Understanding Young Carers and their Leisure (UYCL): A Critical Participatory Action Research (CPAR) Initiative

by

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Author’s Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Abstract

As of 2012, Statistics Canada estimated there were a minimum 1.2 million young Canadians supporting a family member or friend with a long-term health condition, disability, or as an older adult (Statistics Canada, 2012). Young carers voices and perspectives are predominantly missing from representations of their lived experiences in research, social policy, and support services. Leisure may have important implications for supporting young carers in their care roles; however, little attention has been brought to understanding young carers' meanings and experiences of leisure.

This critical participatory action research (CPAR) project partnered with young carers and staff supporting them to expand our understandings of young carers' experiences of care and how those care experiences shape leisure. Our team, made up of staff from two young carer organizations in Ontario and four, bright young carers, collaboratively and critically explored dominant conceptualizations of young carers and their leisure to better understand how to support young carers in their care roles. Drawing on critical youth studies and an authentic partnership approach, our CPAR process brings attention to the possibilities of involving young carers in actions and decision-making throughout all phases of the research.

Our CPAR project brought attention to four key themes: There is Nothing Unnatural About Being a Young Carer: It's About Just Being Human; Tensions in Understandings and Experiences of Young Carers; Leisure as Relational Moments of Rejuvenation in Everyday Life, and; Being Acknowledged as Relational Beings. Through privileging the perspectives of young carers, our findings contribute an alternative conceptualization of young carers and their leisure, filling gaps in research, policy, and practice.

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Dedication

For my mother and father.

You have provided me a foundation of love
through which my unique experiences and perspectives
have continued to flourish and grow. Thank you.

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SECTION ONE

Chapter One: Laying the Foundation

Rationale

In the early 2000s, researchers and service providers began to acknowledge the growing number of young people who provide informal and unpaid support to a loved one. The term young carer refers to children, youth, and young adults under the age of 25 who have extra responsibilities and offer support to a family member due to a chronic illness, disability (physical or intellectual), mental health concern, substance misuse, parental absence, or other social or cultural factors (e.g., language barrier, etc.) (Aldridge & Becker, 1993; Chadi & Stamatopoulos, 2017; Charles, Stainton, & Marshall, 2008; Stamatopoulos, 2015). As of 2012, Statistics Canada estimated that there were over 1.9 million young Canadians, aged 15 to 29, supporting a family member or friend with a long-term health condition, disability, or as an older adult (Chadi & Stamatopoulos, 2017; Statistics Canada, 2012). It is important to note that this data excludes Northern Canada and children under the age of 15, which leaves out a significant number of children and youth who support a relative or friend (Stamatopolous, 2016).

An overwhelming number of young people in the Statistics Canada 2012 census brought attention to the rewarding aspects of supporting a relative or friend; however, one third of these young Canadians also reported feelings of anxiety, worry, and fatigue because of their care roles (Statistics Canada, 2012). This is congruent with various studies that suggest young carers carry out similar tasks as their adult counterparts, but lack the necessary life experience, training, and knowledge, exposing them to several health risks such as stress, anxiety, and emotional distress (Becker, 2007; Becker & Sempik, 2019; Charles et al., 2008; Stamatopoulos, 2016; Stephen et al., 2019). Further, few of these young carers have access to services and supports to help them with their care roles. As Stamatopoulos (2016) concluded, roughly 1 in 944 young Canadians are receiving some sort of support in their care roles. This estimate serves as a minimum value due to underreporting and methodological shortcomings of the survey instruments employed. Echoing this statement, perceptions from policy makers and service providers suggest that "the number of 'hidden' young carers is substantially greater than the number of young carers in contact with service organisations" (Smyth et al., 2011, p. 153; see also: Aldridge & Becker, 1993; Becker, 2007; Rose & Cohen, 2010; Stamatopolous, 2016). What is most concerning is that given the 13.5% increase of young carers between 1996 and 2006 (Statistics Canada, 2012; Stamatopolous, 2016), it is highly likely that the number of young carers has increased significantly since the 2012 census, yet I was unable to find any up-dated numbers. The outdated and shocking statistics listed here speak to the ongoing lack of concern and disregard for young carers' experiences. As a young carer myself, I find this unacceptable and extremely problematic.

Given the high and growing number of young carers, both in Canada and worldwide, it is also concerning that research relevant to this group of young people has only begun to develop within the last 20 years; thus, our understanding at present is quite limited. Within the limited number of studies that do exist, literature has predominantly focused on the negative consequences of supporting a loved one at a young age (O' Dell et al, 2010; Rose and Cohen, 2010). Specifically, O'Dell et al. (2010) state that "the mainstream construction of young carers positions the young person as a tragic victim of circumstance" (p. 650). Rarely does the young carer literature bring attention to the rewards, in addition to the challenges, that are present in the caring experience. Further, much of the young carer research that exists focuses analysis at understanding individual experiences at a micro level, seeking to remedy problems by locating them within young carers' unique situations (Cooklin, 2010; Earley et al., 2007; Joseph et al., 2009). Little research employs critical theory to draw attention to and question the social structures that continue to leave young carers unsupported and unheard (O' Dell et al., 2010; Rose and Cohen, 2010). In this research, I draw on critical youth studies to address these crucial gaps in the young carer literature.

According to Stamatopoulos (2016) there are no policies acknowledging young carers in Canada and very few emerging non-profit organizations providing support and programming directly tailored to young carers. Specifically, in Canada there are only three organizations that I am aware of that provide support services specific to young carers, two of which are in Ontario, The Young Caregivers Association (YCA) in the Niagara Region and The Young Carers Program (YCP) in Toronto. The third young carer organization is located in Vancouver and is named the Comox Valley Youth as Caregivers Program; however, in this research, I will be predominantly focusing on the young carer organizations in Ontario, the YCA and YCP. In addition to providing support services, the YCA and the YCP offer leisure programming tailored to young carers' interests and needs. For instance, the YCA has heavily incorporated leisure into their Powerhouse program which aims to "teach young [carers] life and personal development skills, provide opportunity to connect with other [young carers], bring [carer] families together, and reinforce self care" (The Young Caregivers Association, 2020). Further, both the YCA and YCP suggest that leisure helps to reduce feelings of isolation while strengthening young carers' capacity to cope with their life circumstances (The Young Caregivers Association, 2020; The Young Carers Program, n.d.). Indeed, in conversations with staff from both the YCA and the YCP about programming, leisure was identified as playing an important role in the lives of young carers (personal email and online face-to face meeting communication with Cayleigh Sexton and Chelsea- Anne Alex, June 4, 2021).

Multiple studies have demonstrated that leisure has the potential to positively influence young peoples' lives by enhancing well-being (Matzka & Nagl-Cupal, 2020), supporting human and identity development (Kleiber & McGuire, 2016), and facilitating meaningful relationships (Haworth & Hill, 1992; Shin & You, 2013; Trainor et al., 2009). For example, young peoples' involvement in leisure activities positively affects their development of social behaviour through creating meaningful and sustainable relationships (Sauerwein et al., 2016; Stevens et al., 2004). Further, leisure spaces may benefit young carers' psychological and social well-being through providing much needed comfort and support during challenging circumstances and strengthening relationships both within and beyond the care relationship (Jenzon & Goodwin, 2012; Matzka & Nagl-Cupal, 2020; Sexton, 2018). Very little leisure research, however, is specific to young carers and therefore our understanding of leisure in the context of young carers is extremely lacking and in need of much further examination.

A large majority of research on leisure and care has focused on adult carers. Although some of this research points to the complexities of leisure in the lives of adult carers, much of this research suggests that leisure plays an important role in assisting adult carers in their care roles, contributing to their physical, psychological, and social well-being (Chiu et al., 2020; Gahagan et al., 2007; Stevens et al., 2004). Despite the important benefits of leisure for adult carers, this research also points to the challenges experienced by adult carers, especially women who provide the majority of adult care, in maintaining leisure lifestyles and accessing leisure (Williams et al., 2014; Sharma et al., 2016). More specifically, adult carers who lack adequate supports, such as respite services, often are forced to disengage from valued leisure activities, preventing them from experiencing the psychological relief, meaningful relationships, and social support that these activities provide (Becker & Sempik, 2019; Rogers, 2001; Stevens et al., 2004). Leisure as it is predominantly represented in this literature is quite inaccessible to carers because it requires significant investments of time and energy. Emerging literature has begun to explore alternative conceptualizations of leisure in the context of care (Lopez, 2018). More specifically, as moments of restoration in everyday life. Given the important role of leisure for adult carers demonstrated in this body of research, it is possible that leisure may also play a similar role in the lives of young carers. Similar to older carers, young carers may also experience challenges in accessing leisure. There are real differences, however, between young carers and adult carers, and coupled with the growing numbers of young carers, there is an urgent need for research that focuses on exploring young carers' experiences and meanings of leisure in the contexts of care.

As a young person who supports a loved one with a mental health concern and substance misuse, I have been provided with unique insights into the challenges and rewards of living as a young carer. My experiences have provided me with maturity, strength, and resiliency; however, with few support services in my youth and young adulthood, it was often challenging to balance caring for my family member, while caring for myself. Given the lack of attention brought to young carers, it is not surprising that I had remained unaware of the term ‘young carer’ until well after completing my undergraduate degree. As a result, I navigated through the toughest years of my youth and young adulthood feeling relatively alone in my situation, unaware that there were others in the same situation as me, and unaware of what might be available, if anything, to support me. When I became aware of the concept, young carer, I began searching out research and literature focused on young carers. As I began to find and read the limited literature that did exist, I became increasingly concerned with the lack of meaningful engagement and voices of young carers in this literature. In fact, almost more frustrating than the lack of supports available to young carers was what I perceived as the continuous disregard for their extremely valuable voices and stories. Recognizing that young carers hold deep knowledge about their lives and experiences, I strongly believe they should be supported in sharing their stories and experiences and being active members in shaping the practices and policies that influence them. It is for these reasons that I sought to do my Master’s thesis with the aim of providing a space for young carers to share their experiences and play an active role in the research process and social change to ensure that young carers are better supported going forward. I looked to critical youth studies (CYS) and theories to inform this research; a discussion I turn to next.

A Grounding in Critical Youth Studies and Theories

As mentioned by Rose and Cohen (2010), conceptualisations of childhood, youth, and young adulthood are socially constructed and therefore change across time and culture. Historically, the level of assistance expected of children has shifted over time to reflect the needs of changing contexts. For instance, in the Global North during the 19th century, child labour was not considered inappropriate as it was economically necessary for children to work to support the needs of the family (Heywood, 2001). During this time, children were viewed as economically valuable and capable throughout their childhood and into their adulthood. Fast forward to the present day in the Global North, and childhood is viewed as a time of protection and dependency (Ibrahim et al., 2014) where a child is "not finished yet" (Wihstutz, 2017) and primarily of value as a *future and productive citizen*; one who contributes to the economic stability of society (Wyn, 2015; Smith, 2015). From these conceptualizations, in the Global North, young people are presented as 'becomings' rather than 'beings' (Wihstutz, 2017, p. 275). As a result, childhood, youth, and young adulthood are all understood and accepted as a time where it is the adults' responsibility to take care of young people as they follow along a normal trajectory towards adulthood (O'Dell at al., 2010; Smyth et al., 2011). This approach has "spawned a rationale for interventions that prevent nonnormative development or that enable those who have gone 'off track' to be returned to the mainstream" (Smith, 2015, p. 24). For instance, when a child's lived experiences deviate from environments that are considered unproblematic and free of decision making "such as working to support the family instead of attending school or dealing with an abusive event(s)," the adult world (society) intervenes (Smith, 2015, p. 22). Given that the 'norm' is for adults to take care of children in the Global North, it is neither expected nor encouraged to take on caring responsibilities at a young age (Becker 2007; Freeman 1998; O' Dell et al., 2010). Doing so creates an alternative to the idealized version of childhood, youth, and young adulthood which places young carers who carry high levels of 'adult-like' responsibilities as being outside this 'norm' and following a different trajectory (Charles et al., 2008; O'Dell, 2010). As O'Dell et al. stated:

> *Children are viewed as in a state of becoming and positioned as vulnerable and unable to negotiate the world of adults. Within this mainstream view, social competence is accorded at particular ages (Fleer 2006) and therefore young carers transgress taken for granted assumptions about the competence and abilities of children, where the assumption is that children are to be cared for rather than care for others* (p. 644).

In addition to the responsibilities that come with supporting a family member as a young person, further challenges arise when young carers hold themselves to standards that do not reflect their lived experiences. Throughout my youth and young adulthood, I have often felt like an outlier in my social circles. I can distinctly remember a period in my life where I felt the most isolated because I wouldn't share my story or my experiences with most people in fear of them not understanding my situation. Knowing that my experience was not the 'norm' led me to feel and remain hidden to avoid another reminder that I should be living a life that is more "consistent with socially accepted constructions of childhood" (Rose and Cohen, 2010, p. 481).

A central tenet of CYS is that "scientific and dominant discourses promote the cultural construction of youth as a separate social category, which is reproduced and institutionalized through hegemonic power relations between youth and adults" (Wright, 2020, p. 33). Discourses are systems of reasoning that rely on patterns of repetitious ideas, language, moral frameworks, and narratives (Lesko, 2012). Specifically, CYS brings attention to discourses of youth, which are patterns of heavily ingrained discourses that naturalize particular ways of conceptualizing youth and generate restrictive frameworks through which youth are understood and managed (Smith, 2015; Wyn, 2015). According to Griffin (1993) and Wright (2020), youth discourses can generate, legitimate, reproduce, and institutionalize certain arguments, concepts, institutional practices, and social structures while preventing and silencing others. These youth discourses "function across time and social institutions and appear to be natural, common sense, invisible, and indisputable" (Wright, 2020, p. 33).

Early literature that explores the phenomenon of young carers draws on and encourages this construction of a 'normal' childhood. Specifically, one of Becker and Aldridge's (1993) first papers on young carers in the UK is titled 'The Lost Children,' referring to the constructed notion that young carers have lost out on significant aspects of a symbolic, 'normal' childhood (O' Dell et al., 2010). As a result, young carers are understood in a profoundly negative view (i.e., living tragic lives and victims of their circumstances) based on an assumption that young caring produces a loss of opportunity to be a 'normal' child, youth, or young adult (O' Dell et al., 2010; Rose & Cohen, 2010; Smith, 2015; Smyth et al., 2011; Wyn, 2015). In this way, "young caring is viewed as not 'real life' but an obstacle in the way of achieving the 'reality' of being a child, [youth, or young adult,]" leading many to see young carers as being in need of rescue (O' Dell et al., 2010, p. 652)**.** As a result, young carers are stuck in limbo, living on the borders between 'real life' and what 'real life' is supposed to be; opposing and embodying specific identities that submit to the 'norms' of the Global North. CYS scholars have critiqued this perspective, arguing:

> *"What is needed are models of growth that accommodate multiple sideways paths to growth, rather than one single, invariant, hierarchical, stage-like process of growing 'up'" (Ibrahim et al., 2014, p. 59).*

As previously mentioned, in the Global North, young people are typically understood through psychological and/or physical stages of development (Quijada Cerecer et al., 2013;

Wyn, 2015). These “hegemonic understanding[s] of childhood [have] placed children at the lower margins of society” (Wihstutz, 2017, p. 175) and “positions youth in opposition to adulthood whereby young people grow into or toward adulthood or grow out of or away from childhood (Quijada Cerecer et al., 2013, p. 217; see also: Smyth et al., 2011). CYS scholars seek to challenge the transitional life-stage paradigm that works to divide childhood from adulthood (Quijada Cerecer et al., 2013, p. 217). Further, they offer necessary criticism to adult-centric institutions (e.g., family, school, legal, etc.) that intend to educate young people toward adulthood in specific ways and protect them from the realities of daily life (Ibrahim et al., 2014; Quijada Cerecer et al., 2013). Through acknowledging the multidimensionality of youth and the influence of social structures on the lived experiences of young people (Lee et al., 2020), CYS creates a “distinction between the lives of young people and the way young people are categorized and represented in social discourses, cultural practices, and policies” (Quijada Cerecer et al., 2013, p. 217). This distinction is especially relevant to young carers, as their lived experiences often transcend ‘normal’ life-stage expectations, trajectories, and paradigms (O’ Dell et al., 2010). As a result, dominant conceptualizations of young carers are informed by problematic assumptions that are based on the constructed ‘norms’ associated with childhood and adulthood. These assumptions work to reinforce inaccessible spaces, opportunities, programming, and resources (Wright, 2020) for young carers (O’ Dell et al., 2010).

