creating a calm and warm environment to support individual artistic creation of digital stories as research partners completed steps together within a workshop setting.

Constructivism: Relationship of Reciprocity. When guided by a constructivist paradigm, it is crucial to establish a "relationship of reciprocity" (Mills et al., 2006, p. 9) within the entire research team. This aspect of constructivist epistemology is especially relevant to participatory arts-based research with children. To facilitate collaborative research with children, the researcher must intentionally reflect on how to reduce power imbalances by implementing a flexible and unstructured research environment, where research partners have the freedom to share their thoughts, views, and suggestions as they work through the artistic process (Coemans & Hannes, 2017; Coyne & Carter, 2018; De Vecchi et al., 2017). For the present study, sibling

participants had full control over the creation of their digital stories and were engaged as partners in the analysis of what the stories expressed about their pediatric HSCT sibling donor experience.

This relationship of reciprocity also includes a process of "developing relationships, encouraging dialogue, joint learning that is aimed towards children's and young people's self-understanding and agency as well as to the self-understanding of the researchers involved" (Coyne & Carter, 2018, p. 7). To encourage the process of shared meaning-making and co-construction of knowledge with children, researchers need to adopt a continuous cycle of observation, reflection, and adaptation (Coyne & Carter, 2018). I engaged in this cycle (observation, reflection and adaptation) through the writing of in-depth field notes across the research process (multiple meetings with the sibling donor research partners, see Table 2 below); the field notes were written and analyzed immediately following meetings with research partners. Field notes were also written by my advisor (CW). The ongoing, iterative analysis of the field notes facilitated the evaluation of the progress of the research and allowed me to gain a better understanding of research partners as individuals, the culture of the group, and my reflections were integrated into subsequent meetings across the research process. During Meeting Two, the *Digital Storytelling Workshop* (see Table 2 below for more details), research partners confirmed that the arts-based medium of digital storytelling (De Vecchi et al., 2017; Lang et al., 2019) allowed them to express their donation stories in the way that was significant to them.

Constructivism: Cues From Children. During the research process, I took my cues from the sibling donors regarding the flow, pace, design, and unfolding of the creation of a digital story (Coyne & Carter, 2018). As they engaged as a group to create individual digital stories, research partners members listened to each other's ideas, and made suggestions and

shared their thoughts. This was important to ensure the process adhered to the co-construction and shared meaning-making, which is central to participatory approaches and the constructivist paradigm (Coemans & Hannes, 2017; Coyne & Carter, 2018).

Methodology

Participatory Methodology

Participatory research methodological approaches with children require researchers to have a thorough understanding of child development and children's rights and to believe and trust that children can share their interpretations, are knowledgeable and collaborative (Bergold & Thomas, 2012; Coyne & Carter, 2018; Christiansen & James, 2017; Groundwater-Smith et al., 2015; Hart, 1998; Hart, 2008; Lundy et al., 2011; United Nations, 1989). The primary objective of utilizing participatory research methodology in this study was to actively promote the involvement of pediatric sibling donors by providing a secure, developmentally sensitive context for children/youth to express their donation experiences through digital-storytelling (Christiansen, & James, 2017; Groundwater-Smith et al., 2015; Lambert, 2018; United Nations, 1989; Winther Klippenstein, et. al., 2021).

The main aim of participatory research is to provide members of marginalized groups with a voice and the opportunity to have their voices heard (Bergold & Thomas, 2012; Kellett, 2010). Participatory methodology with children emphasizes that research is done *with* children instead of *on* children, recognizing children as competent, capable collaborators actively participating in the research process (Eckhoff, 2019). Engaging children in research spaces that honour their right to express themselves (Article 12) and actively participate in studies about their experiences reflects dignity and respect (Lundy et al., 2011). A participatory methodology that honours the researcher’s reciprocal relationship with children/youth as research partners can

increase children's sense of empowerment, self-esteem, and self-confidence (Haijes & van Thiel, 2016; United Nations, 1989).

This requires clear communication between the researcher and research partners regarding what the structure of this participatory research relationship will look like, including "the boundaries of the communicative space; the type of participation; leadership" and "opportunities to express anxiety" (Bergold & Thomas, 2012, pp. 197, 198). Communicating the outline of the participatory process ensures Article 13 of the UNCRC, which focuses on ensuring children receive the information necessary to confidently share their views, opinions, and perspectives and contribute meaningfully (United Nations, 1989). To uphold Article 13, the researcher must consciously use language appropriate to children's developmental levels and abilities, which can be supported using arts-based methods that recognize children's ability to express themselves through hands-on, interactive, and creative activities (Linder et al., 2018; United Nations, 1989).

The participatory methodology fosters a sense of control for pediatric siblings in the expression of their donation experiences (Coyne & Carter, 2018). Due to the potentially distressing or sensitive aspects of their donation experiences, siblings retelling their donation stories may trigger feelings of distress (Winther Klippenstein et al., 2021). A participatory methodology supports the time and space for reflection and reflexivity for children to derive meaning from their experiences of both stress and growth (Bergold & Thomas, 2012). Researchers need to establish a research environment that is a safe space for participants to contribute stories of their experiences (Bergold & Thomas, 2012). This safe research environment includes recognizing that participatory methods require researchers to spend time with children, get to know them individually, and establish a research relationship that will

encourage children to feel comfortable enough to participate (Eckhoff, 2019). Researchers also need to ensure that adequate psychosocial support is available for children/youth who may experience distress, which was integrated into the study process (Bergold & Thomas, 2012; Coyne & Carter, 2018; Eckhoff, 2019).

A participatory approach allowed research partners to explore their thoughts and emotions within a UNCRC framework (United Nations, 1989). Adopting active, arts-based methods facilitated participatory methodology. In engaging the pediatric sibling donors as research partners, I worked to fulfill Articles 12 and 13 by creating a research environment where they felt supported and held artistic control over how and what aspect of their stories they chose to express. Additionally, the research partners led the analysis of the digital stories created in this study, holding agency over what aspect of their stories were most important to highlight and communicate in the research findings.

Arts-Based Research

Arts-based research (ABR) approaches are an emerging qualitative approach that involves the use of any art form or combination of art forms at any stage in the research process (Boydell et al., 2012). ABR is best suited for research projects that involve active involvement from research partners or participants (Boydell et al., 2012; Chilton & Leavy, 2014; Coemans & Hannes, 2017). Different terms are used in the literature to refer to ABR, such as arts-informed research, arts-informed education, and a/r/tography, and these terms change depending on the use of art and the academic discipline (Coemans & Hannes, 2017, p. 43). Arts-based research expands on and enhances traditional qualitative methods by providing alternative or supplementary techniques to language-based qualitative methods (Coemans & Hannes, 2017).

According to a scoping review conducted by Boydell et al. (2012), arts-based health research (ABR) can be more engaging and empowering for research partners than traditional qualitative methods. Boydell et al. (2012) found that engaging in ABR therapy can provide therapeutic benefits and new insights about life experiences, resulting in enhanced confidence, self-esteem, passion, and creativity. Additionally, research partners expressed increased trust when actively and creatively involved in the research process. The arts can provide a platform that feels less vulnerable than describing feelings and emotions with words or through self-reports, thus producing exciting and rich data (Boydell et al., 2012; Coemans & Hannes, 2017). The products of ABR are primed for disseminating knowledge and can potentially engage the public and interested community members in a more accessible manner (Boydell et al., 2012; Chilton & Leavy, 2014). This active, creative process may also provide research partners with therapeutic relief and can serve as an accessible knowledge translation tool for the larger community (Fraser & al Sayah, 2011).

There are many genres of ABR (Chilton & Leavy, 2014). The three main genres are literary, visual, and performance art (Chilton & Leavy, 2014). Literary genres include poetry and fictional writing, and performative art uses dance, installation, new media technology, and film (Chilton & Leavy, 2014). Visual genres consist of photography, drawing, painting, sculpture, and ceramics, to name a few (Chilton & Leavy, 2014). For the present study, the arts-based medium used was digital storytelling, a relatively new but growing ABR method that combines storytelling and images with digital technology (Lambert, 2018; Lang et al., 2019).

Digital Storytelling. Digital stories, the creative products of the digital storytelling process, are 2-5 minute movies combining images, video, and a voiceover of the participant sharing their personal story (De Vecchi et al., 2017; Lang et al., 2019). Digital stories are often

individually created within a group setting to facilitate a collaborative, supportive, and encouraging artistic environment (De Vecchi et al., 2017).

Digital storytelling is an appealing arts-based research approach for children and adolescents who live and learn within a digital culture (Wilson et al., 2015). Adolescents may be particularly interested in digital stories because many adolescents share stories daily on social media through phones, iPads, or computers (Goodman, 2013). Given that digital stories are short and engaging, they can be easily shared with diverse populations (de Jager et al., 2017) to communicate life experiences, build awareness and influence attitudes.

Digital stories may be an ideal way for pediatric sibling donors to express their donation experiences, including meaningful and challenging aspects. In a previous literature review, I identified and described both the traumatic symptoms and growth gained by sibling donors from the donation experience (Winther Klippenstein et al., 2021). Trauma symptoms included post-traumatic stress symptoms, anxiety, depression, stress, guilt, blame, and general emotional distress (D'Auria et al., 2015; Erden et al., 2019; Gizli et al., 2017; Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003; Packman et al., 1998; 2003; Pelletier et al.., Fairclough, Stegenga, & Pentz 2014; Pentz et al., 2012, 2014; Pot-Mees & Zeitlin, 1987; Stegenga et al., 2019; Switzer, 2016; White et al., 2017; Wiener et al., 2008; Wilkins & Woodgate, 2007). Simultaneously, sibling donors expressed personal gains and growth post-donation (D'Auria et al., 2015; Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003; Packman et al., 1998; Pelletier et al., 2014; Pentz et al., 2014; Wilkins & Woodgate, 2007). These growth experiences were framed as characteristics of post-traumatic growth (Tedeschi and Calhoun, 2004), which describes positive psychological growth acquired due to the struggle of facing challenging circumstances. The co-existence of trauma symptoms and post-traumatic growth creates a complex experience for

sibling donors, the details and nuances of which may be too sensitive to convey through traditional interviews or surveys (Boydell et al., 2012). Digital storytelling may present a safe and comfortable way to share the most relevant pieces of their story without exchanging words or providing distressing details of their experience (de Jager et al., 2017). Also, sibling donors may feel less vulnerable sharing their donation experiences through expressive arts methods where they can exert creative freedom (Driessnack, 2006). Upholding rights of participation within the UNCRC, pediatric sibling donors can express their voice while deciding the content of their digital stories: the pictures, videos, music, as well as the story they most want to tell (de Jager et al., 2017; United Nations, 1989).

The digital storytelling approach was used to address the two main research objectives. Firstly, I aimed to gain a better understanding of the experience of sibling donors, specifically through the medium of digital storytelling. Secondly, I aimed to explore the experience of sibling donors in sharing their voice through the specific arts-based medium of digital storytelling (de Jager et al., 2017) using a child sensitive methodology (Coyne & Carter, 2018). To ensure that I constructed a safe, supportive and secure research environment for pediatric sibling donors, paying special attention to the process of ethical reflection and approval was crucial.

Ethics

Assent and Consent

A parent from each family completed a written informed consent to permit pediatric sibling donors (under 18 years of age) to participate (Appendix B). Pediatric siblings then completed an oral and written assent for their participation (Appendix C). Siblings who were young adults (18 years or older) at the time of study enrollment, completed an adult written informed consent (Appendix D). All sibling donors needed to have experienced sibling donation

at 18 years of age or younger. The sibling who received the transplant was informed about the study and was provided with an oral and written assent form (Appendix E) for their sibling's participation in the study. This was done to ensure that they were comfortable with their siblings sharing their experience of HSCT and to honour their own present feelings about the transplant experience.

Participants under the age of 18 provided their assent in both written and oral form, while participants who were over 18 years old at the time of the study provided their consent by signing a written form and orally.

Consent and assent were written in lay, developmentally appropriate language and included clear information about the purpose of the research, an explanation of the three research meetings, the risks and benefits of participating, details of that participation, how the research findings would be disseminated (including their invited participation in determining dissemination activities), the honorarium they would receive ($150 gift card in the form of a VISA cash card), and aspects of privacy and confidentiality. Verbal assent or consent were also sought from sibling donors across the research process, which included prior to each aspect of data collection, reflecting an ongoing assent/consent process (Coyne & Carter, 2018).

Ethics and Site Access Approval

Prior to conducting this study, I obtained human ethics approval from two university ethics boards and a site access board (Appendix F, G & H). I recruited participants through a tertiary centre blood and marrow transplant program.

Recruitment

Prior to submitting ethics and site access applications**,** I emailed the medical lead of the clinical site to introduce the study, answer any questions and share my site access application.

The medical lead suggested I join a monthly clinical team meeting to share my proposed research with the pediatric BMT team. The HSCT nurse clinicians played a central role in identifying potential sibling donor participants, and the initial introduction of the study to potential families of research participants.

Once the university ethics board and site access approvals were received, I emailed my recruitment letter to the medical lead of the clinical team (Appendix I). Two pediatric blood and marrow transplant nurses reviewed the sibling donor database for participants who met my eligibility criteria, which included: children and young adults who were donors for their siblings' HSCT within the past few years, were 6-18 years old at the time of donation, and were able to write and speak in English. Once potential participants were identified, the recruitment letter was mailed to the homes of eligible families through the clinical program. The clinic nurses followed up with each potential family by phone two weeks after the study introduction letter was mailed to them. If families and the sibling donor were interested in learning more about the study, they were asked permission to have their contact information shared with the principal investigator (AWK). The pediatric blood and marrow transplant nurses emailed me with this contact information, which was password protected. In the first round of recruitment (December 2022), two families expressed interest, I emailed these families, and one responded that they would like a follow-up phone call. As the potential sibling donor participant was under 18, the initial phone contact was with the parent, who agreed that their child would like to participate.

The first round of recruitment only yielded one interested participant, so a second round of recruitment occurred in January 2023 and five recruitment letters were mailed by the pediatric blood and marrow nurses. Three young adults and two adults (over 18 years of age) expressed interest in hearing more about the study. Each of the families and interested sibling donor

participants were contacted and provided further information about the study through an introductory zoom meeting where the study and process of consent/assent were discussed. In this introductory zoom meeting, I also introduced and discussed the three potential research meetings that research partners could choose to participate in for this study. Throughout the study, I also remained sensitive to respecting individual sibling donor choices about how each partner engaged in the planned meetings across the study process. Please see details of Meetings One to Three, in Table 2 below. Each meeting held with sibling donor research partners during the inquiry process is described in further detail in the data collection section (p. 49).

The Research Partners. The six participants in the study were siblings who were donors for their brother or sister's hematopoietic stem cell transplant within the past five years. All participants were pediatric (18 years of age or under) at the time of donation. The ages of research partners at time of study enrollment ranged from 12 years to 21 years old. The participants were diverse in race and ethnicity, though no demographic information was obtained to maintain anonymity. However, five research partners lived within Winnipeg and one in a small town outside Winnipeg; five participants identified as male, and one participant identified as female. The participants' first names or chosen pseudonyms were: Oba, Ire, Azeem, Liam, Chris, and Nick. These six research partners analyzed digital stories, categorizing Post-Its into six main themes.

Both myself and my PhD advisor, Dr. West, attended all three meetings within the data collection process, and wrote field notes. I alone analyzed group interviews from Meeting Two and Three. Dr. West's field notes complemented my own and added a different perspective to the researcher's experience.

Table 2: Research Meetings with Sibling Donor Partners

Meeting Name	Location	Description	Forms of Data Collection	Forms of Data Analysis
Meeting One: Getting to Know You April 1st, 2023 10:00 a.m. to 11:00 a.m.	Zoom, online	• I asked all research partners (including myself and my advisor (CW)) to participate in two 'get to know you' activities (see **Appendix I: Meeting One Script**). ▪ First activity: Each research partner chose an item that reflected their identity, usually related to their hobbies and interests. ▪ In the second 'get to know you' activity, partners drew a circle and filled it with the most important people, places, and things in their lives. ▪ Review of the Digital Storytelling Workshop Guide and Plan (Appendix C, D) and the Analysis Meeting Plan (Appendix E) ▪ Review of digital story choices (i.e., photographs they have or choose to take, drawing a picture). ▪ Discussed how they might start writing their story in preparation for Meeting Two.	Field notes (PI and Dr. West)	Field notes (PI and Dr. West)
Meeting Two: Digital Storytelling Workshop April 8th, 2023 9:00am to 4:00am	5 participants in person at a university setting; 1 research partner online on Zoom.	**Appendix J: Meeting Two Script** • PowerPoint presentation: workshop agenda, confidentiality, copyright, seven DS steps. • Research partners created digital stories about their sibling donor experience after viewing two examples from YouTube. • At the end of the second meeting, research partners discussed their experience of creating digital stories. Responses were audio-recorded with a digital recorder (Appendix K: Meeting Two Digital Storytelling Workshop Experience Questions).	• Field notes (PI and Dr. West) • Digital stories created • Discussion about sibling donor's experience of DS creation was transcribed after this meeting	• Field notes (PI and Dr. West)
Meeting Three: Data Analysis Meeting April 29th, 2023 9:00am to 12:00pm	5 participants in person at a university setting; 1 research partner online on Zoom.	• Partners returned to the university to view DS and analyze themes. (See **Appendix L: Research Partner Data Collection**). • Partners used Post-it notes to group important ideas from the viewed DS (digitally recorded, themes identified). • PI (AWK) presented the initial findings from Meeting Two, which acted as a form of member checking (see Appendix M: Member Checking Script). • Near the end of Meeting Three, I asked for research partners' ideas about sharing the research findings (see Appendix N: Sharing What We Learned).	• Field notes (PI and Dr. West) • Transcribed data analysis discussion: Sharing What we learned	• Field notes (PI and Dr. West) • 4 DS analyzed by research partners)

Introductory Zoom Meeting. I held an initial introductory meeting with parents and the potential sibling donor participants in March 2023; each meeting lasted about one hour (Appendix J). This introductory zoom meeting continued the research consent/assent process which began when families (and sibling donors) indicated their interest in this study. Only sibling donors participated in this study as research partners, no other family members were research participants. Before this meeting, I mailed a Digital Storytelling Workshop Guide (Appendix K), Digital Storytelling Workshop Plan (Appendix L), Analysis Meeting Plan

(Appendix M), Parental/Guardian Consent and Pediatric Assent forms (Appendix B & C) or an Adult Informed Consent form (Appendix D) (for young adult participants 18 years of age or older) to each family home. This was done to ensure that interested participants had comprehensive information about all aspects of the study and could ask any relevant questions during the introductory Zoom meeting, where consent/assent would be obtained. In the introductory zoom meeting, I introduced the research study and reviewed the consent and assent forms, ensuring all questions or potential concerns were addressed. I described the research process, including the three meetings each research partner would be invited to participate in: 1) Meeting One, *Getting to Know You* Zoom meeting, 2) Meeting Two, *Digital Storytelling Workshop*, and 3) Meeting Three, *Data Analysis Meeting*. Once children/young adults agreed to participate, I delivered an iPad to research partners' homes. At this time, I asked if the research partner needed a brief tutorial on how to use the iPad and iMovie, which they would use to create their digital story. All six research partners were familiar with using an iPad and felt comfortable exploring iMovie independently. A few research partners indicated that they would Google instructions if they struggled with iMovie. Each child/young adult research partner participated in all three research meetings. By the end of the introductory zoom meetings, all six potential participants agreed to participate as research partners in the study.

Anonymity and Confidentiality. Confidentiality was maintained throughout this study. Following the *Digital Storytelling Workshop* (Meeting Two), *Data Analysis Meeting* (Meeting Three) research meetings, the digitally recorded discussions with sibling donor research partners were transcribed to a written document by the PI (AWK).

Guided by the UNCRC (United Nations, 1989), research partners were offered the choice to use their first names or choose a pseudonym name to represent their thoughts, feelings, and

contributions within the research study. Issues of anonymity and confidentiality related to digital stories were carefully addressed with research partners throughout the research process and shared with parents/legal guardians of the child/young adult research partners.

During the research study, all data collected was stored in a locked filing cabinet at my home or on a password-protected shared drive set up by information technology staff at the University of Manitoba. All information provided will continue to be stored in a locked filing cabinet in my home. In September 2032, all data will be destroyed using electronic deletion and confidential shredding services at the University.

Risks and Benefits

One potential risk of participating in the study was that research partners could become upset or distressed as they recalled their donation experience during group discussions and in the creation of their digital story. This did not happen, but within each of the consent/assent forms (Appendix B, C & D), Introductory Zoom Meeting (Appendix J), and before Meeting One, Meeting Two, and Meeting Three, I reminded research partners, and their families that support was available from the clinical HSCT program, if they became upset or distressed. I explained that they could stop their participation at any time if this happened. Information on how to access emotional support is detailed in the consent/assent documents (Appendix B, C & D) as well as how to withdraw from the study if the research partners wanted to stop participating in the study.

A potential benefit of the study was increased understanding about the pediatric hematopoietic sibling stem cell donor experience for the research partners, as well as future pediatric sibling donors, families, and health care professionals. This knowledge may help guide healthcare professionals as they support child/young adult siblings who become donors. It may also help families facing the HSCT journey, with a child undergoing transplant and a sibling

donor, to understand what it is like for siblings to experience the BMT donation process. This study suggests that siblings who have undergone pediatric HSCT donation might benefit from sharing their experiences in a digital storytelling format. This method helped sibling donors to express their donation experience in a creative, arts-based approach, which may be more effective than traditional questionnaires or narrative interviews previously used in practice and research.

Data Collection and Analysis

Data Collection

The data collection and parts of the analysis in the study occurred across three research meetings (see Table 2), and in three forms: researcher field notes taken by Dr. West and PI (AWK) during meetings one to three (Thorne, 2016; Thorne et al., 2004), two transcribed group narrative interviews with research partners (*Digital Storytelling Workshop* and *Data Analysis Meeting*) transcribed and analyzed by the PI (AWK) using interpretive description (Thorne, 2016; Thorne et al., 2004), and through the digital stories which were thematically analyzed by research partners during the *Data Analysis Meeting* (Meeting Three).

Meeting One: 'Getting to Know You' Meeting. On Saturday, April 1st, 2023, I arranged a meeting with all research partners over Zoom from 10:00 a.m. to 11:00 a.m. All six research partners and my advisor, Dr. West, attended the Zoom meeting. To learn more about each research partner, I asked all participants (including myself and my advisor) to participate in two 'get to know you' activities (see Appendix N: Meeting One Script). For the first activity, I asked each research partner to choose and share an item that represented their identity. The items that research partners chose centered around hobbies and interests. To increase the comfort of research partners with these activities and extend the creation of relationships, my advisor and I

shared our activity responses before the sibling donor research partners were asked to. Research partners were eager to share, and as the presentations went on, the conversation felt lighter. All research partners seemed engaged, and many laughed or nodded as others presented their items.

For a second 'get to know you' activity, research partners were asked to draw a circle, and to draw within the circle the most important people, places, and things in their lives. All research partners felt comfortable explaining the drawings/words in their circles, and the first piece each sibling donor highlighted was family, describing their family members as the most essential aspect of their circle. This was a wonderful exercise to get to know who and what was most important in their lives, and to begin to form a sense of community. Secondly, they highlighted places they have been with family that were special. These shared moments created a light-hearted feel to the conversation, and research partners were open, expressive and keen to describe these special family moments. Building community is a critical piece of participatory research, especially with children and youth to help them feel more comfortable, safe, heard and valued (Coyne & Carter, 2018). This experience also highlighted the unique interests, hobbies, and family members of the research partners, and built a foundation of trust for our future in-person meetings.

After getting to know you' activities, I reviewed the Digital Storytelling Workshop Guide and Plan (Appendix K & L) and the Data Analysis Meeting Plan (Appendix M) and the choices they could make within their digital story (i.e., photographs they have or choose to take, drawing a picture). We also discussed how they might start writing their story in preparation for the *Digital Storytelling Workshop* (Meeting Two).

Meeting Two: Digital Storytelling Workshop. I facilitated the digital storytelling workshop, supported by Dr. West, on Saturday, April 8th, 2023, from 9:00 am- to 4:00 pm at a

local university (Appendix O: Meeting Two Script). I presented a PowerPoint presentation which outlined the agenda for the day, provided information about confidentiality and copyright, and information on the seven steps of digital storytelling from Story Center (Lambert, 2018). The presentation included information on the structure of how to write their donation story, and finally, links to a few digital stories that we viewed together as inspiration to guide the creation of the research partners' digital stories. Below, I describe information about confidentiality and copyright, the seven steps of digital storytelling from Story Center (Lambert, 2018), and the guidance that was provided on how sibling donor research partners might structure their written stories.

Confidentiality. Since the digital stories being created were expressions of a personal experience of pediatric HSCT donation and the research partners were children and young adults, maintaining confidentiality was imperative to create a supportive, safe research environment. Research partners were reminded to keep information shared within the meeting private, to only refer to themselves and others by their first names or chosen pseudonyms, and that only Dr. West, another committee member (Dr. Mignone), and myself would have access to data collected. The research partners were also informed that digital audio-recordings of segments of the *Digital Storytelling Workshop* and the *Data Analysis Meeting* discussions would be deleted immediately after they were transcribed and would be stored on a password protected, university shared drive that was accessible only to members of the research team (in addition to other forms of data). Research partners were again informed that all data would be deleted from the university, password-protected shared drive by April, 2027. There were no questions from research partners.

Copyright. To ensure research partners adhered to copyright protocol, first and foremost, they were asked to only use pictures of themselves, places, or things within their digital stories or ensure they had permission to use photos of others. They were also reminded that they held ownership of their story and would decide how it was shared. During the research process, partners were given the option to store a personal copy of their digital story on an encrypted USB drive. They were also presented with three choices for sharing their digital story: 1) delete all other copies of their digital story; 2) share their digital story with other research partners for viewing during the *Data Analysis Meeting* (Meeting Three); and/or 3) share their digital story with research partners at the *Data Analysis Meeting* and permit me to keep a copy of their digital story for future research presentations. Regardless of the option each research partner chose, they were reminded that all digital stories would be deleted after five years. There were no questions from research partners regarding confidentiality or copyright, so we discussed the seven steps of digital storytelling as described by Story Center (Lambert, 2018).

