We're stronger as a family": Family experiences and relationships in an adapted physical activity camp

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Abstract

Adapted recreation programs involving the entire family may offer ways to enhance relationships in families with a child living with a disability because they enable participating together in new and potentially empowering experiences. This study examined family members' perspectives on their lived experiences with their relationships within their family and how they perceived they were affected by their participation in an adapted summer camp for families with a child living with a disability. We conducted a collective case study with five families who participated in a week-long camp. A focus group was conducted with each family and analyzed using reflexive thematic analysis. Participation in the camp impacted family relationships by reducing isolation for mothers; alleviating stress and anxiety which helped families bond; providing shared experience which led to mutual understanding, communication, and support; improving independence and confidence of the child living with a disability; facilitating sibling bonding and parent comfort with giving siblings more responsibility; and enhancing families' confidence to participate in family activities beyond the camp. These findings elucidate how participation in this type of program can impact relationships in families that include a child living with a disability and inform future program design.

Key Words: disability, children, adolescents, family relationships, adapted recreation, qualitative inquiry

Children and adolescents living with a disability tend to be insufficiently active because they may face limitations to being able to participate with others and to perform tasks independently when accessing recreation programs (Arbour-Nicitopoulos et al., 2022; Heah et al., 2006). Parents caring for a child living with a disability often experience stress, isolation, frustration, and financial challenges due to inadequate community supports and fragmentation of care that puts a burden on parents (Ono et al., 2019). Parents of a child living with a disability have reported viewing family recreation as a way to enhance family relationships and provide opportunities for skill and personal development, particularly for children with a disability for whom such opportunities are often not available (Mactavish & Schleien, 2004). The COVID-19 pandemic exacerbated this lack of opportunities when programs were forced to close, and families raising a child living with a disability reported increased stress and anxiety during the pandemic (Neece et al., 2020). Despite the potential for physical activity programs to have a beneficial impact on interpersonal relationships in families with a child living with a disability, there is little research examining families' experiences with these relational processes. We therefore examined family members' perspectives on their lived experiences with their relationships within their family and how they perceived those relationships were affected by participation in an adapted physical activity summer camp for families with a child living with a disability. This study was conducted during a program closure caused by the COVID-19 pandemic, so we also inquired about the impact of programs being unavailable that year.

Conceptual Framework

The conceptual framework for this study is informed by the social relational model of disability (Reindal, 2008) and Bowen's family systems theory (Brown, 1999). The social relational model of disability considers both the biomedical and social sources of disability and

focuses on how disability is constructed in the context of societal power imbalances that disable individuals with impairments (Reindal, 2008). It acknowledges that people have impairments that can be diagnosed medically but suggests that whether an impairment becomes a disablement is determined by socially imposed restrictions imposed on people with impairments, and disablism is thus a form of social oppression (Reindal, 2008). Thus, disability is the inability to participate in normative activities due to a combination of the individual's impairment and social oppression (Haslett & Smith, 2020). Based on the tenets of this theory, we have chosen to use the wording *individuals living with a disability* throughout this research.

The social relational model of disability proposes three types of disablism: structural disablism, psycho-emotional disablism, and internalized oppression (Haslett & Smith, 2020). Structural disablism is the inability to participate in opportunities, services, or activities because of an impairment (Haslett & Smith, 2020), such as when a child is not able to attend a recreational activity because of their impairment. Psychoemotional disablism includes both direct and indirect forms. Direct psychoemotional disablism involves discriminatory or patronizing actions, such as when a child with a disability is talked over or ignored because of their impairment. Indirect psychoemotional disablism occurs when there are psycho-emotional consequences of not being able to participate in activities, such as when a child feels isolated after not being able to participate in a recreation program because of their impairment. Internalized oppression refers to negative thoughts and feelings people with disabilities may have about themselves as a result of living in a society where they do not always feel welcome (Haslett & Smith, 2020). Adapted physical activity programming may create environments that reduce disablism.

Bowen's family systems theory describes how family interactions may influence family relationships and the individuals within them, and provides a perspective on how family members' individual experiences and interactions can impact those relationships. Families are complex social systems whose members have cohesive, emotional connections that allow them to be considered as a unit that is interdependent to some degree, and interactions among members affect each other. Families can be considered in terms of family structure, individuals' roles within the family, and how these roles are continually forged over time (Brown, 1999).

Bowen's family systems theory identifies eight interrelated concepts that characterize family relationships and interconnected emotional system. (1) Differentiation of self describes how individuals can be emotionally connected to the family but still act autonomously and make self-directed choices, as compared to having pressure for conformity and efforts to control each other within the family and strong needs for external approval and acceptance to validate the self. (2) Triangles describe the three-person relationship(s) in families. Triangles are considered to be the building block of larger relational systems and the smallest stable relationship unit because they can accommodate more tension than dyadic pairings. They are dynamic bonds that can involve taking sides in conflicts, and fluctuating roles as insiders or the odd person out. (3) Nuclear family emotional systems include four relationship patterns that can create challenges for emotional functioning within the family: marital conflict, dysfunction in a spouse, impairment of a child, and emotional distance. Of relevance to this study, the impairment of a child pattern does not necessarily occur in families with a child with an impairment, but rather refers to an emotional pattern that can occur whereby one or both parents experience anxiety about the child and focus excessive worry on them, which encourages that child to become more reactive and can impair their differentiation of self. (4) Family projection processes occur when a

parent transmits their own anxieties and emotional problem onto a child by overly focusing on that child. (5) Emotional cut-off occurs when an individual copes with unresolved negative emotions by disconnecting from the family, either physically or by emotionally distancing themselves. (6) Multigenerational transmission process explain how patterns and roles within relationships and tendencies toward differentiation of the self are passed down from generation to generation. (7) Sibling position describes how the age order of children impacts their roles within the family by affecting their experiences with leadership and interacting with those older and younger than themselves. Pertinent to this study, it also discusses how a sibling of any age order can be functionally older or younger (e.g., take on more or less responsibility in the family) if one of the siblings experiences an impairment that affects their functioning. (8) Societal emotional process refers to societal events that may stress the family system (Haefner, 2014; Brown, 1999). This theory provides a framework for interpreting interconnected family roles, interactions, and patterns of emotions and behaviour.