CYS scholars focus much attention on the presence and dominance of youth discourses in adult-centered institutions such as schools. According to Wyn (2015), schools commonly take up assumptions that mark the “child as being separate from the adult world (society), who in early childhood does not have the cognitive capacity or lived experiences to make rational and reasonable decisions about what is or could happen to them" (p. 22). These taken for granted assumptions promote and reinforce youth discourses that represent childhood as a time of dependency, and that youth are without insight and agency (O' Dell et al., 2010; Smith, 2015; Wyn, 2015). Since young carers experience times of resiliency, strength, and action in their care roles (Smyth et al., 2011; Stamatopoulos, 2015), dominant discourses of youth as 'innocent' and 'dependent' do not represent the complexity of young carers' real lives (O'Dell et al., 2010). CYS proposes that when young peoples' lived experiences are made to be hidden and their voices silenced, school settings, which are intended for growth and exploration, become oppressive spaces (Carey et al., 2020). Through challenging and deconstructing dominant understandings of youth, it is here that CYS has social justice and social change at its heart. Specifically, CYS scholars insist that youth be supported to actively "engage in actions that create change in organizational, institutional, and societal policies, structures, values, norms, and images" (Jennings et al., 2008, p. 40).

In my experience as a young carer, I felt that I could not share who I was completely with others in adult-centric spaces. Most of the time, when I confided in adults in these spaces about my care role, they invalidated my experiences through not being able to comprehend that a young person could take on a role like mine. This led me to keep an important part of my identity hidden, feel different and out of place, and remain unsupported in spaces where I should have felt the opposite. My experience aligns with findings from Rose and Cohen (2010), in which they suggest that young carers are often required to ask questions and challenge decisions about their family member in an assertive way. This may include advocating for proper medication, support, and resources for their family member. Although sometimes necessary in the care role, this behaviour is often labelled as cheeky and is not generally allowed or encouraged of young people, especially in school-settings (Rose & Cohen, 2010). In this way, societal assumptions not only produce misinformed ideas about all young peoples' lives, but also produce restrictive frameworks that leave young carers unsupported in negotiating their care roles from the position of a young person (O' Dell et al., 2010; Rose & Cohen, 2010).

As studies grounded in CYS are beginning to emerge, there is little leisure literature that draws on critical youth studies, resulting in a lack of understanding of young peoples' leisure experiences from this perspective (Fox, 2020; Wright, 2020). Within the leisure literature that does draw on CYS, findings suggest that young people rarely have opportunities to share their voice or influence decision-making in leisure spaces (Ibrahim et al., 2014; Smith, 2015; Wright, 2020; Wyn, 2015). Leisure spaces are not immune to the previously mentioned powerful discourses of youth that present young people as dependent and in need of protection (Wyn, 2015). As such, and as a means of keeping children and youth safe, risk management becomes a central focus (Jennings et al., 2008), eliminating opportunities for youth to experience risk (Lavie-Ajayi & Krumer-Nevo, 2013). Youth are also often intentionally left out of important leisure-related decisions and decision-making processes (Carey et al., 2020; Quijada Cerecer et al., 2013; Shamrova & Cummings, 2017) in these settings. According to Hopper et al. (2019), youth experience frequent isolation from important decisions and engagement with adults in leisure spaces, which has resulted in marginalizing spaces and misinformed programming. For instance, youth are often characterized by 'what they should be doing' and 'why they aren't doing it' (Ibrahim et al., 2014; Smith, 2015). When youth are not actively involved in decisions about their own leisure, they are at risk of being forced into leisure spaces and opportunities defined by discourses of youth, which may not be meaningful or productive to them (Therlault, 2014). This is especially relevant to young carers, whose lives do not conform to the ideal 'norms' of childhood (O'Dell et al, 2010). In this way, leisure spaces and opportunities are inaccessible to them (Matzka & Nagl-Cupal, 2020) because they are designed to accommodate singular understandings of children and childhood (Smith, 2015). CYS challenges these dominant understandings of young people, suggesting that when spaces accommodate a singular conceptualization of youth, they are not ultimately supportive or helpful in the real lives of many young people (Ibrahim et al., 2014; Smith, 2015; Therlault, 2014).

These discourses of childhood in societies focused on ideals of individualism are challenged in other cultures, particularly cultures where communalism is valued. Cass (2007) suggests that there are many "cultural circumstances where kin reciprocity is paramount in family functioning" (p. 246). This is the case in Morelli et al.'s (2003) study, which explores differences between young children's access to work in four communities: two middle-class European American communities, Efe foragers of the Democratic Republic of Congo, and Indigenous Maya of San Pedro, Guatemala. Specifically, their findings suggest that in both European American communities, children had less access to work that was designated for adults. In contrast, children in Efe and San Pedro had more access to adult work such as running errands, preparing, and cooking food, and caring for other children. In this way, Morelli et al.'s (2003) findings suggest that there are cultural differences in how much value is placed on children's access to adult work and ability to contribute to their family and broader community.

According to Robson (2004), “global processes shape children and young people’s home lives and structure their wider life experiences” (p. 228). In their research with young carers in Zimbabwe, Robson brings specific attention to the international diversity of young people’s experiences of childhood, home, family, and work in a time of increasing globalisation. Specifically, youth of the Global South are increasingly incorporated into divisions of labour, contrasting expectations in the Global North that children should remain out of the work force until adulthood. Similarly, on the Netflix reality show “Old Enough!, Japanese children as young as two years old are seen running errands for their parents (Grose, 2022). In comparison to Japan, Grose suggests that Americans’ have overexaggerated on protectiveness and that in an American version of the show, parents would be framed as irresponsible, or children would be represented as needing more support. As Wihstutz (2017) mentions:

> *The conviction that a ‘proper’ childhood involves being reared by parents within a secure domestic setting and secluded from the dangers of the adult world is underlying, implying childhood as time free of social and economic responsibility, and marked by learning and play, distant from hardship, work, and misfortune (p. 176).*

There is perception in the Global North that caring is ‘ugly’ or incompatible with the range of experiences acceptable in childhood, leading adults to feel a need to shield young people from caring (Wihstutz, 2017). It is here that CYS scholars argue for:

> A need to de-emphasise or challenge myths of childhood (as carefree and protected from the demands of labour) and ‘universal’ discourses on children’s rights purported by the Global North, while supporting children’s and young people’s rights to work under appropriate circumstances (p. 229).

It is through challenging taken for granted discourses of youth that CYS emphasizes that young people hold deep knowledge about their lives and experiences and should therefore help shape the practices and policies that influence them (Fox, 2016). It is from this perspective that I believe it is necessary to both challenge dominant constructions of youth in the Global North that may reinforce marginalizing and inaccessible leisure spaces for young carers and create spaces where youth can share their own stories and shape their own narratives. This research draws on three central tenets of CYS that are most relevant to this work: there is not one single stage-like process of growth, there are multiple sideways paths to growth; dominant discourses of youth reproduce and legitimize singular understandings of young people that do not reflect their lived experiences; and young people are experts on their own lives and have their own agency that is often taken away from them within adult-centric spaces. I now turn to a discussion on how I linked theory and methodology, through grounding in CYS.

Linking Theory and Methodology

Given the critical youth lens grounding this study and the goals of supporting youth agency, illuminating the voices and stories of young carers, and involving youth more in decision-making processes, I found myself drawn to Critical Participatory Action Research (CPAR) as a methodology for this research. Specifically, CPAR provides a space for people not often included in decision-making in research to reclaim ownership over their own stories and play active roles in changing their world (Jennings et al., 2008, Shamrova & Cummings, 2017).

As a young carer myself, I feel strongly that young carers' own voices be upheld at the forefront of research exploring their experiences. Aligning with CYS, this not only entails capturing young carers' elicited words but also their active control in determining how those words are collected and used and what stories they want to tell. CPAR provided a path to do just that; to embrace the potential of all co-researchers by "offering them opportunities to name, explore, and analyze their experiences, and respect them as authors and experts of their own lives" (Mirra et al., 2015, p. 5). Complementing CYS and PAR, an authentic partnership approach (see figure 1) involves working *with* others, not *for* others (Dupuis et al., 2012a, p. 436). Aligning with this approach, I strongly believe in incorporating and valuing all partners' perspectives and including young carers' voices directly in decision making (Dupuis et al., 2012a, p. 436).

Figure 1.

An Authentic Partnership Model (Dupuis et al., 2012a, p. 436)

Dupuis et al. (2012a, 2012b) outlines five components that lend to our research with young carers. An authentic partnership: (1) recognizes that individual voices have been oppressed, silenced, and/or excluded in decision-making, (2) values working and acting in partnership with all stakeholders to address social injustices and inequities experienced by marginalized individuals, (3) views knowledge as power, and joint education, learning and sharing opportunities as important vehicles for social change, (4) respects and values the knowledge and lived experiences of all partners, and (5) involves ongoing critical reflection and conversations in the community as a facilitator of new possibilities (Dupuis et al., 2012b). To mobilize authentic partnerships meaningfully and intentionally, Dupuis et al. (2012a) developed a set of guiding principles which include: a genuine regard for self and others, an appreciation for the synergy of relationships, and a focus on the process. To amplify the partnerships established in our research, I drew on these principles as well as the five enabling factors of the approach to support authentic partnerships throughout our process: connecting and committing, creating a safe space, valuing diverse perspectives, establishing and maintaining open communication, and conducting regular critical reflection and dialogue (Dupuis et al., 2012a).

An authentic partnership approach emphasizes the value of diverse perspectives and voices within the CPAR team and provided me with a scaffolding to authentically involve young carers in decision-making throughout the CPAR process. To sustain genuine and sincere partnerships it was crucial that I recognize the value and power of each person's unique positionality so I could better support the voices, strengths, and abilities of all CPAR team members. Through ongoing reflection with myself and the CPAR team, and continuously reflecting on the use of the five enabling factors, the authentic partnership approach was important in helping us navigate and support a truly collaborative process.

In searching out partners for our CPAR team I reached out to Cayleigh Sexton from the YCA and Chelsea-Anne Alex from the YCP, who both agreed to support our research as co-researchers. They then reached out to young carers in their organisations to tell them about our research and recruited young carers interested in serving as co-researchers on our CPAR team. They were able to recruit four bright young carer co-researchers who all agreed to be actively involved in this research: Saige Johnston, Chloe Chomos, Emaan Fatima, and Bernadette Sarmiento. All members of our CPAR team felt strongly about being identified as a member of the team.

Our Collaborative Purpose Statement

In the early stages of the CPAR process, the CPAR team has met several times over the last several months to collaboratively shape the direction of the research. As part of this collaborative process, we determined that the purpose of this CPAR study was: *to partner with young carers to expand our understandings of young carers' experiences of care and how those care experiences shape leisure.* In doing so, our objectives were to:

- provide a platform to privilege the voices of young carers,
- challenge dominant perspectives of young carers through bringing awareness to their unique experiences, and
- ensure young carers are better supported in their roles by identifying specific ways to support young carers, including in their leisure.

Our study was guided by the following research questions: How do young carers story their experiences of care and leisure in their unique contexts of caring? How do the stories of young carers’ experiences of care and leisure contrast with the dominant constructions presented in the literature? How might service providers and leisure professionals better support young carers in their care roles, including in their leisure? Ultimately, this study is intended to move leisure professionals, organizations, and policymakers to actions that better support young carers and their leisure lifestyles. I provide a much more detailed description of CPAR, our CPAR team, and our CPAR process in Chapter 3: Our Path to Understanding Young Carers and their Leisure, of this thesis.

Chapter Two: Mapping the Young Caring Literature

In this chapter, I explore the existing young caring literature, identifying gaps along the way that our study addressed. Specifically, I begin by establishing an understanding of how young carers' roles are described in the literature. Second, I examine how the young caring literature constructs young carers. Third, I describe the literature that speaks to the lived experiences of young carers. Last, I explore leisure in the lives of young carers, which includes drawing on literature that discusses leisure in the lives of young people and adult carers. Concluding this chapter is an identification of the primary gaps in the young caring literature that our research intends to address.

The Roles of Young Carers

As previously mentioned, young carers are young people under the age of 25 who take on extra responsibilities and provide unpaid support to a family member due to a chronic illness, disability (physical or intellectual), mental health concern, substance misuse, parental absence, or other social or cultural factors (e.g., language barrier, etc.) (Aldridge & Becker, 1993; Chadi & Stamatopoulos, 2017; Charles, Stainton, & Marshall, 2008; Stamatopoulos, 2016). I feel it is important to mention that this definition is useful for identifying and supporting young carers; however, in no way is this an exhaustive and inclusive definition. Instead, it is a working, malleable representation of what is currently known about young carers. There are young carers who may not identify with or align with this definition. For instance, surpassing the age of 25 does not mean someone is no longer a young carer. In saying this, for the purposes of this thesis, I will be drawing on the generally accepted definition of young carers mentioned above.

The level of responsibility involved in supporting a family member and time spent on these responsibilities varies among young carers (Becker, 2007). Specifically, the level of responsibility a young carer may contribute to their family and time spend on these responsibilities are not static. Oftentimes, young carers' level of care responsibility will fluctuate between light to very heavy, depending on circumstances within their unique contexts of care (Becker, 2007). According to multiple scholars, increased time spent on care responsibilities often contributes to feelings of isolation, loneliness, and increased stress (Charles et al., 2008; Collins & Bayless, 2013; Eley, 2004; Lakman, 2015; McDonald et al., 2009; O'Dell et al., 2010; Robinson et al., 2020). As a young carer myself, I often experienced these feelings when I felt my care responsibilities were heavy; however, since I had no supports that were specifically tailored toward my experience as a young carer, I cannot say whether these feelings would have been more positive had I been supported in my care role.

Literature suggests that young carers provide a wide range of support including physical, household, medical, emotional, and social (Frank et al., 1999; Joseph et al., 2008; Lakman, 2015; McDonald et al., 2009; McDonald et al., 2010; Moore et al., 2009; Phelps, 2017; Smyth et al., 2011; Warren, 2007). Physical support may involve helping with personal care such as toileting, mobility, washing, showering, bathing, dressing and undressing, putting someone to bed, and looking after siblings. Household support includes cleaning, meal preparation, cooking, financial tasks, and house maintenance. Medical tasks can involve helping with medication (managing and administering) and transportation to medical appointments. Emotional and social support involves keeping the family member company, their spirits up, driving them to social gatherings or events, and may include supporting the adult carer through ongoing guidance, reassurance, and encouragement. Not all young carers take on all these tasks and multiple scholars suggest there is wide variation in the level or responsibility and care that young carers provide (Aldridge, 2018; Cohen et al., 2015; Lakman, 2015; McDonald et al., 2010; McDonald et al., 2009; Moore et al., 2009; Smyth et al., 2011). However, in comparison to non-caring young people, "young carers spend up to 75% more time on a weekly basis on these types of tasks than non-caring children and youth" (Sexton, 2018, p. 3; see also: Aldridge & Becker, 1993; Smyth et al., 2011; Warren, 2007).

Multiple siblings within a family may take on care responsibilities, and it is common for siblings to assume different levels of responsibility within the family (Sexton, 2018). This means that some siblings may have light levels of care, while other siblings take on heavy responsibilities. These within-family differences are not fully understood; however, scholars have determined that age, gender, birth order, nature of the illness or disability, individual factors, and availability of alternative support sources may influence the level of responsibility a young carer may take on in the family (Becker 2008; Becker et al. 1998; Dearden & Becker, 2004; McDonald et al., 2010; Sahoo & Suar, 2010). According to Dearden and Becker (2004), the average age of young carers rests around 12, although scholars have identified children who provide care at as young as 5 (Aldridge & Becker, 1993). Although some scholars suggest gender may not be a determining factor in who provides care in the family, some researchers have found that females often take on responsibilities related to intimate and household tasks more than males (Dearden & Becker, 2004; Joseph et al., 2009). Further, Smyth et al. (2011) suggest that males may be aware of social norms of masculinity and, in turn, may be more reluctant than females to identify themselves as young carers in fear of judgment from society. Few studies have determined the extent to which birth order or individual factors such as personality and temperament contribute to who undertakes care responsibilities in the family (Lackey & Gates, 2001; Lakman, 2015; McDonald et al., 2009).