The Seven Steps of Digital Storytelling from Story Center. In Table 2 below, I have outlined the seven steps of digital storytelling creation, as created by Lambert (2018), which was presented to research partners in a PowerPoint presentation.

Table 2: Story Center Digital Story Steps

Digital Story Step	Actions
Step 1: Owning Your Insights	• Understand meaning of story you want to tell • Identifying lessons learned to share
Step 2: Owning Your Emotions	• Storyteller is encouraged to pay attention to big emotions surfacing while exploring their story • Naming big emotions • Considering how they can impact the audience on an emotional level with their story
Step 3: Finding the Moment	• Storytellers are searching for a moment where a shift or change in their story alters their journey, requires a new lens, and fosters growth or learning

Step 4: Seeing Your Story	• Storyteller is tasked to find images: including photos or videos, to add visual support to their story, carefully selected to convey precise meaning to the audience
Step 5: Hearing Your Story	• Adds the audio component: an organized, rehearsed, and thoughtfully narrated story • It is essential to consider the choice of words and phrases to capture authentic meaning and when to pause in narration, tone, and volume of voice • Another decision regarding audio in digital storytelling is whether to add music to the background to enhance the images and narrated story or whether music overpowers the story
Step 6: Assembling Your Story	• The storyteller should ensure they have the necessary parts to their story and that the narrated story has a clear beginning, middle, and conclusion • the storyteller can get creative by presenting the images and audio together, a task called "layering" (Lambert, 2018, p. 66)
Step 7: Sharing Your Story	• The storyteller needs to consider their story's purpose and intended audience

The way these steps are organized and carefully described provides practical feedback for the storyteller on how to compose the story, ensuring all pieces are included while also supporting the storyteller to explore the emotional aspects of the story they want to tell, precisely what they learned and what messages they want to convey to connect with others on an emotional level (Lambert, 2018).

After exploring the seven steps of digital storytelling (Lambert, 2018), research partners then viewed two digital stories from YouTube as examples. After each research partner had created their own digital storytelling about their sibling donor experience, they were invited into a discussion together about what it was like to create their digital stories with other sibling donors (responses to these questions were audio-recorded with a digital recorder) (Appendix P: Meeting Two Digital Storytelling Workshop Experience).

Meeting Three: Data Analysis Meeting. On Saturday, April 29th, 2023, from 9:00 am-12:00 pm**,** research partners were invited back to the university to share their digital stories with the other research partners and to participate in the analysis of the created digital stories (identifying relevant themes, see Appendix Q: Research Partner Data Collection). Important ideas identified by sibling partners were grouped using Post-it notes (based on the 'sticky note' method, Burgess et al., 2021) on a large white board, and partners shared their thoughts on the groupings (digitally audio-recorded with a digital recorder). At the end of the *Data Analysis Meeting*, following our shared work on identifying themes related to the viewed digital stories, I (AWK) presented the initial findings from my field notes and the digital, audio-recorded Digital Storytelling Workshop Experience discussion which acted as a form of member checking (see Appendix R: Member Checking Script). Finally, near the end of the *Data Analysis Meeting*, I asked for research partners' ideas about sharing the research findings (see Appendix S: Sharing What We Learned).

Data Analysis

Data analysis followed an Interpretive Description methodology, capturing themes and patterns for practice-based application (Thorne, 2016; Thorne et al., 2004). In Interpretive Description, the researcher's technical knowledge, research background, and personal experiences are major sources of insight (Thorne, 2016). The core of this disciplinary knowledge lies in the discovery of shared realities or recurrent patterns within these experiences (Thompson Burdine et al., 2020). The primary focus is a deeper understanding of individual participants' perspectives with healthy recognition that there are many other participant experiences not explored in just one study, rather than data saturation (Thompson Burdine et al., 2020).

In the study, to respect the rights-based, participatory methodology of the study (Coyne & Carter, 2018; Groundwater-Smith et al., 2015; Christiansen & James, 2017; Lundy, 2011; Bergold & Thomas, 2012; Hart, 1992; 2008) the themes identified by research partners were considered credible and explicitly guided the subsequent stages of data analysis. I analyzed audio recordings of discussions between research partners about their experience creating digital stories in Meeting Two, the *Digital Storytelling Workshop*. During the Meetings One to Three, Dr. West and I recorded field notes (Thorne, 2016; Thorne et al., 2004) based on our observations during the meetings with sibling donor research partners.

In Interpretive Description, once transcribed, the researcher is tasked to work closely with the data, to try and make meaning of participants' experiences and perspectives, and of their own experiences (Thompson Burdine et al., 2020). It is recommended for researchers to thoroughly review data, taking physical notes and highlighting any notable ideas, words, or thoughts (Thompson Burdine et al., 2020). Within Interpretive Description, data collection occurs simultaneously with analysis, to ensure the researcher is immersed in the data/analysis from the start and that researchers generate codes from the data itself instead of from a pre-existing theory (Thompson Burdine et al., 2020). Once I completed my initial analysis, I shared my findings with research partners near the end of the *Data Analysis Meeting* (Meeting Three) as a form of member checking (Thorne, 2008) to ensure I captured the big ideas and takeaways from the research partners' perspectives (Meeting Two Digital Storytelling Workshop Experience discussion) and researcher perspectives (field notes taken by Dr. West and myself).

Member checking has been identified as a research practice with various uses, outcomes, and goals (Mutolsky, 2021; Iivari, 2016). It has the potential to enhance the credibility of qualitative research by ensuring that researchers share and dialogue with the research partners (or

participants) about their preliminary interpretations. Member checking can also serve as a "social justice goal" by amplifying the voices of participants, particularly those in marginalized communities (Mutolsky, 2021, p. 391), and help identify "cultural gaps" in researchers' interpretations of findings and theme organization (Mutolsky, 2021, p. 394). However, part of the challenge with using member checking for data credibility is the lack of specific guidance for researchers and the absence of clear instructions for participants in providing feedback (Mutolsky, 2021). Some researchers prefer to use the term "member reflections" to convey that member checking does not guarantee unanimous agreement with the presented data (Mutolsky, 2021, p. 391). Additionally, ensuring credibility through member checking does not automatically ensure the rigor of research methods and processes (Mutolsky, 2021).

Member checking is recommended in participatory research to engage child and youth participants and improve data credibility by better understanding children's perspectives (Coyne & Carter, 2018; Water, 2018). In this study, I recognized the importance of involving child and youth participants in multiple ways to create a participatory experience. As a result, I deliberately utilized member checking to enhance the active engagement of research partners across data collection and analysis processes. After dialoguing with the research partners about the preliminary findings, I read and re-read Dr. West's field notes, my field notes, and meeting transcription documents, and viewed the digital stories numerous times. In Interpretive Description, themes are identified through the researcher's deep engagement with the data (Thompson Burdine et al., 2020).

After engaging with the various forms of data, I observed that the themes from the field notes, transcribed meeting discussions with research partners, and research partners' analysis of digital stories did not significantly overlap; three distinct areas of knowledge developed from the

separate areas of data collection, which included: 1) The main themes found in the digital stories about the pediatric sibling donor experience; 2) the experience of creating digital stories with other sibling donors and using digital storytelling to express stories of sibling donation and 3) the researcher reflections on using digital storytelling as a data collection method with children and young adults.

Reliability and Credibility of the Data

To address rigor within this study, I applied Lincoln and Guba's (1985) process of trustworthiness. Ensuring rigor standards within qualitative research involves working to represent research partners' experiences as accurately as possible (Streubert Speziale & Rinaldi Carpenter, 2007). Trustworthiness requires that methods satisfy four criteria: "credibility, dependability, confirmability, and transferability" (Streubert Speziale & Rinaldi Carpenter, 2007, p. 49), and reflexivity (Korstjens & Moser, 2018). In the following paragraphs, each criterion is defined, explored, and applied to my participatory arts-based research with pediatric sibling donors to justify how study rigor was ensured with the aim of adding knowledge to the existing literature while accurately presenting the experiences of research partners.

Credibility. According to Lincoln and Guba (1985), credibility refers to the activities that will increase the probability that the findings are credible and represent an accurate reality of research partners' experiences (Maher et al., 2018). My research applied the UNCRC (United Nations, 1989) as a child rights framework to guide pediatric sibling donors through a participatory methodology and to explore if using the ABR method of digital stories to express their donation experiences was meaningful. The credibility of my research is bolstered by the explicit engagement of pediatric sibling donors as research partners, which included sibling donor analysis of the digital stories created in this study. There is a tendency in academia to label

participatory methods as more "childish or less rigorous" (Coyne & Carter, 2018, p. 6) than other methods of qualitative approaches, however when conducting research with children, participatory arts-based research methods that complement children's strengths, interests and preferences can result in accurate and authentic findings to research questions (Coyne & Carter, 2018).

Another strategy I used to increase credibility was "prolonged engagement" with research partners, which assisted me to establish comfort and trust (Maher et al., 2018, p. 3). Prolonged engagement is already an aspect of arts-based research because of the length of time required to produce art, but it is equally vital to ensure time is spent establishing relationships between the researcher, research partner, and entire research team (Boydell et al., 2012; Coemans & Hannes, 2012; Coyne & Carter, 2018; DeVecchi et al., 2017; Langhout & Thomas, 2010; Mignone et al., 2019; Stewart-Tufescu et al., 2019; Wilson et al., 2015). When research partners feel comfortable, this increased trust can affect what they choose to share, their freedom to create, and ultimately the potential richness of the data (Morse, 2015).

I also practiced member checking, which refers to the researcher sharing initial findings with research partners to determine the accuracy of the findings to the research partners' experiences (Streubert Speziale & Rinaldi Carpenter, 2007). Through every research meeting with sibling donor research partners, my advisor and I took detailed field notes to describe the participatory, digital storytelling experience, which were analyzed to assist in identifying research themes (Thorne, 2008). I then brought these initial findings to the research partners during our final focus group to verify their accuracy and engaged actively with the research partners to identify study themes, and their meaning. In this way, I ensured I accurately captured

research partners' authentic views, opinions, and perspectives and recognized these views, opinions, and perspectives as the truth (United Nations, 1989).

The *Getting to Know You Meeting* (Meeting One) before the digital story workshop provided an opportunity for research partners to get to know each other and me and offer their consent to participate in the study. Spending this time together without the pressure or structure of research deadlines was essential so that research partners felt more at ease within future interactions, and to participate in creating digital stories that were authentic to their donation experiences. When we gathered for the Digital Storytelling Workshop Experience Discussion (Meeting Two) research partners appeared relaxed and comfortable while sharing their reflections, bolstering the credibility of the research findings.

Transferability, Confirmability, and Dependability. Transferability relates to the "ability of the findings to be transferred to other contexts and settings" (Maher et al., 2018, p. 3). It is essential to have a dense description of the research context to determine if methodologies, methods, analysis, and findings can be transferred and applied to similar research contexts (Maher et al., 2018; Streubert Speziale & Rinaldi Carpenter, 2007). It is essential for the reader to have sufficient information to determine if they can apply the research methods and analysis to their own context (Drisko, 2024). In our current study, Dr. West and I carefully documented our use of a participatory methodology with children and young adults in detailed field notes. Our goal was to provide sufficient information about the participatory process, the use of digital storytelling, and the analysis with research partners so that other researchers would be motivated to try these methods in their research.

Confirmability requires researchers to "illustrate as clearly as possible the evidence and thought processes that led to the conclusions," including acknowledging any researcher bias they

may bring to the conclusions (Streubert Speziale & Rinaldi Carpenter, 2007, p. 49; Maher et al., 2018). The field notes became the structure to ensure confirmability, clearly illustrating thought processes and contributing to the conclusions of the findings (Streubert Speziale & Rinaldi Carpenter, 2007). Closely related to confirmability, dependability is defined as "the stability of findings over time" (Korstjens & Moser, 2018, p. 121). This stability includes how sound findings, described within field notes and confirmed by research partners, support future research and practice recommendations (Maher et al., 2018). Additionally, the field notes provided a clear audit trail of the PABR process within this research study (Maher et al., 2018).

Reflexivity. Reflexivity is the final strategy to ensure that rigor standards of trustworthiness are met (Lincoln & Guba, 1985). To practice reflexivity, I wrote field notes to capture as accurately as possible my thoughts, struggles, and experiences as a researcher conducting participatory research with children using digital storytelling (Korstjens & Moser, 2018). These field notes captured the development and evolution of the process, describing adjustments, adaptations, and successes of applying a participatory digital storytelling method in real-time (Korstjens & Moser, 2018). Field notes were a place to discuss the limitations I faced engaging with pediatric sibling donors in participatory arts-based research, such as issues surrounding privacy or how to ensure child research partners had an opportunity to express power and agency within the research.

Ultimately, including actual sibling pediatric donors as research partners, the prolonged engagement (Coyne & Carter, 2018), member checking (Streubert Speziale & Rinaldi Carpenter, 2007), and field notes (Thorne, 2008) ensured rigor within the participatory arts-based research process in this study. This contribution to the literature further bolsters the validation of participatory arts-based research as sound scholarly work and may increase the possibility that

more scholars will adopt these rich, exciting, and collaborative methods within their future research, especially in pediatric health and illness.

Chapter Summary

This chapter has presented the philosophical underpinnings, methodology, methods, ethical approval, data collection and analysis processes, which have articulated the rationale behind and sequential process of the research study. Now that I have established this foundation, I will describe the research findings in Chapter Four.

Chapter Four: Findings

The Research Partners and the Researchers

The study sample consisted of six siblings who had donated hematopoietic stem cells to their brother or sister in the past five years. Oba, Ire, Azeem, Liam, Chris, and Nick were the first names or chosen pseudonyms of the research partners. All research partners were under 18 years old at the time of HSCT donation. For privacy and to maintain gender neutrality, research partners will be referred to by their chosen names and non-gendered pronouns (they, their).

I facilitated each meeting and worked with my advisor and research partners to analyze the sibling donor data. As PI, I wrote field notes and analyzed transcribed group interviews. To contribute to the data, Dr. West participated in Meetings One to Three and wrote field notes. Dr. West's field notes provided valuable insights and added to my own observations, increased the rigor of the analysis and offered a unique perspective on the researcher's involvement in this participatory study. The study utilized digital storytelling as a data collection method for pediatric sibling donors to express their donation stories.

Data Analysis

The research analysis was guided by Interpretive Description methodology (Thorne, 2016; Thorne et al., 2004). Recurring themes and patterns in the data were applied with a specific focus on application for practice (Thorne, 2016; Thorne et al., 2004). The research themes that were identified by research partners were considered reliable and were used to guide the rest of the analysis (Bergold & Thomas, 2012; Christiansen & James, 2017; Coyne & Carter, 2018; Lundy, 2011; Groundwater-Smith et al., 2015; Hart, 1992; 2008). Through the active involvement of research partners in the data analysis process, the study respected their rights and was simultaneously guided by participatory methodology (Bergold & Thomas, 2012;

Christiansen & James, 2017; Coyne & Carter, 2018; Lundy, 2011; Groundwater-Smith et al., 2015; Hart, 1992; 2008). During the *Data Analysis Meeting* (Meeting Three), research partners watched four out of six digital stories created by the research partners about their sibling donation experience. Research partners were invited to watch the digital stories and simultaneously take notes of the words or ideas that stood out to them from each story on Post-it notes. I facilitated the process of reading the Post-it notes aloud. We then shared a discussion about the meaning behind each note, followed by identifying the main theme represented by the words or ideas on the Post-it notes from each of the research partners. We then grouped the Post-it notes with similar ideas together and created six overarching themes. The analysis process with research partners is carefully detailed in the section titled "Tell me a Story: Research Partner Data about the Pediatric Sibling Donor Experience" (see p. 63).

Dr. West and I completed detailed field notes related to interactions with research partners following all three meetings. Audio recordings of the research partners' discussion about their experience creating their digital story (*Digital Storytelling Workshop*, Meeting Two) and the shared analysis discussion (*Data Analysis Meeting*, Meeting Three) were included as data. I (PI) transcribed audio-recorded discussions shortly after Meeting Two and Three. I conducted a preliminary analysis of the field notes (PI, advisor) from each meeting and transcribed audio-recorded discussions that took place during the *Digital Storytelling Workshop* (Thorne, 2016; Thorne et al., 2004). Towards the end of the *Data Analysis Meeting*, I shared the key ideas from my initial analysis with the research partners to ensure that their perspectives on the overarching ideas and takeaways from the digital storytelling experience had been captured. This was completed as a form of member checking (Thorne, 2016; Thorne et al., 2004). After the *Digital*

Storytelling Workshop I went through the field notes, and meeting transcription documents multiple times and watched the digital stories several times.

The identification of themes and subthemes was done through an iterative analysis process, where data from different stages of the participatory process were integrated. After analyzing the field notes, transcribed meeting discussions with research partners, and research partners' analysis of the digital stories, three unique areas of knowledge emerged; these unique findings did not overlap, and have been categorized in the following manner: 1) The main themes found in the digital stories about the experience of pediatric sibling donors; 2) the experience of creating digital stories with other sibling donors and using digital storytelling to express stories of sibling donation; and 3) the researcher's reflections on using digital storytelling as a data collection method with pediatric populations.

The Digital Stories

Six digital stories were created; each research partner chose to create their own digital story. Five research partners created their digital stories in person during the *Digital Storytelling Workshop* (Meeting Two), while one research partner created their story at their home during this meeting, participating through Zoom. During the *Data Analysis Meeting* (Meeting Three), four out of the six research partners chose to allow the other research partners to view their digital stories and gave me permission to share their digital stories during research dissemination. One participant allowed me to view their story but did not want it shared with the other research partners or the public, and the other research partner’s sibling who received the transplant asked them not to share their digital story within the analysis process, or research dissemination.

The length of the stories ranged from 1.40 to 2.48 minutes. The digital stories included personal photographs and stock images from Pexels.com. Music was used in two out of the four

digital stories shared with the sibling donor group, which had been selected from the available options on the iMovie app. All digital stories seemed to follow a specific arc or temporal narrative trajectory: their sibling's diagnosis and need for a transplant, discovering they were the best donor match, the experience of being a patient in the hospital, and life after the transplant. The stories were told in a linear, sequential manner. It is worth noting that all siblings of the research partners recovered after the transplant without health complications, and no ill sibling recipients died following their HSCT. Therefore, each digital story ended with the positive recovery of their ill sibling. From start to finish, research partners spent four hours creating their digital stories.

Tell me Your Story: The Pediatric Sibling Donor Experience

During the *Data Analysis Meeting* (Meeting Three), four of the six research partners permitted the research group to view their digital story. While viewing these digital stories, all six research partners were given Post-It notes to write words, thoughts, photos, or ideas that came to mind as they watched the digital stories about the pediatric sibling donor experience. In total, there were 29 Post-it notes with single words or sentences, which were grouped by the sibling donor research partners into six themes: *Pessimism and Acceptance, After Procedure Thoughts, Sibling Support, Family Experience, Connections* and *Hope*. Some of the sentences were brief thoughts about images or words said in the digital stories, and the words were names of images or feelings; these were submitted as data just as they were written, to honour research partner's right to their own thoughts and ideas (Coyne & Carter, 2018; United Nations, 1989). I led a discussion to start the research partner data analysis process, reading out loud the words or sentences on the Post-It notes. There were two phases to this process, as described in my field notes from Meeting Three:

1. “I begin by saying I will re-read the Post-it notes, and when the RPs (research partners) can see a match or a grouping for Post-it notes, we can combine them. After reading the third Post-it note, we are already grouping notes. Once many Post-its have been grouped, I read over the ones left over, and we also group those” (AWK, field notes, April 29, 2023).
2. During this phase, the research partners engaged in a brief discussion to understand the meaning of each Post-it note and explored the deeper implications of the words and phrases on the Post-it notes. The research partners do not argue about the chosen words, but rather suggest additional words or alternate ways to categorize them.
3. “Phase 2 is re-reading Post-its to try and find a central theme or “category.” Finally, I read the category names and reviewed the attached Post-its. There are six identified themes” (AWK, field notes, April 29, 2023).

The shared data analysis experience during the *Data Analysis Meeting* explicitly addressed the research question: What are HSCT donation experiences as understood through the participatory medium of DS as expressed by pediatric sibling donors?

Please see Table 3 for a detailed list of themes and Post-it note examples (sibling donor’s word/phrase responses to the viewing of the digital stories shared during the *Data Analysis Meeting*.

Table 3: Themes and accompanying Post-it notes

Themes	Post-It Notes
Pessimism and Acceptance	• Chosen as a donor • Waves of emotion • Knife endlessly cutting through your skin • Not understanding how dangerous the disease was • Picture of him and his brother • Diagnosed with leukemia

After Procedure Thoughts	• Laughing • Sleeping gas • The operation seems fast and easy, so future patients don't need to be worried • Back Aching
Sibling Support	• The love for our siblings will help us want to do anything to save them • Willing to do anything for sibling • Hospital Jello • Found it cool he had no hesitation • Content with what we have • Easing sibling's pain • Visiting sibling in the hospital • Playing games with sibling in the hospital • I liked the fact that he wanted to see his brother whenever he could • Wanting to save your sibling • Sense of relief • Happy to do the BMT • Relief of doing something • The transplant helps the possible donors feel like they are contributing to heal their sibling • Do everything in my power to make sure he was comfortable
Family Experience	• Family • I will always remember this experience that me and my brother and my family went through
Connections	• Found it amazing they shaved their head in awareness • Friends giving support • I liked how he remembered that the Jets won • Through the lows and highs, we all need each other
Hope	• A sense of uneasiness but a sense of hope • Life after the surgery is always positive for the donor and the patient • Different items or memories to help cope before and after the surgery • Hope

Dr. West reflected on the data analysis process in her field notes: "there were no arguments, and in fact in one situation, they combined their ideas. It went very smoothly, and they were very engaged, so this really supports the idea of participants being active in data analysis" (CHW fieldnotes, April 29, 2023). I remarked, "I felt they recognized the weight of this and were very engaged and invested" (AWK fieldnotes, April 29, 2023). I reflected on my experience of engaging the sibling donors in data analysis, writing, "Oba and Azeem are particularly vocal in this process; Chris chimes in with some ideas, and Nick also makes a few comments. It is interesting to see how research partners group these ideas - and how they come to a consensus on how the categories should be named" (AWK fieldnotes, April 29, 2023).

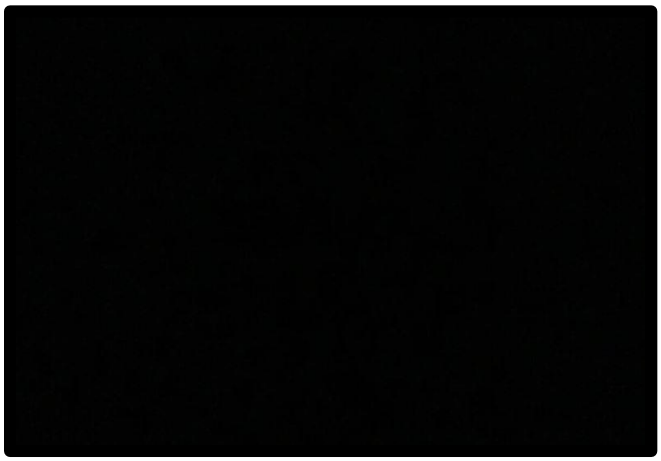
Below, I will present the six themes refined by the research partners. I have included quotes and photo stills from digital stories (with permission) to support the identified themes and visually depict the sibling donor experience as expressed by the research partners in their digital stories.

Pessimism and Acceptance. During the data analysis process, one of the themes emerged as having a unique focus, with a darker or more negative undertone compared to the other themes. While going through the Post-it notes, Nick observed that most of the notes in this group reflected negative emotions. Nick's comment provided an important perspective on the challenging parts of the donor process, which were not as dominant in the research partners' digital stories as the positive aspects and experiences of donation.

The reflections written on Post-it notes to accompany this theme were: "chosen to be the donor," "waves of emotion," "not understanding how dangerous the disease was," and "diagnosed with leukemia." Two research partners focused on the time their family discovered their sibling was ill at the start of their digital story.

Azeem relayed this experience in their digital story, sharing a black screen (Figure 5) as they narrated the discovery that their sibling was seriously ill. “Two months before I turned 10 years old, my older brother, me, and the rest of my family, were loading up groceries from Costco. My brother said he became lightheaded, and he started slurring his words. A few moments after this, he collapsed to the ground” (Azeem, digital story narrative, 2023). Azeem described this scene in vivid detail: they knew the date, where their family was located, and the series of symptoms experienced by their sibling. This moment was etched in their mind, becoming a pivotal part of their digital story.

Figure 1:



(Azeem, Apple Inc., iMovie, 2023).

Coming to realize the severity of the ill sibling’s pain or disease was a significant aspect within each of the research partners’ digital stories. Oba shared Figure 2 to reflect their understanding of the agony their sibling was going through, narrating: "My mom explained the feeling as a knife cutting through your skin endlessly, and I just felt so sad after hearing what my brother had been going through" (Oba, digital story narrative, 2023). The image of the knife is very alarming and can quickly trigger a sense of pain in the person who sees it or hears about it. Oba's capacity to

remember their mother's words emphasizes the strength of their visual representation about coming to realize the extent of their sick sibling's suffering.

Figure 2

(Oba, Pexels, n.d.)

This section also taps into the more negative emotions research partners expressed within the four viewed digital stories. Ire wrote “waves” on a Post-it note to describe their donation experience. When asked to clarify the meaning of this word, Ire, who was joining via Zoom, did not initially provide a response. In response to this question, Azeem asked if Ire was "talking about the waves of emotions going on throughout the time frame" (Azeem, Data Analysis Meeting, 2023). When asked if Ire agreed with this suggestion, they wrote “yes” through the chat option via Zoom, that this meant waves of emotion throughout the time frame of the hematopoietic stem cell donation and transplant. This visual of waves suggests that throughout the HSCT process, emotions fluctuated between high intensity and calmer periods.

After Procedure Thoughts. Following the viewing of four digital stories, research partners identified the first theme titled *After Procedure Thoughts*. This theme reflected research partners post-surgery recovery experiences. This theme contained four Post-it notes which were:

1) laughing, 2) sleeping gas, 3) the operation seems fast and easy so future patients don't need to be worried and 4) back aching.