Physical Activity for Children Living with a Disability

Physical activity (PA) can be a channel for children and adolescents living with a disability to gain independence through meaningful and healthy activity (Groff & Kleiber, 2001) and improve emotional functioning (Martin, 2013). However, children and adolescents living with a disability may face medical, environmental, family, and social barriers that may limit their ability to participate in PA (Martin, 2013). Environmental barriers such as inadequate transportation and facilities, poorly maintained outdoor areas, and lack of assistance for mobility conditions can contribute to structural disablism and impact participation in recreation programs (Haslett & Smith, 2020). Summer camps for children living with a disability could be a positive avenue to decrease the structural disablism experienced and have been shown to provide a

reprieve from isolation caused by living with a disability, increase independence, self-esteem and confidence, and encourage campers to feel pride in their physical capabilities (Goodwin &Staples, 2005; Youngblood et al., 2023). Further, adapted physical activity camps for children living with a disability have the potential to impact families in a variety of ways, such as, enhancing family relationships, decreasing parental worry, and making families more comfortable having conversations surrounding the child's disability (Youngblood et al., 2023).

Parents and peers can have an impact on whether or not children and adolescents living with a disability participate in PA. Negative parental attitudes toward PA are a barrier to participation, particularly for children and adolescents living with a disability who tend to rely on their parents to facilitate their PA involvement (Shields & Synnot, 2016). Additionally, parents often spend considerable time advocating for their child's medical and educational needs due to the lack of accommodations provided in these settings. The need to advocate may leave parents with little time or energy to find appropriate recreation opportunities for their child or themselves (Scholl et al., 2003; Martin, 2013). There are also limited opportunities for family recreation for families that include a child living with a disability.

Parents who have a child living with a disability have reported viewing family recreation as a way to enhance family relationships by bringing them closer and creating opportunities for shared experiences (Mactavish & Schleien, 2004). However, recreating together as a family can be difficult without the support of a program or additional assistance due to varying interests and abilities within the family, and the need for parents to spend more time assisting the child with a disability to make recreation activities possible and equitable (Mactavish & Schleien, 2004). Therefore, family recreational activities most commonly involve a parent recreating with the child with a disability while their siblings are either occupied with other activities or at school

(Mactavish & Schleien, 2004). Finding programs that accommodate the needs of all family members to facilitate participating together can be taxing (Scholl et al., 2003).

Family Relationships

Families are an important developmental context because they are the main social group in which we have lifelong ties (Bronfenbrenner, 2013). Due to disablism imposed by societal inequities, there may be profound impacts on the family when one child is living with a disability. For example, in many families, a large proportion of family resources must go towards that child to manage their impairment and the societal barriers they face because societal supports are lacking (Haefner, 2014). Families raising a child who is living with a disability may face more societal constraints due to the lack of accommodation and societal support for individuals with disabilities. For example, families with a child living with a disability have greater social isolation, parental and child stress, and strained parent relationships than families raising typically developing children (Shields & Synnot, 2016). The social oppression of disablism also means that societal events such as the COVID-19 pandemic disproportionately affect families with a child living with a disability. While the pandemic was difficult for most families, families with a child living with a disability reported higher levels of stress and perceived that they had less social support during the pandemic as compared to families with typically developing children (Neece et al., 2020). Parents reported increased anxiety for themselves and their child living with a disability (Asbury et al., 2021) and worry about the long-term impacts of the pandemic on their child's mental health and social engagement (Neece et al., 2020; Asbury et al., 2021). A meta-analytic study with families with young children with disabilities showed that interventions based on family systems theory and that provide support and build capacity in family relationships can improve self-efficacy and interactions among

family members, and parent and child well-being (Trivette et al., 2010). Therefore understanding these experiences from the perspecgtive of family systems theory may be important for enhancing programs.

Importantly, raising a child who is living with a disability can also have positive impacts on family relationships (Patterson, 1991). Some parents perceive that having a child who is living with a disability has led to them having greater patience and understanding of other people (McConnell et al., 2015). Furthermore, when sufficient supports are in place, families report higher levels of cohesion, stronger family bonds, and less family conflict than families with typically developing children (Townsend & Van Puymbroek, 2017). Indeed, parents of a child living with a disability have reported that the opportunity for their families to spend more time together was a positive outcome of the pandemic because they had positive interactions (Neece et al., 2020), although COVID-19 was overall a challenging time for families with a child living with a disability. The challenges associated with raising a child who is living with a disability may contribute to the family becoming stronger and more resilient (Townsend & Van Puymbroek, 2017), if families are well supported and experiences of disablism are minimized.

Sibling relationships can also be both positively and negatively impacted. Siblings play an important role in development because they are social partners and role models for one another (Mandleco et al., 2003). Siblings of a child who is living with a disability are at a greater risk of developing internalizing behaviour difficulties (Ross & Cuskelly, 2006), possibly related to the stress placed on the family system through one member experiencing the social oppression of disablism. However, parents and teachers of children with a sibling often report that the typically developing sibling tends to exhibit increased warmth, patience, empathy, maturity, and self-control compared with children who do not have a sibling who is living with a disability

(Ross & Cuskelly, 2006; Mandleco, 2003), suggesting that these skills may be learned in part through their interactions with their sibling living with a disability.