Social Constructions of Young Carers

So, what are the dominant discourses of young carers? As mentioned in Chapter One, young caring is often constructed as producing a loss of opportunity to be a 'normal' young person (Aeyelts et al, 2016; Bolas et al., 2007; Lakman, 2015; Smyth et al., 2011). As a result, young carers are predominantly constructed in the literature as 'tragic victims of circumstance' (O'Dell, 2010, p. 650). Although it is very important to express the challenges that come with young caring, it is equally as essential to do so without exaggerating the negative impacts of caring, which may stigmatize young carers and their families (Fives et al., 2019). Further contributing to this depiction of young carers' care experiences as tragic, multiple scholars' position young carers in comparison to an idealized 'normal' child and childhood (Aeyelts et al., 2016; Boumans & Dorant, 2018; Chojnacka & Iwanski, 2021; Cooklin, 2010; Lakman, 2015;). Since young carers have lives outside the normative expectations of young people and familial responsibilities, they are judged and understood as different and deficient compared to non-carers (O'Dell et al., 2010). Judgments about young carers are further developed from the emerging and popular use of the term parentification when referring to young caring. Remtulla et al. (2012) state that 'parentification' occurs when parents willingly and wholly abandon their parental responsibilities and demand their child adopt the parenting role for the maintenance of the family. Other studies suggest that young carers fulfill the parental role in the family when they take on caring responsibilities that are not expected of a child. As a result, young carers are seen as ‘parentified’ and are considered ‘parental-children’ (Borchet et al., 2021; Boumans & Dorant, 2018; Charles et al., 2009; Chojnacka & Iwanski, 2021; Frederick et al., 2020; Hendricks et al., 2021; Kavanaugh & Stamatopoulos, 2021; Rose & Cohen, 2010; Stamatopoulos, 2016).

Parentification is an example of common taken-for-granted assumptions about child and adult roles. Again, not to dismiss the challenges that come with being a young carer and the range of ways the care role can be experienced by different young carers, constantly using parentification as a dominant label in young caring literature constructs young caring experiences as ‘abnormal’ and all young carers as vulnerable and in need of rescue from their care roles (Chojnacka & Iwanski, 2021; Earley & Cushway, 2002; Frederick et al., 2020; Hendricks et al., 2021; Kavanaugh & Stamatopoulos, 2021; Parys et al., 2014). In Heyman and Heyman’s (2013) study, young carers viewed themselves as competent navigators of their own futures and did not share beliefs with academics and service providers about what a ‘normal childhood’ should look like. Since not all young carers are ‘parentified’ (Charles et al., 2009) and the term ‘parentification’ itself is dependent on social constructions of child and adult roles, it is concerning that scholars have shifted to the common use of the term in young caring literature without taking a critical approach (Chojnacka & Iwanski, 2021; Borchet et al., 2021; Frederick et al., 2020; Hendricks et al., 2021; Kavanaugh & Stamatopoulos, 2021).

As young caring literature continues to compare young carers to an idealized norm, young carers are automatically positioned in a state of disadvantage and constantly fall short of societies’ expectations of them (Charles et al., 2009; Heyman & Heyman, 2013; O’Dell et al., 2010; Rose & Cohen, 2010; Smyth et al., 2016). Although scholars have begun to explore the ‘norms of childhood’ that guide most of the research on young carers (Aeyelts et al., 2016; Charles et al., 2009; Heyman & Heyman, 2013; O’Dell et al, 2010; Rose & Cohen, 2010, Smyth et al., 2011), little attention has been brought to deconstructing these taken for granted ‘norms,’ which has resulted in the over-depiction of young carers as vulnerable and at-risk (Aldridge, 2018; Bolas et al., 2006; Cooklin, 2010; Frank & Slatcher; 2008; Gray et al., 2008; Kavanaugh, 2014; Stamatopoulos, 2016).

Although almost every study on young carers brings attention to the challenges that come with caring at a young age (Aldridge, 2018; Cooklin, 2010; Earley et al., 2007; Joseph et al., 2008; Moore et al., 2009; Smyth et al., 2011), few studies are designed in a way that also privilege the positives involved in young caring. Heyman and Heyman (2013) indicate that the “personal gains from [young carers’ care] roles needs to be better acknowledged” (p. 577). Thus, a smaller body of literature has begun to shed light on the positive aspects of caring for young carers, such as developing maturity, responsibility, a positive sense of self, and life skills (Matzka & Nagl-Cupal, 2020; McDougall et al., 2018; Rose & Cohen, 2010). Unfortunately, some of this literature is limited in terms of delving deeply into the complexity of care experiences for young people. For example, Earley et al. (2007) used quantitative methods in the form of a questionnaire that placed questions for young carers into ten categories. Out of all ten categories, 9 were specific to different challenges that young carers experience and one broadly addressed the ‘positives of caring’ (p. 173). In this case, the questionnaire was designed in a way that emphasized the challenges associated with the care experience compared to the positives. Further, this type of method restricted the ability for young carers to speak directly to the positives and negatives of their care experience (Joseph et al., 2019), thus some care experiences not included on the questionnaire may not have been captured. What is most problematic about a focus on a deficit-based approach is that it places fault on the act of caring at a young age rather than exposing structural and systemic factors, and the lack of supports available to families, that marginalize young carers (Gray et al., 2008; Kavanaugh, 2014; Moore et al., 2009).

Given the predominance of negative constructions of young carers, it is not surprising that these discourses can play a significant role in shaping young carers' experiences. In their study, *Constructing 'Normal Childhoods': Young People Talk about Young Carers*, O'Dell et al. (2010) found that young people were very aware of and drew on predominantly negative constructions of young carers, suggesting that dominant discourses present young carers lives as problematic. These constructions are then resisted by young carers as they navigate their care experiences (O' Dell et al., 2010). Since very few scholars have utilized a critical approach in their research, little attention has been brought to the discourses that create specific constructions of young carers and their care experiences. Although there are challenges that come with caring at a young age, socially accepted discourses have the power to marginalize young carers through consistently problematizing their experiences of care (O'Dell et al., 2010; Rose & Cohen, 2010). In addition, there are currently few studies in the young carer literature that utilize phenomenology, narrative, or participatory methodologies and methods (Bolas et al., 2007; Doutre et al., 2013; Skovdal et al., 2009; Jonzon & Goodwin, 2012), which are designed in a way that may encourage and uphold the voices, experiences, and stories of participants (Eley, 2004; Frank and Mclarnon, 2008; Holmes, 2020; Joseph et al., 2019; Phelps, 2012; Phelps, 2017) and provide opportunities to construct an alternative discourse grounded in the lived experiences of young carers. I addressed this gap in the literature by working in partnership with young carers.

With the above limitations of the existing literature in mind, I now set out to describe what we know about the experiences of young carers. Given that most of this literature focuses on the challenges of being a young carer, I will start there.

Experiences of Being a Young Carer

Challenges Experienced by Young Carers in their Care Roles

As previously mentioned, the young caring literature suggests that young carers experience multiple challenges when they are left unsupported in their care roles (Aeyelts et al, 2016; Aldridge, 2018; Bolas et al., 2007; Cooklin, 2010; Earley et al, 2007; Joseph et al., 2008; Lakman, 2015; Moore et al., 2009; Smyth et al., 2011). Specifically, the most consistently found challenge is the isolation that young carers experience (Aldridge, 1993; Aldridge, 2018; Bolas et al., 2006; Frank & Slatcher; 2008; Gray & Robinson, 2009; Gray et al, 2008; Kavanaugh et al., 2015; Lakman, 2015; Moore et al., 2009; Robson, 2004; Rose & Cohen, 2010; Smyth et al, 2011; Stamatopolous, 2015; Warren & Ruskin, 2008). The isolation that young carers experience may result in loneliness and lower levels of life satisfaction (Chalmers & Lucyk, 2012; Collins & Bayless, 2013; Stamatopoulos, 2018).

According to Smyth et al. (2011), many young people who undertake caring roles and responsibilities do not identify themselves as young carers due to the nature of the care relationship. Specifically, the care role is a very natural part of some young carers' lives and as a result, they do not view themselves as 'carers' but instead as simply supporting their family. In a study that explored young carers experiences in Zimbabwe, there was often no-one else to step into the caring role and therefore, taking on caring responsibilities was automatic for many young people (Robson, 2004). In my own experience, caring at a young age was my normal. There was no use in questioning my role because it just simply was my circumstance. The term young carer was completely unknown to me for a long time, as was the idea that there were other young carers out there with similar experiences. It was not until I started speaking about my care experience openly that I came to realize how many young carers I already knew, even in my small social circle. Although I can identify young carers because I now know that the term means, the majority of young carers do not know of the term young carer or consider themselves young carers (Aldridge, 2018; Chalmers & Lucyk, 2012; Stamatopolous, 2018). Aligning with my experience, young carers do not often share their experiences of care with others, further isolating them and limiting the possibilities for them to hear of the term 'young carer' (Aldridge, 2018; Stamatopolous, 2018) In Canada, there is a general lack of awareness of young caring and there are minimal supports available to young carers (Stamatopolous, 2015; Stamatopolous, 2018). As a result, many Canadian young carers remain hidden beyond the reach of the limited supports available to them (Aldridge, 2018; Chalmers & Lucyk, 2012; Sexton, 2018; Stamatopolous, 2016; Stamatopolous, 2018). This isolation and lack of awareness and support has the potential to create new challenges for young carers and exacerbate the challenges they may already experience. These challenges fall within the realms of consequences on education, future employment, social opportunities, physical and mental health, and well-being (Aldridge, 2018; Ali et al., 2012; Bolas et al, 2007; Chalmers & Lucyk, 2012; Earley et al, 2007; Fives et al., 2013; Hamilton & Adamson, 2013; Hill et al., 2011; Lloyd, 2013; Moore et al., 2009; Polkki et al., 2004; Stamatopolous, 2015; Warren, 2007).

Given that young carers often spend a significant amount of their time caring for their family member, participation in education may be constrained (Becker & Sempik, 2019; Fives et al., 2016; Hamilton & Adamson, 2013; Wong, 2016). Specifically, young carers' attendance may be impacted, with some deciding to drop out completely to provide the necessary support to their relatives (Lakman, 2015). Further challenges regarding attendance include lateness, difficulty completing course work and homework, and restricted peer networks (Ali et al., 2012; Chalmers & Lucyk, 2012; Eley, 2004; Warren, 2007). Depending on the level of responsibilities taken on by young carers challenges may be intensified by tiredness and a lack of time to fulfill school-related tasks at home. Some scholars found that these academic challenges led to poorer future financial standing and career choices among young carers (Fives et al., 2013; Hill et al., 2009; Lloyd, 2013; Moore et al., 2009; Stamatopoulos, 2018).

There are few studies that focus on the economic realities and financial implications for young carers in the young caring literature; however, many scholars briefly report on economic and financial challenges as factors that influence the experiences of young carers. Particularly, socio-economic disadvantage has been constantly identified as a factor that impacts young carers (Fives et al., 2013; Hill et al., 2009; Lloyd, 2013; Moore et al., 2009; Stamatopoulos, 2018; Vizard et al., 2019). In their study, Fives et al. (2013) identified that young carers often lived in households without any adult in paid work. This led several families to be heavily dependent on whatever income support they were entitled to by the government and/or resulted in young carers seeking employment to financially support their household. Similarly, Robson (2004) found that most young carers in Zimbabwe supported their households through "financial and material help to alleviate poverty by combating loss of income and the cost of looking after a sick and possibly bedridden individual" (p. 242). When exploring the influence of the COVID-19 pandemic on young carers' mental health, King (2021) found that young carers were consistently worried about their family's financial situation. According to King, financial stressors often exacerbated mental health challenges such as worry and anxiety among some young carers. Particularly, young carers expressed concerns about the uncertainty and potential instability of the future in relation to their economic realities (Martin, 2021).

Within the young caring literature, various scholars have brought attention to the challenges that young carers experience in relation to social opportunities (Aldridge, 2018; Ali et al., 2012; Chalmers & Lucyk, 2012; Earley et al., 2007; Joseph et al., 2019; Leu et al., 2020). Specifically, Aeyelts et al. (2016) described how some young carers experience bullying and harassment due to stigma surrounding their care roles and/or the family member they are supporting. For instance, Robson (2004) found that Zimbabwean young carers and their relatives felt reluctant to share their care experiences with others due to stigma about HIV/AIDS. The fear of judgement from others that young carers may experience further inhibits the development and maintenance of meaningful social relationships (Aeyelts et al., 2016; O' Dell et al, 2010; Richardson et al., 2009; Rose & Cohen, 2010). Similar to challenges with completing school-related tasks at home, young carers do not often have a lot of time after school to build social relationships with friends, engage in extra-curricular activities, or attend social events (Barry, 2011; Earley et al., 2007; Gray et al., 2008). According to Warren (2007), young carers often lack free time, making leisure activities more challenging to participate in. Although various studies in the young caring literature demonstrate that leisure activities and spaces are inaccessible to young carers (Barry, 2011; Earley et al., 2007; Eley, 2004; Gray et al., 2008; Stamatopoulos, 2018; Warren, 2007), very few studies explore young carers' meanings and experiences of leisure. I will come back to a discussion on leisure in the lives of young carers later in this chapter.

Some literature also points to the consequences of care on the mental and physical health of young carers. For example, various scholars have brought attention to the emotional impacts of care among young carers such as frustration, anger, guilt, and confusion, all of which are more pronounced when the young carers feel they do not have a choice in providing care (Ali et al., 2012; Bolas et al., 2007; Chalmers & Lucyk, 2012; Doutre et al., 2013; Earley et al., 2007; Hamilton & Adamson, 2013). In contrast, findings suggest that when young carers feel they do have a choice in taking on caring responsibilities, they experience greater life satisfaction (Hunt et al., 2005), lower distress (Lakman, 2015), and are able to adapt to changing roles (Pakenham et al., 2007).

Various scholars have also found that young carers experience stress, anxiety, and depression (Obadina, 2013; Pakenham et al., 2007; Sahoo & Saur, 2009) and report low self-esteem and low perceptions of their overall well-being (Banks et al., 2002; Chalmers & Lucyk, 2012; Collins & Bayless, 2013; Stamatopoulos, 2018). According to Dharampal and Ani (2019), young carers who provide support to a family member with a mental illness or substance misuse may have a greater potential for mental health challenges, especially when unsupported. Various scholars have also described to the behavioral challenges that young carers may face when unsupported in their care roles. For instance, many young carers experience emotional outbursts, self-harm, difficulty sleeping, and lower concentration (Cluver et al., 2012; Collins, & Bayless, 2013; Cree, 2003; Nagl-Cupal et al., 2014). Further, young carers may also experience physical health issues associated with their care roles such as tiredness, exhaustion, and backache as a result of caring responsibilities (Robison et al., 2020). However, physical health issues may also be exacerbated by young carers' constant feelings of worry and stress (Becker & Becker, 2008; Cluver et al., 2012; Collins & Bayless, 2013). These emotional, physiological, and behavioral challenges can affect young carers in multiple domains such as at home, in their social relationships, and at school (Aldridge, 2018; Thomas et al., 2003; Warren, 2007).

Despite the emotional and physical aspects of care, young carers often have limited to no access to resources that prioritize restoration and self-care (Moore et al., 2009). Specifically, Polkki et al. (2005) expressed that the young carers in their study used self-taught practical and emotional strategies to to manage the impacts of their care roles, with some young carers turning to unhealthy strategies long-term such as substance use. Coupled with a lack of choice, a lack of access to resources for restoration may also contribute to the high levels of stress that young carers experience.

Given the abundance of literature that reports on the potential challenges that young carers may experience in their care roles, multiple studies confirm that there is a significant need for supports that are designed to be accessible to young carers in their care roles (Bolas et al., 2006; Frank & Slatcher; 2008; Gray & Robinson, 2009; Gray et al, 2008; Kavanaugh et al., 2015; Lakman, 2015; Moore et al., 2009; Robson, 2004; Rose & Cohen, 2010; Smyth et al., 2011; Stamatopolous, 2015; Warren & Ruskin, 2008). I turn to this discussion next.