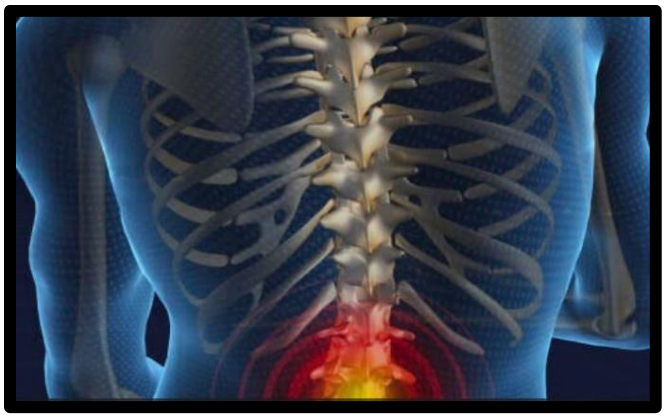
Figure 3 shows a visualization of the flavour of sleeping gas (also referred to by research partners as "laughing gas"), a common term used for nitrous oxide, which is an inhaled anesthetic aiming to provide sedation in medical procedures with a lower risk of adverse effects (Jain et al., 2024). Chris recalls that "the next morning, a doctor came to escort me to the operation room. I laid down on the operation table. They asked me a question of which flavour of sleeping gas I wanted, and I chose bubble gum. They applied the sleeping gas, and then it seemed like only seconds that I slept and then I woke up in a room. I nearly forgot I was in the hospital" (digital story narrative, 2023) (see Figure 3). In the data analysis discussion, Azeem and Oba mentioned the use of "sleeping gas" or "laughing gas" during their surgery without expressing any positive or negative feelings towards it. They simply remembered it as a medical aspect of their procedure. Ire also commented about the word "laughing" as: "I like, at the end of it, I said a funny joke, that's what the "laughing" is about" (Ire, Data Analysis Meeting, 2023). When I asked if this laughing was due to the laughing gas, Ire replied "probably" (Ire, Data Analysis Meeting, 2023). In this case, it is unclear whether the laughter resulted from sleeping gas or laughing gas. Nonetheless, it provided a break in the tension during donation surgery and was a procedural memory recalled by multiple research partners.

Figure 3:

(Chris, Personal photo, 2023).

Another “after procedure thought” was the back pain many research partners felt post-surgery, due to the surgical site in the lower back. Below is a visual from a digital story (Figure 4) from Pexels (Pexels.com) of the lower back coloured red, to indicate pain or soreness. In Azeem’s digital story, the following thought was shared: “I don’t remember a lot after that, just seeing my brother sleeping. After a few days of having bandages wrapped around my back, and being unable to walk, they let me go home” (Azeem, digital story narrative, 2023).

Figure 4:



(Azeem, Pexels, n.d.)

Figure 5 is Oba's reflection of his back pain post-surgery, as they narrate in their digital story: "I wake up on my side with a scorching back ache, but I was just glad it was over with" (Oba, digital story narrative, 2023). Two of the four digital stories mentioned back pain after surgery, while no other physical symptoms were reported by research partners.

Figure 5:

(Oba, Pexels, n.d.).

The theme of *After Procedure Thoughts* appears to reflect the experiences of the research partners as patients during donation. Even after years, some of the medical symptoms continued to be fresh memories for sibling donors, which formed a crucial part of their digital stories about their donation.

Sibling Support. The theme that was most prevalent in the analysis conversation was *Sibling Support.* This theme had the highest number of Post-it notes (n=9). Examples of phrases written on the Post-it notes include: "willing to do anything for a sibling", "cool they had no hesitation", "wanting to save your sibling" and "sense of relief". This theme displayed the research partners' love for their ill siblings and a close sibling relationship. Nick shared: "When my brother was in the hospital, I tried very hard to stay positive. I was hoping for the best, while preparing for the worst. It felt like I wasn't in control, that anything could happen. I made sure to

visit him, support him, and do everything within my power to make sure he was comfortable" (Nick, digital story narrative, 2023). You can almost hear the desperation in Nick's voice as they recalled the HSCT journey, and the desire to ensure their sibling felt supported and comfortable. Nick uses a black screen (see Figure 6) to express the challenge of staying positive during the HSCT and the lack of control he felt throughout the process.

Figure 6:

(Nick, Apple Inc., iMovie, 2023).

Azeem used a clover leaf (Figure 7) in their digital story to show how they felt to be the closest match for their sibling saying "…the moment I learned that me or my sister were the most likely donors, I prayed every night that it would be me. My brother was the best person I knew, I would do anything to save his life. After a couple blood tests, they declared that I was a better suited donor" (Azeem, digital story narrative, 2023).

Figure 7:

(Azeem, Pexels, n.d.)

Oba expressed a similar experience through the integration of an image of lit candles in their digital story (Figure 8): “I ended up being the closest match with my brother. My mom asked if I wanted to do it, and with no hesitation I said yes, I wanted to save him from all the pain he had been through;” Oba continued, “I wanted him to have fun without worrying about having another crisis. They kept on asking if I was forced to do it, because I think me doing this on my own will was very important. So, I said yes, confidently” (Oba, digital story narrative, 2023). In this case, I am unsure who “they” is that Oba refers to, perhaps the health care professionals, his family, or even their brother. I also wondered why they felt it necessary to include that they were asked several times if they were “forced to do it” (Oba, digital story narrative, 2023) and that he made the decision independently. Regardless, Oba sounded confident in their decision and felt it was essential to include this comment about how they confidently decided to donate.

Figure 8:

(Oba, Pexels, n.d.)

Another sibling donor focused on the night before the procedure in their digital story, “I noticed that there was another foldable bed beside my brother’s hospital bed, so I stayed at the hospital over night” (Chris, digital story narrative, 2023). The desire to stay connected and close to their siblings, regardless of whether this meant abandoning their comfortable bed at home, was a crucial memory to express for Chris and echoed by Azeem. Sibling donors wanted to be physically close during the transplant process to maintain their connection.

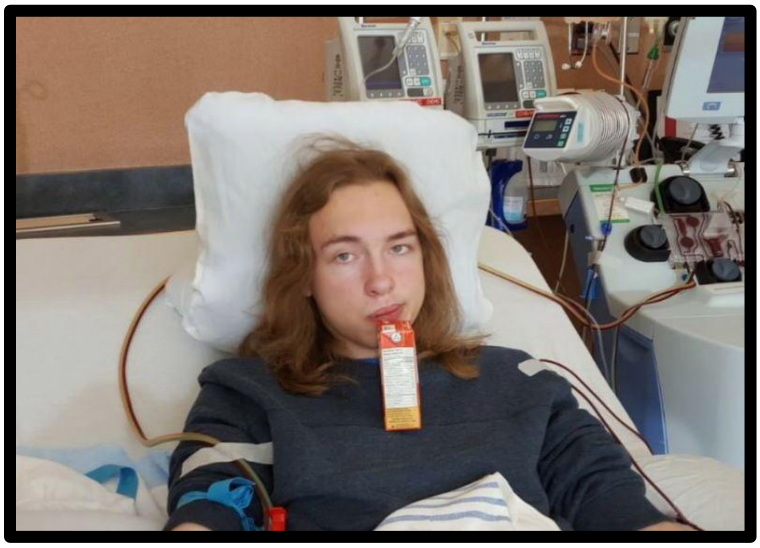
Figure 9:

(Chris, Pexels, n.d.)

Nick used the photo below in their digital story (Figure 10), narrating the importance of being able to do something to help his ill sibling:

> I was so happy that there was finally something I can do. I was ecstatic. I knew I was going to do it the moment I heard it because I'd already been through several surgeries and procedures before this point. So, at this point sitting hooked up to a dialysis machine for a couple hours wasn't really that big of a deal to me. I would have done that like in a heartbeat (Nick, digital story narrative, 2023).

Figure 10:



(Nick, Personal photo, 2023).

It is worth noting that all research partners reported having a positive relationship with their siblings both before and after the HSCT treatment. It is unclear whether this was due to a loving and supportive family environment or a naturally close sibling relationship. However, each sibling expressed a strong love and a sense of relief in being able to assist their ill sibling. It would be intriguing to hear from a sibling donor who had a strained or distant relationship with their sibling and was faced with the prospect of donating stem cells. What would their story be?

Family Experience. Many research partners described the impact of this HSCT on their whole family. Although there was less discussion of family, the research partners deemed it important to include *Family Experience* as a relevant theme in their digital stories. The two Post-it notes representing this theme were "family" and "always remember this experience that me and my family and my brother went through." It is interesting to note that there was a significant difference in the level of emotion expressed towards family experiences or bonds compared to the feelings of love expressed towards siblings. Neither of the Post-it notes explicitly mentions an emotion, but instead, they merely reference the family and acknowledge the experience they went through together.

In their digital story, Chris shared a photo of the hospital building where their sibling received their HSCT while narrating the follow part of their story: "I will always remember this experience, and what my family, me and my brother went through" (Chris, digital story narrative, 2023). Perhaps there is more to the visual image of the treatment centre and what it conjures for Chris in relation to the HSCT experience, but this is unknown.

Azeem concluded their digital story with a photo of their entire family on a trip, taken post-surgery to celebrate the success of the transplant, and they added: "I still remember that trip. It was the first time I saw my brother so happy in so long" (Azeem, digital story narrative, 2023). This memory of the opportunity to travel and spend time together as a family, which brought visible happiness to their brother, helped sustain Azeem throughout the HSCT donor experience.

Connections. The fifth theme was titled: *Connections*. The Post-it notes in this category reflected the support of friends and family, and the importance of having a support group during HSCT. Nick included a photo of themselves with some friends who had shaved their heads to raise awareness for kids with cancer (photo not included to protect the privacy of Nick's friends)

in their digital story. The timeline of this photo, whether it happened before or after donation and transplant, is unclear, but the moment was critical. Nick shared: “my friends and I all shaved our heads at a school event to raise awareness and funds for kids with cancer” (Nick, digital story narrative, 2023). It is not clear who initiated this event, but it was a significant moment for Nick as it supported a sense of feeling connected to others during challenging times.

Chris also shared a moment of connection with their family when returning from the hospital post-donation and post-transplant:

Chris described in their digital story that when their sibling came home from the hospital, “we watched a Winnipeg Jets game, and the Jets won” (Chris, digital story narrative, 2023). I think it was important that Chris and their family spent quality time together watching a hockey game (see hockey jersey, Figure 11). The fact that the team they were supporting won the game might have added to their sense of accomplishment after the stem cell donation and transplant, making it a fitting end to their experience.

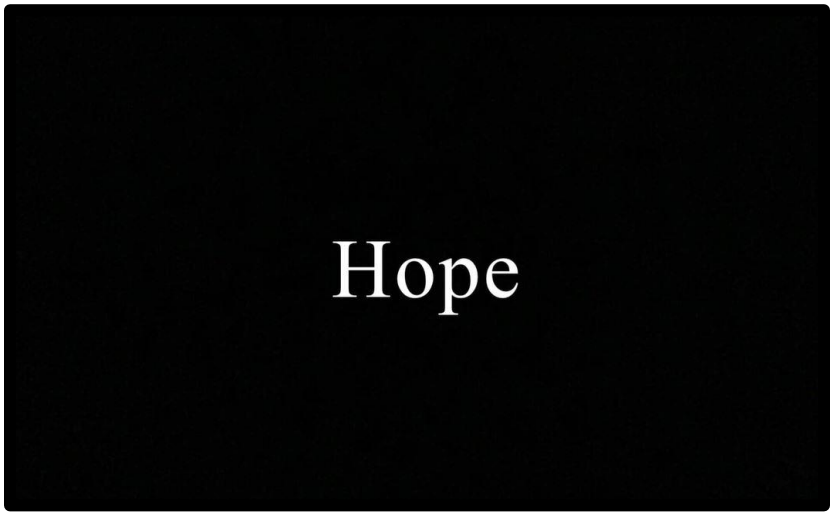
Figure 11:

(Chris, Personal photo, 2023).

Hope. The sixth theme was labeled *Hope*. For perspective, one definition of hope is: "to cherish a desire with anticipation: to want something to happen or to be true" (Merriam Webster online, 2023, para. 1). Within this research, the theme *Hope* was reflected in four Post-it notes with the reflections "sense of uneasiness but a sense of hope," "life after surgery is always positive", "different items or memories to help cope before and after surgery", and "hope". The six digital stories expressed a positive feeling throughout HSCT; these positive feelings were juxtaposed with the challenging aspects of the donation and transplant experience, conveying the hope that everything would eventually lead to a positive outcome.

Nick began his digital story with a black screen and the sound of rain falling as he narrated: "fear…anxiety…a sense of uneasiness…but yet, there was hope" (see Figure 12) (Nick, digital story narrative, 2023). Nick used Figure 12 again at the end of their story, narrating: "All in all, donating stem cells was an experience of hope, and I am so glad I was able to do it" (2023). Nick sensed that the experience was positive, and even though feelings of "fear, anxiety and a sense of uneasiness" were experienced (Nick, digital story narrative, 2023), the success of the transplant indicated that maintaining hope throughout the process was worthwhile.

Figure 12:



(Nick, Apple Inc., iMovie, 2023).

Oba narrated in their digital story (with the visual in Figure 13), “Now, life after the surgery has been great for me. I’ve discovered a new passion for basketball, it’s my happy place, it’s just always been there” they continued “whenever I play, everything goes quiet. It’s peaceful, beautiful, like a rainbow in the sky. And I just feel content with what I have” (Oba, digital story narrative, 2023). Oba's reflections on life after surgery were overwhelmingly positive, and the donation experience may have facilitated growth on their part as they discovered new hobbies and a sense of peace, similar to Nick.

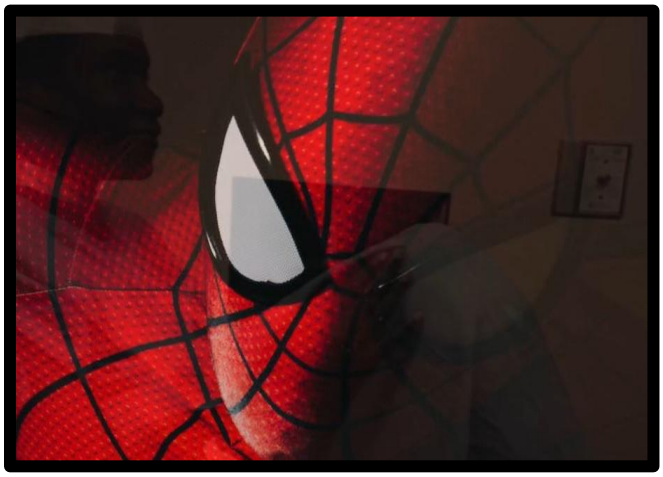
Figure 13:

(Oba, Pexels, n.d.)

Azeem and Chris shared images of a memory and item that brought comfort pre and post-surgery, perhaps providing comfort and ease during the challenging experience of HSCT donation. Azeem described Figure 14 in their story:

> My brother had to stay in the hospital for around a week or so, as he prepped for the surgery, but I didn’t want to leave him. Whenever I visited, I’d bring him Clay Oven from down the street, and then we’d play Spiderman games together. I didn’t want to leave my brother, so every day when my dad came back to work, I would beg him to let me go see him, and I’d stay with him all night (Azeem, digital story narrative, 2023).

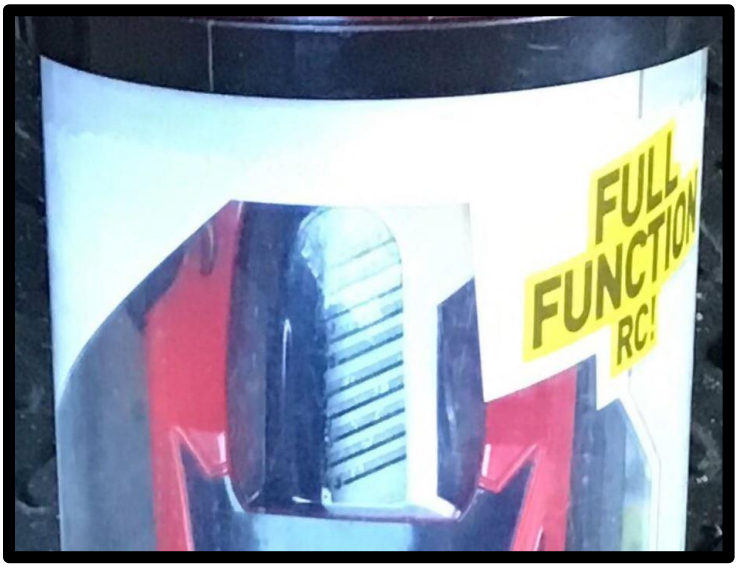
Figure 14:



(Azeem, Pexels, n.d.).

Using the image of Figure 15, Chris described an item that may have contributed to helping them adjust after the surgery. Chris shared that after the surgery, “a doctor came and gave me two choices: a remote-control car or a Lego set, and I chose the remote control car” (Chris, digital story narrative, 2023).

Figure 15:



(Chris, Pexels, n.d.).

Two perspectives on the theme of *Hope* were evident in the Post-it notes and visuals used within the digital stories. The first perspective of *Hope* revolved around the success of the donation and transplant and the positive recovery of the ill sibling and research partners. The second perspective alludes to activities (playing Spiderman together) or items (remote control car) that were sources of comfort or ease during the challenging time in the hospital, pre or post-donation surgery. I define the *Hope* experienced by sibling donor research participants as a positive outcome resulting from a successful transplant, and/or any events or items that provided positive support throughout the challenging donation and transplant process.

Reflection on the Process: Research Partner Digital Story Creation Experience

The goal of using digital storytelling in this study was to offer pediatric sibling donors an opportunity to tell their donation stories creatively and collaboratively. It was essential to have a chance to facilitate a discussion with research partners about their experience using digital storytelling to tell their donation stories and if they felt digital storytelling had the potential to be a therapeutic tool for helping pediatric sibling donors express their stories. After the sibling donors created their digital stories, I (AWK) led research partners through a group discussion (Meeting Two, Digital Storytelling Workshop Experience Discussion) focused on feedback about their experience of creating a digital story (Appendix P).

In addition to the feedback from sibling donors during our group discussion, Dr. West and I documented field notes to describe the participatory, digital storytelling experience guided by interpretive description methodology (Thorne, 2008). I analyzed the field notes and transcribed the group discussion I facilitated with sibling donor research partners, identifying key themes. After completing the analysis, I shared the themes with the research partners during the

Data Analysis Meeting (Meeting Three) to verify the accuracy of the preliminary results. This aspect of data analysis addressed the question: How do pediatric siblings experience the process of exploring their pediatric HSCT donation experience through digital storytelling? Moreover, do pediatric sibling donors believe digital storytelling would help future sibling donors express their voices in a creative, participatory manner?

I will begin by sharing the themes generated from the feedback provided by the research partners. An analysis of the research partners' responses highlighted four main themes about their experience of using digital storytelling: 1) community and connection, 2) digital storytelling - new and fresh 3) therapeutic process, and 4) privacy.

Community and Connection. In research, the term "community" often refers to "community members" or "groups" (Kelly, 2022) and can also mean "community partners" (Brown, 2018). However, it is rarely clearly defined. I resonate with Amauchi et al.'s (2018) definition that community is based on "self-identity, solidarity, and relationship building" (p. 5). I believe the research partners' sense of identity as sibling donors and solidarity in their shared experience significantly contributed to the development of community within the research process. For example, when asked about their experience creating digital stories with other pediatric sibling donors, Nick, Oba and Chris spoke about the opportunity to meet other siblings. Nick reflected that it was "interesting to meet other BMT sibling donors" (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023) and that there were instant feelings of being "included and accepted" (Oba, Meeting Two Digital Storytelling Workshop Experience Discussion, 2023). Oba shared that "we are all the same" (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023), and Chris stated that they were "not too nervous" because "everyone went through the same thing" (Meeting Two Digital Storytelling Workshop

Experience Discussion, 2023). The experience of connection between this small group of pediatric sibling donors was echoed through Azeem's (2023) statement about the other sibling donors: "when they talk about something, you can just relate to it." (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023). For example, Chris shared their memory of requesting a Jello when they visited their sibling in the hospital. During this discussion, Nick connected with this memory, saying, "yeah, like uh when you brought up the thing with the Jello," later adding, "always Jello and apple juice" (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023). In field notes, Dr. West reflected on this exchange, writing that Chris "recalled the Jello in the hospital after the donation (he found an image of it that he held up for others to see). The other research partners laughed and seemed to connect with this image" (fieldnotes, April 8, 2023). Doucet et al. (2022) noted that providing children and youth who have shared similar experiences with empowering opportunities for social connection can help normalize their experiences.

This discussion occurred in a smaller board room of a university, which included a long table with chairs, and a projector at the front of the room. Dr. West remarked: "I noticed that all the in-person participants had chosen to sit parallel, along one side of the table. I said, "everyone is sitting on the one side of the table," multiple participants nodded." Indeed, research partners chose to sit side-by-side instead of across from each other, although water bottles and exercise books were placed at opposite sides of the table (CW, field notes, April 8, 2023). Perhaps the seating arrangement was intimidating, and research partners chose to sit beside one another along one side based on comfort level, rather than directly across from each other (AWK, CW, field notes, April 8, 2023). However, as the day progressed, Dr. West reflected in her field notes: "this

was the first time they had been able to be in person with/meet other sibling donors. And perhaps this felt a bit overwhelming" (fieldnotes, April 8, 2023).

One aspect that helped ease sibling donors into community and connection was when I asked research partners if they would like any music as they worked, and Oba suggested playing some ambient music. The room immediately felt calm and comfortable after playing this relaxing, no-word music (field notes, April 8, 2023). I do not know if all research partners felt comfortable after I began playing music (I did not individually ask), but it did feel as though there was more of an ease to the work after the music began playing.

Kelly (2022), also define community within their arts-based, participatory research as members of the same group who connect through communication, action and reflection together. Within this research, after working alongside each other on digital stories, a meaningful aspect that contributed to the creation of community and bolstered a sense of connection was the clapping that followed the showing of each digital story. Dr. West reflected that "one interesting observation is that after the viewing of the first DS, one of the sibling participants started clapping, and after the showing of each DS…clapped for each other. Each participant worked on the Post-it notes soon after the clapping" and they "had clear thoughts/ideas/words to write on the notes as part of the analysis process" (field notes, April 8, 2023). I also acknowledge that after viewing digital stories that research partners did not need a lot of time to think about what to write on their Post-it notes (field notes, April 8, 2023). I believe that the clapping was an acknowledgment of the power of digital stories and the recognition of the vulnerability required for research partners to tell their stories of donation and share those stories in a group setting with other sibling donor research partners' as well as myself and Dr. West. Not only did this action contribute to community among siblings, but also among the entire research group.

In relation to the end of *Data Analysis Meeting*, Dr. West wrote that "there were non-verbal clues that the participants were connecting with each other differently – they began to look back and forth at each other, smiling at times, with small but increasing moments of verbal interaction" and there were "moments of what I felt were deep recognition in the context of their donation experience" (field notes, April 8, 2023). Nick also remarked during this discussion, "I never thought I'd meet anyone else who'd been a bone marrow transplant donor" (Data Analysis Meeting, 2023). Upon hearing this, other research partners nodded. Dr. West reflected in her field notes, "they are isolated in many ways as they go through that experience – in the sense that they don't have an opportunity (that I am aware of) to meet other sibling donors prior to, during, or after their donation experience" (field notes, April 1, 2023). Making a digital story about their donation experiences with other sibling donors beside them echoed this reflection. Despite the privacy and individual focus present in each sibling donor's digital story creation, being embedded in a workshop environment, where they created side by side was an important aspect of the digital storytelling process.

Digital Storytelling - New and Fresh. At the end of the *Digital Storytelling Workshop* (Meeting Two), research partners discussed how digital storytelling could be used to express the donation experience in a "fresh" and "new" way (Oba, Meeting Two Digital Storytelling Workshop Experience Discussion, 2023). Oba also described the experience as "fun" and that they could "put what he wanted" in their story, which spoke to a feeling of holding control over the story's content and the way their story was told. Oba also stated, "it's not known to do this; what you're doing with us, keep going." Azeem also shared that participating was "cool" (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023).

Research partners also spoke about the unique nature of the creative process of using photos and narration to capture their donation stories. Nick remarked about the novelty and value of the medium of digital storytelling: "I've definitely thought about it before but not to like the level of making something creative out of that experience" (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023). In my field notes during the digital storytelling workshop, I remarked on how this creative process unfolded, writing that some research partners would "write their story, add photos or select images first and then story, or take time carefully choosing photos and music" (field notes, April 8, 2023). Moreover, photos seemed to be a less vulnerable way to express the pediatric sibling donation experience; Oba remarked that sharing their donation stories was an "easier way to do with photos" (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023), and they could "express" themselves "really well with photos." As well, the use of photos helped to "capture the moments" and Chris concluded that it was easier to tell their "experiences using photos and iMovie" (Chris, Meeting Two Digital Storytelling Workshop Experience Discussion, 2023).

The digital storytelling workshop took place on a Saturday, in a large board meeting room. In field notes, Dr. West remarked, "each of them was assisted in finding a quiet space where they could be alone to record their story. It was helpful to be in a large…building, where they had multiple floors/seating areas where each of them could find a quiet and private spot to work on the recording of their story, and the modification of their images, transitions between images, their voice recorded story and any music they had chosen for their digital story" (fieldnotes, April 8, 2023). Dr. West also remarked:

> "Andrea and I let them lead in terms of what they needed during the digital story creation. There is something important that happened in letting them have agency in that,

letting them guide and work through the process of story expression in the way that each of them felt they needed to" (fieldnotes, April 8, 2023).

As well, "these sibling donors were given choice/freedom in how they created their digital story, and each of them did it *their* way – with minimal help/support from Andrea or I" and "although not said verbally, for me, there seemed to be a non-verbal message that they wanted/needed to create/record/write their stories by themselves, privately, in their own time" (CHW, fieldnotes, April 8, 2023). There was minimal discussion with research partners about the story they wanted to tell; this is likely due to the information and instructions presented in the PowerPoint during Meeting Two (*Digital Storytelling Workshop*), or perhaps research partners knew their story, or had an intuitive sense of what was important to express. Regardless, the writing process of digital stories remained quiet; partners needed time to think about their stories and to work out how this story would be told.