Purpose

The purpose of this study was to examine family members' perspectives regarding their lived experiences with their relationships within their family and how they perceived they were affected by their participation in an adapted summer camp for families with a child living with a disability. The COVID-19 pandemic began during the planning stages of this study. As a result, the 2020 camp was cancelled and this study focused on families who participated in the 2019 adapted summer camp, and queried them about both their experiences related to the 2019 camp, and how they perceived the camp not being offered in 2020 affected their families. This study aimed to address the following research questions: (a) how are family members' perceptions of family relationships affected following participation in a family adapted PA camp, and (b) what are families' experiences regarding family relationships after losing the opportunity to participate in an adapted PA camp due to COVID-19?

Methods

Methodology and Design

We used a relativist ontology and constructivist epistemology with a collective case study design and reflexive thematic analysis methods to address the research question. A relativist ontology acknowledges that there are multiple realities, and reality is socially constructed through human experiences (Creswell & Poth, 2013). A constructivist epistemology acknowledges that knowledge is gained through interactions with others, and that we can learn about people's subjective realities and how they interpret the world by studying lived experiences (Lincoln, Lynham, & Guba, 2018). Constructivism also asserts that the researcher's

experiences, relationship to who and what they are studying, and interactions in the research process influence their interpretations and are integral to developing the findings (Lincoln, Lynham, & Guba, 2018). We chose a collective case study design because it allows examination of multiple systems (families) that are linked through a common experience (participation in the family adapted recreation camp; Stake, 2005). A collective case study approach allowed us to examine each family's interactions within their families, as well as examine patterns of and differences in experiences between families (Algozzine & Hancock, 2017). We used reflexive thematic analysis (Braun & Clarke, 2019; 2022) as the method of analysis as it provides a flexible framework for identifying and interpreting shared patterns of meaning that involves critical consideration of the role of the researcher and the research processes in generating knowledge.

Positionality

The first author, who conducted the data collection and the primary data analysis is a White female in her twenties who has worked with individuals living with a disability in a variety of contexts. She does not have a disability or a family member living with a disability and is very physically active. She worked as a camp coordinator at the adapted program in 2019 and had met all families prior to their involvement in this study at that time. She also was the coordinator in the camp in 2018, and some but not all of the families in this study attended that camp also. In her role as the camp coordinator the first author regularly interacted with and participated in activities, such as hiking, mountain biking, and kayaking, with the families. She formed relationships with the families through these interactions. This experience enhanced her rapport with the families, and her understanding of the camp context and how families interacted at the camp. The second author, who was extensively involved in the analysis as a mentor to the

first author is a non-disabled White woman in her 40's with expertise studying social relationships in PA contexts and using qualitative methodology. The third, fourth, and fifth authors provided perspectives based on their expertise in pediatric rehabilitation medicine and neuro-disabilities, adapted PA, and sport injury prevention and epidemiology. In light of the philosophical assumptions we acknowledged that the first author has her own experience at the camp. She made sure to acknowledge the participants experiences at the camp and how those may differ from her own. Each participant has their own experience at the camp and we used the philosophical assumptions to help address and understand these unique experiences.

Program

Rocky Mountain Adaptive is a non-profit organization based in Canmore, Canada. The aim of this organization is to make outdoor activities accessible to individuals with disabilities through a variety of programs. This study focused on their week-long summer overnight Friends and Family Camp, where families participated in outdoor physical activities with their child living with a disability. The goal of this camp was to provide an opportunity for families to participate in physical activity programs together as a whole family, which is an experience that can be rare for families including a child living with a disability. Families participated in hiking, biking, and kayaking facilitated by camp staff during the day. Families had their own cabins where they cooked their own meals and were able to spend time together when no activities were scheduled. Social hours and campfires were offered every evening, giving families opportunities to socialize with one another. Participants in this study attended the camp in the summer of 2019 and were unable to attend in 2020 because the program was suspended due to COVID-19.

Participants

We used total population sampling (Morse, 1991) to invite all 11 families who had attended the camp in August 2019 to participate in the study. The program who provided the camp emailed all families who attended the camp to ask for consent for the research team contact them about this study. Seven families provided consent to contact. The first author then called all seven families and invited them to participant in the study. Of those families five families responded to recruitment messages and participated. Focus groups were conducted with families where eligible to participate in the study if at the time of recruitment, they (1) were fluent in English, (2) were available to participate in the focus group, (3) attended the summer camp in 2019. Across all families five mothers, five children living with a disability (female = 3, male = 2), and three male siblings participated. At the time of the focus groups mothers were 45-53 years of age, siblings were 7-12 years old, and the children living with a disability were 10-18 years old. All siblings were younger than the child living with a disability. All families spoke English as a first language, and all mothers, siblings, and the majority of children with a disability identified as Caucasian, with one child with a disability identifying as Latino and Caucasian. Three mothers were married, one was separated, and one was widowed. Two fathers attended the camp with their family but chose to not participate in the focus group. The children had a variety of disabilities including Cerebral palsy, Down's syndrome, cognitive impairments, and rare genetic conditions. One individual with a disability was a wheelchair user, the rest were all ambulatory. All experienced some form of a cognitive impairment.

Families included children (under 10 years of age) and adolescents (10 to 19 years old; World Health Organization, n.d.) living with a disability. However, throughout the study we refer to the individual with a disability as the child regardless of their age, and other children in the family as siblings, brothers, or sisters to describe their role within the family. While it is

recognized that families are diverse, and can include individuals other than parents and children, all families who participated in this study defined their family in terms of parents (including mothers, and sometimes also fathers) and children (including the child with a disability, and sometimes also brothers and/or sisters).