Supports Available to Young Carers

In their review of young carer services in Canada, Aldridge (2018) indicates that Canada is in a 'preliminary' position, which is "marked by very little in the way of a national awareness of young carers and no dedicated legislative supports" (p. 179). Although Canada has a handful of locally driven services available to young carers and a developing research base, there is "still very little targeted programming to assist them in their [care] roles" (p. 180). According to Aldridge (2018), more recent studies have turned away from early intervention and prevention of caring at a young age and have begun to focus on supporting young carers within their care roles (Chadi & Stamatopoulos, 2017; Rose & Cohen, 2010; Smyth et al., 2011; Stamatopoulos; 2016); however, this shift is not necessarily reflected in studies that focus on reviewing young carer services, which predominantly still discuss early intervention and prevention (Aldridge, 2018; Stamatopolous, 2016). Although it may be ideal to have preventative strategies that focus on providing support to the whole family where a young carer exists, there are multiple barriers that delay the existence of these supports (Stamatopoulos, 2016). These barriers include lack of funding to support these broader initiatives and the integration of supports, and identification strategies within schoolboards.

Currently in Canada, all available support services to young carers are both assistance and mitigation-based, with supports "aimed at assisting youth in their care roles (via counselling, information on other services or self-help techniques and access to peer support groups) and/or mitigating some of the negative consequences experienced (via respite-based services, educational assistance and training and employment assistance)" (Stamatopoulos, 2016, p. 190). Among these available services, there are very few that specifically tailor to young carers (Aldridge, 2018; Chadi & Stamatopolous, 2017; Joseph et al., 2019) and all are provided at a local level (Aldridge; 2018; Herman Nao et al., 2020; Stamatopolous, 2016) with much inconsistency across communities in terms of what is available. Although the supports in Canada are not preventative, they aim to support young carers within their care roles, acknowledging that caring is sometimes a significant and appreciated part of young carers' identities and lives. Since support services and programming are not available to young carers during school hours, they are often extra-curricular in nature and generally take place after school. Due to the unpredictability of young carers' lives and lack of promotion of the very limited services available, these supports are not often accessible to young carers (Becker & Sempik, 2019; Chadi & Stamatopoulos, 2017; Charles et al., 2008; Cooklin, 2010; Heyman & Heyman, 2013; Purcal et al., 2012; Stamatopoulos, 2016; Stamatopoulos, 2015).

In summary, most of the young caring literature that mentions young carer supports report on the absence and inaccessibility of support services for young carers as a part of understanding the young carer experience (Becker & Sempik, 2019; Chadi & Stamatopoulos, 2017; Charles et al., 2008; Cooklin, 2010; Heyman & Heyman, 2013; Purcal et al., 2012; Stamatopoulos, 2016; Stamatopoulos, 2015). The majority of studies that focus on supports available to young carers are primarily concerned with reviewing the type of services that exist (Aldridge, 2018; Stamatopolous, 2016), with some prioritizing preventative services and others supporting assistance and mitigation services. I could not find any studies that prioritized young carers' own perspectives about what could better support them in their care roles, which I found very disheartening. In response to this, Joseph et al., (2019) asks for researchers and professionals to take a step back from taking an expert frame of reference. In doing so, they call for participatory and action led research that can provide greater insights into the lived experiences of young people, their needs, and how these needs can be met. This research answers this call through its grounding in CYS, which views young people as experts of their own lives and calls for the active inclusion of them in decision-making about their lives. Further, our study drew on CPAR, which provides the space for young carers to become active partners in the research process.

Rewards Associated with Being a Young Carer

> *"Caregiving has changed my life to cope with adverse situations. It has made me aware of how I should handle the sick and taught me to be active and positive in doing work'' (Syprose, in Skovdal et al., 2009, p. 587).*

Although the challenges experienced by young carers and the lack of supports available are most often reported on, there are multiple rewards that are associated with being a young carer (McDonald et al., 2010; O' Dell et al., 2010; Pakenham et al, 2007; Phelps, 2017, Skovdal et al., 2009). Specifically, young carers often take on a lot of responsibilities in their families which, in turn, encourages a sense of agency (O' Dell et al., 2010). Further, the multiple responsibilities that young carers take on assists them in being able to quickly adapt in unexpected situations (Pakenham et al., 2007) and minimize problems (Early et al., 2006) when changes to their roles occur (McDonald et al., 2010). Coupled with adaptability, McDonald et al. (2010) mention that some young carers are quite intuitive, coming to know a person's needs, preferences, and what to do to support them. This coincides with findings from Skovdal et al. (2009) who indicate that young carers "are often able to draw on a range of coping strategies and manage their difficult circumstances extraordinarily well" (p. 593). Through advocating for their loved one, young carers develop a range of practical, care-related, and social skills (Heyman & Heyman, 2013; Rose & Cohen, 2010) that benefit and define their future selves (Early et al.,2007; Thomas et al., 2003). Specifically, young carers have been found to often choose careers in caring professions (Banks et al., 2003; Dearden & Becker, 2003; Hamilton & Adamson, 2012). Some young carers mention these career choices and aspirations may be due to being intrinsically caring, while others feel their young carer roles had nurtured aspects of their personality that led them to caring professions. These aspects included being more caring, altruistic, enduring, and sympathetic (Charles et al., 2010; McDonald et al., 2009; Phelps, 2017; Sahoo & Suar, 2010).

As mentioned, young carers may experience various challenges in their care roles, leading them to experience resiliency (Kavanaugh, 2014; Matzka & Nagl-Cupal, 2020). However, the young carer experience is messy and fluid, and young carers may shift from feeling more resilient to less resilient depending on their unique contexts of care and as their circumstances change. Along with resiliency, caring as a young person builds maturity and a sense of responsibility (Banks et al., 2002; Fives et al., 2013; Nagl-Cupal et al., 2014; McDonald et al., 2009), which young carers view as an assistance to them (McDonald et al., 2010). Additionally, young carers have unique knowledge and understanding of illness and disability (Banks et al. 2001; Cooklin, 2010; Dearden & Becker 2000; Lackey & Gates 2001; McDonald et al., 2009; Phelps, 2017; Thomas et al. 2003) and their care experiences canenhance family relationships and closeness (Chalmers & Lucyk, 2012; Charles et al., 2010; Doutre et al., 2013; McDonald et al., 2010; Stallard et al., 2004). Although there is a recognition of the complexities of care and the need to explore the challenges and rewards of care for young carers, our understanding of the possibilities of care for young carers remains limited (Heyman & Heyman, 2013).

In various studies young carers asked that their diverse and multiple experiences and care roles be better understood, and questioned services for their lack of availability and accessibility (Heyman & Heyman, 2013; Stamatopolous**,** 2016**;** Aldridge, 2018; Kavanaugh & Stamatopoulos, 2021; Leu & Becker, 2017) Given the lack of literature that explores young carers experiences of care in all its complexity, it seems this call has not yet be answered. With this project, we intended to address these gaps in the young caring literature by drawing on CYS and taking guidance from our team to privilege the voices of young carers. In doing so, we aimed to identify specific ways to better support young carers within their care roles.

Leisure in Lives of Young Carers

Benefits of Leisure for Young People

According to Hopper et al. (2019), leisure is an "intrinsically motivated, meaningful, and nonobligated/unrestricted activity" (p. 247). This is the way that leisure is often described in literature that explores young people and young caring. Feminist and other critical scholars, however, have critiqued leisure as a non-work activity, free-time, or a state of mind (Russel, 2013) as these dominant conceptualizations often simplify the complexity and messiness of leisure (Lopez et al., 2021; Lopez, 2018). Specifically, contemporary meanings of leisure as time free from obligations or nonwork kinds of experiences (Russel, 2013) may not necessarily accommodate young carers who spend a significant amount of their time supporting a family member. Alternative understandings of leisure reject the work-leisure binary and the notion that leisure can only be experienced outside of obligatory roles or work-like activities (Lopez, 2018). For instance, Lopez et al. (2021) conceptualizes leisure as being “comprised of moments, in between and betwixt the boundaries of work, whether in person or virtual, and all else” (p. 4). This shapelessness of leisure may be helpful when thinking about time stressed people such as carers, especially given that their experiences of leisure may be interwoven with their care roles (Lopez, 2018). In fact, Dupuis (2000) found that care was an important space for experiences of leisure for some women. Given that leisure is often described as being subjective to the person experiencing it (Freire, 2012; Unger & Kernan, 1983), no specific definitions of leisure will be operationalized in this study. Additionally, a main objective in this study is to find specific ways to better support young carers in their leisure, however they define it, which comes from exploring young carers’ own accounts of how they use and conceptualize leisure in their lives.

Much of the literature on leisure in the context of youth points to the importance of leisure to the health and well-being of young people, and yet very little is known about leisure in the lives of young carers. Additionally, most of this literature operationalizes contemporary meanings of leisure as a non-work activity, free time, or state of mind (Russel (2013), which may not accommodate all young peoples’ experiences and meanings of leisure. To further understand how leisure might benefit young carers, I first drew on literature that focuses on young peoples’ experiences of leisure. Grounding in developmental psychology, Weybright et al. (2019) suggest that leisure is an important developmental context for adolescence and young adulthood due to its role in promoting opportunities for self-determined behaviours (Bean et al., 2016; Caldwell & Witt, 2011). Specifically, scholars indicate that leisure provides young people with the relative freedom “to experiment with a number of behaviours that may contribute to or detract from their health" (Weybright et al., 2019, p. 239; see also: Caldwell & Faulk, 2013). According to Fredriksson et al. (2018), foundations for future patterns of adult health are established in adolescence and young adulthood. Similarly, Cassidy (2005) suggests that leisure spaces provide young people with opportunities to develop leisure behaviours and habits which predict and influence the healthy or unhealthy leisure behaviours taken up in adulthood. Although this developmental perspective may have important implications for young people, it draws on a singular understanding of leisure and young people, resulting in the assumption that all young people experience and think about leisure in the same way. Since leisure may be much more complex, I feel it is important to consider contextually relevant and diverse understandings of leisure before claiming the benefits are universally applicable to all young people.

Other research emphasizes the significant role leisure plays in the development of identity, autonomy, competence, and initiative (Caldwell & Witt, 2011). According to King et al. (2009), leisure time must be viewed as a vital chance for young people to experience exploration, curiosity, and self-reflection, as well as to develop social and problem-solving skills. These skills may facilitate the formation of social relationships and new identities, all of which translate into adulthood (Fredriksson et al., 2018; Trainor et al., 2009).

Scholars further suggest that leisure promotes resilience in young people when they are faced with challenges (Matzka & Nagl-Cupal, 2020). For example, Stevens et al. (2019) found that leisure-based participation in social circus-arts built resilience to adversity through positively influencing socialization skills and building peer networks of support. In addition to discussing resiliency, literature indicates that leisure assists young people in coping and managing various major life stressors (Trainor et al., 2009; Trenberth & Dewe, 2002). Specifically, multiple scholars mention that structured leisure programming facilitates the development of healthy coping strategies and that leisure spaces are associated with providing an ‘escape’ from life stressors (Cassidy, 2005; Grobe Schlarmann et al., 2008; Hopper et al., 2019; Iwasaki & Hopper, 2017; Nagl-Cupal & Hauprich, 2018). In a study by Weybright et al. (2019), participants “characterized leisure by a sense of freedom from expectations, especially when they seemed overwhelming” (p. 251). This study suggested that a momentary release from present life circumstances can be influential in promoting an ability to cope among young people (Cassidy, 2005; Hopper et al., 2019; Iwasaki & Hopper, 2017; Iwasaki et al, 2006; Weybright et al., 2019).

Although leisure may support feelings of resilience and coping among young people, young people may experience resilience when faced with challenging life experiences, especially when they do not have the supports available to help them navigate those life experiences. A focus on resilience as the preferred outcome or response labels people who do not demonstrate resilience as somehow deficient and their circumstances as problematic. Given that resiliency is a dominant concept in leisure literature, I believe it is important to be aware that not all young people who are faced with challenges are resilient and there should not be expectations for them to be resilient or cope effectively all the time. Benefits of leisure specific to resilience and coping may or may not be relevant to young carers, as they are dependent on conceptualizations of leisure as a non-obligatory activity which may not be accessible to carers (Lopez, 2018). I could not find any literature that privileges leisure as creating moments or opportunities for restoration in everyday life in the context of young people.

According to Vacchiano and Bolano (2020), leisure is a determinant of health and well-being for young people. Various studies suggest consistent leisure participation results in lower levels of emotional distress, aggression, and antisocial behaviour (Harrison & Narayan, 2003; Mahoney & Stattin, 2000; Rhodes & Spencer, 2005). Further, multiple scholars indicate that involvement in leisure facilitates the development of meaningful and sustainable social supports (Hopper et al., 2019; Sauerwein et al., 2016; Weybright et al., 2019), which may play a critical role in young peoples' health and well-being (Fullagar et al., 2017a, 2017b; Mannell & Kleiber, 2013; Mansfield, 2021; Young et al., 2018). Specifically, meaningful relationships are typically co-constructed and thus, often result in feelings of safety, support, and trust (Fogel, 2004; Hopper et al., 2019; Smyth, 2017). Additionally, structured and unstructured leisure activities help young people cultivate support through developing teamwork and social skills, emotional learning, and establishing adult networks (Hansen et al., 2003; Larson et al., 2006; Wilson et al., 2010). Beyond providing a space for young people to share stories and engage in meaningful dialogue with others (Theriault, 2017), leisure can facilitate positive developmental experiences that influence behaviours, decision-making, and networks of support throughout adolescence and into later life (Fredriksson et al., 2018). Despite the potential positive connections between leisure and well-being for young people reported in the literature, it is likely that the relationship between leisure, health and well-being is far more complex. Leisure might also have negative implications for the health and well-being of young people, for example, when harmful leisure experiences, like drinking or illegal drug use, are used at the primary ways of responding to stresses (Weybright et al., 2019).

Young Carers' Challenges in Accessing/Experiencing Leisure

As mentioned earlier, our understanding of leisure in the context of young carers is extremely limited. I could only identify two studies that focus on leisure in the lives of young carers (Jonzon & Goodwin, 2012; Matzka & Nagl-Cupal, 2020), which will be further explored in this section. Out of the two studies, Matzka and Nagl-Cupal (2020) described the benefits of leisure as a psychosocial resource supporting resiliency among young carers. The study by Jonzon and Goodwin explored young carers' experiences of play in the care context. Their study focused on gaining a deeper understanding of experiences of play in the context of daughters who were caring for their mothers with multiple sclerosis. Most studies in the young caring literature primarily focus on understanding young carers' experiences of care and, as a result, mention leisure in passing as a domain that is influenced by young carers' care experiences.

According to various scholars, young carers face challenges in accessing and experiencing leisure (Banks et al., 2001; Butler & Astbury, 2005; Eley, 2004; Hopper et al., 2019; McAndrew et al., 2012; Warren, 2007). Although there is little exploration into how and why young carers experience challenges accessing leisure, many studies that focus on the experiences of care report that young carers may disengage or miss out on leisure opportunities due to the limited free time available to them in their care roles (Butler & Astbury, 2005; Eley, 2004; Matzka & Nagl-Cupal, 2020; Warren, 2006). According to Warren (2006), when young carers do participate in leisure and recreational activities away from home, they are more likely to be based at school rather than in community programming. This is because young carers lack time for leisure and play outside of school (Butler & Astbury, 2005), and community programs are not structured in a way that accommodates young carers lives (Matzka & Nagl-Cupal, 2020). Despite many young carers experiencing challenges in accessing and experiencing leisure, Banks et al. (2001) indicates that young carers reported social and recreational activities as a vital need in their lives.

As I mentioned above, Jenzon and Goodwin (2012) focus on understanding the play experiences of daughters who care for their mother with multiple sclerosis. In their study, young carers indicated that they preferred solitary play and participated in more independent activities, since group activities did not often accommodate their spontaneous schedules. Further, Jonzon and Goodwin (2012) found that young carers roles led them to lose out on play opportunities since their priorities were often focused on their family member. Multiple young carers in their study indicated that they would only engage in organized activities that their friends engaged in, even if they were not interested in those activities. These organized activities were more easily accessible to the young carers because their friends' parents could drive them to the activity. In this way, Jonzon and Goodwin (2020) suggest that many young carers are put in positions where they must sacrifice their own interests just to engage in some sort of activity with others. I find this extremely saddening, especially when coupled with our limited understanding of young carers' leisure and how we can better support them in their care roles, including in their leisure.