Therapeutic Reflection. Research partners noted the potential for digital stories to aid individuals therapeutically and help prospective donors make informed decisions about donations. Nick shared that "going back and thinking about it, it's like - oh, I guess this is how I felt and like it was therapeutic like you said like it was good to go back and think about it" (Meeting Two, Digital Storytelling Workshop Experience Discussion, 2023). Nick's comment indicated that they may not have had time or the opportunity to reflect on the experience after the donation. The digital story creation provided focused space and time to remember the donation journey, pre and post-donation, and to sift through some of the emotions and thoughts associated with their experience. Oba reflected, "I enjoyed it, I think it helped me even though like, I'm healed, I think it helped me just realize like oh, this is something that wasn't really something I see as like something bad that happened to me, because I wanted to see my brother better, but it

was just like a blessing and an opportunity to be able to help with that" (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023). Dr. West added in her field notes that Oba "found the process very helpful, and I remember (them) talking about how meaningful it had been that (they) were so actively involved in the process of the research/digital storytelling making" (fieldnotes, April 8, 2023). According to Oba, the donation experience was a blessing, because he was able to participate in their brother's recovery and their brother recovered fully (at the time of this study).

Another aspect of digital storytelling that encouraged therapeutic reflection was the creative control given to research partners over their stories. This also connects to the theme of digital storytelling as a "new and fresh" way to tell their story (Oba, Meeting Two Digital Storytelling Workshop Experience, 2023). Azeem suggested digital storytelling was a "different way to share what you're thinking" (Meeting Two, Digital Storytelling Workshop Experience Discussion, 2023). Chris echoed this comment, adding that digital storytelling was an "easier way to express your emotions instead of just saying it" (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023), which probed Azeem to add, "it would be harder to just say this in front of other people than just to say it on your own" (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023). As a result, digital stories can be less vulnerable than verbal retellings of personal stories in the presence of others (Boydell et al., 2012; Coemans & Hannes, 2017). Nick compared this process to an interview experience, where the story is recounted in words: "rather than just like an interview, cause an interview it's like on the spot you don't have time to really think about it. This way it's um, you get a lot more depth out of it" (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023). This highlights the benefits of the arts-based medium of digital storytelling, with the mix of photos,

music, and narrated stories, which can provide the depth Nick alluded to. These layers accentuate the story and give it a richness that is impossible to achieve through a narrative interview (Rahiem, 2021).

Privacy. Once the digital stories were completed, one theme identified from the Meeting Two, Digital Storytelling Workshop Experience Discussion, was a sense of privacy around sibling donors' donation stories. Nick said, "I never really thought about sharing this experience out loud with someone" (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023). Azeem shared that "no one in my family knew" and that they "told one friend" because they "didn't want to show off, just wanted to help" (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023).

There were privacy concerns about sharing their donation stories from their siblings who received the transplant and other family members. Before we viewed the digital stories in Meeting Three (*Data Analysis Meeting*), I (AWK) wrote in my field notes that one of the sibling donors had “already let me know they do not want to share their story with the group today" (fieldnotes, April 29, 2023). Moreover, just before viewing the stories, Liam was "texting with their sibling, to check if it is ok to share the story. The sibling responded “no,” so that digital story was deleted from the main screen and my computer" (fieldnotes, April 29, 2023). Dr. West wrote, "we honored this choice – as we moved through the viewing of the first few DSs/Post-its note process, he asked if they could read his story to us, which allowed his story to be part of the analysis process with the other sibling donors" (CW, fieldnotes, April 29, 2023). I (AWK) wrote in field notes that Liam "asks if they could read their story, without sharing photos. They read their story out loud. I appreciated this compromise! I feel they wanted to be a part of the sharing process, in some way" (fieldnotes, April 29, 2023).

At the same time, Dr. West wrote that Chris "shares that their father has expressed concern over who will see the story. They ask to call them over the phone. Once they return, they say they feel comfortable sharing their story with the group today" (fieldnotes, April 29. 2023). This highlights another aspect of the private process of creating digital stories. The stories are not only private to the research partners but also to their families, including their sibling who received the transplant (AWK, fieldnotes, April 29, 2023; CW, fieldnotes, April 29, 2023). Both Dr. West and I wondered, in field notes, who owns the story and what parts are told? Who has permission to share the HSCT story? (AWK, fieldnotes, April 29, 2023; CW, fieldnotes, April 29, 2023).

The question of assent and consent is also raised here. My committee and I felt it was essential to get assent from the sibling who was the HSCT recipient as a way of acknowledging their treatment experience. This was and is also their journey; they are the patient, and their experience should be acknowledged, recognized, and respected. It was morally and ethically important to seek the transplant recipient's permission before sharing their sibling donor's donation experience publicly or integrate it within the shared analysis process with research team members and the other sibling donors. However, this can also create a barrier for sibling donors who want to share their own stories, which are equally valuable and deserve to be heard (Bergold & Thomas, 2012; Coyne & Carter, 2018).

Beyond concerns about personal privacy, research partners may have become more comfortable sharing their stories over time, as most had donated four or five years ago, except for one. For one research partner, the quietest during discussions, it had only been six months since the donation. When asked about the ideal time to donate, Oba shared "before and after" (the donation): "before to prepare, after to pick themselves up," and he added, "better things are coming" (Oba, Meeting Two Digital Storytelling Workshop Experience Discussion, 2023). Oba

also suggested that digital stories would be helpful for potential sibling donors "who don't know about like what to decide, whether they want to do it or not; I think like our stories will help them like, want to do it more" (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023). Dr. West suggested that the timeline of digital story creation be six months to a year after donation, and most research partners agreed with this timeframe. Some of the reasons they suggested for waiting six months were to allow for time to "let things settle and play out" (Nick, Meeting Two Digital Storytelling Workshop Experience Discussion, 2023), to "not be too stressed" (Chris, Meeting Two Digital Storytelling Workshop Experience Discussion, 2023), because the "donor is still sensitive" or there has not been "enough time to heal" or if the brother or sister they donated to "has not fully recovered" (Nick, Meeting Two Digital Storytelling Workshop Experience Discussion, 2023). Oba agreed that creating digital stories would be beneficial for potential future donors to see, saying that "if there are other kids out there who don't know about like what to decide whether they want to do it or not, I definitely think like our stories will help them like, want to do it more" (Oba, Meeting Two Digital Storytelling Workshop Experience Discussion, 2023).

The themes mentioned above suggest that the digital storytelling experience provided a sense of community and connection among sibling donors. Digital storytelling is a new and effective method that can be considered therapeutic, but it is important to have conversations around the privacy of how and when these stories are shared. This study provides initial, valuable insights about how to bring digital storytelling to pediatric hematopoietic stem cell donation and other medical experiences of children and youth.

Reflection on the Process: Researcher Experience

The discussion during the Meeting Two Digital Storytelling Workshop Experience with research partners was valuable and constructive. It provided insights into the process of creating digital stories with children and youth as a means of data collection. As a researcher, it is important for me to thoughtfully reflect on this experience as well. As I did not have prior experience using participatory methods or digital storytelling with children and youth, I knew it would be imperative to keep field notes about this process to share insights on the value of this approach, as well as the challenges that arose. The following section discusses key method reflections from the field notes written by myself and Dr. West during the inquiry process. These reflections are divided into five sections, covering various aspects of the research process. These include the three meetings with participants, as well as three critical aspects of digital storytelling creation, namely the story writing process, digital story creation and technology issues, and engaging in data analysis with research partners.

Research Partner Meetings. An important aspect of the participatory methodology is the researcher's commitment to sustained engagement and to spending a significant amount of time with research partners; additionally, the creation of a safe research environment where partners feel seen and heard is critical (Bergold & Thomas, 2012; Eckhoff, 2019). To begin the inquiry process, I first spoke with a parent over the phone if the research partner was under 18 years of age, or directly with the research partner if they were 18 years of age or older. If the parent or adult research partner was still interested in participating, I arranged a Zoom meeting with the parent(s) and sibling donor, or adult sibling donor, to further explain the research study, establish trust, and get to know each other better. I continued to engage the sibling donor research partners across the three meetings, as guided by participatory methodology. Within the

research meetings, time was spent getting to know participants and creating a community of inquiry. During Meeting One: *Getting to Know You,* Dr. West and I shared our items first to help research partners feel more comfortable sharing theirs. By the end of this meeting, I observed research partners sharing increased eye contact with the camera and contributing more of their thoughts and ideas (Dr. West, fieldnotes, April 1, 2023). Dr. West noted, "I think this meeting was an important part of the continued relational process of engaging them in their unique place in the world/what they love… I think this process was important also because the transplant tends to be about the patient, the brother/sister who is ill - and focusing on what is unique to these siblings, what they love, invites them to think about that" (fieldnotes, April 1, 2023). By the end of this first meeting, it seemed that the research partners were engaged with us as researchers, as well as each other, and expressed their enthusiasm for participating in this study.

A challenge during the *Digital Storytelling Workshop* (Meeting Two) was that one research partner could not attend in person. We were able to facilitate the participation of this research partner using large screen video conferencing equipment and Zoom (hybrid meeting). The remaining research partners attended in person (five sibling donors). This study involved interactive digital story creation and participatory data analysis. Using Zoom was a helpful tool for ensuring the research partner's participation in the *Digital Storytelling Workshop*, but it also limited the hands-on assistance that we could provide during digital story creation. This research partner did not request assistance in creating their digital story, but it is still worth discussing this potential challenge.

Another challenge for this research partner was finding a quiet space to listen to the instructions provided to all research partners through a PowerPoint presentation (shared through zoom). As Dr. West wrote in her field notes, the research partner on zoom seemed to be

"repeatedly looking at someone off of the zoom screen (in different directions at times)" (fieldnotes, April 8, 2023). I do believe we managed this challenge; however, this research partner was quiet and shared less thoughts and ideas than other sibling donors who were present in person. The partner's virtual participation on Zoom, given that all other sibling donor partners were in the room, may have contributed to decreased involvement and connection.

Meeting One was only one hour long (all participants online on Zoom), while Meeting Two was a much longer day (7 hours) to share instructions and examples about how to create a digital story, as well as time for the sibling donor partners to create their own digital story. In reflecting on this day, I wrote in my field notes about how I might approach this differently in future work; it may have been helpful to combine the *Getting to Know You Meeting* (Meeting One) and the beginning of the *Digital Storytelling Workshop* (Meeting Two). Providing sibling donors with information about how to create their digital story in Meeting One may have allowed research partners to begin creating their digital stories on their own (fieldnotes, April 8, 2023). By the end of Meeting Two, I felt "physically, mentally and emotionally exhausted" (AWK, fieldnotes, April 8, 2023), and I did not do the mental and emotional work of creating a digital story. Dr. West also remarked that by the end of the day "each of the siblings seemed tired, and I was reminded of how intense this process can be (making a digital story) when you do it over multiple sessions – yet, they remained determined, and each of them were focused on creating their story" (fieldnotes, April 8, 2023). Adding time to the *Getting to Know You Meeting* (Meeting One) to also integrate some learning about digital storytelling could facilitate preparation work at home and could reduce the time required for the *Digital Storytelling Workshop* (Meeting Two). Finding a suitable time for all research partners to spend an entire day together during the *Digital Storytelling Workshop* was also a challenge. Therefore, it might be

helpful to shorten the workshop day and allow the participants to complete some work on their stories at home. Alternatively, dividing the workshop into two half-days could also be a practical solution, which would provide some time for reflection and work in between digital storytelling sessions. The following section will further discuss this, exploring researcher feedback about digital story writing and creation.

Story Writing. One aspect of digital story creation unique to other digital forms of storytelling is the focus on the narrated story that accompanies photos, videos, and music (Lambert, 2018). According to the seven steps of digital storytelling proposed by Story Center, step five is known as "hearing your story" (Lambert, 2018, p. 64). The written story guides the order, presentation, and flow of photos, videos, and music and can create an emotional tie to the audience through chosen words, phrases, and tone (Lambert, 2018). During the seven-hour Meeting Two (see Appendix K, *Digital Storytelling Workshop Plan*), I had allotted 45 minutes for story writing, which was insufficient. In my field notes, I reflected on the "need for one and a half to two hours for story writing. It might be a good idea to do this on your own time…. I do not want to rush research partners in this final process, but it must be done within a timeframe" (fieldnotes, April 8, 2023). This process did proceed smoothly, as Dr. West wrote: "In this story writing phase, they worked individually…there were minimal questions, and each seemed intent/knew what they most wanted to write about in their story" (fieldnotes, April 8, 2023). Each research partner had different techniques for writing their story, most chose to write the whole story, word for word in the notepads provided. Dr. West noted that Chris "asked me if I had a red pen - I went and got him a few different coloured pens, which he used to underline/highlight certain aspects of his story in his notebook" (fieldnotes, April 8, 2023). Some research partners preferred to use their iPad to write their stories, however, as Dr. West shared

"unfortunately, the iPad did not have word on them, and (they) didn't seem to want to use the notes program" (fieldnotes, April 8, 2023). It would be beneficial if research partners could work on their stories at home, allowing them the time they need to write and a choice of preferred writing method.

Digital Story Creation. Another aspect of the digital story creation process that deserves some reflection is the time needed to record stories and edit the final product. In my field notes, I (AWK) reflected that "recording also takes longer than anticipated…Also, there was need to build in more time for editing the digital stories - choosing music, adding text, editing time photos are displayed to match the voiceover/story" (fieldnotes, April 8, 2023). I checked in with research partners 5-10 times to track their editing progress. I could hear the beeping from iMovie to indicate that research partners were recording and re-recording their narrated stories. This process took well over two hours, and I faced difficulties in giving research partners enough time and freedom to feel secure and satisfied with the final output of their stories. I had to balance this with the need to finish before 3 p.m. so we could start discussing the sibling donor experiences of creating their digital story. I felt the weight of my role as a researcher. I wanted to stay on task for the day while also honoring the care and effort research partners were dedicating to their stories. Dr. West wrote:

> Two of the participants who were in person for the DS workshop (Chris; Azeem) asked to take their iPads home so that they could finish their digital story. One sibling donor partner needed to add some personal photographs that were at home, and another partner continued to work on (their) story after the day ended, as they waited for their dad to pick them up" (fieldnotes, April 8, 2023).

Two research partners asked to take their iPads home for more time to work on their stories, while the other four partners patiently waited for them to finish.

Technology Issues. Using a "new and fresh" (Oba, Meeting Two Digital Storytelling Workshop Experience Discussion, 2023) media method like digital storytelling presented some technology issues. We encountered a few technological challenges, mainly around exporting the finished digital stories from the iPads onto the encrypted USB sticks for sibling donor participants to take with them (Meeting Two and Three). In my field notes, I noted the following: “we had to figure out a way to transfer a digital story from an iPad onto an encrypted USB drive and then onto my computer to save the story in a shared drive, if the research partner granted this permission” (fieldnotes, April 8, 2023). Dr. West reflected on this same experience, writing that the “connector to transfer one of the iPad stories onto the encrypted USB stick didn't recognize the stick so that one needed to be transferred to Andrea's laptop directly. This process slowed the technology piece down at the beginning of the workshop" (fieldnotes, April 29, 2023). During the *Data Analysis Meeting*, this process took 30 minutes prior to starting the viewing of the DS together. I struggled to get the two stories from the research partners who took the iPads home from the *Digital Storytelling Workshop* off their iPads. I added that "the challenge as well is that USBs are encrypted with research partner's fingerprints, so any time there is a transfer, we needed their fingerprints. Some of the research partners were on their phones as they waited; this was a waste of time, highlighting that every effort should be made before viewing stories to get stories on USBs for participants, and on the confidential shared drive" (fieldnotes, April 29, 2023).

I was frustrated by this unexpected time requirement and felt pressured to quickly solve it to continue with the activities planned for the *Data Analysis Meeting*. Dr. West remarked that "this

is one reason why supporting the completion of the digital stories is important prior to the analysis meeting, which may mean giving more time between the digital storytelling workshop and analysis meeting or re-working the DS workshop to provide some post-workshop time" (fieldnotes, April 29, 2023). Thankfully, we both remarked that research partners waited patiently, engaging with their phones, but this supports the idea presented above that research partners work on their stories at home so that they can finish on their own time but before the data analysis meeting begins. I believe that using encrypted USBs is crucial to ensure the security and privacy of digital stories. However, it is worth considering and investigating a way to simplify the process of transferring the story onto a computer, saving it onto a protected shared drive, and then copying it onto the USB drive.

Another challenge was ensuring the internet connection was strong so that research partners could access copyright free images through a website called "Pexels," (Pexels.com) which provides free, non-copyright images. There were some issues accessing the Pexels website, though we cannot be sure if this was a website or internet connection issue. Unfortunately, as it was a Saturday, there were no IT professionals available to aid at the workshop location.

Lastly, one of our research partners joined us online which added an extra challenge of facilitating the *Digital Storytelling Workshop* (Meeting Two) and *Data Analysis Meeting* (Meeting Three) in a hybrid format (using both zoom and in-person). Overall, the session ran relatively smoothly, with only one issue where the research partner on zoom could not hear. However, another research partner who was present in person was able to assist in resolving this technology issue. It is worth noting that participatory research is best facilitated in person as it allows for more hands-on collaboration. When one participant joins meetings virtually, it can

create communication and engagement barriers between research partners, as well as between the participant and researchers. I do not know if this was a factor, but the research partner who joined through Zoom was very quiet, contributed only a few words verbally to the conversation, or through the Zoom chat option during the *Digital Storytelling Workshop*. This could have been related to this research partner's comfort level in general, or a consequence of using online software when all other sibling donors were present with us in person. Zoom can be an excellent way to ensure inclusive and accessible access to participation, however, it can impact the core benefits of participatory research; that it is hands-on, active, engaging, and collaborative (Coyne & Carter, 2018; Groundwater-Smith et al., 2015; Linder et al., 2018).

Data Analysis. The data analysis with research partners component was vibrant and beneficial, as Dr. West wrote, "participants' chairs were pulled in and bodies leaning toward Andrea/poster-board. Each offered their thoughts/ideas" adding that "this was the most animated and engaged they had been through the entire data collection process, and they were strongly invested in identifying the themes from the stories they had viewed" (fieldnotes, April 29, 2023). This process occurred in a large room, which provided enough space to feel comfortable while also creating a closer space to work on data analysis together. I was able to place the poster board on the table, and each of the sibling donors present in person gathered around it. I reflected that I might have been able to create a more engaging environment if I had made the process more physically interactive, where research partners could get up and move Post-it notes into categories on the board. In my field notes (AWK, April 29, 2023), I mentioned that in the future, I would relocate the poster board to a more accessible location. However, I believe it would be beneficial to have the research partners more involved in reorganizing the Post-it notes into the appropriate categories. This would add a more collaborative feel to the process, and perhaps the

research partners would feel even more comfortable contributing to the conversation. As well, Dr. West remarked that "if there had been the opportunity to review and think through the digital stories between meeting One and Two this could have been a rich discussion (as part of member checking) that would have further added to the analysis process" (fieldnotes, April 29, 2023). I believe that if we had more time to review the digital stories multiple times, and if we had adequate space and time to reflect on each component such as the photos, music, and unique experience of pediatric sibling donors, we would have been able to provide more profound and richer reflections on the overall experience.

Member Checking. A critical piece of both the participatory and collaborative aspects (Coyne & Carter, 2018; Groundwater-Smith et al., 2015; Linder et al., 2018) of honouring children's right to have their voice heard and their opinions taken seriously (United Nations, 1989) and to ensure rigor within the research process (Streubert Speziale & Rinaldi Carpenter 2007), was conducting member checking (Coyne & Carter, 2018; Streubert Speziale & Rinaldi Carpenter, 2007; Thorne 2008;2016). During Meeting Three (*Data Analysis Meeting*), I shared my preliminary data analysis with the research partners. This was to ensure that the ideas I gathered from my field notes and the transcripts of the group interview conducted during Meeting Two, the Digital Storytelling Workshop Experience Discussion, were consistent with the sibling donor partners' experiences. Member checking occurred after watching digital stories and participating in data analysis. The research partners appeared fatigued. The situation could have been an opportunity to gather valuable insights, viewpoints, and ideas from the individuals involved in creating digital stories. Presenting the information when they were relaxed and refreshed could have led to more meaningful feedback. The hurried delivery of information for their review might have overwhelmed them and influenced their feedback.

Chapter Summary

This chapter provided information about the research partners in this study. The first section of findings titled “Tell me Your Story: The Pediatric Sibling Donor Experience” presented six themes: After Procedure Thoughts, Pessimism and Acceptance, Sibling Support, Family Experience, Connections and Hope. The themes reflect a variety of aspects of the pediatric sibling donor experience, and the range of emotions sibling donors may experience, addressing the research question: 1) What are HSCT donation experiences as understood through the participatory medium of DS as expressed by pediatric sibling donors?” The development of digital stories satisfied research partners' rights to express their opinions in accordance with Article 12 of the United Nations Convention on the Rights of the Child (United Nations, 1989). No additional analysis of the categories was done, and research partners' opinions were regarded as legitimate and important which is congruent with participatory methodology (Coyne & Carter, 2018; United Nations, 1989).

The data analysis of research partner meeting transcripts and researcher’s field notes by Dr. West and myself were explored in the second category of study findings, "Reflection on the Process: Research Partner Digital Storytelling Creation Experience”, within the following four themes: 1) community and connection, 2) digital storytelling - new and fresh 3) therapeutic process, and 4) privacy. These research findings addressed the following research questions: 2) How do pediatric siblings experience the process of exploring their pediatric HSCT donation experience through digital storytelling? And 3) Do pediatric sibling donors believe digital storytelling would help future siblings donors express their voice in a creative, participatory manner?

The third section of findings presents my interpretive description analysis of the researchers' field notes, entitled "Reflection on the Process: Researcher Experience." The researcher reflected on five researcher reflections related to the participatory, arts-based research process guided by UNCRC Article 12: story writing, digital story creation, technology issues, data analysis, and member checking. These findings are particularly relevant for future researchers who wish to work with children in a participatory manner using various art forms, particularly digital storytelling.

In the next chapter, I will discuss the research findings in the context of previous literature and consider how the findings relate to the UNCRC theoretical framework. I will also highlight how these findings contribute to the limited literature on the experience of pediatric sibling donors through participatory research using art-based mediums.

Chapter Five: Discussion

In this research, I used the United Nations Convention on the Rights of the Child (United Nations, 1989), participatory research methodology (Coyne & Carter, 2018), Interpretive Description (Thorne, 2016; Thorne et al., 2004), and digital storytelling (Lambert, 2018) to explore the experiences of HSCT pediatric sibling donors. In the following section, I will offer interpretation and context for the qualitative themes identified in the research findings. These themes were identified within three analysis categories: 1) Tell me Your Story: The Pediatric Sibling Donor Experience; 2) Reflection on the Process: Research Partner Digital Story Creation Experience; and 3) Reflection on the Process: Researcher Experience. I will interpret the significance of these themes within existing literature about the pediatric sibling donor experience and highlight how these findings further extend knowledge on the experience of HSCT sibling donation, the use of digital storytelling with children and youth, as well as implications for practice, policy and research.

Tell me a Story: Research Partner Data about the Pediatric Sibling Donor Experience

Six research partners created digital stories about their sibling donation experiences and collaboratively analyzed those stories which led to the development of six themes: 1) after procedure thoughts, 2) pessimism and acceptance, 3) sibling support, 4) family experience, 5) connections, and 6) hope.

Previous sibling donor literature has focused predominantly on psychosocial risks ((D'Auria et al., 2015; Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003; Packman et al., 1997a, 1998; Winther Klippenstein et al., 2021). A comparison of the psychosocial distress themes within that literature with those identified from the digital stories within this research highlights the unique nature of each sibling donation experience – psychosocial distress and

experiences of meaning and growth co-exist. Further, what differentiates this study is that the analysis of digital stories was led by sibling donors research partners rather than academic researchers. The differences in the current study's themes raises questions about whether the child rights framework, attentiveness to experiences of growth as well as distress, digital storytelling approach (de Jager et al., 2017; Lambert, 2018) and/or participatory methodology (Coyne & Carter, 2018) facilitated the expression of unique and more nuanced aspects of the HSCT sibling donor experience.

In the present study, the social, emotional and personal growth experienced by sibling donors was especially meaningful and adds unique knowledge about the pediatric HSCT sibling donor experience. It specifically highlighted the desire of pediatric sibling donors to alleviate their ill sibling's pain and the importance of sustaining a feeling of hope throughout the HSCT treatment process. Sibling donors' experiences of growth will be further delineated following a discussion about how the themes in this study align and contradict findings from previous literature.

Psychosocial Risks

Distress, fear and anxiety related to HLA testing. The first psychosocial risk related to pediatric sibling stem cell donation identified in scholarly literature is the expressed fear and anxiety related to HLA testing. Contrary to the literature, within our analysis, none of the sibling Post-it notes, or their discussion, focused on fear and anxiety about needle pokes or fear related to HLA testing. Perhaps the memory of the needle pokes had faded over time for most siblings since the donation. Research partners identified a theme titled: A*fter Procedure Thoughts*, which reflected sibling donor experiences during the post-donation recovery period. The theme contained four Post-it notes: 1) laughing, 2) using sleeping gas, 3) the operation seemed fast and easy, so future patients don't need to worry, and 4) experiencing backaches. Within the previous

literature, once siblings were determined to be a match, siblings experienced fear over the actual donation procedure (Hoag et al., 2018; MacLeod et al., 2003; Packman et al., 1997a, 1997b; Wiener et al., 2008; Wilkins & Woodgate, 2007). In the research, research partners expressed fears and concerns about their ill sibling's recovery, rather than about the donation procedure. They also understood their sibling's suffering, which may have motivated them to donate and made them less afraid of the donation procedure.