Data Collection

Ethical approval was obtained from the University of Calgary Conjoint Health Research Ethics Board. Two adults with experience living with a disability and supporting adapted recreational programs were consulted to review the focus group guide and demographic interview guide. The first author conducted a pilot focus group with a family with a child living with a disability who was not involved in the camp in order to obtain feedback about the focus group questions and to identify points that needed to be clarified or enhanced to obtain responses from a variety of family members. This pilot focus group was not recorded and the data was not used as part of this study, as they did not have direct experience with the particular camp that was the focus of the study. The family from the pilot focus group gave the author feedback about sounding more confident when asking questions and to make more eye contact while interviewing. Additionally, they gave feedback on multiple questions about how the questions could be adjusted to increase understanding (e.g., changing words so children would understand better). Following the pilot focus group, families who had attended the camp in 2019 were contacted via phone by program staff and asked for their consent to be contacted by the researchers. The first author then called each consenting family and invited them to participate in the study. Data collection took place between October 2020 – January 2021. Demographic information about the child's diagnosis and family members' backgrounds was collected via a 10–15-minute audio recorded telephone interview with a parent. In all cases this interview was

with the mother. Mothers electronically signed a consent form or verbally consented to participate in this study before the start of the interview. Participants were not compensated for participating in this study.

Focus groups were conducted via Zoom with each family, with all family members who agreed to participate. Consent was collected from all parents and individuals who were 14 years of age or older who were deemed by their parents to have the capacity to provide informed consent. Parental consent was obtained for all individuals under 14 or who were unable to provide consent for themselves, and assent was obtained from those individuals whose parents provided consent for them prior to the start of the focus group. Focus groups lasted 18 – 60 minutes (M = 36 minutes) and were audio recorded. The focus group moderator (first author) used a semi-structured focus group guide (see supplementary file) that included questions regarding the family's experience at the camp, family relationships and family recreation during and after the camp, and the impact of the suspension of the camp due to the COVID-19 pandemic. Having multiple perspectives allowed us to gain an understanding of the camp experience from the various individuals in the family and how they communicated with each other about the experience as a family. Since, each family member holds a different role, power dynamics, and experiences in the familial unit it is important to hear their varied perspectives to understand the dynamics of the family as a relational unit. Reflexive field notes were written after each focus group to document the first author's critical reflections on their experience in the focus group, main topics of discussion, the family's interactions during the focus group, and aspects of the focus group that stood out to the researcher. Audio recordings were transcribed verbatim and checked by the first author for accuracy. Each family member was given an alphanumeric code indicating their family's study number and their role in the family (mother =

M, child with a disability = C, sibling = S). NVivo 12 software (QSR International Pty Ltd., 2018) was used for managing data during analysis.

Data Analysis

Our approach to reflexive thematic analysis was experiential and guided by our relativist and constructivist underpinnings in that it focused on understanding people's own perspectives and understandings and aimed to explicate the multiple realities expressed within the dataset. Initial phases of analysis were primarily inductive and focused on semantic, explicit meaning of the data, and progressed towards incorporating theoretical constructs that fit with the emerging inductive themes and latent or implicit meanings later in the analysis process (Braun & Clarke, 2019; 2022). The first author conducted all interviews and was the primary person conducting analysis. They also wrote reflexivity notes prior to interviews, after all interviews and throughout the analysis process. The reflexive notes included any thoughts regarding how their position and lived experiences may influence the research process and their perceptions of the data and non-verbal communication within families that they noticed during the focus groups.

The first author began by reading and re-reading each family's transcript to understand the overall meaning. Each transcript was read again, and inductive codes were created to identify sections of text that expressed meaning pertaining to the research questions. That process was repeated for each family, with data with similar meaning coded together and new codes being created as new ideas were inductively identified. Several rounds of coding were conducted with each transcript, with the initial focus being on understanding the sematic meanings, and later rounds focusing on latent meanings. Following each round of coding, codes were reviewed and codes with similar meanings were grouped together, and the lead author met with the second author to discuss the coding process and to question and challenge codes and interpretations. The

first author then reviewed the coding and identified candidate themes that conveyed patterns of shared meaning. Codes were re-examined and collated to check for consistent coding across the dataset. Candidate themes were compared across families and connections between themes were identified. Names and definitions of the themes were created, and the themes were interpreted using the social relational model of disability and Bowen's family systems theory. The themes were discussed over several iterative rounds of discussion with the second author, and a report was written describing each theme highlighting shared meaning and contextualized participant perspectives, interpreting themes across families and using theory and incorporating quotations to illustrate the findings. All authors provided feedback on the final themes.

Rigour

Rigor was supported by using Braun and Clarke's (2022) 15-point checklist for conducting high quality thematic analysis, engagement with reflexive journaling, and frequent in-depth discussions of analytic decisions between the first and second author throughout the research process. The checklist includes ensuring rigorous process such as checking transcripts against recordings; thorough coding including repeated review of data and codes and ensuring themes are distinct and internally coherent; ensuring balance between describing and interpreting; devoting extended time to analysis to ensure deep reflection; clearly explaining thematic analysis in the written report; and ensuring a fit between method, claims, language, and philosophical tenets (Braun & Clarke, 2022).

The lead author kept a reflexivity journal throughout the study to detail her experience with the research process, how it affected her, the impact she may have had on participants and the study, how her positionality may have affected the research process, and thoughts about the research such as emerging themes, connections between the themes, analytical questions, and

challenges encountered. The first author also engaged in frequent discussions with the second author who reviewed codes and emerging themes, questioned and challenged her interpretations, provided guidance on moving from sematic to latent coding, discussed the process of interpreting the data using theory and the perspective across all families, and mentoring on the research process and thematic analysis methods.

Results

Six themes described how the camp influenced family relationships. We describe the central meaning of each theme, with supporting quotations and interpretations using theory.