Benefits of Leisure for Young Carers

Similar to the literature that reports on young carers' challenges in accessing and experiencing leisure, the benefits of leisure for young carers has rarely been explored. Instead, it is briefly reported on as part of young carers' care experiences. As previously mentioned, I could only find two articles within the young caring literature that bring attention to young carers' experiences of leisure (Jonzon & Goodwin, 2012; Matzka & Nagl-Cupal, 2020), one of which focuses on the benefits of leisure for young carers (Matzka & Nagl-Cupal, 2020). Specifically, Matzka and Nagl-Cupal (2020) explored the psychosocial resources that contribute to resilience among young carers in Australia. In this study, being able to spend leisure time was a significant psychosocial resource used by young carers to manage their care responsibilities.

Many young carers view leisure as obligation-free time and consistently use it to distance or distract themselves from the challenges in their lives (Jonzon & Goodwin, 2012; Matzka & Nagl-Cupal, 2020). Practicing sports, getting in touch with nature, and being creative in personal leisure time were also found to foster resilience in young carers (Ungar et al., 2005; Cunningham et al., 2016) and help young carers find balance in their complex lives (Matzka & Nagl-Cupal, 2020). Young carers appreciated leisure both independently and with others in structured programming, like extra-curricular activities; however, structured programming is not often possible (Matzka & Nagl-Cupal, 2020; Ungar et al., 2005). Independent leisure has been found to provide young carers with time alone to reflect on their own experiences and thoughts, find peace of mind and relaxation, as well as to pursue their personal interests, all of which are fundamental to their individual and familial well-being (Doutre et al, 2013; Grobe Shlarmann, 2008; Nagl-Cupal & Hauprich, 2018).

Opportunities for social interaction and connections through leisure can also be important for young carers. According to Matzka and Nagl-Cupal (2020), friendship was a resource that was universally addressed by all young carers in their study as an essential resource for them. Further, Ungar et al. (2005) mentioned that structured leisure activities may provide important opportunities for young carers to develop meaningful relationships that help foster resilience. Specifically, Matzka and Nagl-Cupal (2020) found that young carers met peers in similar situations through activities organized by social service providers. Young carers were more willing and comfortable socializing with these peers, indicating that they could discuss their experiences more freely without fear of judgement.

To sum up, there are very few articles in the young caring literature that mention leisure. Of those that do, the majority focus on understanding young carers' care experiences and in turn, briefly report on leisure as a domain that is influenced by the care experience. I could only find two articles that specifically explore leisure in the lives of young carers, which I view as very problematic. Further, leisure in the lives of young carers is likely far messier and more complicated than the current literature suggests. For example, although leisure is identified as an important benefit and coping resource for young carers, there might be instances when it also is problematic or harmful for young carers. As mentioned earlier, when harmful leisure experiences, such as drinking or use of illegal drugs, are used as a primary coping mechanism, leisure could have significant detrimental consequences for young carers. Additionally, in leisure spaces where young carers do not feel understood or where they might experience bullying or other forms of abuse, these opportunities likely exacerbate rather than assist young carers in their care roles. When exploring leisure in the context of adult carers, Weinblatt and Navon (1995) found that, for some carers, leisure was actually perceived as threatening to the health and well-being of carers, and a breeding ground for feelings of depression, anxiety, loss of control and betrayal of the person they were caring for. For these reasons, adult carers intentionally avoided leisure. Whatever the case, our understanding of meanings and experiences of leisure in the contexts of care for young people is extremely limited. There is an urgent need to better understand the range of ways leisure is understood and experienced in the lives of young carers.

Insights from the Literature on Leisure in the Lives of Adult Carers

Given that there is little research specific to leisure in the lives of young carers, I found myself turning to the literature on leisure in the context of adult carers to see if insights might be gained to inform this study on young carers. Much of this literature highlighted the challenges in accessing leisure for adult carers, with many studies reporting that adult carers are likely to disengage from leisure activities due to lack of free time (Becker & Sempik, 2019; Dupuis & Smale, 2000; Stanfors et al., 2019; Stevens et al., 2004) and/or feelings of worry in spending time away from their loved ones (Pienaar & Reynolds, 2015; Romero-Romeno et al., 2014). According to Bedim and Guinan (1996) adult carers “tend to reduce or abandon social interactions, hobbies, church-related activities, and fitness pursuits” (p. 228). Similar to the young caring literature, various studies have found that when unsupported, adult carers may experience health consequences and restrictions in social and leisure opportunities (Lakman, 2015; Williams et al., 2014; Sawatzky & Fowler-Kerry, 2003).

Consistent with the limited literature focused on young carers, leisure is described as playing an integral role in satisfying adult carers’ needs and contributing to physical, psychological, and social well-being (Chattillion et al., 2012). Specifically, leisure opportunities provide adult carers with “time for reflection, mental peace, and tranquility, liberating renewal and revitalization” (Chiu et al., 2020, p. 125). Further, meaningful leisure engagement is identified as an important coping mechanism for adult carers (Chiu et al., 2020) and contributes to increased physical and mental well-being (Losada et al., 2010; Schryer et al., 2015). According to Bedini et al. (2018), when adult carers are satisfied with the time they spend engaging in leisure and the quality of the leisure experience, they are better able to cope with stressors in their lives, such as caring for a loved one. These results indicate that it is not simply the frequency of leisure involvement that influences adult carers' ability to cope, but rather the quality of the leisure experience (Bedini et al., 2018).

Largely missing from the young caring literature are studies that explore leisure as "defined according to the situational context of events or activities, rather than the activities themselves" (Dupuis, 2000, p. 260). Although Jonzin and Goodwin (2012) mention that young carers in their study were eager for them to understand the contexts in which their play experiences were embedded, their focus was predominantly on gaining an understanding of participants' experiences of play. In this way, they did not specifically explore *how* experiences of play are influenced by care contexts but noted that leisure as context-dependent should be further understood. It is here that I turn to literature on adult carers to gain further insight into how meanings and experiences of leisure are influenced by care contexts.

According to Dupuis and Smale (2000), carers may ascribe very different meanings to leisure which, in turn, influence how they might experience it. For example, adult daughters caring for a relative in a long-term care home who did not define their care as an obligation, experienced it differently, more positively, than carers who did view their roles as an obligation, and this further shaped their meanings and experiences of leisure in the care context (Dupuis & Smale, 2000). Further, Dupuis (2000) mentions that "the qualities and characteristics of a specific context as a whole influence individuals' perceptions of that context as leisure" (p. 260). This means that leisure could be experienced in any type of activity beyond traditional leisure-type activities if the context is defined as leisure by the individual experiencing it. Leisure as context-dependent is very important to consider in this study, as young carers may ascribe meanings of leisure to activities that are not traditionally assumed to be leisure. Dupuis and Smale (2000) also brought attention to the notion that carers might intentionally choose to avoid leisure because of the problems that it might evoke for them. In this way, many adult carers felt that leisure was a waste of time given their efforts toward keeping their family member alive or well and, as a result, engaging in leisure brought negative feelings. As I mentioned earlier, it is crucial to consider that leisure in some circumstances may be perceived as harmful instead of helpful. In this study, I remained open to the range of ways that young carers might describe and experience leisure, paying close attention to how young carers described their specific care experiences and how those meanings might have shaped understandings and experiences of leisure in their lives. This literature also reminded me of the importance of being aware of and critically reflecting on my own assumptions throughout this research as leisure might not always be beneficial or helpful in specific care contexts.

Although some of the challenges to and the benefits of leisure are relatively similar between adult carers and young carers, both Rose and Cohen (2010) and O'Dell et al. (2010) emphasise that the young caring experience is vastly different than the adult caring experience due to societal norms surrounding childhood, adulthood, and the roles expected within each life stage. As a result, young carers have unique experiences that may differ greatly from what is known about adult carers (O'Dell et al., 2010; Rose & Cohen, 2010; Wyn, 2015).

Summary of the Literature

Young carers take on a wide variety of care responsibilities and may experience multiple challenges and rewards within their care roles. There are important gaps in the literature that we set out to address with this research. First, the young caring literature predominantly focuses on emphasizing the challenges and consequences of caring at a young age, compared to the rewards. In this way, the young caring literature depicts young carers as living outside the ‘norms’ of childhood, operating from a deficit-based approach instead of a strengths-based approach. Thus, the common construction of young carers in existing literature depicts all young carers as abnormal and in need of protection. I believe this negative construction is problematic and largely due to the lack of critical theories in the young caring literature and the lack of participatory methodologies and methods, which are designed to emphasize participants’ own voices and shed light on their lived experiences. Since CYS and CPAR upholds young carers’ voices and actively involves them in decision-making, we addressed the lack of emphasis on young carers’ own voices by grounding this research in principles of CYS and utilizing CPAR as an approach and methodology in this research. Second, the young caring literature consistently identifies the lack of supports available to young carers, however, little attention has been brought to the ways that support services -including leisure- can be more accessible to young carers within their care roles. Further, there is a lack of understanding of what young carers themselves believe is needed to better support them in their roles. Therefore, this research aims to identify ways to better support young carers in their lives and leisure. Finally, very little research has explored leisure in the lives of young carers. We aimed to fill this gap by exploring the complex ways that leisure might be understood and experienced in the lives of young carers.

SECTION TWO

Chapter Three: Our Path to Understanding Young Carers and their Leisure

As mentioned in my first chapter, critical participatory action research (CPAR) was used as the methodology for this research. In this chapter, I outline our CPAR approach and process that guided our exploration of leisure with young carers. More specifically, I first describe the meaning of PAR and its principles, our CPAR team, and our CPAR process. I then move towards outlining our decision-making stage, followed by a brief note on our research context, and ethical considerations to account for in this project. Next, I provide a discussion on the steps involved in our chosen data collection method, narrative research conversations. Last, I discuss how our data analysis framework, critical creative hermeneutic analysis (CCHA), unfolded throughout our CPAR process.

Before I turn to my discussion of CPAR, I would like to remind readers about the purpose, the objectives, and research questions of this CPAR project. The purpose of this research was *to partner with young carers to expand our understandings of young carers' experiences of care and how those care experiences shape leisure.* In doing so, we aimed to provide a platform to privilege the voices of young carers, challenge dominant perspectives of young carers through bringing awareness to their unique experiences, and ensure young carers are better supported in their roles by identifying specific ways to support young carers, including in their leisure. Our study was guided by the following questions:

1) how do young carers story their experiences of care and leisure in their unique contexts of caring?

2) how do the stories of young carers' experiences of care and leisure contrast with the dominant constructions presented in the literature?
3) how might service providers and leisure professionals better support young carers in their care roles, including in their leisure?

Democratising the Research Process through PAR/CPAR

> *"[T]he focus of social change is not entirely about escaping oppressive situations; it is also about escaping that piece of the oppressor planted deep within each of us"*
> *(Freire, 1970, as cited in Grimwood, 2015, p. 180).*

Throughout my own experiences as a young carer, I rarely if ever felt that I had control over my own story. Often, I found that the adults in my life took ownership over my story to advocate for me. Although I always appreciate the advocates in my life, I was not often enabled or supported in advocating for myself with my own story. As a result of these experiences, my perspective upholds that young carers should have active control over their stories and voices in our research. Not only did this entail capturing young carers' elicited words in our study but also providing young carers with the tools to maintain ownership over those words. PAR is an approach that allowed me to do just that; "bring people into research through affirming their own knowledge, regarding them as active agents of change instead of research subjects and recognizing that they are the most capable of analyzing their own situations and their own solutions" (Grimwood, 2015, p. 169).

In PAR, researchers develop partnerships with community members to identify issues of local importance, determine ways to explore these issues, and take action on the newly acquired knowledge (Fortune et al., 2015). As Trinh-Minh-ha (1989, p. 101) emphasised:

> *… speaking nearby or together with certainly differs from speaking for and about (cited in Watkins & Shulman, 2008, p. 266).*

As mentioned by Dupuis and Whyte (2017), "people who are marginalized in our communities can and should actively contribute to planning and evaluating services and to research intended for them" (p. 103). Through a CPAR approach, knowledge is democratized (Groundwater-Smith, 2012), and power relations are reconceptualized in ways that move away from traditional views of researcher as 'expert' (Fortune et al., 2015). In this way, social change is at the heart of CPAR, with change also happening within the research process. Through challenging the traditional distance between the researcher and the researched, PAR brings together community members and participants, creating collaborative space to generate "significant questions for research, to gather relevant 'data,' to work together toward understandings, and to embody these in action, creatively transforming their situations" (Watkins & Shulman, 2008, p. 270). This type of research partnership requires ongoing commitment to reflexivity to ensure the consistent engagement in authentic dialogue with all members of the research process (Liebenberg, 2018). Through deepened dialogue, we become more aware of not only common ground but also differences within our team, maintaining our own accountability to each other and the CPAR process (Watkins & Shulman, 2008).

Principles of PAR/CPAR Guiding our Study

Liebenberg (2018) described four essential elements of PAR: participation, action, research, and social change. *Participation* in the form of direct research collaboration with participants and communities throughout the project is a focus of PAR (Dupuis & Whyte, 2017; Fortune et al., 2015; Liebenberg, 2018). In other words, PAR team members are actively involved in decision-making throughout the process and have a direct say in the focus of research and how it will be conducted and shared. This requires them to be aware of and understand the research process and the importance of their involvement in it (Liebenberg, 2018). According to Shamrova and Cummings (2017), children and young adults are often left out of decisions in the research process, preventing their voices from being heard. In supporting young peoples' right to participate in research, CPAR steers away from the sole use of children and young adults as sources of data. To support the active participation of co-researchers, I was responsible for preparing them for our research process and sharing my research experience and knowledge so that team members had the tools necessary to make informed decisions throughout the research process. In this sense, "power comes from collective commitment" in which team members are actively involved in the project (Liebenberg, 2018, p. 2; see also: Fortune et al., 2015).

PAR/CPAR is also *action*-oriented and uses *research* as a means of determining and promoting action: it is "action combined with participation and research that intends to bring about *social change*" (Liebenberg, 2018, p. 2, emphasis added). Specifically, PAR/CPAR demands careful consideration of how findings are shared, ensuring that relevant messages are communicated and understood to advocate for and prompt the desired change. In this way, CPAR is emancipatory and critical in our process as individuals examine and challenge the role of larger social, political, economical, and cultural conditions that shape their identities and actions (Miskovic & Hoop, 2006). As Freire (1989, p. 81) noted:

> *[T]rue dialogue cannot exist unless the dialoguers engage in critical thinking […] thinking which perceives reality as process, as transformation, rather than as a static entity—*

> *thinking which does not separate itself from action, but constantly immerses itself in temporality without fear of the risks involved (as cited in Watkins & Shulman, 2008, p. 281).*

Building on these essential features, Kemmis and McTaggart (2005) outlined seven features of PAR that we used to guide our CPAR process:

1) PAR is a *social process:* a process that explores the relationship between individual and social realms. In our study, we expanded our understandings of young carers' experiences of care and of leisure as it is influenced by care roles and dominant discourses of youth. We relied on critical conversations within the team about issues that impacted our individual lives and what social realms those issues stemmed from.
2) PAR is *participatory:* PAR "engages people in examining their knowledge and the ways in which they interpret themselves and their action in the social and material world" (Kemmis & McTaggart, 2005, p. 567). In our study, young carers came together with staff working in young carer organisations to serve as members of the CPAR team. Both co-researchers and participants had an active role in exploring what leisure means to them in relation to their care roles. Further, young carer co-researchers reflected on their own roles and relationships throughout the CPAR process, leading them to explore who they are and the actions they undertake as young carers and young people.
3) PAR is *practical and collaborative*: Our project unfolded through acknowledging that young carers are unsupported, unheard, and predominantly without access to resources that might support them in their care roles. Co-researchers, which included

community partners and young carers, were active in collaborative decision-making throughout the entirety of the research process.