I found it surprising that the fear of needle pokes and the distress over the actual donation procedure, which have been commonly reported in previous research literature (Hoag et al., 2018; MacLeod et al., 2003; Packman et al., 1997a, 1997b; Wiener et al., 2008; Wilkins & Woodgate, 2007), was not part of the research partner's digital stories in this study. In previous literature, the time since donation ranged widely from 4 months to 15 years. (D'Auria et al., 2014; MacLeod et al., 2003; Packman et al., 1997a, 1997b; Weiner et al., 2008). However, for five out of the six research partners in this study, it had been at least five years since their donation occurred, so the specific hospital-based procedural memories were perhaps not as fresh in the research partners' memories. It has been found that the fear of needle pokes decreases with age (McLenon & Rogers, 2018) and tends to dissipate 2 minutes post-needle (Waxman et al., 2017). When children and youth feel that they "just have to endure this" for medical reasons, such as being tested to see if they are a match to donate for their ill sibling (Sorensen et al., 2021, p. 8), this motivation may mitigate the fear. It is also possible that the time sibling donors had to reflect on their HSCT experience and the successful recovery of their ill sibling after the donation may have impacted the most meaningful memories about their donation experiences.

Experiences of an overwhelming pressure to donate. In previous studies, sibling donors have reported feeling pressured to donate and experiences of being excluded from family

decision-making conversations about donation (Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003; Packman et al., 1997a, 1998; Pentz et al., 2014; Rinaldo et al., 2022; Stegenga et al., 2019). It is important to note that these studies occurred post-donation, so do not capture in the moment reflections of this decision-making process for sibling donors. In the four digital stories analyzed in Meeting Two (*Data Analysis Meeting*), none of the research partners reported feeling pressure to donate. In fact, during the Digital Storytelling Workshop Experience discussion at the end of Meeting Two, Oba shared that they were asked (they did not specify by whom) if they felt pressured to donate, but they made an independent decision (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023). Further, the research partners described in their stories how proud they felt to donate and how happy they were to be able to contribute to their siblings' recovery.

Guilt and blame following the death of the ill child. It is important to acknowledge that digital stories created by sibling donors who have experienced the death of their ill sibling post-HSCT donation may be very different than those analyzed within our study. None of the research partners expressed guilt or blame because all the ill siblings survived.

A sense of emotional and physical isolation from parents following donation.

Within previous literature, sibling donors expressed that they felt emotionally and physically isolated from their parents after their donation, when the focus returned to the sibling undergoing HSCT (D'Auria et al., 2015; Erden et al., 2019; Gizli et al., 2017; Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003; Packman et al., 1997a, 1997b; Pelletier et al., Pentz et al., 2012, 2014; Pot-Mees & Zeitlin, 1987; Stegenga et al., 2019; Switzer et al., White et al., Wiener et al., 2008; Wilkins & Woodgate, 2007; Zajac-Spychala et al., 2020). Experiences of isolation from parents did not appear within the analyzed digital stories; one research partner spoke of physical

and emotional isolation they felt after their donation, but this was not isolation from their parents, but from their ill sibling who was still in the hospital recovering.

In previous literature, the time since donation for siblings was reported to range from 4 months to 10 years (D'Auria et al., 2014; MacLeod et al., 2003; Packman et al., 2004; Weiner et al., 2008). In this research, the range was from 6 months to 5 years. Some research partners who were nearing the 5-year mark since donation may have forgotten the feelings of isolation. Additionally, with the recovery of their ill sibling (all ill siblings recovered in this research), they were so relieved and happy for the recovery that they may have forgotten these feelings. The theme *Sibling Support* included the Post-it notes "visiting sibling in the hospital"; "playing games with sibling in the hospital"; "I liked the fact that he wanted to see his brother whenever he could". The research partners in the study shared that they did have opportunities to spend time with their parents and siblings whenever possible. Contrary to previous literature, there were no conversations focused on research partners being cared for by other family members or friends, or left alone at home while their parents were taking care of their sick siblings in the hospital (D'Auria et al., 2015; Erden et al., 2019; Gizli et al., 2017; Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003; Packman et al., 1997a, 1997b; Pelletier et al., Pentz et al., 2012, 2014; Pot-Mees & Zeitlin, 1987; Stegenga et al., 2019; Switzer et al., White et al., Wiener et al., 2008; Wilkins & Woodgate, 2007; Zajac-Spychala et al., 2020).

Positive Gains and Growth

In this study, there were similar positive gains and personal growth themes to those identified in the previous literature on sibling donation. I will now discuss the themes from the digital stories that related to positive outcomes and growth after donation using the categories of posttraumatic growth identified by Tedeschi and Calhoun (2004). These posttraumatic growth

categories were previously used within a narrative review on HSCT sibling donation experiences to identify experiences of posttraumatic growth (Winther Klippenstein et al., 2021). These categories of posttraumatic growth include "appreciation for life," "closer relationships with others," "gains in personal growth and strength," and "spiritual growth" (Tedeschi & Calhoun, 2004, p. 6). The existing literature mentioned the desire of sibling donors to actively contribute to their ill sibling's recovery (D'Auria et al., 2015; Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003; Pentz et al., 2014); however, this research emphasized the sibling donor's desire to alleviate their ill sibling's pain, and their desire to save the ill sibling. Also, it emphasized the significance of sibling donors finding ways to maintain a sense of hope throughout the entire HSCT process.

Appreciation for Life and Personal Growth and Strength. Within the previous literature, pediatric sibling donors often expressed a sense of purpose after donating, and gratitude for life (Hutt et al., 2015). Donors have previously reported feeling happy and relieved upon discovering that they were a match for their sick siblings and appreciated the opportunity to actively contribute to their sibling's treatment (D'Auria et al., 2015; Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003; Pentz et al., 2014; Rinaldo et al., 2022). Within my study, some of the Post-it notes in the themes of *Sibling Support* and *Pessimism and Acceptance* included statements such as "wanting to save your sibling," "sense of relief," "happy to do the BMT," "the transplant helps the possible donors feel like they are contributing to heal their sibling," and "chosen as a donor." These affirmative and robust statements show that the research partners were grateful for the chance to contribute to their sibling's health and appreciated the opportunity to actively aid in their recovery.

New Growth Finding: Desire to Alleviate their Sibling's Pain. Further to the feelings of gratitude to contribute to their sibling's recovery, in this study, sibling donors made strong statements during the *Data Analysis Meeting* about a desire to alleviate their sibling's pain and ultimately, save their life. In four of the five digital stories, the narrated story began with a detailed account of their sibling's illness and a description of the pain the ill sibling had endured. The language used by research partners in their recorded stories about donation acknowledged the severity of their sibling's pain and their desire to end this pain. Post-it Notes included the following phrases "easing sibling's pain", "relief of doing something", "Do everything in my power to make sure he was comfortable" and "the transplant helps the possible donors feel like they are contributing to heal their sibling." Strong statements, such as "everything in my power," expressed the sibling donor's fierce desire to stop their siblings' suffering, no matter what was required. The statements about wanting to save their sibling contained emotionally charged, passionate language compared to those reported in previous literature.

In addition to the robust statements about wanting to alleviate their ill sibling's pain, was research partner's desire to "save" their sibling's life. Post-It notes such as "the love for our siblings will help us want to do anything to save them", "wanting to save your sibling" and "willing to do anything for sibling" reflected research partners desperate yearning to contribute to saving their sibling's life. Within the previous literature, sibling donors have described these sentiments, but the language used in these digital stories expressed a deeper acknowledgment and understanding of their siblings' level of pain and their desire to end that pain. This desperation to save their sibling's life was linked to the worst-case scenario of their ill sibling dying, and previous literature has described the feelings of guilt and blame that sibling donors

felt if their ill sibling died post-transplant (D'Auria et al., MacLeod et al., 2003; Packman et al., 1997a, 1997b).

Closer Relationships with Others. The reflections by pediatric sibling donors on the experiences of developing closer relationships with their ill sibling, family, and friends was the area of growth most closely aligned with findings from previous studies. According to previous literature, sibling donors expected their ill siblings to be available for them in the future (D'Auria et al., 2015). After the HSCT, the whole family became closer, and the trauma of HSCT encouraged them to rely on each other for support, which strengthened the family bonds (Hutt et al., 2015; Weiner et al., 2007). Similarly, research partners described closer relationships with siblings and the family, as reflected in the themes: *Sibling Support*, *Family Experience*, and *Connections*. It is clear from previous literature and confirmed by the themes identified by research partners in this study that individuals felt closer to both their siblings and family after donation. Their experience strengthened the bonds and connections between the donor and the ill sibling, as well as with their family and friends who supported them throughout the donation process.

During the *Data Analysis Meeting* (Meeting Three), Nick's digital story stood out to other research partners due to the support Nick had received from their friends during the HSCT process. The mention of friends as a source of support was only briefly noted in the previous literature. According to the literature, sibling donors preferred to confide in friends and family for information processing about HSCT and their donation, and for processing their feelings after donation, rather than seeking help from a mental health professional (Rinaldo, 2022). It is reassuring to know that Nick not only felt supported by their ill sibling and family, but they also received significant emotional support from their friends. The importance of support from

friends may increase with age, when friends become just as significant a source of support as family (Paris et al., 2019).

Spiritual Growth. The final positive outcome of posttraumatic growth is spiritual growth (Tedeschi & Calhoun, 2004). However, spiritual growth has received minimal recognition as an aspect of growth post-donation for pediatric sibling donors in the previous literature reviewed. Wilkins & Woodgate (2007) referred to prayer as a coping response for sibling donors during the HSCT process, and did mention sibling donors' sense of "hopefulness" as a coping mechanism (E33). Within this study, research partners did not specifically mention spiritual growth in relation to prayer or religion. Building on Wilkin's and Woodgate's (2007) identification of hopefulness, hope emerged as an important theme during the Data Analysis Meeting and is presented as a novel finding related to the sibling donor experience.

Growth Finding: Hope. Research partners identified the theme of *Hope*, with Post-it notes: "sense of uneasiness but a sense of hope", "life after surgery is always positive for the donor and the patient." and just "hope." In Nick's digital story, they started reflecting on the fear they felt when their sibling became ill but ended their digital story with a sentiment of hope. To try and comprehend the concept of "hope" reflected by research partners within their digital stories and Post-it notes (Data Analysis Meeting, 2023), I read Rafferty et al.'s (2020) work which applied Snyder's hope theory (2002) to understand parents' caregiving experiences for their medically complex child. Snyder's hope theory (2002) proposes that there are three aspects to hope: goals, pathway and agency (Rafferty et al., 2020; Snyder, 2002). Snyder defines goals as hopeful planning, pathways as the route to achieve goals, and agency the motivation to pursue said route (Rafferty et al., 2020). In their research, Rafferty et al. (2020) identified the parent's goal while caregiving for their medically complex child as trying to optimize their child's quality

of life, the pathways were created through support networks with health care professionals, family and friends, and agency was conceptualized as a positive emotional mindset.

The use of the word "hope" by research partners in some of their digital stories may reflect a goal of easing the pain of their ill sibling and providing comfort. The pathways to achieving this included making donations and remaining physically close to their siblings during their recovery in the hospital. Additionally, the support from family and friends contributed to their sense of agency in this situation (Snyder, 2002). It is important to understand how research partners maintained a sense of hope during the difficult and challenging aspects of HSCT. It is also crucial to identify the specific supports and resources needed in practice to help sibling donors maintain this sense of hope. The concept of 'hope' emerged as a significant finding in this study. It is worth noting that all the ill siblings and donors had fully recovered at the time of this study, which may have led sibling donors to hold more positive feelings about their HSCT donation experience. It is possible that this sense of hope may not have been as prevalent, or even present, if there had been any complications during the donation process or if the recipient did not recover. It is clear though, that maintaining a sense of hope provided a source of positive strength and motivation for research partners throughout the fear and worry they experienced during the HSCT process.

The digital stories created by the research partners focused on their love for their siblings and their desire to alleviate their siblings' pain and suffering. They also emphasized the critical need for a community of family and friends to support siblings throughout the donation process. Another important finding was the significance and power of maintaining this sense of hope throughout the HSCT treatment, and the donation process.

Reflection on the Process: Research Partner Digital Story Creation Experience and Researcher Experience

After conducting the *Digital Storytelling Workshop* to address the second and third research questions, "How do pediatric siblings experience the process of exploring their pediatric HSCT donation experience through digital storytelling?" and "Do pediatric sibling donors believe digital storytelling would help future sibling donors express their voice in a creative, participatory manner?" I led a group discussion with research partners, referred to as the Digital Storytelling Workshop Experience Discussion (*Data Analysis Meeting*, Meeting Two). I used interpretive description methodology (Thorne, 2008) to analyze the transcribed audio discussions with participants and the typed field notes from meetings. The analysis identified four themes: 1) community and connection; 2) digital storytelling - new and fresh; 3) therapeutic process; and 4) privacy. I will explore these themes in greater depth by addressing the impacts of using the UNCRC as a theoretical framework (United Nations, 1989) for this work and combining the knowledge from the literature on participatory research with children/youth and the use of digital storytelling (Coyne & Carter, 2018; de Jager, et al., 2017). Additionally, I will share my own insights as a researcher on the experience of conducting participatory research with children, utilizing digital storytelling as the chosen method.

Community and Connection. Creating a sense of community within the research environment is crucial for effective participatory methodology, which emphasizes collaboration between members of the research team (Coemans & Hannes, 2012; de Jager, et al., 2017; De Vecchi et al., 2017). I want to highlight the hour or so spent with each research partner via Zoom for the introductory meeting, which occurred as part of the consent/assent process. The purpose was to provide information about future research meetings, go through the consent/assent forms,

and engage relationally with each individual research partner. After the Zoom meeting, I visited participants' homes to go through consent forms and explain the in-person research process.

During these face-to-face recruitment meetings, two research partners' mothers shared photos of the HSCT experience. While looking at these photos, the sibling donors shared comments, stories, and memories. I also gained a sense of which sibling donors were more comfortable speaking about their experiences and noticed that younger sibling donors (ages 12-14) seemed more reserved, while older ones (ages 18 and 21) were more at ease. The sibling who had donated only 6 months prior to this study was also more reserved compared to those who had donated 5 years ago. I felt honoured to hear some of the details of their HSCT experience and tried to create a calm and comfortable tone, adding humor where appropriate, in these introductory meetings. I explained to participants that they would be invited to be research partners, and that I wanted to create a collaborative research process. I aimed to carry this sentiment to the research environment to empower research partners to exercise their creative freedom and have control over their digital story (Coyne & Carter, 2018; Eckhoff, 2019). Creating this research environment was crucial: it required time, effort, and space to enable research partners to share their stories and participate comfortably (Eckhoff, 2019).

The *Getting to Know You Meeting*, which included two "breaking the ice" activities, as well as the ambient music I played during the *Digital Storytelling Workshop* (Meeting Two), helped to create a safe and comfortable environment for the research partners. During the *Digital Storytelling Workshop* and *Data Analysis Meeting*, I spent time getting to know the participants. This ongoing connection throughout all three research meetings was imperative to creating and sustaining a comfortable environment and was crucial in assisting research partners to feel at ease when participating in and sharing their stories (Eckhoff, 2019). In the Digital Storytelling

Workshop Experience Discussion (held at the end of Meeting Two), Nick, Chris and Oba indicated that they appreciated the opportunity to meet other sibling donors, and that they felt comfortable participating together as they had shared the experience of HSCT donation. They also bonded over shared memories, such as being served Jello as a snack during their hospitalization for the donation procedure (*Data Analysis Meeting*, 2023). Though the sibling donors were initially quiet as the *Digital Storytelling Workshop* began, the mood lightened later in that meeting, evidenced by increased smiles and conversations between the research partners (AWK fieldnotes, April 29th, 2023; CW fieldnotes, April 29th, 2023). After watching each of the digital stories, they showed each other signs of recognition and support by clapping (AWK fieldnotes, April 29th, 2023; CW fieldnotes, April 29th, 2023).

During the *Digital Storytelling Workshop*, I had hoped to create a collaborative and participatory experience for research partners. The plan was for them to work together, share photos, explain their donation experiences, and discuss their stories. However, this did not happen as expected. The research partners worked independently on their stories, but they seemed focused, calm, and comfortable working this way (AWK fieldnotes, April 8th, 2023; CW fieldnotes, April 29th, 2023). As a researcher, I advocate for a more collaborative approach, so I could have facilitated this by pairing research partners intentionally or asking them to discuss their photos, stories, and work together to create digital stories. Moreover, I could have scheduled a gathering in advance, outside the university, for example in a park, suggestions made by other researchers using participatory with young children (Coyne & Carter, 2018) to facilitate chances for research partners to engage in conversations, to familiarize with each other, and to help the group become more at ease with each other. However, I was concerned that providing too much direction could exacerbate the power imbalance in research (Coyne &

Carter, 2018). The UNCRC framework helped me ensure that the research partners were actively involved and comfortable with the process of creating their digital stories and that they were given the freedom to have an individual creative experience, where they felt their authentic voice was reflected (United Nations, 1989). Though the digital storytelling workshop process deviated from what I had originally envisioned, I took cues from the research partners by observing where they chose to work on their stories (spread out in private spaces) with whom (alone) and checked in to gauge the time they needed (Coyne & Carter, 2018).

An environment of calm and comfort persisted during the *Data Analysis Meeting*, where research partners freely and reciprocally exchanged ideas and thoughts, reached agreements, and collaborated on the main themes they felt were important from their viewing of digital stories about sibling donation (AWK, fieldnotes, April 8th, 2023; CW, fieldnotes, 2023). A change I could have made, as discussed in Chapter 4 (p. 95), would be to spend some time in the *Getting to Know You* meeting to go through the seven steps of digital storytelling (Lambert, 2018). This may have allowed research partners to start creating their digital stories in the comfort of their homes. As previously discussed in Chapter 4 (p.68), each research partner appeared very focused on the creation of their digital stories, which was a deeply personal and individual experience (AWK fieldnotes, April 8th, 2023; CW fieldnotes, April 29th, 2023). Enabling research partners to initiate or finish this process at home, without the constraints of time and space, could provide an additional creative opportunity for expression.

Digital Storytelling - New and Fresh. During the Digital Storytelling Workshop Experience discussion (Meeting Two), the research partners talked about using digital storytelling to express their donation experiences in a new and innovative way (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023). They shared their creative process

of using photos and narration to capture their donation stories, which felt easier than verbally telling their stories (Meeting Two, Digital Storytelling Workshop Experience Discussion, 2023). Nick mentioned that before this experience, he had never thought of documenting his donation experience in a creative way (Meeting Two, Digital Storytelling Workshop Experience Discussion, 2023). Digital storytelling offered a new outlook on how sibling donors might share their personal stories and experiences through digital media. This feedback from research partners supports the use of digital storytelling as a safe and creative way to express private and personal stories of HSCT donation.

During the *Digital Storytelling Workshop*, I noticed that different research partners followed different creative approaches (AWK, fieldnotes, April 8th, 2023). Some preferred to write their story first and then added photos or selected images, while others carefully chose photos and music before writing their story (AWK, fieldnotes, April 8th, 2023). It was fascinating to observe how each approach resulted in a unique and individual experience for every research partner. The creative process of crafting digital stories was quiet, perhaps because the research partners needed the space, time and quiet to contemplate their stories and decide the most effective way to communicate them.

When it was time to record their voices, the research partners chose to move away from each other and spread out throughout the building (AWK fieldnotes, April 8th, 2023; CW fieldnotes, April 8th, 2023). The choice to find their own place to create their digital story on the iPad might have been due to two reasons. Firstly, reading their stories aloud for others to hear may have made them feel vulnerable or embarrassed. Secondly, it could reflect a need for privacy and ownership over their donation story as it was created, allowing them to hold a boundary around who could hear it, and when it would be shared. As I offered peripheral support

to the sibling donors, I observed that some research partners were recording and re-recording their stories to ensure they got it right (AWK, fieldnotes, April 8th, 2023). They looked very focused and concentrated on their work. A tension existed between respecting their time, and following the workshop schedule, with the inherent time constraints. Following their request for more time, research partners worked on their stories for an additional 20 minutes. However, I was concerned that this might cause issues for the next activity, which was a discussion about the sibling donors' experiences of participating in the digital storytelling workshop (AWK, fieldnotes, April 8th, 2023). As it turned out, the discussion was shorter than I had anticipated.

The USB sticks were encrypted with their fingerprints for privacy. This made transferring data time-consuming, and I felt pressure to address the issues quickly. It took 30 minutes to resolve the problem. In the future, I will ensure the digital stories are preloaded on USB sticks and my computer before meetings. The experience was stressful but provided important lessons for future projects.

The morning had internet connectivity issues, causing problems for research partners who needed copyright-free images from Pexels for digital stories on their iPads. No IT support was available on Saturday. Scheduling the workshop on a day with IT support could have prevented these issues.

I ensured that all research partners could attend our meetings by offering the Zoom option if they could not be present in person. One partner joined remotely but did not actively engage, mainly using the chat function. This raised concerns about using a hybrid format with only one remote participant.

In this study there was a tension between the participatory methodology (Coyne & Carter, 2018) which favours hands-on, collaborative in-person research opportunities for children, and

Article 12 from the UNCRC (United Nations, 1989) which encourages opportunities for children to express their thoughts and opinions with as few limitations as possible (Bala & Houston, 2015). This approach ensures that children's opinions are given due respect (United Nations, 1989) and allows for opportunities for answering questions, providing information, and quickly modifying research design and methods as required (Coyne & Carter, 2018; United Nations, 1989). To facilitate effective communication, it is important to have open and welcoming spaces, which according to Bergold and Thomas (2012), is best done in person. Digital stories have historically been created collaboratively in a group setting to foster a supportive and encouraging artistic environment (De Vecchi et al., 2017). I acknowledge that further considering the use of technology as a means of remote participation for children is worthwhile, as it may provide a sense of safety and comfort, resulting in their authentic voice being shared but there may be unique challenges in offering a hybrid environment for participatory workshops with children.

Therapeutic Reflection. The creation of digital stories provided research partners with dedicated space and time to recall their donation experience, both before and after the donation, and to sort through some of the emotions and thoughts associated with the experience. The arts can offer a medium to share experiences that are difficult to express in words (Boydell et al., 2012; Coemans & Hannes, 2017). During the *Digital Storytelling Workshop*, I was moved by the combination of photos, music, and narrated stories in the digital stories the sibling donors created; there was a depth and richness that perhaps a narrative qualitative interview could not achieve. Some of the feedback from research partners included Nick describing the digital story creation as “therapeutic”, and instead of an interview provided more “depth” to a story, while Oba reflected that the experience allowed him to realize the opportunity to donate for their sibling was a “blessing” (Meeting Two, Digital Storytelling Workshop Experience Discussion,

2023). Azeem and Chris reflected that digital storytelling was an easier way to express their thoughts and feelings about the HSCT donation experience (Meeting Two, Digital Storytelling Workshop Experience, 2023). The research findings suggest that since the process of creating a digital story was done independently, each research partner had more control over the kind of therapeutic reflection they experienced. Research partners had the freedom to choose how deeply they would engage and express their donation story; participatory methodology (Coyne & Carter, 2018) created the environment for them to hold ownership and agency within the creation process.

The sibling donors chose the photos and music they used, as well as crafting the story they wanted to tell. This allowed for a unique and personalized storytelling experience that was therapeutic for the sibling donors. They had the opportunity to reflect on their experience while also having the agency to modify which aspects of their story were told, especially if they felt intense emotion. This reflects the autonomy, control, and freedom of using digital storytelling with children and youth, and in the specific context of HSCT sibling donation. With their own iPad and space, the research partners were in charge, deciding what story they most wanted to create and share (Boydell et al., 2012; Driessnack, 2006; United Nations, 1989).

Privacy. Research has demonstrated that digital storytelling can serve as a therapeutic approach for reflecting on personal experiences (Boydell et al., 2012; Coemans & Hannes, 2017). This is closely linked to the significance of privacy, as sharing personal stories through digital media may be less emotionally vulnerable than sharing them verbally (Boydell et al., 2012; Coemans & Hannes, 2017). During the Digital Storytelling Workshop Discussion (Meeting Two), Nick and Azeem shared that they had never told anyone about their donation experience before due to a reluctance to call attention to their experience in the context of what

their ill sibling was going through (Meeting Two Digital Storytelling Workshop Experience Discussion, 2023). This sense of privacy and not wanting to pull attention away from the ill sibling spoke to an aspect of selflessness. These expressions were also shared on the Post-it notes (*Data Analysis Meeting*) within the theme of *Sibling Support*.

The discomfort of a sibling and parent with two research partners sharing their stories about donation experiences raised the question of who owns the story and who makes the decision of how and when it is shared. The goal of using the UNCRC as child rights framework for this study was to ensure the right for children to express themselves freely while minimizing restrictions (United Nations, 1989). How can we ensure that sibling donor stories are told while simultaneously supporting family members who may feel discomfort with the telling of donation stories? How might the stories be shared within families, to facilitate dialogue about the HSCT experience and sibling donation as well as to explore the benefits and challenges of sharing these stories with others? It is worth noting that if any of the research partners were under the age of 18, their parent or guardian was contacted to obtain permission for their participation in this study. If any of the research partners were under 18 years of age, they could only participate with a parent's signed consent, not just their own written and verbal assent. I remembered the concerns about assent and choice to donate for pediatric sibling donors noted in previous literature (D'Auria et al., 2015; Hutt et al., 2015; Packman et al., 1998; Pentz et al., 2012). Even though obtaining their consent for HLA testing and donation is recommended by the Canadian Paediatric Society, it is not a legal requirement (Coughlin, 2018).

In our study, even if the research partner was over 18 years of age and did not require parental consent to participate, they still needed to obtain assent from all siblings who received the transplant from them. This assent form was added to my ethics applications to recognize the

ill sibling who received the transplant as part of the story. However, this raises the question of whose story and experience is centered in family life, and within the process of HSCT donation. The ethical requirements could be viewed as roadblocks that prevented research partners, whether they were considered children or adults, from being the sole decision-makers and owners of their story and who could hear it (United Nations, 1989). Although the digital stories were about the pediatric sibling donor's experience, and research partners were the decision-makers behind choice of photos, narrated story and music, ultimately how and when this story is told was not their decision alone. This also reflects the relational and ethical complexity in the sharing of sibling donation stories, as well as how those complexities might be better addressed in clinical practice.