Reducing Isolation for Mothers

Most mothers discussed how attending the camp was supportive because they were around other families who have a child living with a disability. Raising a child who is living with a disability can be isolating due to both structural disablism (e.g., lack of connections with other parents whose children are participating in activities together if the child with a disability is prevented from participation) and feelings that other parents do not understand their experiences dealing with the various forms of disablism experienced by their child. Attending the camp removed those barriers of disablism and brought families together at the camp, which helped mothers feel like they were not alone in dealing with the challenges they faced. One mother noted how the camp “Definitely made me feel not alone in our situation and having talked with other families about how they deal with certain things or solve certain problems. Or how they planned for the future, it felt really supportive” (M4). This ability to talk to other parents who share similar experiences made the mothers feel more included and less alone as a parent of a child living with a disability. Families’ experiences and interactions varied, and mothers acknowledged that every family’s journey is different. But th,ey also had commonalities, and

they cherished relating to other families through the camp. One mother who stated that she felt isolated before the camp noted that "Everyone is totally different and unique and everyone has gone through different journeys with their kid but there are some similarities, and it was nice to talk to people who had gone through similar things" (M2). Mothers appreciated and enjoyed talking about challenges they face with families who understand what it is like to raise a child who is living with a disability. This is a type of support they did not always get when socializing with families who have typically developing children. Having support outside of the family can provide another outlet for parents, in this case especially mothers, to cope which can reduce the tension placed on family relationships. It can also help them cope with the societally created stress for families with a child with a disability by providing opportunities to share information and resources, provide emotional support, and validate their reality, helping them feel less alone.

With the suspension of programs for COVID-19, families no longer had the camp or other activities to participate in with other families with children living with a disability, so families felt especially isolated. Mothers in particular felt isolated during normal times, and this isolation was heightened during the pandemic. The program was not available, and alternative options available to some families with typically developing children were not realistic given their families' needs, intensifying the burden of the pandemic for these families. One mother who discussed how exhausted and isolated she felt during the pandemic stated:

The structural disablism and societal barriers experienced by the family increased throughout the pandemic, and the stress of COVID-19 was a significant negative societal emotional process affecting these families. While the pandemic was isolating for everyone, the impact on families with a child with a disability was even more severe. Concerns about the potential negative health impacts of contracting COVID-19 were often heightened for their

children, and the public health restrictions in place and their trust in other people's compliance with those restrictions was often not sufficient for them to engage with other people even as much as was allowed under the restrictions. Some families were unable to leave their house at all during some periods of the pandemic because of their child's medical needs, which was difficult for families. Some mothers' tone of voice expressed a sense of desperation when discussing this isolation, and the lack of certainty about how much longer they would need to carry on in these conditions.

Alleviating Stress and Anxiety Helped Families Bond

Mothers limited the degree to which they directly discussed daily stress associated with raising a child living with a disability in the focus group with their children present. However, it was apparent from the discussions that the mothers typically did most of the work and dealt with many challenges related to taking care of their children. Mothers expressed anxiety about their child participating in PA, and consistent with the idea of nuclear family emotional systems when a child has an impairment, the various forms of disablism their child faced in PA led them to have a great deal of worry focused on their child living with a disability. The camp relieved some of this stress by providing a context where mothers knew their child would be taken care of and safe while participating in PA. The assistance provided to their child living with a disability by the staff and volunteers at the camp allowed mothers to set aside some of the duties they would typically shoulder to overcome the structural disablism faced by their child living with a disability and made it possible for them to focus on bonding with their entire family. A mother who felt frustrated and saddened by the fact that here child couldn't always participate with the family stated:

> It meant a lot to us because [child's name]'s particular disability just usually means that he can't participate at the same level. So, skiing or biking or almost any outdoor activity, if [child's name] comes with us it usually requires me as the single parent to stay with him at all times. So, being part of the camp meant that with other volunteers we were able to. I can enjoy my other children on an activity just as much as being with [child's name] because there was somebody else to kind of make sure that he was safe and kept up with the group. (M4)

The camp gave families time to relax and bond by taking the burden off mothers. Reducing mothers' stress provided some relief to the triangles in the family unit because mothers did not have to be so preoccupied with the needs of their child living with a disability, which decreased family stress and gave them time to enjoy themselves and bond.

Conversely, when the camp was suspended due to COVID-19, the children with a disability struggled with the lack of activity, and many expressed feeling lonely, which is a result of indirect psychoemotional disablism. "[M1:] How does it make you feel? [C1:] I don't like it, I feel lonely. [M1:] You feel lonely. [C1:] I'm so sad." Seeing their child struggle put pressure on mothers to plan developmentally appropriate and engaging activities for their children. Mothers typically felt stressed and exhausted from having to plan and deliver all their children's activities, on top of the increased workload that all parents faced during COVID-19.

> It was a full-time job. I went from being busy to being insanely busy trying to do home schooling. … We had more time to fill, which can be good and bad. Trying to just mentally come up with the energy to think of things to do that everyone would enjoy or think of things to do to keep everyone active or at least going outside once a day. (M4)

Mothers clearly did not want this stress to be transmitted to their children, and seemed as though they were putting a positive spin on the situation when discussing it in front of their children. But it was clear that their workload, stress, and exhaustion increased in the pandemic, and the break provided by the camp was missed. As in the previous theme, although the pandemic caused difficulties for all families experiencing this societal emotional process, the structural disablism faced by children living with a disability and the lack of the camps as a source of support meant that this stress was disproportionately felt by these families with a child living with a disability.

Shared Experience Led to Mutual Understanding, Communication, and Support

Families discussed how they are not typically able to participate in physical activities together because the accommodations needed for the child living with a disability to participate are often not available, a form of structural disablism. The camp provided opportunities to participate together and allowed families to develop shared experiences. Siblings enjoyed being able to include the child living with a disability in activities and felt they had missed out on participating in PA together in the past. One family with two typically developing siblings expressed how they had felt sad because many of their memories of participating in PA did not include their sibling living with a disability. A brother who was excited to have an activity to participate in with his sister noted:

> I really like it and I kind of felt really happy for it because we could actually enjoy something together with our sister [C1], rather than she enjoying it and [my brother] and I not having a clue what she was doing or talking about. So, I really enjoyed it that we all could share fond memories of it and that we all enjoyed it together. [S1A]

Many children living with a disability preferred to participate with their family members: “[M5:] Do you like doing activities on your own like when I drop you off somewhere or do it as a

family? [C5:] Family." Although one child expressed that participating without their family would have meant more opportunity to have independence.