4) PAR is *emancipatory*: PAR "aims to help people recover, and release themselves from, the constraints of irrational, unproductive, unjust, and unsatisfying social structures that limit their self development and self determination" (Kemmis & McTaggart, 2005, p. 567). In a society that constantly conceptualizes young caring as "not 'real life' but an obstacle in the way of achieving the 'reality' of life" (O'Dell et al., 2010, p. 652), it is empowering and comforting to build friendships with peers who are also young carers. Meaningful relationships have developed among team members throughout the CPAR process. Specifically, young carer co-researchers have mentioned that they can fully be themselves when interacting with team members. Since there is not often opportunities for young carers to share their own stories and hear stories from other young carers, young carer co-researchers have especially valued conversations with each other. Young carer co-researchers have expressed on multiple occasions that conversations within the team have inspired them to think differently about young caring, leading them to challenge and question the structures that influence their own lives. Further reflections on meaningful relationships are discussed in Chapter four and five of this thesis.

5) Although PAR is taken up and used in many different ways, in this study PAR is *critical*: This feature partly refers to helping people recover and release themselves from constraints within public and social media including problematic dominant discourses, their modes of work, and social relationships of power (Kemmis & McTaggart, 2005). It

forces us to intentionally attend to structures and relational processes that oppress young carers. Through engaging with co-researchers as active decision makers in this research, we have challenged traditional power imbalances between the researcher and researched, adult and young person. Although power in research can never truly be balanced, I ensured that each CPAR team member was as actively involved in the process as they felt comfortable and motivated to be. Additionally, we allowed space in CPAR meetings to reflect on discourses of youth and taken-for-granted assumptions about young carers and young people. Having this space to critically reflect on the ways young carers and young people are understood encouraged our team to reconsider and navigate our own assumptions. These critical reflections will be discussed further in Chapter four of this thesis.

6) PAR is *reflexive*: PAR involves a deliberate process through which people hope to transform their practices through ongoing critical and self-critical reflection and action (Kemmis & McTaggart, 2005). In one of our first team meetings, we developed a team meeting guideline that has provided us with the opportunity to be critical of ourselves and the process we were working together to design. Additionally, we continued to create and maintain space for critical and self-critical reflection in our meetings. Specifically, we intentionally built-in time within our process for reflecting on the research process, our own perspectives, assumptions, and experiences, and how those perspectives and experiences might be influencing the team, research, and decisions made.

7) PAR aims to *transform both theory and practice*: Theory and practice is of equal value in PAR. Documenting our process contributes to theory through bringing attention to the importance of working alongside young carers in research (Kemmis & McTaggart, 2005) Actively involving and hearing from young carers in this research provided an important opportunity to critique dominant discourses and theorizing about young people and young carers. Understanding care from their perspectives and experiences we hope will also provide insights that might change present and future services and supports for young carers. Transformation within the CPAR team was also evident throughout the process as we opened spaces to critically reflect on our assumptions about care. We hope that this study continues to transform theory and practice well after its completion.

Introducing the Young Carers and their Leisure (UYCL) Team

Establishing the UYCL Team

Caring for my family member is a significant and influential part of my identity. It both influences and is influenced by my daily experiences, and I embody this part of my identity in all I do. Naturally, I gravitated towards doing research alongside young carers, and after delving deeper into different methodologies, CPAR resonated the most with me. Through reflecting on my own knowledge and experience, I knew that it would be crucial to draw on the expertise from both community partners working with young carers and young carers themselves in this research. In doing so, I began to flow in the direction that CPAR would take me in. I began by reaching out to Cayleigh Sexton, who is the Director of Programs and Services at the YCA, to learn more about young carers and the services that were available to them. Cayleigh has an academic background in Concurrent Education in Child and Youth Studies and a Master's in Child and Youth Studies. She has worked with the YCA for six years. After talking with Cayleigh about my thesis ideas and hope of using CPAR, she enthusiastically agreed to join me as a partner in this research. Through our initial conversations, I then decided to reach out to Chelsea- Anne Alex, who is the Young Carers Program Coordinator at the YCP, to widen the knowledge and experience within our team. Chelsea has an academic background in psychology and has experience working with young people in positions such as a Child and Youth Worker and Community Support Worker for young adults with dual diagnoses. She has worked with the YCP for four years. The first few meetings consisted of conversations with Cayleigh and Chelsea about CPAR and how we wanted to approach our research. Once we aligned in our understanding of CPAR principles, I planned a rough schedule of the research process that included all the potential decisions that needed to be made in partnership with the team. When Cayleigh, Chelsea, and I had a better understanding of what the CPAR process might look like, Cayleigh and Chelsea reached out to the young carers to explore their interest and willingness to join the CPAR team as co-researchers.

In conversations with the Research Ethics Office at the University of Waterloo, it was determined that I would not need ethics approval in the planning phases of this CPAR process. However, the young carer organisations I partnered with wanted to ensure that young carers had information about the project and informally agreed to participate as co-researchers in the project. I developed an information sheet (see Appendix A) that Cayleigh and Chelsea passed along to potential young carer co-researchers and their guardians (if necessary) to ensure they were well informed of their role as co-researchers in the planning phases of this CPAR process.

Within a month or so, we had four young carers join the CPAR team, ready to make decisions about the research.

Our final CPAR team included seven co-researchers, including myself. Co-researchers agreed to be identified as members of the CPAR team and included community partners, Cayleigh Sexton (YCA) and Chelsea-Anne Alex (YCP), and young carers, Saige Johnston, Chloe Chomos, Emaan Fatima, and Bernadette Sarmiento. Saige and Chloe support their parent, and Emaan and Bernadette support their sibling. Each team member was acknowledged and valued as a co-researcher, each actively involved in ongoing decision-making. Together, we engaged in critical, authentic dialogue as we made decisions about our research. Our project and team name (UYCL) was developed by the young carer co-researchers.

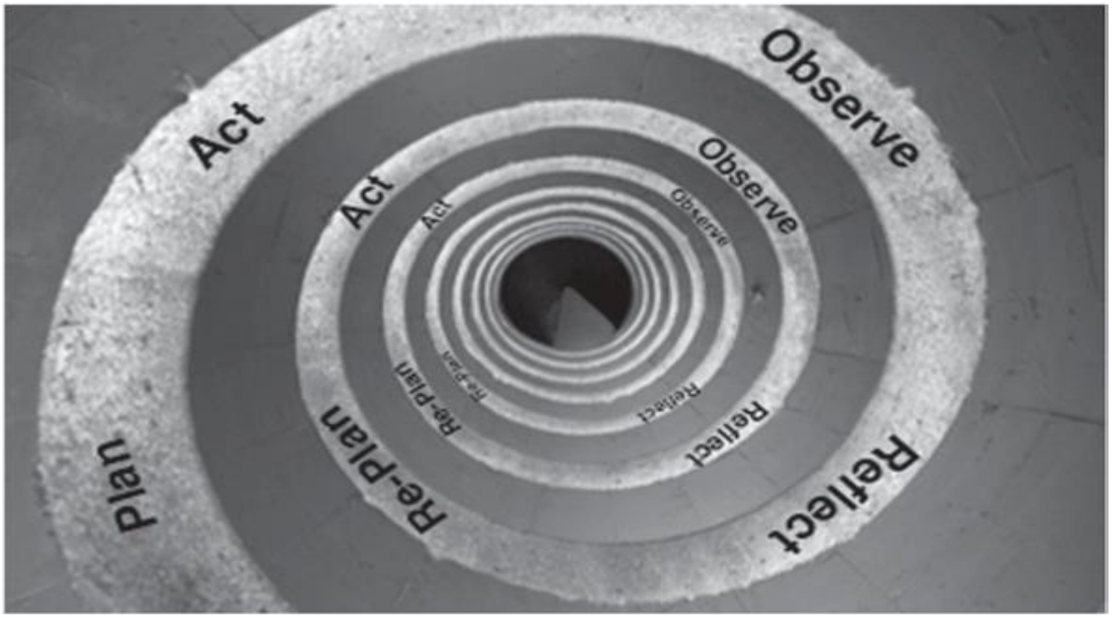
Once we confirmed our team, we began meeting bi-weekly to begin the steps of the action research spiral, which are to plan, act, observe, reflect, re-plan, act, observe, and reflect again, and so forth (Kemmis et al., 2014). Throughout the process, we continued to engage deeply in the action research spiral (see Figure 2), supported by an Authentic Partnership Approach (Dupuis et al., 2012a) as described in Chapter One (see Figure 1), seeing the spiral as being fluid and emergent, rather than a linear process. According to Kemmis et al. (2014), the CPAR process is not often as neat as this spiral; however, what matters most is that co-researchers have a "strong and authentic sense of development and evolution in their practices, their understandings of their practices, and the situations in which they practice" (p. 19).

Recognizing and appreciating that participation exists on a continuum was a necessary element of our process. Specifically, since young carers are very busy in their personal lives and their care roles, we intentionally built flexibility into our process. That means that throughout the research process, some co-researchers were more involved at certain stages than others. For instance, Chloe Chomos, who is one of our young carer co-researchers, was heavily involved in our decision-making phase and stepped back during the later phases of the project. Chloe and I remained in contact, checking in and updating each other as necessary during these later phases of the research. Within our team, co-researchers' desired role and level of participation were negotiated throughout the entirety of the research process

As the facilitator of the CPAR team, there were times when schedules just did not line up. This is when I especially drew on an authentic partnership model, to ensure that I supported the needs and preferences of our team instead of prioritizing my own timelines. Since there is a specific window of time to complete research within a Master's thesis, staying true to the principles of an authentic partnership model proved challenging at times. This is where the action research spiral was useful in our CPAR process, as it provided us with a loose cycle that encouraged ongoing collaboration, reflection, and action. This ongoing collaboration, reflection, and action encouraged us to maintain our team guidelines (please see Appendix B), such as honesty and transparency, and supporting each other through continuously checking-in with each other. Below I outline our CPAR process while using the action research spiral as a guide to represent our process in a structured way. However, as previously mentioned, our process was complex, and sometimes messy, and far more fluid than this structure implies.

Figure 2.

The Action Research Spiral (Kemmis et al., 2014, p. 19)



Stage 1. Connecting and Committing

Plan

Although coordinating our first meeting in the middle of the summer proved challenging, our first meeting as a complete team was held on July 19th, 2021. In the conceptualization phase of this project, as we made decisions to support the development of my research proposal, we met regularly, usually bi-weekly, with some breaks in between to accommodate team members' schedules and periods when we were waiting for ethics approval. We then aimed to meet at least monthly and returned to meeting more frequently during the analysis phase of the project.

Prior to each meeting, I developed a preliminary meeting outline that I sent out to each co-researcher. These outlines include the meeting topic, the activity, the agenda, and questions to think about before the meeting. For a summary of each meeting, please see Table 1: A

Summary of UYCL Team Meetings and each team meeting outline in Appendix C. The outlines served as a guide for our meetings; in instances when other items or topics for conversation came up, we were flexible and open to go where the meeting needed to go. Additionally, to accommodate the team's changing schedules, some meetings were split into two small group meetings or one-on-one catch-up meetings with individual co-researchers and myself. For the purposes of this thesis, I recorded these split meetings as one team meeting. Additionally, there were times during the decision-making phase that were very busy for co-researchers, for instance, between Meeting 5 and 6. This resulted in meetings occurring less frequently at times.

Table 1.

A Summary of UYCL Team Meetings

Meeting #/Date	Primary Purpose of Meeting	Key Tasks
Meeting 1: July 19th, 2021	Introduction and Developing the Purpose of Research	Action -Determined individual strengths -Developed purpose statement Observe -Sat with developed purpose statement -Decided that it needed to be more specific
Meeting 2: August 2nd, 2021	Revisiting the Purpose, Exploring Leisure in the Context of Care, Developing Research Questions, and Exploring Participatory Action Research	Action -Adjusted purpose statement -Brainstormed questions about young carers that we wanted answered Observe -Sat with adjusted purpose statement

		-Decided to refine statement with emphasis on partnerships
Meeting 3: August 17th, 2021	Revisiting the Purpose, Developing Research Objectives and Further Developing Research Questions, and Exploring Methods of Data Collection	<u>Action</u> -Refined purpose statement -Developed research objectives -Explored method of data collection <u>Observe</u> -Sat with research questions -Determined that research questions need to be more critical -Reflected on choice for data collection method
Meeting 4: September 20th, 2021	Recapping and Reflecting on Team Process to Date	<u>Reflection</u> -Reflected on meetings and decisions thus far -Reflected on what we wanted out of these meetings and if we were achieving those goals thus far -Reflected on how we feel in meetings and about the research thus far
Meeting 5: October 14th, 2021,	Re-visiting Research Objectives, Developing Interview Questions, Determining Next Steps, and Reflecting on Our Experiences	<u>Action</u> -Revisited and Simplified research objectives and ensured they aligned with the critical lens grounding the research -Began developing potential narrative research conversation questions -Talked about collaborative data analysis <u>Observe</u> -Sat with our newly developed research objectives

Meeting 6: December 3rd, 2021	Revisiting and Developing Research Questions, Summarizing and Discussing all Decisions Made to Date	Action -Revisited and brainstormed research questions -Developed a summary of all decisions made to date Observe -Sat with our newly organized research questions -Read over and reflected on our summary of decisions made to date
Meeting 7: January 21st, 2022	Checking in with Team Members, Reflecting on where we are in the Process, Reflecting on Care Experiences	Reflection -Reflected on meetings and decisions thus far -Reflected on supports that we needed to continue in the process -Reflected on the roles we wanted to have in the process -Reflected on what we learned thus far in the process -Reflected on our own experiences

Acting and Observing

The focus of our planning process was on getting to know each other, building relationships, learning about CPAR and critical youth studies, and solidifying important details of our research process. So, the actions we had taken to this point focused on the tasks associated with this planning. After each team meeting, each co-researcher left with a sense of next steps. In this initial phase of the research process, it was my responsibility as the research facilitator to ensure that team members were provided with the necessary tools to make research decisions. Therefore, in this phase, in addition to reviewing the meeting plans prior to the meetings, team members actions involved actively contributing to the decision-making processes and activities within the meetings.

To prepare for each meeting, I ensured that team members had the meeting outline in advance. This allowed team members to reflect on the outline, add feedback or additional items for discussion, or document any thoughts prior to the meeting. As mentioned above, oftentimes our meetings did not end up flowing exactly as planned; however, this speaks to the collaborative nature of our meetings and allowed us to dive deeper into our process and aspects of it that were most important to the co-researchers. Within each meeting during the decision-making phase, there was an action (see table 1), with the exceptions of meetings four and seven which were reserved primarily for reflection and sharing stories.

Reflect

At the beginning and end of each team meeting, we allowed time to reflect on the research process, our own thoughts and perspectives, as well as our team guidelines (Appendix B) and the authentic partnership model. Specifically, we were guided by reflective questions identified in the authentic partnership process. We explored questions such as: What supports or resources do I/my partners need in order to support my/their inclusion; How can I/we nurture and support the strengths and uniqueness of others; How are the opinions and perspectives of all partners shared; I have learned thus far that….; How can I/we ensure that all partners are supported, heard, and valued in our meetings; How have my/our understandings of others changed over time and; what actions are needed to move forward? (Dupuis et al., 2012a, p. 440-442). In addition to the reflecting we did during our meetings, young carers specifically expressed that they wanted more time to share stories, experiences, questions, and advice with each other in meetings. We decided to devote specific meetings for this purpose, including meetings four and seven. As a result, we worked hard together to create an inclusive and safe(r) space where we could all share in our knowledge and experience of being a young carer without fear of judgement or misunderstanding and so we could learn from each other.

At the end of our first planning cycle, the team had come to consensus about the purpose and objectives of the research and began making initial decisions about key aspects of the research process so I could include these decisions in my proposal. These decisions were finalised in Stage 2 and Stage 3 of our process, including reaching out and communicating with participants, data collection strategies, and our analysis framework. After a brief note about the context of our study and a discussion on how we attended to ethical considerations, these decisions will be described next.

COVID Considerations

Heavily influencing this research is the context within which this study was conducted. Specifically, with the COVID-19 pandemic far from being eradicated, there were special considerations that arose throughout the research process. The presence of COVID-19 played a role in how CPAR looked in this study, bringing specific attention to how we might re-imagine partnerships and collaborative decision-making in an online environment. Our CPAR meetings, recruitment, data collection, analysis, representation of data, and interpretation of data looked different than intended because of the pandemic. As a result, this study took place completely virtually.