Family privacy complicates the viewing of digital stories, and this aligns with the literature where pediatric sibling donors expressed the limited autonomy, they felt over the actual decision to donate, which created psychosocial distress (Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003; Packman et al., 1997a; Pentz et al., 2014; Rinaldo et al., 2022; Stegenga et al., 2019). I worried that full autonomy was not felt over the digital stories the research partners had created, and it was shared ownership of the story, rather than individual ownership. Questions about how ill siblings and families are supported and educated about the importance of attending to sibling donor’s unique experiences, voice, and assent to HSCT donation are also raised in the tensions present within the research findings.

Pediatric sibling donors’ voices are important and deserve to be empowered and amplified. Digital storytelling provides children and youth sibling donors with an arts-based, developmentally sensitive approach that can facilitate the expression of their voices and HSCT donation experiences. However, it is impossible to ignore that the HSCT process is a family

experience, which impacts many members of a family. Research partners acknowledged this within the theme *Family Experience*, with Post-it notes "family" and "I will always remember this experience that me and my brother and my family went through."

Although I felt some discomfort about the family members' potential interference with ensuring research partners felt they had a right to share their stories (Article 12, UNCRC, 1989), I also trusted that research partners would ultimately make this decision, as siblings who were donors telling their stories, but also as members of their families.

Research Findings, Study Strengths and Limitations

The current study builds on existing literature about pediatric HSCT sibling donor experiences through alignment with previously reported psychosocial risks, while also highlighting unique areas of growth and gains sibling donors can experience. The research findings indicate that siblings were eager to assist their brother or sister during their recovery, experienced a sense of increased family closeness after the HSCT, received support from both family and friends, and emphasized the importance of maintaining hope throughout the HSCT experience. They did not seek attention or recognition after their donation and kept their stories private, and throughout their digital stories, highlighted their sibling's experience with a sense of hope that they would recover, and life would be more positive.

The study adds to the existing research on arts-based participatory research with children by highlighting rights-based research with children and youth that facilitated their active and creative engagement and contributions to data collection and analysis, producing rich and authentic findings related to the experience of HSCT sibling donation. The research partners felt a sense of community and connection while working together, and they also had the opportunity to use digital storytelling as a creative approach for expressing their donation experiences. The

benefits of using child rights, participatory methodology (Coyne & Carter, 2018) to conduct research with children and youth was supported. The research partners invested significant time and effort in selecting their photos and crafting their stories, which showed their dedication and engagement with the methodology and method of digital storytelling.

After reviewing digital narratives and following the guidance of research partners, it became evident that children and young adults can confidently and proficiently draw meaningful conclusions from research data, using their own words. The research partners collaborated by agreeing with each other, adding words or ideas to suggested themes, and working together to determine the final themes they viewed as most meaningful in digital stories. As a researcher witnessing this collaborative data analysis, the experience of creating and analyzing data was powerful.

The study offers valuable insights to encourage researchers to pursue active, participatory research with children using arts-based data collection methods. Next, I will discuss the study's strengths and limitations, as well as its implications and recommendations for future research, policy, and practice.

Study Strengths

One of the key critiques of previous research focused on sibling donors in pediatric hematopoietic stem cell transplantation (HSCT) is that the methods used to collect data may not have allowed children to express their donation experiences fully (Winther Klippenstein et al., 2021). However, in the present study, sibling donors were invited to participate as research partners and given agency and control over the digital stories they created. We provided individual iPads with the iMovie app to the research partners right from the beginning of the study, allowing them to download personal photos for their digital stories at home. During the

Getting to Know You Meeting (Meeting One), research partners were given the choice about what information they shared about themselves. They were reminded that I would continuously seek verbal assent/consent for their participation throughout the research process, and they could withdraw from the study at any point. This was done to ensure that research partners felt like active members in this research and maintained autonomy over their donation story and how it was told (Bergold & Thomas, 2012; Coyne & Carter, 2018).

The aim of this dissertation study was to work with children and youth instead of conducting research on them (Coyne & Carter, 2018). During three research meetings, we spent time getting to know each other and encouraging research partners to freely create their own digital stories. We made sure our research partners had enough privacy and time to work on their stories, and we collaborated on data analysis without re-analyzing it separately. Also, we asked our research partners how they would like the knowledge to be shared. I believe that by doing all this, we were able to ensure that the rights of the child and young adult participants, who were also our research partners, were respected.

Another strength of this study was the use of digital storytelling as an arts-based research method. This method provided a creative and hands-on experience for the research partners to tell their donation stories (Boydell et al., 2012; Chilton & Leavy, 2014; Coemans & Hannes, 2017; Linder et al., 2018). During the Digital Storytelling Workshop Experience Discussion, research partners gave feedback that digital storytelling could be used as a therapeutic approach for pediatric sibling donors before and after donation to help them process some of the complex emotions experienced during HSCT donation. Digital storytelling may help children, youth and young adults ruminate over potential growth and gains experienced (de Jager et al., 2017). While draw-and-tell interviews have been used in the past (Driessnack, 2006; Foster & Whitehead,

2019; Linder, et al., 2018; Rollins, 2005), this study explored the effectiveness of digital storytelling as a storytelling approach for pediatric sibling donors. Digital storytelling has significant potential for use in clinical practice with families and siblings who are facing pediatric HSCT donation and may be one approach that could assist sibling donors in sustaining their hope across HSCT, which was identified by sibling donors in this study as central to their experiences of meaning and growth across HSCT.

A further strength of this study was the use of participatory methodology (Coyne & Carter, 2018) where research partners collaborated on the analysis of the digital stories of HSCT sibling donation experiences. This allowed research partners to share their thoughts and ideas (United Nations, 1989) and contribute meaningfully to the findings, as well as work together to describe the main themes that were identified about the pediatric sibling donor experience. The process went smoothly, and the siblings were highly engaged; the research partners identified six main themes, which were not further analyzed to respect research partners' capability to interpret their own created data and that of other sibling donors (Coyne & Carter, 2018; United Nations, 1989). There is an ongoing debate among researchers who use arts-based methods in research with children over who should analyze the data created by the children - the children or the researchers (Driessnack, 2005; Driessnack, 2006). Some researchers choose to analyze the final artistic product to address their research questions and objectives, for example, Bryan et al. (2019) used draw-and-tell techniques with children with leukemia in a hospital but chose to rate drawings in terms of how relevant they were to the illness experience using 0-4 scoring criteria which was applied by the researcher. Packman et al. (1998; 2003) had art therapists apply scoring systems to Kinetic Family Drawings and Human Figure Drawings created by siblings of pediatric hematopoietic stem cell transplant recipients, to assess their emotional distress.

In contrast, some researchers believe they do not have the right to analyze these artistic expressions, and if they are analyzed at all, it should be done by the artist, as Foster and Whitehead (2019) described that "interpretations of the drawings" were "undertaken in synergy with the child's description of the drawing to limit the likelihood of false inferences" (p. 105) and that "the child's description and interpretation of the drawings in conjunction with the content of the drawing are what comprised the data" (p. 113). Further, Driessnack (2005; 2006) stated that "most analysts have approached children's drawings through direct methods of interpretation, focusing entirely on the researcher's or clinician's interpretation rather than on the child's explanation of what the drawing means" (2006, p. 1415). In research exploring children's drawings of fear, Driessnack (2005) chose not to share the drawings as part of the dissemination of data.

I would side with researchers who do not analyze children's artistic creations. I believe that children have the right to own and hold a unique voice to interpret the art they create, grounded in my adoption of the UNCRC. Through this framework I believe that children have agency, ownership, and a right to their stories and creations (United Nations, 1989) which are accepted as the truth, and do not require further analysis to generate meaning.

It is important to note that the study was significantly strengthened by the digital stories created, making them ideal for knowledge dissemination (de Jager et al., 2017). The short and engaging nature of digital stories allow them to be easily shared with a variety of diverse populations (de Jager et al., 2017). Research partners have been invited to participate in future presentations, however, during the *Data Analysis Meeting* (Meeting Three), research partners were unsure about who they wanted to share the findings with, and whether they wanted to be involved in the dissemination process. Nonetheless, it was important to offer them this choice, and they will be

offered the chance to participate again in the future. Four research partners have given me permission to share their digital stories publicly (Goodman, 2013). These stories are expected to be impactful and meaningful and will hopefully present the experiences of pediatric sibling donors in a compelling manner.

Another strength of the research lies in its interdisciplinary approach. As a child development specialist with research experience in the field of children's rights, I have worked to provide research partners with autonomy to express their views and opinions (Article 12, United Nations, 1989). I provided research partners with a comfortable working environment and space to work on their digital stories, they were given the choice to decide the content of their stories, and their participation was confirmed verbally multiple times. Additionally, they also had the opportunity to actively participate in the data analysis process. To respect their capability and competence, the data analysis findings related to the digital stories were not further analyzed by me but were deemed valid as analyzed by the research partners themselves (Driessnack, 2006). This approach was explicitly guided by the principles of participatory methodology (Coyne & Carter, 2018) and the United Nations Convention on the Rights of the Child (United Nations, 1989).

Using arts-based methods in the context of children's illness experiences, in combination with a focus on child rights and participatory methodology, offers a unique and multi-layered perspective that has led to these insightful findings by research partners and through other aspects of my analysis.

Limitations of this Study

There are inherent limitations which I have identified for this research study. Firstly, although this study was described as being guided by participatory methodology (Coyne &

Carter, 2018), the research partners were not involved in all the decision-making processes: they were not involved in developing the research questions, data collection methods, the sequence of data collection, or decisions regarding documentation of the data (ie., researcher field notes, transcription of some meeting elements). Given that I lacked previous experience with participatory research with children and youth and this was a doctoral study with time limitations, I had to carefully consider which aspects of the research could be fully participatory and which required a more structured approach to ensure the success of the doctoral research project. These inquiry decisions also carefully considered the time and energy of the research partners, as participatory research demands time spent together fostering a sense of community.

Most participatory research with children and youth is not fully participatory but instead provides numerous opportunities for children and youth to actively participate, and for their voices, opinions, and ideas to be taken seriously (Coyne & Carter, 2018). The approach aligns with Hart's (1992) ladder of participation, which encourages researchers to engage with children on the three highest levels of the ladder, reflecting the intentions of Article 12 within the UNCRC: "adult-initiated, shared decisions with children," "child-initiated and directed," and "child-initiated, shared decisions with adults" (p. 22). Therefore, my goal was to adhere to the level of participation described as "adult-initiated, shared decisions with children" (Hart, 1992, p. 22), as the research partners had input on meeting dates, times, and had complete control over their digital story content, as well as the meaningful contributions they made to the collaborative development of findings from the data analysis of four of the digital stories.

I want to note knowledge I gained through this experience: even when opportunities for full participation in research are offered to children and youth, they may still choose not to participate. Before conducting this research, I thought that offering a fully participatory

experience was the ideal approach, representing the highest level on Hart's (1992) ladder of participation. I believed that if I did not provide this level of participation to my research partners, I would fail to deliver a rights-based and participatory experience. However, upon reflection, I realized that children's and youth's interest in participation depends on several factors, including their temperament, personality, comfort level, the sense of community within the group, and their previous experiences with opportunities to participate, collaborate, or contribute. Hart's ladder of participation (1992) presents a simplistic and hierarchical perspective on children's involvement in research. It fails to encompass the full range of participation options available. In contrast, more contemporary models, such as Sheir's (2001) pathways to participation and Lundy's (2007) framework outline the essential elements for child participation and provide a more flexible guide for researchers working with children. Simply offering opportunities for participation does not guarantee that children and youth will engage; what I discovered is that it is crucial to present children with choices. While they may not decide the data collection method, providing a variety of options can encourage their involvement. For example, in this research, we used digital storytelling, but offering children the opportunity to draw, write a song, or compose a poem or story could create more comfortable avenues for participation. I appreciated gaining this insight, as it emphasized the spectrum of participation rather than the idea of full participation. This understanding allows us to engage and invite children to participate in ways that feel safe, comfortable, and exciting for them.

The second limitation is a bias in the recruitment approach. I appreciated the help of the nurses in the pediatric blood marrow program who personally reviewed the sibling donor database for participants who met eligibility criteria. During this process, they carefully considered past sibling donors who may be interested in participating and then contacted these

families. This approach meant that participants were not purposively chosen and may have felt some pressure from the pediatric nurses who may have been with them through their donation and their family's HSCT journey. It is important to note that the pediatric nurses only contacted the families to inquire about their interest in hearing more information after they received a letter of introduction from the medical program director, myself and my advisor. They were not involved in explaining the study to potential sibling donor participants, or other aspects of the recruitment process. However, this process remains a bias, as I am uncertain how the pediatric blood and marrow program nurses made their selections when going through the database for example if they took into consideration age, gender, time since donation or if their ill sibling recovered after donation. Regardless, to ensure the privacy of children and families who go through the HSCT journey, the nurses need to be the gatekeepers of this information and made the selection of potential sibling donors based on the inclusion and exclusion criteria identified for this study. If possible, I would explore the option of recruiting pediatric sibling donors from a facility where I feel more comfortable and have greater professional connections, such as a child care centre or school.

In connection with the sampling bias, there was also a limitation in the age range of pediatric sibling donors who participated. The age requirement for participants in this study was 7 to 18 years old at the time of donation. However, because some research partners donated 5 years prior to study enrollment, two of them were over 18 years old, and the age range of research partners was 12 to 21 years old. I was hoping to gather experiences from a wide range of children to identify any differences or similarities based on age. Additionally, I have more experience working with younger children and wanted to give voice to their experiences because often, younger children are not considered capable of sharing valid experiences (United Nations,

1989). I also wonder how the finished digital stories might vary creatively based on age. The four digital stories that research partners granted permission to view in the *Data Analysis Meeting* (Meeting Three) followed a similar story arc, but perhaps a variety of ages would produce different artistic expressions of the pediatric donor experience.

Another limitation was that all siblings of the research partners physically recovered after the transplant. As a result, each digital story concluded with the positive recovery of their ill sibling. The perspective of the pediatric sibling donor whose ill sibling does not recover is not present in these stories or reflected in the themes. Therefore, these findings do not represent the full spectrum of experiences for pediatric sibling donors, especially psychosocial risks such as guilt and blame, throughout the donation experience and in relation to the death of an ill sibling post-HSCT.

I do think it is also relevant to propose that it may have been a limitation that I am not a registered nurse and have never worked as a pediatric nurse with children, youth and families through the HSCT journey. I have delved into the literature regarding the pediatric sibling donor HSCT experience and learned medical terms, but I do not have formal education in nursing theory or practice. I found aspects of this dissertation that required medical information or reflections challenging to write. Though I have extensive education about children's rights and development, and extensive experience working with children, I want to acknowledge that not being a nurse may be a bias in this work and this dissertation writing. However, the other side of this is that not being a nurse may have led me to ask different research questions, choose different methods/methodology and see perspectives that a nurse or other health care professional may not have.

Recommendations for Future Research, Practice and Policy

Recommendations for Practice and Policy

The study findings confirm that pediatric sibling donors develop growth and positive gains from their donation experiences, as found in previous literature (D'Auria et al., 2015; Erden et al., 2019; Hoag et al., 2018; Hutt et al., 2015; MacLeod et al., 2003; Packman et al., 1998; Pelletier et al., 2014; Pentz et al., 2014; Wilkins & Woodgate, 2007; Rinaldo et al., 2022; Winther Klippenstein et al., 2022). In this study, research partners described an intense desire to save their ill sibling with their donation, supported by a strong sense of hope. Therefore, it is recommended that psychosocial support services before and after donation within pediatric blood and marrow transplant be re-imagined from a strength-based perspective, to support the positive, growth-based aspects of pediatric sibling donation (Winther Klippenstein et al., 2022). Additionally, the integration of arts-based approaches such as digital storytelling can be highly effective in giving children and youth the space and modality to express aspects of their experiences which are not shared or communicated. HSCT sibling donation may help promote personal and relational growth for sibling donors, which could significantly contribute to their overall well-being. The work highlights the need for a balanced perspective on psychosocial growth, as well as potential distress in clinical practice.

An additional recommendation for practice is that sibling donors could view previous donor's digital stories about their experiences before donating. This could help anticipate what they can expect during the process and normalize the complex emotions sibling donors experience. Health care professionals may also use digital storytelling as a tool to support siblings in expressing their fears and anxieties about the treatment process, as well as the sources of support that are important to them as they experience donation (Heiney et al., 2002). The use

of digital storytelling is not limited to pediatric siblings who become stem cell donors. It can also be beneficial for children and youth undergoing other medical procedures or facing diagnosis and/or treatment for serious illness. Digital stories can be easily created on an iPad using the iMovie app, allowing children and youth to engage in storytelling while in the hospital or at home for the processing of medical information and human experiences of illness which may include psychosocial distress and/or growth. Health care professionals in pediatrics could receive training in digital storytelling through Story Center (storycenter.org) and then share this knowledge with colleagues or facilitate digital storytelling with pediatric patients. This creative, artistic expression could become a valuable practice with children and youth trying to make sense of medical information, process complex and painful emotions, and maintain a positive or hopeful outlook during serious pediatric illness. By using the positive experiences of sibling donors as an example, hospitals could integrate digital storytelling into the range of artistic expression opportunities available to children and impacted by serious illness. Further, digital storytelling may assist children in expressing and sharing their illness experiences with family members and promote shared and supportive decision-making processes in pediatric serious illness.

Recommendations for Future Research

The findings of the study emphasize the importance of researchers utilizing qualitative, arts-based, participatory methodologies to foster relationships, facilitate dialogue, and give voice to siblings within the research process (Coyne & Carter, 2018). The study received positive feedback from sibling donors who participated as research partners and created digital stories about their donation experience which suggests that expressive art methods, such as digital storytelling may provide an engaging and creative form of expression for pediatric sibling donors to share their experiences of psychosocial distress or growth.

Previous studies on the experience of pediatric sibling donors have generally used qualitative methodologies, such as grounded theory (D'Auria et al., 2015; MacLeod et al., 2003; Pentz et al., 2012), hermeneutic phenomenology (Wilkins & Woodgate, 2007), or thematic content analysis (Pelletier et al., 2014; Stegenga et al., 2019; White et al., 2017; Wiener et al., 2008). Using participatory and arts-based research methodologies (Coyne & Carter, 2018) would enhance the developmental sensitivity of available research evidence. Children can easily recall and communicate information through hands-on, interactive, and creative activities that engage their senses, such as painting, drawing, symbolic play, or digital storytelling (Linder et al., 2018).

It is important to explore how digital storytelling can be used to help understand and support the feelings of potential pediatric sibling donors before and after donation. Previous research has shown that sibling donors often feel fear about the potential pain of donation, and this fear is worsened by a lack of information from healthcare professionals about the donation process (Hoag et al., 2018; MacLeod et al., 2003; Packman et al., 1997a, 1997b; Rinaldo et al., 2022; Wiener et al., 2008; Wilkins & Woodgate, 2007). In this research, Oba suggested that viewing digital stories about the pediatric sibling donor experience would be helpful for potential sibling donors who are unsure whether they want to participate or not. Maybe if potential pediatric sibling donors could watch digital stories beforehand, it could give them information about the process, help them understand the emotional journey, and allow them to connect with others who have been sibling donors. This connection could make potential sibling donors feel less alone and give them a sense of hope during the HSCT process.

If I were to continue this research with pediatric sibling donors, I would have a couple clear goals. The first suggestion is to conduct a fully participatory study involving children and youth who have been sibling donors. This would involve collaborating with children and youth and

giving them the opportunity to make decisions about every aspect of the research process. It would require a longer research commitment and the genuine interest and engagement of the research partners. However, this approach would enable children and youth to be fully involved in research about themselves and their lives (Coyne & Carter, 2018). Secondly, I would try to engage younger children. I believe it would be impactful to involve younger sibling donors, specifically those aged 5 to 12 years, and encourage them to share their stories. This age group was absent from the creation of digital story themes, and it would be valuable to gain insight into the perspectives, views, and thoughts of younger sibling donors regarding their donation journey.

The study also invites the opportunity to further explore the use of digital storytelling as an approach to help children and young adults to process their thoughts and feelings prior to and/or following medical procedures. Given that digital stories are easy to make with the use of only an iPad, they are an accessible, creative way for children and young adults to express themselves and tell their stories (de Jager et al., 2017; De Vecchi et al., 2017; Goodman, 2013; Wilson et al., 2015). It would be interesting to further explore the outlets that children and young adults currently use to process and express their medical journeys. Additionally, it would be beneficial to investigate whether digital storytelling could be a helpful approach for them to share their stories while they are in the hospital and after. It would also be helpful to better understand at what point during the medical process creating digital stories would be most meaningful and potentially therapeutic, and how to facilitate opportunities to create them.

Knowledge Dissemination

The findings from the research will be disseminated through conference presentations and publications in peer-reviewed professional interdisciplinary journals. Two conferences I am especially keen to present at are those hosted by the *Canadian Association for Psychosocial*

Oncology and *The International Society of Paediatric Oncology* annual conferences, which would include health professionals who work with children and families experiencing HSCT. I also believe that the findings around participatory, arts-based research with children would be relevant at the *Early Years Conference*, at the University of British Columbia, for professionals or researchers who work with children, to encourage and provide guidance related to the use of participatory, arts-based methods in care.

As a recipient of a 2021-2022 Research Manitoba PhD Health Studentship in partnership with the Children's Hospital Research Institute of Manitoba (CHRIM), I am encouraged to present at weekly "Research Rounds" to share this project with fellow CHRIM researchers. Additionally, as a student in the Department of Community Health Sciences, this research will be shared through the weekly "*Bold Ideas Colloquium Series*", which showcases research to encourage scholarly thinking and potentially expand professional networks.

During the final meeting with research partners, I asked them to share their ideas and thoughts on how to disseminate the findings of our research. We discussed the possibility of sharing the findings with specific healthcare professionals or other potential sibling donors. One idea was to present the findings to healthcare professionals within the local Blood and Marrow Transplant Program. To recognize the rights-based (United Nations, 1989), participatory methodology (Coyne & Carter, 2018) of this research, and ensure that research partners have a voice in how the findings are shared, research partners will be invited to attend and participate in these presentations, and if they would like, they can share their digital stories.

Finally, as an instructor of Early Childhood Education, these findings can be disseminated when relevant through course content to students, who work with children and families in Manitoba. The information within these findings may provide students with

knowledge and understanding about how to support families, including siblings, who are facing a variety of health crises. I feel that the variety of dissemination opportunities, within healthcare and early years education, reflects the interdisciplinary aspect of this study. I aim to reach a broad group of researchers, educators, and professionals who work with children in different capacities. I hope in the future to disseminate these findings within a digital story, to mirror the creative, inviting and innovative method to share findings.

Conclusion

In previous research on pediatric HSCT donor siblings, a significant limitation has been the use of data collection methods that may have limited the ability of children and youth to fully express their donation experiences (Winther Klippenstein et al., 2021). Within this doctoral research, I worked to recognize sibling donors as research partners in the inquiry process using arts-based, participatory research methodology (Coyne & Carter, 2018) and the UNCRC (United Nations, 1989). My aim was to provide sibling donors with ownership over the research process in which they shared their donor experiences. Within the study, sibling donors were invited to be research partners not research participants; this reflected their significant role and agency in this research, were supported in creating their own digital stories about their donation experience and contributed to the shared data analysis process with the researchers (AWK, CHW) and other sibling donors. Through a collaborative data analysis process, research partners identified six themes that described the experiences of pediatric sibling donors including: *Pessimism and Acceptance, After Procedure Thoughts, Sibling Support, Family Experience, Connections*, and *Hope*. As well, through discussions with research partners about the participatory experience of creating DS with other pediatric sibling donors, and research reflections through field notes written by Dr. West and myself, I used interpretive description methodology (Thorne, 2008;

Thorne, 2016; Thorne et al., 2004) to identify four additional themes related to the sibling donors' experience of creating a digital story: *Sense of Community and Connection, Digital Storytelling - New and Fresh, Therapeutic Reflection* and *Privacy.*

Exploring the voice of siblings through arts-based, participatory approaches can help clinicians, family members, and researchers gain new perspectives on how to support sibling donors and their families. Digital storytelling has untapped potential for use in clinical practice with families and siblings facing pediatric HSCT donation. Engaging, arts-based approaches such as digital storytelling hold the potential to facilitate the expression of voice and illuminate experiences of growth and strength in the context of sibling donation. When children and young adults' rights are recognized and fulfilled in research spaces, they are given opportunities to share their experiences as competent, capable, and equal partners, and may feel more comfortable sharing their authentic experiences. This research also highlights the predominance of gains and growth experienced by research partners who were pediatric sibling donors and have highlighted the importance of supporting sibling donors to sustain hope across the HSCT treatment process.