Having the opportunity to spend uninterrupted time together and experience each other's company in novel PA settings contributed to a better understanding of each other, an increased willingness to participate in activities together, and feelings that they grew closer and became a stronger family. As one mother stated, "I think from my perspective, we're stronger as a family" (M1). Parents and siblings felt they better understood the child's disability. Mothers discussed how this understanding improved siblings' patience with the child living with a disability.

> It's the slowing down at camp and not having the tight schedule that we sometimes feel like we have here. So they're less rushed now when they speak to [child's name] …And I can see how much more patient they are after having spent quality time with him at camp. (M4)

This patience and deeper understanding of each other allowed siblings to communicate with each other better, which led to stronger triangles among family members and in the family as a unit.

Families noticed that some of these positive impacts were declining as they were not able to attend the camp in 2020. "I think those regular intervals of stepping away are super important. And the longer you go between intervals, the easier it is to kind of fall back into your bad habits of normal ways of rushing through things" (M4). Families had fewer opportunities to do activities together: "This year just seemed really off because we didn't have that opportunity to go camp. Like we did lots of activities separately" (M2). They valued the camp and its positive impacts, and its suspension impacted their interactions. The opportunities provided by the camp can be seen as a reduction in indirect socioemotional disablism that allowed the child living with a disability and their family to benefit from participating together once barriers were removed.

Improved Independence and Confidence of the Child Living with a Disability

Most families discussed how participating in the camp increased the independence and confidence of the child living with a disability. One mother who was excited about her child's new independence discussed how her child now helps more around the house.

> He gets so happy just being able to participate and so proud of himself. And even now if he is downstairs watching a movie or playing with Legos, if I call him to tell him the dishwasher is ready to unload, he'll come upstairs right away. He doesn't want anyone else to do it. That's kind of his thing and he's so proud of himself. (M4)

Seeing the child so proud of themselves made the families very happy to see the child living with a disability have this experience. The camp scaffolded the child living with a disability participating in increasingly independent activities. Those experiences increased the child's differentiation of self as they were able to act more autonomously from their family unit, and increased mothers' confidence in their child's ability to do things more independently. One family discussed how the child living with a disability has talked about going to an overnight camp on their own, demonstrating greater independence and confidence, and how the family's experience at camp allowed the mother to see if that would be possible for their child.

Parents felt more comfortable putting their child in new programs because of the confidence their child developed at the camp. The children living with a disability also discussed the joy of being more independent, as opportunities for independence tended to be less available to them. 'It feels pretty good that I don't need help like I used to when I was little' (C3). Further, when asked by their mothers and/or siblings if they feel more confident, most children living with a disability indicated that they did. Mothers discussed how their child's independence and confidence gave them joy for their child, in contrast to the anxiety felt previously. 'It gives me

happiness to see her confident and approaching people and talking' (M3). After seeing this independence and confidence, mothers felt like their child was capable of more than they originally thought, and they had courage to plan for the future. A mother who was very excited about being able to plan for her child's future stated:

> [Child living with a disability] is turning 18 in a couple of weeks …So we're looking into transitioning into him being an adult which will involve different activities, different volunteer opportunities for him, possibly employment. Which will be a transition for the whole family. But I think the camp kind of helped us prepare for that and prepare for us to do that as a team. (M4)

Sibling Bonding made Parents Comfortable Giving Siblings Responsibility

As siblings spent more time with the child living with a disability and understood and communicated with them better, mothers recognized that their typically developing children were better equipped to support the child living with a disability. As a result, parents felt more comfortable giving their typically developing children more responsibilities.

> During the school year they would all go to a day camp.... I didn't have any aid support to send with [child living with a disability] so the boys often had to give her extra support or help out a little bit so she was doing what the group was doing. And I think that after the camp and after they saw how maybe to interact in a little bit different way to provide some guidance, it helped out when I needed that help. (M1)

Having the opportunity to send their typically developing children had aids replaced some of the mother's stress since they didn't have to worry about if their child would be comfortable with an aid. Additionally, the brothers were very happy to have this responsibility.

All children living with a disability in this study were the oldest sibling in the family unit, so opportunities for them to provide support were examples of them taking on the role of a functionally older sibling based on family systems theory, and shows how sibling positions may function in families including a child living with a disability. Accessing support from siblings also strengthened triangles involving mothers, the child living with a disability, and the sibling providing support, and gave the mothers an opportunity to access this source of support in their family and take stress off of the relationship between the mother and the child living with a disability. However, with the suspension of camp in 2020, some of this stress returned. Mothers seemed deflated when talking about how their typically developing children seemed to have lost patience for their sibling living with a disability and seemed to be less close. The triangles strengthened during the camp may have started to deteriorate with the stress of the pandemic and loss of the opportunity to attend the camp and boost those relationships again.

Confidence to Participate in Family Activities Beyond the Camp

Families appreciated the opportunity to try new activities in a safe environment, which increased confidence in their collective abilities to engage in recreation activities outside of the camp. Several families now do more recreation as a family, which they enjoy: “It’s great that I can do other activities now” (C3). Prior to attending the camp, mothers often felt nervous about trying activities as a family such as kayaking, hiking, or biking, which is an example of how nuclear family emotional systems related to parental anxiety about the wellbeing of a child with an impairment can affect the family unit. The opportunity to try these activities in a safe environment increased their confidence, decreased the mothers’ anxieties toward PA and opened new possibilities for recreational activities.