Attending to Ethical Considerations

After the proposal defense, this project protocol was submitted to the University of Waterloo Research Ethics Board prior to approaching potential participants. At this stage in the process, we collected formal consent from all co-researchers. This consent form emphasised the importance of confidentiality and co-researchers were asked to acknowledge that they were both informed and aware of their responsibility to keep information private during our process. Co-researchers were told that they were not to share anything outside of meetings and to keep all documents shared in a safe and private space where others could not see the documents. Especially in the presence of research conversations containing descriptions of experiences that may contain sensitive and personal information, reviewing the importance of confidentiality was critical. Please refer to Appendix D for the Co-Researcher Formal Consent Form. Written consent was also obtained from all participants involved in this project and I describe what that involved when I describe our recruitment and data collection processes later in this Chapter.

Maintaining safety and ensuring co-researchers and participants were well supported was crucial during this project. To ensure safety, the YCA and the YCP had access to resources and services that they were ready to provide to young carers if support was needed throughout and following the research process. Given that the young carer co-researchers and participants involved in this study were also time-limited people, it was crucial to maintain flexibility and understanding throughout this research. Specifically, research conversations and team meetings often took place in the evening to accommodate the unpredictable schedules of young carers. Further, since I had to maintain my own timelines as part of this thesis work, co-researchers were constantly reminded that their participation and roles could look differently depending on their own contexts. In this way, co-researchers took on stronger roles at different times during this study. Sometimes research conversations and team meetings needed to be rescheduled, and I ensured that I accommodated participants and co-researchers to the best of my ability while still remaining honest about my own timelines.

Through recognizing that I am an insider to the young carer population, self-care ethics were an important part of our research. According to Kumar and Cavallaro (2017), researchers must recognize the need to assess risks to their own safety in addition to that of participants'. Throughout the process beginning in the early phases of planning, I regularly met with my supervisor, Dr. Sherry Dupuis, where we de-briefed about different aspects of the project and my experiences as a facilitator of this CPAR process. Committed to being a relational scholar and to supporting a mutual sharing of experiences, I also needed to be open to sharing my own experiences as a young carer who provides support to a family member. This was emotional to me at times, and I found drawing on my support network around me and attending to reflexivity helped me navigate my own emotional journey throughout this process. According to Johnson and Parry (2015), reflexivity is an often-used self-care strategy in which a researcher documents their own positionality and subjectivities throughout the research process. I followed through with reflexivity in the form of an ongoing journal, where I documented my intimate feelings and closely followed the nature of my own well-being. When I dive into my own experiences as a young carer, I sometimes feel overwhelmed and emotional. Regular communication with Cayleigh and Chelsea was extremely helpful for me and integral to ensuring that I was conscious of, and attended to, my own mental well-being. Throughout this

CPAR process, I have moved through multiple challenges and exciting milestones. During these times, I have relied on my family, our CPAR team, and my supervisor, Dr. Sherry Dupuis, which has been an enormous support.

Stage 2. Reaching Out and Communicating with Participants

Plan

To obtain rich descriptions and depth into participants' understandings of young carers experiences of care and leisure, this study involved a small number of seven participants. As there is no generally held guideline for the number of participants required in a CPAR study, we drew on the principles of CPAR to make a case for our decision. Since CPAR prioritizes strong collaboration with participants, choosing a smaller sample led to greater quality of conversations between the research team and participants (Liebenberg, 2018). As a result, young carers' needs and wants were more effectively heard (Liebenberg, 2018). Given that young carers are often misunderstood and not comfortable sharing their personal stories (Becker 2007; Becker & Sempik, 2019), it is especially important to build space for trustworthy and safe relationships to flourish within and between the team and the young carers involved in this study (Roulston, 2010). In other words, encouraging honest, open communication through providing a safe(r) space for young carers to contribute to this study was paramount. In addition to our three young carer co-researchers, who were interested in also being participants, we reached out to four young carers to participate in our research and share their stories with us.

Since Roulston (2010) indicates that participants should be able to speak to the phenomenon that is being studied, in order to participate in this study, participants needed to identify as a young carer, between the ages of 12 to 25, and provide support to a family member due to a chronic illness, disability (physical or intellectual), mental health concern, substance misuse, parental absence, or another social, economic, or cultural factor (language barrier, etc.). Our team decided that our study would involve participants between the ages of 12-25 due to the virtual nature of the study and the methods of data collection being used. Specifically, both Cayleigh and Chelsea indicated that in their experiences, young carers twelve and older were better able to navigate virtual spaces and articulate their experiences during open-ended research conversations.

Prior to reaching out to participants, co-researchers Cayleigh with the YCA, Chelsea with the YCP, and I engaged in two meetings to plan out how recruitment might work. After these two initial meetings with Cayleigh and Chelsea, the whole team came together to finalize co-researchers' roles and availability for research conversations. We also took this meeting as an opportunity to celebrate accomplishments in the CPAR process and in our lives thus far. To see a summary of these meetings, please refer to Table 2: Drafting a Plan for Recruitment. Within these meetings, we decided that participants would be purposefully recruited in partnership with co-researchers, Cayleigh and Chelsea. More specifically, I provided Cayleigh and Chelsea with a recruitment details form for themselves (Appendix E), and invitation email template and (see Appendix F) that they then shared with young carers and/or their guardians within their organizations. The young carers and/or their guardians communicated with Cayleigh or Chelsea their interest in participating in the study. Once Cayleigh and Chelsea identified potential participants, they provided participants with a consent and confidentiality form to sign (Appendix G). The young carers and/or their guardians passed their signed consent and confidentiality forms to Cayleigh or Chelsea, who then returned them to me. Once consent to participate was confirmed, I began speaking directly with participants and/or their guardians to schedule the narrative research conversations.

Table 2.

Drafting a Plan for Recruitment

Meeting #/Date	Primary Purpose of Meeting	Key Tasks
Meeting 1A: February 10th 2022	Determining a Plan for Recruitment, Solidifying Recruitment Details, Reviewed Consent Forms	<u>Action</u> -Developed details for recruitment -Determined a timeline for recruitment -Established details about participants -Reviewed consent forms -Reached out to participants <u>Observe</u> -Sat with edited consent forms -Waited to hear back from participants
Meeting 1B: March 10th 2022	Discussing Recruitment Progress, Discussing Timelines, Discussing Co-Researchers' Different Roles	<u>Action:</u> -Talked about where we were at in terms of recruitment -Discussed involving co-researchers as participants -Determined a realistic timeline for recruitment -Explored how each co-researcher wanted to be involved in the process -Reviewed and edited information letter and confidentiality and consent form <u>Observe</u>

		-Sat with idea to involve co-researchers as participants -Waited to hear back from participants -Sat with plan for new timelines
Meeting 2: March 10th 2022	Discussing Timelines, Becoming Familiar with Narrative Research Conversation Guide, Discussing Participation, Availability, and Scheduling for Data Collection, Decided on Data Analysis, Celebrated Achievements in Process and Life	Action -Confirmed the timelines we want to try to stick to -Reviewed narrative research conversation guide -Discussed co-researchers' interest in being participants -Determined availability of each co-researcher -Developed a plan for scheduling research conversations -Brainstormed what we wanted analysis to look like and decided on Critical Creative Hermeneutic Analysis -Celebrated accomplishments in process and changes in our lives Observe -Made some last editions to the narrative research conversation guide -Sat with decisions about becoming a participant as well as co-researcher -Sat with decision about analysis -Reflected on availability

Coordinating and Conducting Narrative Research Conversations

The team chose to use research conversations as the primary data collection strategy for this research. Through taking guidance from a Critical Creative Hermeneutic Approach

(Lieshout & Cardiff, 2011), our team chose to purposefully refer to ‘interviews’ as research conversations in our study (Watkins & Shulman, 2008). Research conversations recognises the relational nature of conversations. To encourage my own vulnerability as the research facilitator, Watkins and Shulman (2008) suggest the loosening of the formal interview process of question and response. This includes facilitating a more open process and talking back and forth with participants, viewing the interview as a relational conversation. Not only does this allow for the exploration of commonalities and differences, but it also introduces greater complexity to the research process through encouraging co-creation and reciprocity. Specifically, when both participants and research facilitators have the space to engage in collaborative authentic conversations, deeper meanings and diverse perspectives may surface. Further, when interviews are considered research conversations, power dynamics between the researcher and participant are challenged. This allows for more relaxed, honest conversations, where trust and authenticity are of the utmost importance. Given the power of language in maintaining research power dynamics, replacing “interview” with “research conversation” promotes “mutuality, reciprocity, free-ranging, and spontaneous aspects of the research encounter” (Watkins & Shulman, 2008, p. 285). To ensure the dialogue in data collection aligns with CPAR and an authentic partnership approach, we continued with this language.

Many CPAR processes also drew on arts-based approaches, particularly when working with marginalised people (Dupuis et al. 2012b), lending well to inquiry methods such as narrative storying (Shamrova and Cummings, 2017). Specifically, Marsh et al. (2018) suggest that narrative is “based on the belief that we are able to understand and give meaning to our lives, as human beings, through our stories” (p. 335). In this way, narrative aims to understand life as it is lived and interpreted in participants' own words (Toolis & Hammack, 2015). According to Grant et al. (2015), narrative re-storying, "defined as a personally and relationally transformational method of reflexive inquiry," often plays a significant role in providing rich descriptions of experiences (p. 280). Since narrative research conversations heighten participants' stories, support them as partners in meaning-making, and ensure their voices are heard (Anderson & Kirkpatrick, 2016; Toolis & Hammack, 2015), the method fit well with our objective of privileging the voices of young carers.

Prior to engaging in the narrative research conversations, our team met once on March 10th, 2022, to prepare for the narrative research conversations. We started this meeting off with a game and a check in to reflect on how we were feeling at this point in the process. After the game and reflections, we discussed what the narrative research conversations might look like, what role we each wanted to have in the narrative research conversations (if any), and we finalized any decisions about the narrative research conversation guide (Appendix H). We also determined young carer co-researchers' availabilities so that we could schedule the narrative research conversations with participants more seamlessly. Young carer co-researchers were adamant that we continue to represent the narrative research conversations as informal conversations as they believed that this might help young carer participants feel more comfortable sharing their stories with us. Further, we reviewed the research conversation guide and as part of that process our team decided that we would rephrase question two in our narrative research conversation guide. Specifically, the young carer co-researchers mentioned that free time might not be the best phrase to use given young carers' busy lives. As a result, we started brainstorming words that could replace free time in our second question. Words such as rejuvenate, refresh, and fun came up during this brainstorming session, leading us to change 'What do you like to do for fun in your free time?' to 'What do you like to do for fun or to refresh?' Young carer co-researchers' rationale for this decision was that they felt the terms refresh and rejuvenate aligned better with their understanding of leisure compared to a term such as free time.

Acting and Observing

Within this study, participants were asked to engage in one individual narrative research conversation lasting approximately one hour in duration virtually with assigned co-researchers and me. Since co-researchers indicated an interest in sharing their stories during meetings, I reached out to young carer co-researchers to ask if they would also like to engage in research conversations as participants. Three young carers on the team indicated interest in engaging in the research conversations as participants. When young carer co-researchers were facilitating research conversations with me, Cayleigh, Chelsea, and I ensured that co-researchers were matched with participants that they did not know from the YCA or YCP.

Together our team conducted seven research conversations over a period of approximately one month. Three of these were with young carer co-researchers and four were with young carer participants. Of the four research conversations with young carer participants, two of them were co-facilitated by me and one young carer co-researcher. The third research conversation was co-facilitated by me and another member of the research team, and the fourth research conversation was facilitated just by me due to last minute scheduling conflicts. As requested by some of the co-researchers, two of the three narrative research conversations with young carer co-researchers were facilitated by me; the third was co-facilitated by me and another member of the research team. Please refer to Table 3: Summary of Participant Group for more information about participants. Pseudonyms are used in place of participants real names in order to protect the identities of the participants.

Table 3.

Summary of Participant Group

Participant Pseudonym	Age	Description
Brandon	13	Carer to parent living with Multiple Sclerosis (MS); enjoys listening to music, playing video games, and hanging out with friends
Evelyn	19	Carer to older brother who is on the autism spectrum; enjoys doing creative activities and spending time hanging out with their brothers
Johnny	15	Carer to parent living with Multiple Sclerosis (MS); enjoys playing video games, participating in team and individual sports, and going on long walks or jogs
Maya	15	Carer to younger brother who is on the autism spectrum; enjoys watching movies and shows (alone and with family), reading a good book, and hanging out with friends
Layla	13	Carer to younger brother who is on the autism spectrum; enjoys reading, activities such as sewing and baking, sports such as squash and boxing, and spending time alone and with friends
Alice	18	Carer to older brother who is on the autism spectrum; enjoys reading comic books, drawing anime, hanging out with friends, and playing musical instruments
Rose	17	Carer to parent living with Amyotrophic Lateral Sclerosis (ALS); enjoys cleaning their room, having the tv as background noise, spending time lying in bed on their phone, watching movies, spending time with friends and family, and going for runs in the mornings

All research conversations were facilitated on Zoom. Following guidelines from narrative interviewing (Pederson, 2013), the research conversations replicated a free-flowing conversation to support the telling of stories and the participants' own words and thoughts to come more easily to them (Anderson & Kirkpatrick, 2016; Quinney et al., 2016). Therefore, the narrative research conversations were loosely structured, including three open-ended questions that generally addressed who participants are as young carers and how they experience their care roles, how they experience leisure and what it means to them, and their perspectives of supports/services available to them. Co-researchers and I used specific probes to support the telling of stories, which can be seen in our narrative research conversation guide (Appendix H). Given that we intended for the research conversations to be loosely structured and support the telling of stories, there were multiple instances where co-researchers and I asked questions that were not on our research conversation guide. For instance, when a participant would begin to discuss a story that related to dominant discourses of youth, I would probe them further to learn more. Additionally, one co-researcher asked a participant about their siblings and another co-researcher wanted to learn more about an activity that a participant mentioned they liked to do to refresh. I video/audio recorded and transcribed research conversations verbatim to ensure that participants' own words were heard effectively. Further, I transcribed all narrative research conversations shortly after they were completed. Identifying information about the young carer participants was removed during transcription and prior to analysis with our team. Each young carer co-researcher who agreed to also become a participant felt confident in identifying themselves as a participant during analysis within the PAR team; however, all identifying information about *all* participants was removed prior to analysis.

Reflect

The narrative research conversations provided young carers with the foundations for relationally transformative conversations, which I will speak more about in Chapter 4 of this thesis. Multiple conversations extended beyond the time allocated for the narrative research conversations. For instance, once I stopped the recording for the narrative research conversations, multiple young carers wanted to continue sharing their stories and hearing mine. For some young carers, conversations were about topics that came up during the research conversation that they wanted to talk more about and for others, they simply wanted to continue the conversation beyond the narrative research conversation. Even though the young carers who participated in research conversations were all associated with either the YCP or YCA, they indicated that beyond those organizations they do not have a lot of opportunities to speak about young carers with young carers. This made our research conversations quite special.

In addition to the reflections we had as a team after facilitating the narrative research conversations, conversations with young carer participants encouraged my own reflexivity. For instance, in one conversation that extended beyond the narrative research conversation, Rose and I spoke about similar experiences of having a parent (or adult in our life) with a substance misuse. As we had the conversation, I found myself pulling back against how much to share with Rose and how much not to. Although this may seem innocent of a decision at first glance, my reasoning behind it was that I felt the need to protect Rose from the reality of my experience. After deciding to share my story with Rose, I realized that they had already been exposed to my reality in their own lives. This conversation truly challenged my own assumptions about young people and caring. Specifically, the idea that caring should be hidden from young people, even though young carers often experience the very things that adults try to hide from them. Without the narrative research conversations opening space to talk about these stories, I would not have had the opportunity to trouble my own assumptions about young people and caring.