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Appendix A: Review of Literature

A review of the literature: The experiences of pediatric sibling hematopoietic stem cell donors

Table 1 General characteristics of studies exploring pediatric sibling donors of HSCT

Author	Country	Sample Size (transplant status)	Methodology	Measures
1. D'Auria, Fitzgerald, Presler & Kasow (2015)	Canada	8 sibling donors (successful)	Qualitative	Semi-structured, open-ended interviews
2. Erden, Kuskonmaz,Cetinkaya, Unal & Oszungur (2019)	Turkey	30 HSCT recipients; 20 donors; 30 nondonors	Quantitative	Kiddie Schedule for Affective Disorders and Schizophrenia (K-SADS) Children's Depression Inventory State-Trait Anxiety Inventory for Children State-Trait Anxiety Inventory Rosenberg Self-Esteem Scale Hollingshead-Redlich Scale
3. Hoag, Igler, Karst, Bingen & Kupst (2018)	USA	9 sibling donors (6 successful; 3 unsuccessful)	Mixed methods	Semi-structured interview The Child Behavior Checklist (ages 6-18) Youth Self-Report (ages 11-18) Adult Self-Report (age 18-59) The Ways of Coping Questionnaire The Network of Relationships Inventory The Faces of Pain Scale Revised
4. Hutt, Nehari, Munitz-Shenkar, Alkalay, Toren & Bielorai (2015)	Israel	36 sibling donors, 50 parents of pediatric patients	Quantitative	Questionnaires: Donor's attitude questionnaire regarding stem cell transplant Parent's attitude questionnaire regarding the sibling donor experience
5. MacLeod, Whitsett, Mash & Pelletier (2003)	Canada	15 sibling donors (8 successful; 7 unsuccessful)	Qualitative	Interviews

6. Packman et al. (1997a; 1997b; 1998; 2003; 2004)	USA	44 siblings; 21 donors, 23 nondonors (all successful)	Mixed methods	Semi-structured, forced-choice and open-ended interviews using: The Revised Children's Manifest Anxiety Scale The Child Depression Inventory The Rosenberg Self-Esteem Scale Child Post-Traumatic Stress Reaction Scale Kinetic Family Drawing Revised Human Figure Drawing
7. Pentz et al. (2014)	USA	T1= 12 sibling donors T2= 12 sibling donors T3= 10 sibling donors	Mixed methods	Interviews The Satisfaction with Decision Scale Decision Regret Scale
8. Switzer et al. (2016)	USA	105 pediatric: 5-7 years= 19; 8-12 years= 45; 13-18 years= 41	Mixed methods	The Pediatric Quality of Life Inventory Health Related Quality of Life Open-ended question (parents)
9. Wallace et al. (2014)	USA	3 sibling donors; 27 nondonors	Mixed methods; intervention vs. control group	Medical Characteristic Revised Children's Manifest Anxiety Scale- Second Edition Piers-Harris Children's Self-Concept Scale- Second Edition UCLA PTSD Index for DSM-IV McMaster Family Assessment Device Creation of Art (not scored)
10. Wiener et al. (2008)	USA	14 sibling donors: 11 siblings living (3 recipients deceased)	Qualitative	Retrospective interviews
11. Wilkins and Woodgate (2007)	Canada	8 siblings: 3 donors; 5 non donors (all recipients living)	Qualitative	Semi-structured, open-ended interviews

Appendix B: Parents' or Legal Guardian Informed Consent

Andrea Winther Klippenstein, M.Sc., B.HEc., B.A.
Interdisciplinary PhD Candidate
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89 Curry Place
University of Manitoba
Winnipeg, Manitoba
Canada R3T 2N2
umwinthe@myumanitoba.ca

PARENTS' OR LEGAL GUARDIANS' PEDIATRIC INFORMED CONSENT

Study Title: Empowering Pediatric Sibling Hematopoietic Stem Cell Donor Voices through Digital Storytelling

Principal Investigator: Andrea Winther Klippenstein, M.Sc., B.HEc., B.A.
Interdisciplinary PhD Candidate
College of Nursing
Department of Community Health Sciences
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Co-Investigators: Christina H. West, RN, PhD
Associate Professor
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Dr. Javier Mignone, PhD
Associate Professor

Department of Community Health Sciences

University of Manitoba

Email: Javier.mignone@umanitoba.ca

Dr. Shannon Scott, RN, PhD

Professor, Canada Research Chair for Knowledge Translation in

Child Health

Faculty of Nursing

University of Alberta

Email: shannon.scott@ualberta.ca

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what participation will involve. Participation is voluntary and declining to participate will have no negative consequences. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

WHAT IS THE PURPOSE OF THIS RESEARCH?

The purpose of this qualitative study is to use a child rights-based, participatory research approach to understand the experience of pediatric sibling hematopoietic stem cell donation through the arts-based method of digital storytelling (the creation of a 3–5-minute video story using photographs, drawings, a recorded written story, and/or music). Adopting a child rights, participatory focus means brother/sister donors will be invited to be research partners, which means they will actively participate in decisions about the creation of their digital story and will be invited to help us understand what the digital stories created say about the experience of being a sibling donor. Throughout the study, sibling donor research partners will have choices and opportunities to contribute their thoughts, ideas and opinions, which will impact how the study unfolds.

WHAT WILL MY CHILD BE ASKED TO DO, IF THEY PARTICIPATE IN THIS RESEARCH?

Each child/young adult who participate in this research, will be asked to participate in three meetings:

Meeting One - 'Getting to Know You' Meeting: Andrea will arrange a meeting with all research partners (sibling donors). To learn more about each participating child/young adult, she will ask them to participate in two 'get to know you' activities. During this meeting, she will also review the Digital Storytelling Workshop Guide and Plan (Meeting Two) and the Analysis Meeting Plan (Meeting Three). Andrea will review the different aspects of a digital story (ie. photographs children have or choose to take with an iPad, drawing a picture). Andrea will also talk about how each child/young adult can start writing their story in preparation for the digital storytelling workshop (Meeting Two).

Meeting Two - Digital Storytelling Workshop: In our second meeting, research partners (sibling donors) will be supported in creating their own digital story about their donation experience. This workshop will be facilitated by Andrea and Tina (Dr. Christina West) and will be 6 hours in length. After creating their digital story, participating brothers/sisters will be invited to explore together what it was like to create their digital stories with other research partners. With their permission, our conversation about brothers/sisters' experiences of creating a digital story will be audio-recorded with a digital recorder. Research partners will be given snacks and a pizza lunch during this workshop. Child/young adult research partners can choose whether they would prefer to attend this meeting alone or with their parent/caregiver present.

Meeting Three - Making Sense of what the Digital Stories Say About Sibling Donation in BMT: Research partners will be invited to share their digital stories with the other participating brother/sister donors, and to participate in determining the meaning of the created digital stories (what we learn about sibling donation from the digital stories). Important ideas identified by research partners will be grouped together using Post-it notes and partners will share their thoughts on the groupings. With the permission of brothers/sisters, this meeting will be audio-recorded with a digital recorder. At the end of Meeting Three, Andrea will present her initial thoughts about what she is learning from the researcher patterns. Finally, Andrea will ask research partners' ideas about how we should share the learnings from this project with other families, brothers/sisters, researchers and/or health care professionals. This meeting will take approximately 3 hours, and a morning snack will be provided. Child/young adult research partners can choose whether they would prefer to attend this meeting alone or with their parent/caregiver present.

Andrea will complete detailed field notes related to interactions with research partners during and following Meetings One to Three.

Pandemic guidelines/restrictions: Due to the evolving nature of the COVID19 pandemic, if there are safety concerns regarding gathering in person, or if child/young adult research partners would prefer to meet virtually, then data collection will occur via Zoom rather than in a room at the Helen Glass Centre for Nursing, University of Manitoba.

All meetings and the digital story creation are voluntary. Your child/young adult can decline to participate in any of the discussions and/or activities at any time throughout this research study.

WHAT ARE THE RISKS?

Your child/young adult may become upset or distressed as they recall their donation experience during group discussions and digital story creation within this research project. If they become upset, the researcher(s) will ask if they would like to end participation. If this happens, and they would like to talk to someone about this, there is support available from the Manitoba Blood and Marrow Transplant Program (MBMT). Please call (204) 787-4918 (direct line) or (204) 787-7095 (Pediatric Clinic) to speak to a BMT nurse in the pediatric outpatient clinic at CancerCare Manitoba. Andrea or Tina are also available to refer your child to this clinic for support.

ARE THERE ANY BENEFITS IN PARTICIPATING?

If you agree to participate in this study, there may or may not be a direct benefit to you. The understanding gained in this study may help guide health care professionals in how to better support child/young adult siblings who become donors. As well, this is a participatory study where these sibling donors are research partners and have the opportunity to actively make research decisions while also telling their donation story in a creative, hands-on way.

DOES MY CHILD/YOUNG ADULT HAVE TO PARTICIPATE?

Participation in this study is completely voluntary. Even if your child/young adult decides to participate, they may withdraw at any time and/or refrain from answering any questions they prefer not to answer, or from participating in any arts activity. Assent will be continually sought across the research process.

Your child/young adult may withdraw from the study by speaking to one of the researchers in person, or by contacting one of them by phone or email (contact information for the researchers is at the top of this consent form). In the event your child/young adult withdraws from this study, you and your child/young adult can choose what happens with the information already given the researchers. You can choose to: 1) still have the information included in the research study, or 2) have the information that was recorded or collected destroyed through permanent deletion or using a confidential shredding service at the University of Manitoba.

HOW WILL THE RESEARCH FINDINGS BE SHARED WITH RESEARCHERS, HEALTH CARE PROFESSIONAS, AND OTHER CHILDREN/FAMILIES?

The findings from this study may be presented at a health conference and/or to health care professionals/families interested in this research at health care/education facilities or may be published in a professional journal. In these instances, full name would not be discussed or revealed to anyone. Children/young adults will have the choice of using their first name, or a

pseudonym. Your child/young adult will retain full control over their digital story and we will not use it in a presentation or research article without their explicit verbal permission.

WILL MY CHILD/YOUNG ADULT BE PAID FOR PARTICIPATING, OR WILL I HAVE TO PAY FOR ANYTHING?

Your child/young adult will receive a $150 honorarium for participating. Because they are considered 'research partners' in this study and members of the research team, it is important that this active role is recognized and compensated. The honorarium will also cover any costs you might incur, such as parking or transportation costs.

WILL RECORDS BE KEPT PRIVATE?

All information that your child/young adult provide will remain confidential. Confidentiality will be maintained at all times except in situations in which there is a legal requirement to disclose (i.e., abuse situations). The researcher would then be legally required to notify the appropriate authority. Please note, that if your child/young adult includes any identifying information in their digital story, this may make them identifiable in the event that it is shared in a research presentation. We will carefully discuss ways for child/young adult research participants to keep their identity private in the digital storytelling workshop.

The Meeting Two (discussion about research partners' experiences with making a digital story about sibling donation) and Meeting Three (Making Sense of what the Digital Stories Say About Sibling Donation in BMT) discussions with sibling donor research partners will be transcribed from the digital recordings to a word document. Sibling donor research partners will be given the opportunity to either use their first names or choose a name that will represent their contributions. We do acknowledge that some people will feel strongly that their real first name should be used and we will respect your child/young adults' wishes. If your child/young adult choose to remain anonymous, we will ask your child/young adult to choose a name that they feel comfortable with that we can use when referring to their contributions. Only members of the research team will have access to the information obtained during this research study. Full names will not be on any research data but will have been replaced by a study number and the name that has been chosen to acknowledge each child's/young adult's contributions.

As well, Andrea will be taking field notes throughout her interactions with sibling donor research partners. In these field notes, only first names or chosen names will be used to identify participants.

During this research study, all data collected in Manitoba will be stored in a locked filing cabinet password protected computer, or shared drive created by the University of Manitoba which will only be accessible by Andrea and her advisor, Dr. Christina West. Once this research study is completed, all information provided will be stored in a locked filing cabinet, stored in a secure, password protected computer, or in a shared drive created by the University of Manitoba which will only be accessible by Andrea and her advisor, Dr. Christina West. In March 2027, all data

will be destroyed using electronic deletion and the confidential shredding services at the University of Manitoba.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your child/young adult's participation in the research project and agree to their participation as a research subject. In no way does this waive their legal rights, nor release the investigators, or involved institutions from their legal and professional responsibilities. Your child/young adult is free to withdraw from the study at any time, and/or refrain from answering any questions they prefer not to, or to refrain from any activities without consequence. Your child/young adult's continued participation should be as informed as during the initial parent/legal guardian consent/assent process, so you should feel free to ask for clarification of any new information throughout participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. If you have further questions concerning matters related to this research, please contact:

Andrea Winther Klippenstein, M.Sc., B.HEc., B.A., College of Nursing, Rady Faculty of Health Sciences, University of Manitoba at umwinthe@myumanitoba.ca.

This research has been approved by the Research Ethics Board 1 at the University of Manitoba. If you have any questions or concerns about this research you may contact the Human Ethics Coordinator at (204) 474-7122, or by email at: humanethics@umanitoba.ca.

_____	_____
Parent/Guardian's Name	Signature and Date
_____	_____
Parent/Guardian's Name	Signature and Date
_____	_____
Child's Name	Signature and Date
_____	_____
Researcher and/or Delegate's Name	Signature and Date

Andrea will, as appropriate, explain to your child/children the research and his or her involvement. Your child/young adult will also complete a pediatric assent form. Andrea will check with your child on an ongoing basis to confirm that they wish to continue to participate.

If you wish to receive a summary of the research results, please leave your email address or other preferred means of contact below. This information will be stored separately from the research data. A summary of the research results will be sent to you as soon as it is available, following completion of the research study.

_____ We would like to receive a summary of the research results

Contact Information:

Appendix C: Pediatric Assent Form

Andrea Winther Klippenstein, M. Sc., B.HEc., B.A.
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PEDIATRIC ASSENT FORM FOR CHILDREN AND YOUNG ADULTS

(7-17 years of age)

Study Title: Empowering Pediatric Sibling Hematopoietic Stem Cell Donor Voices through Digital Storytelling

Principal Investigator: Andrea Winther Klippenstein, M.Sc., B.HEc., B.A.

Interdisciplinary PhD Candidate

College of Nursing; Dept of Community Health Sciences

Rady Faculty of Health Sciences, University of Manitoba

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Co-Investigators: Christina H. West, RN, PhD

Associate Professor

College of Nursing

University of Manitoba

Email: christina.west@umanitoba.ca

Javier Mignone, PhD

Professor

Department of Community Health Sciences

University of Manitoba

Email: Javier.mignone@umanitoba.ca

Shannon Scott, RN, PhD

Professor, Canada Research Chair for Knowledge Translation in

Child Health

Faculty of Nursing

University of Alberta

Email: shannon.scott@ualberta.ca

I, _____, state that I am ___years of age and wish to take part in this project exploring the experiences of brothers and sisters who have been blood and marrow (BMT) donors for their brother or sister. I was a sibling donor ____years ago. I understand that as a research partner in this study, I will be asked to create a digital story about my donation experience. I can choose with whom and how I share the digital story I create. I also understand that I will be a research partner invited to help share my ideas and make some decisions in this study.

I understand that if I decide to be a part of this project, I will be asked to participate in three meetings:

Meeting One - 'Getting to Know You' Meeting: Andrea will arrange a meeting with me and the other research partners (brothers/sisters who have been donors). To learn more about me, Andrea will ask me to participate in two 'get to know you' activities. In this meeting, Andrea will also go over the digital storytelling workshop guide and plan and the analysis meeting plan. Andrea will explain the different choices I might make for my digital story (ie. photographs I have or choose to take, drawing a picture). She will talk with me about how I can start writing my story to prepare for the digital storytelling workshop.

Meeting Two - **Digital Storytelling Workshop**: The second time we meet, I will bring my photographs and written story, and Andrea and Tina (Dr. Christina West) will help me create my very own digital story. I understand this meeting will take about 6 hours, and I will be given snacks and a pizza lunch. I will be invited to explore with the other research partners (brothers/sisters who have been donors) what it was like to create our digital stories in this workshop. I understand that Andrea will audio-recorded our conversation about what it was like

to make a digital story near the end of the digital storytelling workshop (with a digital recorder). I can choose to come to this workshop alone or with a parent or caregiver.

Meeting Three: Analysis Meeting: I will be invited back to share my digital story with the other brothers/sisters who have been donors, and to help with identifying big ideas and thoughts from watching the digital stories that have been made. These big ideas and thoughts will be grouped together using Post-it notes. I understand that our conversation about the digital stories we have made will be audio-recorded with a digital recorder. At the end of Meeting Three, Andrea will share some ideas/thoughts from earlier meetings, to see if I agree/disagree with what she is thinking about this project, and to offer anything important that I think Andrea has missed. Finally, Andrea will ask me for my ideas about how we should share what we have learnt together in this project. I understand I can attend alone or with a parent or caregiver. This third meeting will last around 3 hours and Andrea will provide a snack.

If I participate, I will receive $150 honorarium to thank me for my time and contributions to the project.

I understand that the researchers will ask me to create a digital story about my donation experience. I will be provided with an iPad so I can make take pictures for my digital story. I understand that if I have my own iPad, I am welcome to use it for this project. I also understand that at the end of this project I will need to return the iPad to Andrea. If I say it's okay, Andrea will be able to show my digital story to other families, researchers, or health care professionals so that they can better understand what it is like for brothers/sisters to be a BMT donor. I understand that I will keep my digital story and will have ownership and control over my story. Andrea and the other researchers will not show my digital story without first asking my permission.

I understand that my full name will never be used in this project, to protect my privacy. I can choose to use my first name or create a name I would like to use to represent my contributions to this project and the digital story I make.

I understand that I will be invited to share my ideas of who I would like to share the findings of this project with and will be invited to attend or participate in these presentations, if I would like to do so. I can also choose not to attend or participate in these presentations.

I understand that taking part in this project is my choice, and if I decide not to be in the project, no one will be upset with me. Even if I first decide to be in it, I can still quit at any time. I can quit by telling Andrea, Tina, or my parent/caregiver. I understand that if I quit, I can decide if I want my digital story to still be used in the project. If I don't want my digital story to be a part of the project anymore, I understand that the copy Andrea has of my digital story will be deleted (destroyed). If I quit, I can choose to keep my digital story, or have the researchers destroy it.

I understand that nothing in the study will be done to me that could hurt me. However, if I become sad, upset or feel overwhelmed I can ask for help or to talk to my parents or someone else.

I understand that Andrea and Tina may write a paper or give a talk about what they learned so that others can also learn more about how children and young adults experience actively participating in projects and using digital storytelling to help brothers/sisters tell their stem cell donation stories. I understand that in any paper or talk, the name that I choose will be used.

I understand that if I have any questions about the project at any time, I can ask Andrea or Tina or my parent(s)/caregiver(s). I understand that it is up to me if I want to be in this project.

Yes ☐ No ☐ I agree to participate in this project and create a digital story about my experience being a BMT donor.

Yes ☐ No ☐ I agree to participate in this project as a research partner, and to attend a meeting where I will be asked my ideas about the digital stories that have been made in this project by other BMT donors (children and young adults).

Yes ☐ No ☐ I agree be asked questions about how I think what was learned in this project should be shared with other families and doctors/nurses who are interested in what BMT is like for brothers and sisters who donate.

_____	_____
Child's Name	Signature and Date
_____	_____
Researcher and/or Delegate's Name	Signature and Date

Would you like to hear about what we learned from this project after we are finished?

Yes ☐ No ☐

Appendix D: Adult Informed Consent

Andrea Winther Klippenstein, M.Sc., B.HEc., B.A.
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ADULT INFORMED CONSENT

Study Title: Empowering Pediatric Sibling Hematopoietic Stem Cell Donor Voices through Digital Storytelling

Principal Investigator: Andrea Winther Klippenstein, M.Sc., B.HEc., B.A.

Interdisciplinary PhD Candidate

College of Nursing

Department of Community Health Sciences

University of Manitoba

Email: umwinthe@myumanitoba.ca

Co-Investigators: Dr. Christina H. West, RN, PhD

Associate Professor

College of Nursing

University of Manitoba

Email: christina.west@umanitoba.ca

Dr. Javier Mignone, PhD

Professor

Department of Community Health Sciences

University of Manitoba

Email: Javier.mignone@umanitoba.ca

Dr. Shannon Scott, RN, PhD

Professor, Canada Research Chair for Knowledge Translation in Child Health

Faculty of Nursing

University of Alberta

Email: shannon.scott@ualberta.ca

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what participation will involve. Participation is voluntary and declining to participate will have no negative consequences. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

WHAT IS THE PURPOSE OF THIS RESEARCH?

The purpose of this qualitative study is to use a child rights-based, participatory research method with pediatric sibling hematopoietic stem cell donors as they create digital stories to express their donation experiences. Adopting a child rights, participatory focus means sibling donors will be invited to be research partners actively participating in decisions around the data creation process, and discussing main findings. As well, sibling donors will use digital storytelling as a developmentally-sensitive, creative way to tell their donation stories. These digital stories will be shared within the research group of sibling donors to discuss themes related to the sibling donation experience. Throughout the study, sibling donor research partners will have choices and opportunities to contribute their thoughts, ideas and opinions, which will impact how the study unfolds.

WHAT WILL I BE ASKED TO DO, IF I PARTICIPATE IN THIS RESEARCH?

If you participate in this research, you be asked to participate in three meetings:

Meeting One - 'Getting to Know You' Meeting: Andrea will arrange a meeting with you and the other research partners (sibling donors). To learn more about you she will ask you to participate in two 'get to know you' activities. During this meeting, she will also review the

Digital Storytelling Workshop Guide and Plan (Meeting Two) and the Analysis Meeting Plan (Meeting Three). Andrea will review the different aspects of a digital story (ie. photographs you have or choose to take with an iPad, drawing a picture). Andrea will also talk about how you can start writing your story in preparation for the digital storytelling workshop (Meeting Two).

Meeting Two - Digital Storytelling Workshop: In our second meeting, you and participating research partners (sibling donors) will be supported in creating your own digital story about your donation experience. This workshop will be facilitated by Andrea and Tina (Dr. Christina West) and will be 6 hours in length. After creating digital stories, everyone will be invited to explore together what it was like to create digital stories with other research partners. With your permission, this conversation will be audio-recorded with a digital recorder. You will be given snacks and a pizza lunch during this workshop.

Meeting Three - Making Sense of what the Digital Stories Say About Sibling Donation in BMT: You will be invited to share your digital story with the other participating brother/sister donors, and to participate in determining the meaning of the created digital stories (what we learn about sibling donation from the digital stories). Important ideas identified will be grouped together using Post-it notes and research partners will share their thoughts on the groupings. With your permission, this meeting will be audio-recorded with a digital recorder. At the end of Meeting Three, Andrea will present her initial thoughts about what she is learning from the researcher partners. Finally, Andrea will ask your ideas about how we should share the learnings from this project with other families, brothers/sisters, researchers and/or health care professionals. This meeting will take approximately 3 hours, and a morning snack will be provided.

Andrea will complete detailed field notes related to interactions with research partners during and following Meetings One to Three.

Pandemic guidelines/restrictions: Due to the evolving nature of the COVID19 pandemic, if there are safety concerns regarding gathering in person, or if child/young adult research partners would prefer to meet virtually, then data collection will occur via Zoom rather than in a room at the Helen Glass Centre for Nursing, University of Manitoba.

Creation of Digital Stories to Capture Donation Experience

In Meeting One and Two, you will receive more information regarding the elements/pieces of a digital story. You will be asked to take photos/choose music of places/things that remind you of being a sibling donor. You will receive an iPad and a quick tutorial on how to take photos.

At Meeting Two, sibling donor research partners will gather to create digital stories. Andrea and Christina will be there to guide you through the whole process and to help put your story together.

Once you have completed your digital story you will have the option to choose whether a photograph can be taken of your digital story, or whether you would like to retain full control. Regardless if you choose to have your digital story photographed or not, you will maintain the original copy of the digital story.

In Meeting Three, all sibling donor research partners will be invited to present their stories to the group. During these presentations, you will be asked to write down "ideas" "thoughts" and "images" on Post-it notes, that stood out as examples of what it is like to be a sibling donor. Then as a group, we will go through the Post-it notes to try and decide on main themes/ideas that represent the sibling donor experience. This will be audio-recorded, and the main words, thoughts and ideas will be part of the data analysis. In this way, you are an active research partner, contributing to data analysis.

WHAT ARE THE RISKS?

You may become upset or distressed as you recall your donation experience during group discussions and digital story creation within this research project. If you become upset, the researcher(s) will ask if you would like to end participation. If this happens, and you would like to talk to someone about this, there is support available from the Manitoba Blood and Marrow Transplant Program (MBMT). Please call (204) 787-4918 (direct line) or (204) 787-7095 (Pediatric Clinic) to speak to a BMT nurse in the pediatric outpatient clinic at CancerCare Manitoba. You can also ask one of the research study staff to refer you to this clinic for support.

ARE THERE ANY BENEFITS IN PARTICIPATING?

If you agree to participate in this study, there may or may not be a direct benefit to you. The understanding gained in this study may help guide health care professionals in how to better support child/young adult siblings who become donors. As well, this is a participatory study where you have the opportunity to actively make research decisions while also telling your donation story in a creative, hands-on way.

DO I HAVE TO PARTICIPATE?

Participation in this study is completely voluntary. Even if you decide to participate, you may withdraw at any time and/or refrain from answering any questions you prefer not to answer, or from participating in any arts activity. Assent will be continually sought at every step of the research process.

You may withdraw from the study by speaking to one of the researchers in person, or by contacting one of them by phone or email (contact information for the researchers is at the top of this consent form). In the event that you withdraw from this study, you can choose what happens with the information already given the researchers. You can choose to: 1) still have the information included in the research study, or 2) have the information that was recorded or

collected destroyed through permanent deletion or through the use of a confidential shredding service at the University of Manitoba.

HOW WILL THE RESEARCH FINDINGS BE SHARED WITH RESEARCHERS, HEALTH CARE PROFESSIONAS, AND OTHER CHILDREN/FAMILIES?

The findings from this study may be presented at a health conference and/or to health care professionals/families interested in this research at health care/education facilities or may be published in a professional journal. In these instances, full names would not be discussed or revealed to anyone. You will have the choice of using your first name, or a pseudonym. As explained, you can choose whether you retain full control over your digital story and not have it photographed as a part of the study.

WILL I BE PAID FOR PARTICIPATING, OR WILL I HAVE TO PAY FOR ANYTHING?

You will receive a $150 honorarium for participating. Because you are considered a 'research partner' in this study and members of the research team, it is important that this active role is recognized and compensated. You will not incur any costs.

WILL RECORDS BE KEPT PRIVATE?

All information that you provide within the discussions and art activities will remain confidential. Confidentiality will be maintained at all times.

The Meeting Two and Three discussions with sibling donor research partners will be transcribed from the digital recordings to a written document. You will be given the opportunity to either use your first name or choose a name that will represent your contributions. We do acknowledge that some people will feel strongly that their real first name should be used and we will respect your wishes. If you choose to remain anonymous, we will ask you to choose a name that you feel comfortable with that we can use when referring to your contributions. Only members of the research team will have access to the information obtained during this research study. Full names will not be on any research data but will have been replaced by a study number and the name that has been chosen.

As well, Andrea will be taking field notes throughout my interactions with sibling donor research partners. In these field notes, only first names or chosen names will be used to identify participants. This document will be kept in a locked cabinet.