> I'm comfortable in a kayak but I hadn't been comfortable taking [child living with a disability] out just knowing my own capabilities being able to keep us in the boat and upright. And if it were to tip over, having help get us back in the boat, which we didn't have happen, thank goodness. But knowing that was there gave us the security to try something different. (M4)

The same mother was able to go on a family canoe trip in the summer, which she previously considered unimaginable. The camp even increased their desire to try other activities beyond those offered at the camp. Having the opportunity to try accessible activities in a safe environment was important to mothers and increased families' abilities to participate in recreational activities together. The camp decreased the structural disablism families experienced during PA, which decreased families' stress and increased their collective confidence to participate in more physical activities.

Discussion

The purpose of this study was to examine family members' perspectives regarding their lived experiences with their relationships within their family and how they perceived they were affected by their participation in an adapted PA summer camp for families with a child living with a disability. While families' experiences varied, there were six themes that described common impacts of participating in the camp. The camp impacted family relationships by reducing isolation for mothers through facilitating connections with other families. Accommodating the needs of the child with the disability to participate in physical activities alleviated stress and anxiety which helped families bond. Participating together provided families with a shared experience which led to mutual understanding, communication, and support. The child living with a disability improved their feelings of independence and confidence, which

impacted mothers' confidence in their child. The camp also facilitated sibling bonding which made parents more comfortable giving siblings responsibility for supporting the child living with a disability. The experience of the camp also gave families confidence to participate in family activities beyond the camp. The findings illustrate experiences of disablism faced by these families in PA contexts, how those experiences affect family interpersonal processes, and how some forms of disablism and interpersonal difficulties can be alleviated with appropriate supports.

Attending the camp was an opportunity where parents could relax knowing their child who is living with a disability would be accommodated. This ability to relax gave mothers in particular an opportunity to step out of their typical caregiving role, which allowed them to focus on family bonding. Finding appropriate programs and activities was particularly difficult during program shutdowns during COVID-19, reinforcing how important the camp was for families. This finding is consistent with research showing parents of children living with disabilities faced increased stress and worry about their child's opportunities for social engagement (Asbury et al., 2020). Families raising a child who is living with a disability tend to face higher levels of stress when finding recreation programs, in part because parents tend to worry that programs won't be accommodating of their child with a disability (Scholl at al., 2003). Parents engage in a considerable amount of labour to overcome certain barriers to participation (Goodwin & Ebert, 2018). Having an activity where mothers knew that their child would be safe and accommodated for in physical activities can decrease the stress on families and the worry parents may focus on the child living with a disability, which has positive effects on family relationships (Brown, 1999). It is important to acknowledge the disproportionate burden placed on mothers evident in this study and in similar studies on recreation in families with a child living with a disability

(Mactavish & Schleien, 2004). This burden on mothers is particularly notable in light of feminist criticisms that family systems theory does not sufficiently address gender-based power differences and the additional burdens placed on mothers in patriarchal society (Brown, 1999), and the disproportionate burden on women in caregiving roles and people living with disabilities and their families during COVID-19 (Jesus et al., 2021; Power, 2020).

Families felt as though they were able to develop a better understanding of one another, due to an increase in participating in PA together at the camp. This sense of understanding increased the family members' abilities to support one another, and the strength of the triangles in the family. Family members developed a better understanding of how to effectively support the child with a disability. Support from family members is very important to individuals living with a disability because they may not always feel supported because of the different forms of disablism they face in everyday life (King at al., 2006; Martin, 2013). Support within the immediate family is associated with better psychological and social well-being and lack of support from family members may cause the child living with a disability to feel angry, which may then decrease their emotional well-being (King et al., 2006). Support and communication may have an impact on family members' emotional functioning, thus impacting the nuclear family emotional system (Brown, 1999). The camp gave family members the ability to support one another, and families experienced changes in family communication and functioning.

Family members felt they tended to grow more patient with the child living with a disability and learned how to communicate with them more effectively. Similar to other research with families with a child living with a disability (Mactavish & Schleien 2004), outside of the camp context, mothers in this study were the primary person organizing PA experiences and participating in PA with the child living with a disability. Therefore, the support facilitating the

child's participation was particularly impactful for mothers in terms of alleviating that responsibility and freeing their time and attention to focus on other aspects of their relationships in the family and enjoying time together. Since family members were not always able to participate in PA with the child living with a disability, attending the camp gave them a better understanding of how to communicate in this type of setting. Communication is an effective way to decrease familial stress and behavioural problems in children living with a disability and their siblings (King et al., 2006). Families experienced positive changes regarding family relationships, and the closure of the camp in 2020 led families to feel as though some of the positive changes were fading due to not being able to participate in the camp. Not being able to participate in recreation during the pandemic led to more family time together, but was challenging for parents who had to compensate for lost programs and services and have reported worrying about the impact on their children's development (Neece et al., 2020). Similar concerns were apparent in this study, such as with mothers' exhaustion at planning suitable activities and loss of the opportunity to boost or further improve family relationships at the camp.

Children and adolescents living with a disability and their siblings do not always have an opportunity to participate in recreation together because the sibling who is living with a disability often needs more assistance or accommodations (Mactavish & Schleien, 2004). Having an opportunity to participate in activities together increased the typically developing siblings' understanding of their sibling's disability. This understanding contributed to the siblings' patience and communication with their brother or sister. Typically developing siblings often enjoy and value supporting their siblings with a disability in athletic endeavours (Blazo et al., 2014). A similar effect was found in this study in how excited siblings were to have to opportunity to participate in recreation with their sibling living with a disability. In some studies,

typically developing siblings have reported unpleasant experiences when participating in PA with their brother or sister living with a disability due to communication difficulties (Pit-Ten Cate & Loots, 2000). In contrast, participants in this study suggested that participating in recreation together when the child with a disability's needs are accommodated can enhance sibling communication. This improved communication and understanding led to parents having more confidence in the sibling's responsibility to support the child living with a disability, which increased the support available in the family, with positive repercussions for the family system.