During this research study, all data collected in Manitoba will be stored in a locked filing cabinet or password protected computer in a research office at the College of Nursing, Rady Faculty of Health Sciences, University of Manitoba. Electronic copies of information collected will be kept on a password-protected computer. Once this research study is completed, all information you provide will be stored in a locked filing cabinet in a research office at the College of Nursing,

Rady Faculty of Health Sciences, University of Manitoba. The electronic copies of the information you provided will be stored in a secure, password protected data repository. Only the research team members will have access to the data. In September 2032, all data except for the educational video will be destroyed using electronic deletion and the confidential shredding services at the University of Manitoba.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to your participation as a research subject. In no way does this waive your legal rights, nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer not to, or to refrain from any activities without consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification of any new information throughout participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. If you have further questions concerning matters related to this research, please contact:

Andrea Winther Klippenstein, M.Sc., B.HEc., B.A., College of Nursing, Rady Faculty of Health Sciences, University of Manitoba at umwinthe@myumanitoba.ca.

This research has been approved by the Research Ethics Board 1 at the University of Manitoba. If you have any questions or concerns about this research you may contact the Human Ethics Coordinator at (204) 474-7122, or by email at: humanethics@umanitoba.ca.

_____ _____

Participant's Name Signature and Date

_____ _____

Participant's Name Signature and Date

_____ _____

Researcher and/or Delegate's Name Signature and Date

If you wish to receive a summary of the research results, please leave your email address or other preferred means of contact below. This information will be stored separately from the research data. A summary of the research results will be sent to you as soon as it is available, following completion of the research study.

_____ We would like to receive a summary of the research results

Contact Information:

Appendix E: Pediatric Assent Form for Sibling Donor Participation

Andrea Winther Klippenstein, M. Sc., B.HEc., B.A.
Interdisciplinary PhD Candidate
College of Nursing;
Department of Community Health Sciences
University of Manitoba
89 Curry Place
Winnipeg, Manitoba
Canada R3T 2N2
umwinthe@myumanitoba.ca

PEDIATRIC HSCT RECIPIENT ASSENT FORM FOR SIBLING DONOR PARTICIPATION (7-17 years of age)

Study Title: Empowering Pediatric Sibling Hematopoietic Stem Cell Donor Voices through Digital Storytelling

Principal Investigator: Andrea Winther Klippenstein, MSc., B.HEc., B.A.

Interdisciplinary PhD Candidate

College of Nursing; Dept of Community Health Sciences

Rady Faculty of Health Sciences, University of Manitoba

Email: umwinthe@myumanitoba.ca

Co-Investigators: Dr. Christina H. West, RN, PhD

Associate Professor

College of Nursing

University of Manitoba

Email: christina.west@umanitoba.ca

Phone: (204) 474-8001

Dr. Javier Mignone

Associate Professor

Department of Community Health Sciences

University of Manitoba

Email: Javier.mignone@umanitoba.ca

I, _____, state that I am ___years of age and understand that my sibling who was a donor for my blood or marrow transplant (BMT) wishes to take part in this project exploring the experiences of siblings who have been BMT donors for their brother or sister. I also understand that my sibling will be asked to create a digital story about their BMT donation experience on an iPad. I understand that my siblings' digital story may include photographs/drawings, music and a narrative/audio-recorded story. I understand that my sibling will retain a copy of their digital story, and will be given the choice about if and how it is shared to help other children/families and health care professionals understand what was learned in this research project. I understand the digital story my sibling creates will not be about me or my BMT experience, but about my sibling's experience of donating for my BMT, and it will be told from their point of view.

I understand that my sibling's full name will never be used in this project, to protect their privacy. They can choose to use their first name or create a pretend name (pseudonym) to acknowledge the thoughts, feelings and ideas they share during the research project and within their digital story.

I understand that Andrea and Tina (Dr. Christina West) may write a paper or share a presentation about what they learned so that others can better understand the experience of sibling BMT donation. I understand that this project will also help Andrea and Tina learn about the benefits and challenges of working with children as research partners in projects similar to this one. In any paper or presentation, I understand the name my sibling chooses will be used.

If I have questions about this research project, I can contact Andrea or Tina (Dr. Christina West).

_____ _____

Child's Name (BMT Recipient) Signature and Date

_____ _____

Researcher and/or Delegate's Name Signature and Date

Verbal Assent: Yes ☐ No ☐

Would you like to hear about what we learned from this project after we are finished (expected January 2024)?

Yes ☐ No ☐

Contact Information:

Appendix F: Research Ethics Approval: University of Manitoba

University of Manitoba | Research Ethics and Compliance

Human Ethics - Fort Garry
208-194 Dafoe Road
Winnipeg, MB R3T 2N2
T: 204 474 8872
humanethics@umanitoba.ca

RENEWAL APPROVAL

Effective: August 1, 2023 New Expiry: August 16, 2024

Principal Investigator:	Andrea Klippenstein
Advisor(s):	Christina West
Protocol Number:	HE2022-0104
Protocol Title:	*Empowering Pediatric Sibling Hematopoietic Stem Cell Donor Voices through Digital Storytelling*

Human Ethics Office as designated by , REB1

Research Ethics Board 1 has reviewed and renewed the above research. The Human Ethics Office is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*- TCPS 2 (2022).

This approval is subject to the following conditions:

i. Any changes to this research must be approved by the Human Ethics Office before implementation.

ii. Any deviations to the research or adverse events must be reported to the HEO immediately through an REB Event.

iii. This renewal is valid for one year only. A Renewal Request must be submitted and approved prior to the above expiry date.

iv. A Protocol Closure must be submitted to the HEO when the research is complete or if the research is terminated.

Appendix G: Research Ethics Approval: Research Resource Impact Committee

RESEARCH RESOURCE IMPACT COMMITTEE (RRIC)

FINAL AMENDMENT APPROVAL

RRIC No. 2022-26

(Please quote on all future correspondence with RRIC)

Amendment Approval Date: February 15, 2023

Project Title: Empowering Pediatric Sibling Hematopoietic Stem Cell Donor Voices through Digital Storytelling.
Principle Investigators: Dr. Andrea

Klippenstein Dear Dr. Klippenstein,

Thank you for submitting the RRIC Request for Amendment Form dated on February 7, 2023 for the above- named study. The Research Resource Impact Committee (RRIC) has approved the submitted revisions.

Please note:

1. Changes to this research project must be reported to RRIC by submitting a "Request for Amendment
   Form" for review and approval prior to implementation of such changes.
2. RRIC uses the same expiry date as University of Manitoba's REB approval certificates. Please send the annual REB renewal certificate to RRIC.Coordinator@cancercare.mb.ca.
3. If data or biospecimens are leaving CCMB premises, a data sharing agreement and/or material transfer agreement is **MANDATORY**.

Yours sincerely,

Sara J. Israels, MD FRCPC
Senior Scientist, CancerCare Manitoba Research
Institute Chair, CCMB Research Resource
Impact Committee

Appendix H: Research Ethics Approval: University of Manitoba

UNIVERSITY OF ALBERTA

RESEARCH ETHICS OFFICE

2-01 North Power Plant (NPP)
11312 - 89 Ave NW
Edmonton, Alberta, Canada T6G 2N2
Tel: 780.492.0459
www.uab.ca/reo

Notification of Approval

Date:	October 3, 2022
Study ID:	Pro00124280
Principal Investigator:	Shannon Scott
Study Title:	Empowering pediatric sibling hematopoietic stem cell donor voices through digital storytelling
Approval Expiry Date:	Monday, October 2, 2023

Thank you for submitting this application to the Research Ethics Board 2, outlining the student research project for which you are a committee member. We have reviewed your application and the attached University of Manitoba Research Ethics Board application and approval.

We acknowledge that valid ethics approval was in place at the beginning of the project and that the human participant research conforms to the TCPS2. The University of Alberta REB relies on and accepts the University of Manitoba REB ethics approval as evidence of valid ethics approval for your participation in this research study.

Any proposed changes to the study must be submitted to the REB for approval prior to implementation. A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the REB does not constitute authorization to initiate the conduct of this research. The Principal Investigator is responsible for ensuring required approvals from other involved organizations (e.g., Alberta Health Services, Covenant Health, community organizations, school boards) are obtained, before the research begins.

Sincerely,

Kimberly Kordov, REB Specialist, for

Dr. Ubaka Ogbogu, LLB, BL, LLM, SJDA
Chair, Research Ethics Board 2

Note: This correspondence includes an electronic signature (validation and approval via an online system).

Appendix I: Recruitment Letter

CancerCare Manitoba
ActionCancerManitoba

MacCharles Unit
675 McDermot Avenue
Winnipeg, MB R3E 0V9

St. Boniface Unit
"O" Block - 409 Taché Avenue
Winnipeg, MB R2H 2A6

www.cancercare.mb.ca
Toll Free: 1-866-561-1026

Dr. Geoffrey Cuvelier, MD, FRCPC

Head, Department of Pediatric Oncology/Hematology

CancerCare Manitoba

675 McDermot Ave,

Winnipeg, MB

R3E 0V9

Phone: (204) 787 - 3594

Parents'/Legal Guardians' Names
Address

Dear "Parents'/Legal Guardians' Names":

I am writing to inform you about a research study presently being conducted in the Manitoba Blood and Marrow Transplant Program, CancerCare Manitoba. The title of this project is "Empowering Sibling Donor Voices in Pediatric Blood and Marrow Transplant." Andrea Winther Klippenstein, who is an Interdisciplinary PhD Candidate in the College of Nursing and Community Health Sciences (University of Manitoba), is leading this research team with the support of her advisor, Dr. Christina West, Associate Professor in the College of Nursing at the University of Manitoba. This research is funded by a research grant through the Manitoba Centre for Nursing and Health Research.
The purpose of Andrea's PhD research is to understand the sibling donor experience in pediatric blood and marrow transplant (BMT) through the use of participatory, arts-based methodology and digital storytelling. The United Nations Convention on the Rights of the Child will be used as an inquiry framework, highlighting children's right to express their views and opinions. Child and youth participants will be invited to participate as *research partners* to acknowledge their agency and the significant value of their contributions.

In this research, children, youth and young adults who were between the ages of 6-18 years of age when they were blood and bone marrow donors for their brother or sister (BMT within the past 5 years) will be asked to share their donation experiences through digital storytelling (creation of a 3-5 minute video story on an iPad using images, music and a narrated story).

Sibling donors will be asked to create their own digital story in a workshop with other sibling donors (online through zoom or in person). Andrea will then invite the participating sibling donors to meet together again to view the created digital stories and help her understand what they see as the most important ideas and messages in the digital stories. They will also be asked to provide suggestions about how Andrea should share what they learnt together in the study, and if/how they would like to participate in sharing the study findings. Participants will receive $75 for participation in a digital storytelling workshop with other sibling donors (as well as Andrea and Dr. West) and $75 for participation in an analysis meeting, for a total honorarium of $150. Each sibling who chooses to participate will decide how they want to participate: this means they may choose to participate in the digital storytelling workshop, by not the analysis meeting. Andrea and Dr. West will honor and respect their choices throughout this project.

Participatory activities that research partners (sibling donors) will be invited to:

- Individual Introductory Meeting with each family (sibling donors and parents) (1 hour)
- **Meeting One:** 'Getting to Know you Meeting' with participating sibling donors (1-2 hours)
- **Meeting Two:** 'Digital Storytelling Workshop' with participating sibling donors (7 hours; includes a pizza lunch and a snack)
- **Meeting Three:** 'Analysis Meeting' - shared viewing & conversation about sibling donors' digital stories (3 hours; includes a snack)

It is important to understand that each sibling donor will maintain control and ownership of their digital story and will be given a copy to take home with them once their digital story is completed. Each sibling donor will choose whether they want to share their digital story with other participating sibling donors (during the analysis meeting), and if/how they want it shared as the researchers communicate what they learned in this study with other families, health care professionals, and researchers.

Note: if face to face data collection is not possible, all meetings will occur virtually by zoom.

Why is this research important?

Understanding the experiences of children and youth who have been BMT donors is important for other children considering BMT donation, their families, and health care professionals working in pediatric BMT settings. This research will facilitate a greater understanding of sibling donor experiences and will provide guidance on how to better support brothers and sisters who are asked to be BMT donors. The research will also guide the development of arts-based, participatory approaches for supporting sibling donors in pediatric BMT.

Participation in this research study is completely voluntary. Two weeks following the mailing of this letter, your family will receive a phone call from a nurse in the Manitoba Blood and Marrow Transplant Program. If you decide you do wish to learn more, and you provide your permission,

one of the BMT nurses will give your contact information to Andrea Winther Klippenstein. Andrea will then contact you to provide more information about this study and will answer any questions you might have. Please feel free to contact Debbie Hanson, Danielle Picard or Andrea Winther Klippenstein at any time. Their contact information can be found below.

Debbie Hanson RN, BN

Pediatric Blood & Marrow Transplant Nurse Clinician | HSC
Winnipeg Shared Health Location: Children's Hospital | CK263
Mail: CK263 - 820 Sherbrook St
Winnipeg MB, R3A 1R9
Phone (204)787-4918

Email: dhanson@hsc.mb.ca

Danielle Picard RN, BN

Pediatric Blood & Marrow Transplant Nurse Clinician | HSC
Winnipeg Shared Health Location: Children's Hospital | CK263
Mail: CK263 - 820 Sherbrook St
Winnipeg MB, R3A 1R9
Phone (204)787-4918

Email: dpicard@hsc.mb.ca

Andrea Winther Klippenstein, PhD Candidate, M.Sc., B.HEc., B.A.

College of Nursing/Department of Community Health Sciences Program

University of Manitoba

89 Curry Place

Winnipeg, MB

R3T 2N2

Email: umwinthe@myumanitoba.ca

Dr. Christina H. West, RN, PhD

Associate Professor

College of Nursing

University of Manitoba

Email: christina.west@umanitoba.ca

Phone: (204) 474-8001

Thank you for considering participation in this research study.

Sincerely,

Dr. Geoffrey Cuvelier, MD, FRCPC

Head, Department of Pediatric Oncology/Hematology
Cancer Care Manitoba
675 McDermot Avenue
Winnipeg, MB
R3E 0V9

This research has been approved by the Research Ethics Board at the University of Manitoba, Fort Garry campus.

Appendix J: Introductory Zoom Meeting

Thank you so much for attending this meeting, and your interest in participating in this research project. If you choose to participate in this project, you will be invited to be a research partner in our project. We wanted to take this opportunity to tell you a bit about the project, about your role as a participant and research partner and to go over the consent and assent forms with you and your parents.

In this project, children/young adults who have been blood and bone marrow transplant (BMT) donors for their brother or sister will be asked to share their donation experiences through digital storytelling. Tina and I will help you to make a 3-5-minute video story (digital story) with 6 to 10 other BMT donors. Your stories will be made on iPads using iMovie: you can use photographs, images we help you find online, pictures you draw, music and you will write and record a story about your experience of being a BMT donor. You will choose how you want to put your story, images, and music together in your video story. This active, creative, hands-on process of making a video story may help you to express and explore your BMT donor experience. You will also be asked if you would like to share your digital story with the other sibling donors in this project and you will be invited to work with us to share what you think those digital stories mean about what it is like to be a BMT donor for your sister or brother.

Because sharing about your BMT donation might make you feel sad or be hard for you, we will make sure the conversations we share with you and the other donors happen in a private space. You can choose to use your first name, or pick another name for your thoughts, feelings and contributions to this project. We will do everything we can to keep your story private, but you need to understand that if you agree to us sharing your story with others to help them learn what donation is like, then your voice or the picture/photographs you choose to use in your digital story may allow them to know who you are. If you want to keep your story private, we will talk with you about how to do that.

After you and the other children/young adults have the opportunity to share their digital story, we will ask you to think about the big ideas from the stories that stand out to you. When you share your ideas, you are a research partner helping us decide what are the most important things we are learning, and to share about this project. Whatever you share will be respected, important and taken seriously. You will receive a $150 honorarium to participate in this project, and we will also enjoy a pizza lunch together on the day of the digital storytelling workshop. The honorarium is to thank you and acknowledge the time you will commit to this project.

If you decide you would like to participate in this project, I will then deliver an iPad mini and show you how to use it. At this time, I will also collect your consent and assent forms and demographic information form. I will also bring you some markers to use in Meeting One and a

map with directions to the Helen Glass Centre for Nursing at the University of Manitoba, where Meetings Two and Three will take place. If we are not able to meet in person due to COVID19, I will book a zoom appointment online for us to meet together as a group (myself, My advisory Dr. Christina West (Tina), and all sibling donor research partners). If you need some time to think about participating, you can send me an email at umwinthe@myumanitoba.ca to let me know what you decide. Then, Tina and I will invite you to a brief zoom meeting with other research partner participants and we will start preparing for our digital storytelling workshop day! We will get to know each other better, and I will ask you what day works for you to meet, and what time. For Meeting Two and Three, you can choose to attend alone, or ask a parent or caregiver to attend with you. You can also choose to quit this project at any time, if you decide it is too hard, or that you don't want to share your story of being a sibling donor.

Understanding the stories of children who have been blood and bone marrow donors is important for other children, families, health professionals and for the places where children are care for when they are sick (clinics and the hospital). The outcomes of this research may be a greater understanding of brothers'/sisters' experiences that can be used to support children to be healthy and happy. Thank you so much for your interest! Please let me know if you have any questions, either today or later by email.

Appendix K: Digital Storytelling Workshop Guide

As a research partner, you will be invited to create a digital story on an iPad mini, which is a 3–5-minute video to tell the story of your donation experience. This movie will combine photos, music and your voice reading your written story. If you choose to, before we meet for our digital story workshop, you can take or find some photos for your story, begin to write your story, and perhaps choose a song that you think you might like to include in your story.

Story: Here are some questions to help you start writing your story about being a donor for your brother or sister:

1. What do you most want people to know and understand about your experience of being a sibling donor?

2. Were there any specific times during your donation that were really meaningful to you? Hard for you?

3. What story do you most want to tell about your donation experience?

Please keep in mind, your story should be no longer than ½-1 page, to help you capture the most important parts of your story.

Photos: Please take some photos on your iPad mini to bring to our workshop, or you can choose photographs that you already have at home. We will also be able to help you look for photographs that remind you of your donation experience during our workshop together. Here are some things to think about for photos for your digital story:

1. Things that remind you of your brother or sister's illness and BMT
2. Things that remind you of becoming a donor for your brother or sister for their BMT
3. People or things that helped you during your donation experience, or now
4. Anything else you think describes how you feel about your donation experience or the transplant experience for your entire family.

*You can take as many photos as you want and delete them later! NOTE: Please make sure if you if take photos of other people, that you ask them first. You will need to tell them you want to use the photograph for the digital story you make in this project and ask their permission to do that. If possible, just take photos of yourself, or objects at home and outside.

For your digital story, you will likely use 10 – 15 photos.

Music: You can choose to add a song, or music you create on an instrument to your digital story. You might want to record yourself singing a song. You can also choose to have no music. Here are a few ideas to help you choose a song for your digital story about your donation experience:

1. A song that reminds you of the time your brother or sister was sick.
2. A song that reminds you of being a donor for your brother or sister.
3. A song that made you feel happy/sad at the time of your donation/BMT.
4. A song that helped you explore your feelings during your donation/BMT.

We will also be able to help you find music in iMovie, if you want some music added to your story but couldn't find anything before we have our digital storytelling workshop.

Appendix L: Digital Storytelling Workshop Plan

Location: Helen Glass Centre for Nursing, University of Manitoba (or virtually via zoom)

9am: Welcome and outline of the day

9:30am- 10:00am: Using iPads: confidentiality and copyright

10:00am- 10:30am: Introduction to the seven steps of digital storytelling, viewing an example of a digital story

10:30am-10:45am: Break

10:45am-11:30am: Working/finishing your written story

11:30am-12:00pm: We will enjoy a pizza lunch!

12:00pm-1:30: Building your story in iMovie: working on iPads, choosing and organizing images

1:30-2:15: Recording stories: Using iMovie, adding images and editing your story

2:15-3:00pm: Discussion: Experience of sharing your donation story through digital storytelling, and the experience of creating digital stories with other sibling donors

We will help you put your digital story together during our workshop day! We are here to help and support you through the whole process. If we are not able to meet in person due to COVID19, and you are not familiar with working with an iPad or iMovie, we would encourage you to invite a parent or caregiver to come with you to the Digital Storytelling Workshop (Meeting Two) to help you build your digital story. If you are not able to finish your digital story before the end of the workshop day, I (Andrea) will meet with you individually to help you finish your story.

Appendix M: Data Analysis Meeting Plan

Location: Helen Glass Centre for Nursing, University of Manitoba (or Zoom)

9:00am: Welcome and outline of the day

9:15-9:30am: Explanation of Post-it notes to capture main ideas/thoughts from viewing the research partners' digital stories.

9:30-10:30am: Viewing of the digital stories together (first half of all digital stories). Research partners will write ideas/thoughts on Post-it notes and will be asked to choose two Post-it notes to share with the group: these Post-it notes will be the ones that best describe the sibling donor experience, as viewed in the digital stories we watch together.

10:30-10:45: Snack

10:45-11:30: Viewing of the digital stories together (second half of all digital stories). Research partners will write ideas/thoughts on Post-it notes and will be asked to choose two Post-it notes to share with the group: these Post-it notes will be the ones that best describe the sibling donor experience, as viewed in the digital stories we watch together.

11:30-12:00: Brief discussion on Andrea's thoughts/ideas from Meeting One ('Get to Know You' meeting) and Meeting Two (Digital Storytelling Workshop)

Appendix N: Meeting One Script

Thanks so much for attending this meeting! We would love to spend some time getting to know you, and for you to get to know each other. Let's do a fun exercise. We'd like you to take a minute and find an object in your house that represents something about you. It can be anything, a teddy bear that shows you love cuddles, or a video game that shows you love gaming or a challenge, or a drawing you drew that expresses your love of art. Once you find your object, we will come back together, and start by having Tina and I share the objects we have chosen. Then, if you choose to, we will invite you to share your object and why you chose it to share with the group.

Let's do one more activity together. If you could grab a piece of paper and the markers I dropped off, I would love for you to draw a circle. Inside that circle, I would like for you to write or draw the most important things in your life. The most important people, places, and things. Once you are finished, let me know - I will start, and then invite you to share your circle with the group.

If you don't want to share your object or circle with the group, that is okay too.

Now, lets go over the digital storytelling workshop guide and agenda. Please let me know if you have any questions!

Appendix O: Meeting Two Script

Thank you so much for coming today to take part in the digital storytelling workshop! To begin, let just take a minute to go over the workshop guide and agenda, then we will start creating our digital stories. Today we will spend time putting together our digital stories on the iPad, having lunch together and then having a final meeting about your thoughts on your experience of making a digital story about being a BMT donor for your brother/sister. Please remember that you can choose to quit this project at any time. If you decide you no longer want to be in this project, you just need to let me know – by talking to me today, or you can ask an adult at home to call or email me after we meet today.

Do you have any questions or are you worried about anything? Great! I am first going to talk about the 7 steps of making a digital story. We will then watch an example of a digital story, which might give your ideas on how you want to create your own story. We will start by help you write/finish your written story, and then work with each of you to make a final decision about the photographs, drawings and images you want to use in your story. Once your images are inserted in your iMovie video, we will have each of you record your written story on the iPad. We will show you how to work through each step. If it is not possible for us to finish everyone's story today, I (Andrea) will follow up with each of you to help you finish your story before we meet again.

Now that you have created your digital story, we would love to hear about your experience making digital stories with other sibling donors. We have a few questions to ask about your experience.

Appendix P: Meeting Two Digital Storytelling Workshop Experience Discussion Questions

1. What was it like to create your digital story with other brothers/sisters who have been BMT donors?

2. Did your digital story capture your thoughts, ideas and feelings about being a sibling donor? Could you tell me more about that?

3. Do you think making digital stories would help kids who are trying to decide whether to be a donor for their brother/sister? As they go through the transplant? Helpful after the transplant process is finished? Probe: How do you think it would be helpful? What do you think would be hard about it?

4. Is there anything else you think it would be important for me to understand about what it was like for you to use digital storytelling to express your BMT donor experience?

Appendix Q: Research Partner Data Collection

As a research partner, I would like to invite you to participate in helping me to decide what are the most important things we are learning in this project, and what we should share with other people who are interested about learning from you. You are the experts about what it is like to be a donor when your brother or sister needs a BMT, and we really want to learn about that from you. As we watch the digital stories together, I would like you to use the Post-it notes to write down things that you think are really important for us to learn about the sibling donor experience. You can choose one word or a phrase for your idea and write it on the Post-it note. After we are finished watching all the digital stories, we will share our Post-it notes, and discuss them together as a group to come up with some main "themes" – 'themes' are a 'researcher' way of saying we want to figure out together what parts of the digital stories about BMT donation are similar and connect together, and what pieces are really important even though they may only have shown up in one or two of the digital stories.

While you watch each digital story, please look for:

1. Photos that you think are interesting/that you think show the sibling donor experience.
2. Words or sentences that stand out to you – those you think are really important for us to remember.
3. Music that speaks to you – music you think helps express the donation experience.
4. What you think the most important message is about what it's like to be a donor for your brother or sister.

After viewing all digital stories:

If you are comfortable, can you please stick your Post-it notes to this bulletin board? I would like to read them and discuss them as a group. Once we read each Post-it, as a group we will try to put each word/idea/thought into groups with similar words/ideas/thoughts. Then, we will try and figure out a word or a few words to describe the most important "big ideas" from the groupings of words/ideas/thoughts. Again, you are the experts, so I want you to decide what words or ideas best describe the BMT donor experience.

Appendix R: Member Checking Script

I would like to share my thoughts and ideas from our first two meetings. I have watched each of your digital stories a few times and have written and thought about what I think are some of the important ideas are about being a sibling donor. Can you let me know what you think of it and if I got anything wrong or if you disagree with any of my ideas? I am also interested in the parts of the digital story that you think reflect your experiences.

1. What did you think about my ideas about your digital stories and experiences you have shared about making a digital story?
2. Do you think my thoughts and ideas captured some of what you experienced as a sibling donor?
3. What do you think I have missed, or not understood about your experiences?
4. What would you add or change from the ideas/thoughts I shared with you today?

Appendix S: Sharing What we Learned

1. Who do you think it is most important for us to share what we learn in this project with? Probe: Doctors and nurses? Potential sibling donors? Other family members who are about to go through a BMT?

2. How would you most like to share these findings? Probe: Would you like to take part in presentations?