Limitations

The need to conduct all focus groups via Zoom rather than in person due to COVID-19 may have impacted the first author's ability to establish rapport with the families. Technical issues and not being able to see all family members in the Zoom screen shared by the family also limited rapport. We needed to perform a retrospective study since camps were suspended due to the COVID-19 pandemic. As a result, focus groups were conducted more than a year after the families were last able to participate in the camp, participants may not have been able to recall some details of the camp. However, this time lag may have allowed the participants to reflect on longer-term impacts from participating in the camp. We conducted the focus groups at a single time point in an attempt to focus on the past experience of participating in this program. However, this may have limited the richness of the data since we were not about to able to examine the impact of ongoing involvement. Since the focus groups were conducted with all family members together, participants may not have felt comfortable sharing some perspectives. It seemed that the mothers were holding back some perspectives so as to not hurt or upset their children, which is a limitation of conducting focus groups with all participating members of the family present. Family members may not feel comfortable opening up in front of each other

which may impact the richness of the data and favour perspectives of those such as parents who have more power in the relationship. However, the focus group design provided the opportunity to examine families interacting with each other, which was a strength given the purpose of understanding the family as a relational unit. No fathers participated in this study. Only two families had fathers participate in the camp and both were not available at the time of the focus group. No older siblings participated in the study either: only one family had a older siblings attend the camp and they were not interested in participating in the study. Not having fathers or older siblings does limit the views represented in the results and our ability to understand the dynamics of the family as a whole. Due to sibling position older sibling may be used to taking on more responsibility for the child living with a disability than is typical for younger siblings, but their perspective was not included in the study. It should be noted that while thick description was attempted limitations such as some of the children's limited ability to express their view about their experiences made achieving thick description more difficult. We acknowledge that the first author previously knew the families beforehand, and as a result families might have been reluctant to share negative experiences with the camp. However, this relationship helped establish rapport which facilitated trust and more detailed responses from families.

Conclusion

The findings suggest that participation in a family adapted PA camp can positively impact family relationships. Families reported feeling supported and experienced less stress, a better understanding of one another, shared experiences among family members, and family and sibling bonding. Further, children living with a disability experienced improved confidence and independence. This study adds to the limited body of research regarding the potential effects of adapted recreation opportunities for families on family relationships by showing relational

mechanisms that may be affected by such programs. Programs that incorporate the entire family in recreation opportunities can tailor their activities to allow for time for familial bonding which may affect communication and support within families. These findings draw attention to the value of creating opportunities for the child living with a disability to demonstrate and experience independence, as those experiences may have positive implications for family relationships. Program practitioners should also be aware of the role they play in alleviating family stress and reducing structural barriers to PA for families with a child living with a disability. Designing programs that attend to these potential benefits may alleviate some of the stress and barriers faced by families and have positive implications for family relationships. Future research should continue to explore how family recreation for families with a child living with a disability can impact family life, and how community programs can be enhanced to better facilitate family interactions.

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Supplemental File

Focus Group Guide

[Numbered questions are asked of all families. Other questions are asked or not depending on what has previously been discussed, and/or to probe for additional information. Comments in brackets are instructions to the researcher.]

1. Tell me about what it was like to participate in the Friends and Family Camp.
    - What was going to the camp like for you as a family?
    - Were there any activities at the camp that were new for you? What was it like to try new activities together?
    - What was it like to help each other in the activities?
    - Were there parts of the camp that you liked? Please describe.
    - Were there any challenges you faced? Any challenges you needed to get through as a family?
    - Questions for children and adolescents
        - Can you tell me more about what it was like for you to go to the camp with your parents?
        - Can you tell me more about what it was like for you to go to the camp with your brother(s)/sister(s)?
        - How did being at the camp make you feel?
        - Can you tell me what it was like to see your older/younger brother/sister do new activities?
        - Did this camp change your thoughts on what [child's name] is able to do?
        - Did going to this camp change your thoughts on what you are able to do?
        - How did going to the camp make you feel?
    - Questions for adults
        - Can you tell me more about what it was like participating in the camp with your children?
        - What was it like seeing [child's name] participate in new activities?
        - Did this camp change you perceptive on what [child's name] is able to do?
        - How did this experience make you feel?

2. Have you noticed any changes in your relationships with anyone else in your family from participating in the camp? If yes, please describe.
    - Have you noticed any changes in relationships between family members?
        - What about relationships with your brother(s) and/or sister(s)?
        - What about your relationship with your parents?
        - What about your relationship with your child?
    - Did going to the camp affect your relationship with any of your family members?

3. [Name of child with a disability], have you noticed anything new that you can do now after going to the camp?
    - Tell me more about that

- Ask other family members
  - As a family have you noticed anything new [child's name] does after participating in the camp?

4. Did you notice any changes in how you talk of listen to anyone else in your family? If so, who? How did it change?
   - Have you observed any other ways the way you talk or listen has changed after the camp?
   - [Ask each family member]: Have you experienced any changes in how you communicate with anyone in your family?

5. Did you notice a change in the amount of activity you do as a family?
   - How has your activity as a family changed?

The next questions are about the loss of opportunities like this camp, because of COVID-19.

6. Did the camp not running this year affect your family? How?
   - How has it impacted your family?
   - How does this make you feel?
   - What does the loss of this camp mean to your family?

7. Did your family face any challenges because you weren't able to go to the camp?
   - Please tell me about those challenges.
   - How did these challenges impact your family?
   - Did the challenges you faced impact family relationships in anyway?
   - How do these challenges make you feel?

Is there something else you would like to share about your experience participating in the camp?

Thank you for your participation.