After conversations with our team about the data collection process, we recognized the role that mentorships may have in young carers lives. Specifically, the narrative research conversations acted as an outlet for younger young carers and older young carers to connect with each other and share their experiences, stories, and perspectives. The young carer co-researchers mentioned that they wished they had young carer mentors in their own lives; older young carers who they could establish a relationship with and connect with over time. Throughout each research conversation, participants and co-researchers were personally and relationally transformed. Our team wonders if the same could happen for young carers through mentorship opportunities. My recommendations for mentorship opportunities will be discussed further in Chapter five of this thesis.

Stage 3. Making Sense of the Stories Using Critical Creative Hermeneutic Analysis

Plan

To ensure that co-researchers were actively involved in interpreting and analysing the study data, our team decided on Critical Creative Hermeneutic Analysis (CCHA) to guide the analysis of the data collected. CCHA is "a research strategy for the analysis of texts in collaboration with others" (Lieshout & Cardiff, 2011). The researcher and/or co-researchers become the facilitator(s), who encourage "the movement between parts and the whole, offering creative expression to blend cognitive and embodied knowledge/perspectives" (p. 226). As Lieshout and Cardiff (2011) emphasize:

> *CCHA is like a tango, a dance of independent souls who connect and contest, continuously moving to and fro, illuminating a new story in the movement (p. 232).*

CCHA is designed to be participatory and involves the use of narrative data, both of which complement CPAR and narrative storying. With very few participatory analysis frameworks available, we decided that CCHA best fits our vision to engage in collaborative analysis with the intention of emphasizing the voices and perspectives of young carers.

Lieshout and Cardiff (2011) suggest that CCHA consists of three principles:

1) Hermeneutic Principles: This principle upholds that "understanding arises from repetitive reading of the data; being open to the concepts being sought; being aware of one's prejudices and critiquing/allowing them to be critiqued in light of newly formulated meanings" (p. 225). In this way, two processes emerge: the hermeneutic circle and the fusion of horizons. The hermeneutic circle proposes that neither a whole text nor the parts of a text can be understood without reference to the other. This results in a constant circle of movement between the parts and the whole. The fusion of horizons begins with the idea that each person has a 'horizon' or presupposition during dialogue with others. This horizon becomes challenged when engaging in dialogue with co-researchers, which results in understandings that are fused with theirs.
2) Principles of Criticality: This principle suggests that "a pre-requisite for critical dialogue is that all stakeholders have a need to understand a situation so that options for action remain relevant and valid for each participant" (p. 225). This consensus is termed

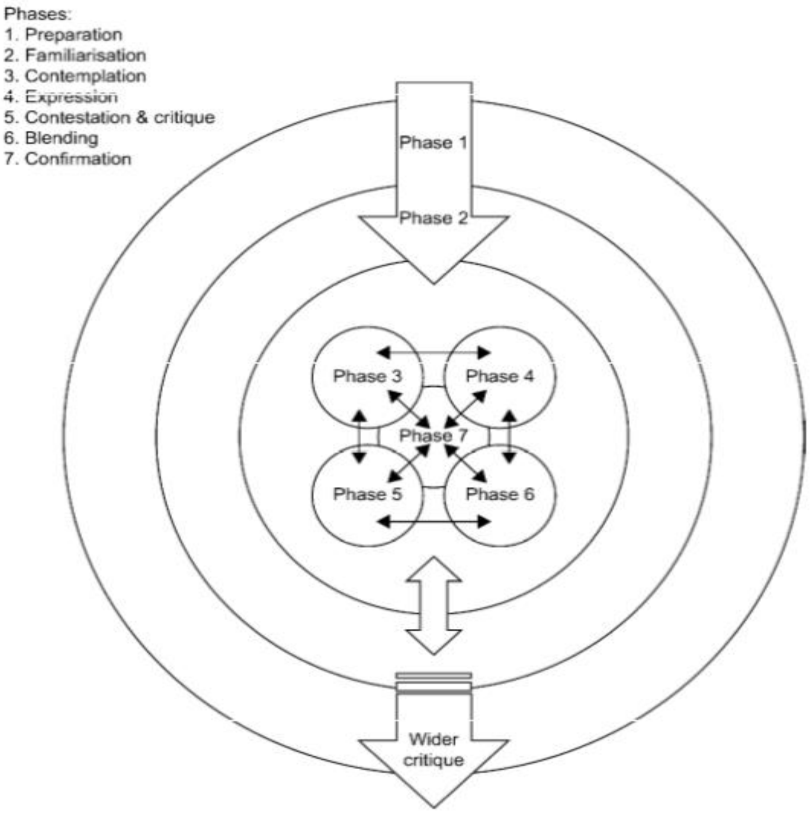
"mutual adequacy," and requires reciprocal trust, deepening truthfulness, morality, and authenticity (p. 226).

3) Principles of Creativity: Critical creativity indicates that the use of creativity and the expressive arts have the potential to reveal unknown aspects of self, bringing embodied knowledge to the forefront, and facilitating data interpretation. The principles of creativity encouraged us to rely on the blending of all types of knowledge to prevent ourselves from being bogged down by linguistic activity and discussions over semantics.

Further, Lieshout and Cardiff (2011) provide a seven-phased framework (see Figure 3) of which we drew on in our research. The purpose of the framework was to support co-researchers in developing themes from narratives within this study. Therefore, since this framework is thematic, we collected quotes verbatim, ensuring participants' own words were represented. As we began the analysis process, we started to reimagine what CCHA might look like in our project. Our CCHA process consisted of four analysis meetings, through which we integrated different phases of Lieshout and Cardiff's CCHA framework (see Figure 3). Below I outline Lieshout and Cardiff's CCHA framework as the grounding for our analysis process and follow it with a representation and discussion of how CCHA truly looked in our process.

Figure 3.

Critical Creative Hermeneutic Analysis Framework (Lieshout & Cardiff, 2011, p. 228)



Phase 1: Preparation.

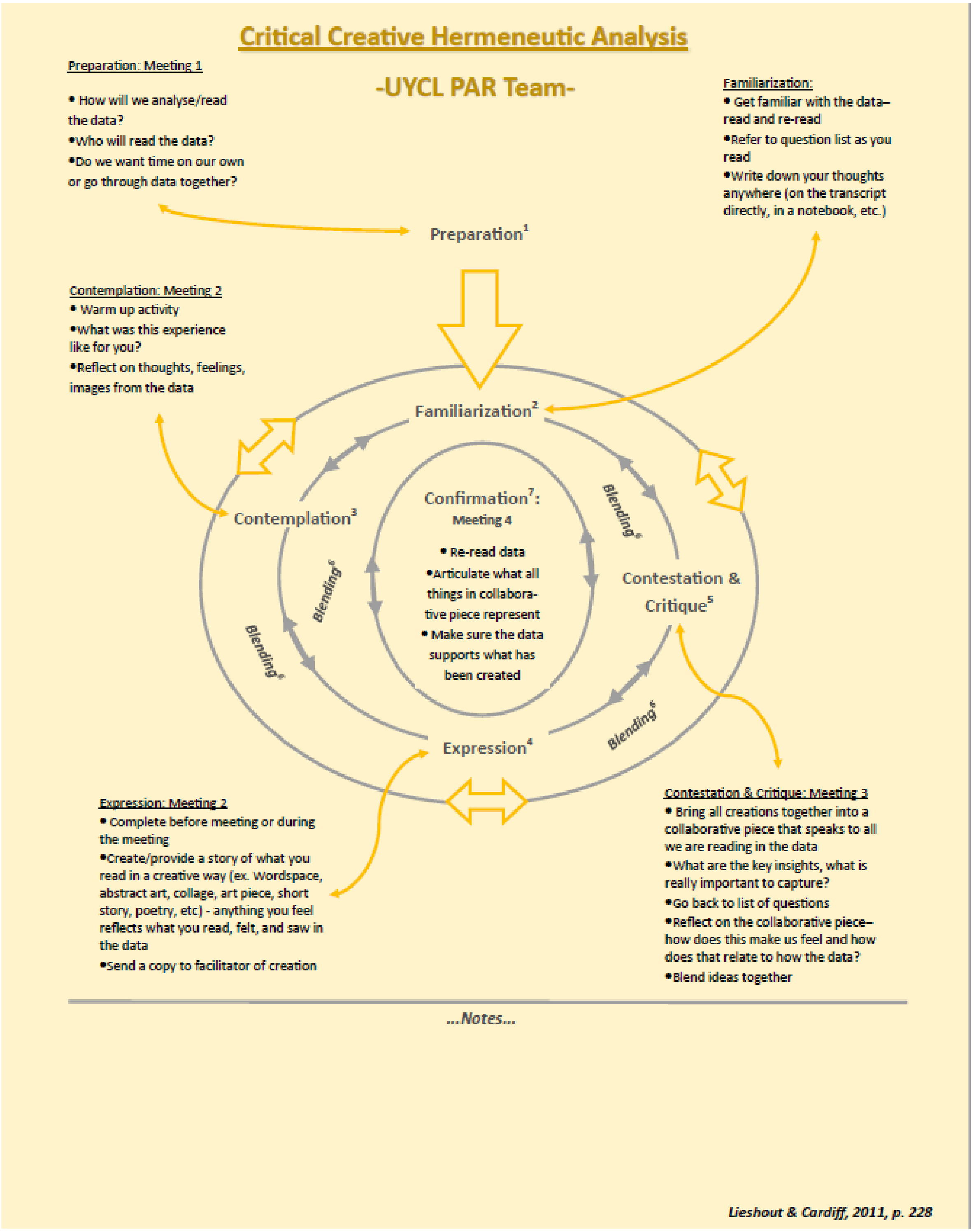
Lieshout and Cardiff mention that this is “where the raw data is prepared/re-presented” (p. 227). To begin the preparation phase of analysis, our team had a meeting on Friday April 22nd, 2022, and, for team members who couldn’t attend the Friday meeting, we met on Wednesday April 27th, 2022. During this meeting we discussed our vision for our CCHA process and how much each member wanted to be involved during the analysis phase. From our previous conversations about how we wanted analysis to look, I developed our own CCHA framework and shared it with the team during our preparation meeting to ensure it fit with our collective vision for analysis. Please refer to *Figure 4*: *UYCL Critical Creative Hermeneutic Analysis Framework in Action* to see the CCHA process we followed.

Our CCHA framework outlines important questions that were asked during the preparation meeting such as: How will we analyse/read the data? Who will read the data? Do we want time on our own or go through the data together? We also discussed the team's preferences for the recording of analysis meetings, specifically our 'Expression,' 'Contestation and Critique,' and 'Confirmation' meetings. All co-researchers involved in analysis were comfortable with our meetings being recorded. Besides one young carer co-researcher who wanted to take a step back during the data collection and data analysis phases of this research, all co-researchers engaged in analysis.

In our preparation meeting, we decided that I would assign each co-researcher to a transcript, ensuring that the young carer co-researchers were not assigned a young carer participant that they may know from either the YCA or YCP. As the research facilitator, I analysed all transcripts, paying specific attention to the two transcripts that were not analysed by any other co-researchers. I kept this information in an encrypted excel file, on my personal computer. After I assigned each co-researcher to a transcript, I prepared an analysis package to send to each co-researcher for analysis. In this package was our CCHA Framework (see figure 4), Instructions for Research Analysis (see Appendix I), Questions to Ponder- Research Analysis (see Appendix J), and the assigned transcript with all identifying information removed. The analysis packages were individually emailed to all the co-researchers involved in analysis on Monday May 9th, 2022.

Figure 4.

UYCL Critical Creative Hermeneutic Analysis Framework in Action



Critical Creative Hermeneutic Analysis

-UYCL PAR Team-

Preparation: Meeting 1

- How will we analyse/read the data?
- Who will read the data?
- Do we want time on our own or go through data together?

Familiarization:

- Get familiar with the data– read and re-read
- Refer to question list as you read
- Write down your thoughts anywhere (on the transcript directly, in a notebook, etc.)

Contemplation: Meeting 2

- Warm up activity
- What was this experience like for you?
- Reflect on thoughts, feelings, images from the data

Confirmation[7]: Meeting 4

- Re-read data
- Articulate what all things in collaborative piece represent
- Make sure the data supports what has been created

Expression: Meeting 2

- Complete before meeting or during the meeting
- Create/provide a story of what you read in a creative way (ex. Wordspace, abstract art, collage, art piece, short story, poetry, etc) - anything you feel reflects what you read, felt, and saw in the data
- Send a copy to facilitator of creation

Contestation & Critique: Meeting 3

- Bring all creations together into a collaborative piece that speaks to all we are reading in the data
- What are the key insights, what is really important to capture?
- Go back to list of questions
- Reflect on the collaborative piece– how does this make us feel and how does that relate to how the data?
- Blend ideas together

...Notes...

Lieshout & Cardiff, 2011, p. 228

Acting and Observing

Phase 2: Familiarization.

In Phase 2 of CCHA, Lieshout and Cardiff indicate that co-researchers are "encouraged to be aware of and document their questions, images that come to mind, and (bodily) feelings when reading the texts and preparing for the meetings" (p. 227). In the familiarization phase, co-researchers were given until Wednesday May 18th, 2022, to familiarize themselves with the data; however, co-researchers continued to familiarize themselves with the data until creative expressions were due. Co-researchers were encouraged to check in with the 'Questions to Ponder - Research Analysis' document while they were reading their transcripts, recording their thoughts and feelings related to the questions. Specific instructions given to co-researchers for the familiarization phase can be seen in Appendix I: Instructions for Research Analysis.

During the familiarization phase, all co-researchers involved in analysis filled out a doodle poll, which is an online resource used to schedule meetings. This doodle poll was intended to outline when co-researchers were available for the next three analysis meetings. Although we did use the doodle poll as a guide for when co-researchers were available, I found it was important for me to remain flexible to any changing schedules. During the familiarization phase, we decided to split our future analysis meetings into two group meetings to accommodate young carers' unpredictable schedules.

Phase 3: Contemplation.

Lieshout and Cardiff consider this phase a "warming-up exercise to assist co-researchers in quieting the mind, enhancing focus, and letting go of any hectic daily practices before starting analysis" (p. 228). The contemplation phase of our CCHA process consisted of one team meeting, split into two 30-minute group meetings. We met for our contemplation meeting on Wednesday May 18th, 2022, at which point each co-researcher had read through their transcript at least once. In this meeting, we reflected on initial thoughts about our transcripts and participated in an activity to bring our minds back to the data in our transcripts. The questions and activity we engaged in during the contemplation phase can be seen in Appendix K.

Our contemplation activity involved choosing between two options: 1) Find an object around you that says something about what you saw in the data and describe it; or 2) find an object that reflects how you think about being a young carer and describe it. From this activity, all co-researchers shared detailed metaphors, thoughts, and feelings related to young caring, leisure, and critical youth studies. Please refer to Table 4 for descriptions of co-researchers' reflections during our contemplation meeting.

Table 4.

Co-researcher Contemplations

Metaphors/Images of Young Caring	Leisure	Critical Youth Studies	Feelings
<u>Candy Wrapper:</u> Sometimes it's nice to just sit in bed and munch on a candy bar all alone. The candy wrapper represents the value of having time alone and being able to cherish time alone. <u>Umbrella:</u> Young carers often open up and shield their care partner(s) from the bad weather. Sometimes the weather can be nice and sometimes it can be bad. In other words, young caring is	Is there a way to provide both asynchronous and synchronous opportunities through young caring organizations? There is an assumption that young people have lots of time for leisure whereas, young	Society views childhood as a time for play, which makes young carers feel like they have been robbed of a better childhood. Co-researchers do not know what this 'better' childhood looks like, just that they do not have it. The phrase 'maturing faster than expected' draws on assumptions	Co-researchers mentioned that reading about young carers is comforting since they experience a lot of the same things. Reading about young carers helped

not static, it shifts and there are times where young carers need to care more or less. Flower: Taking care of a plant requires watering and nurturing for the plant to grow healthy and strong; however, the plant does not give the water back. Young carers do not ask for anything in return when they care, it is selfless. Although young carers do not ask for something in return, it doesn't mean they do not receive something. When the flower grows and blooms, it gives the carer happiness. The relationship between a young carer and their care partner(s) is reciprocal, you do not have to get back exactly what you give. Sunscreen: It is harder to apply when you are putting it on someone else first. In other words, when you are caring for a family member, it is sometimes more challenging to care for yourself. It is easy to forget to put sunscreen on, and the first few times it is much more difficult to remember. But as time goes on, it gets easier. The longer you care, the easier it gets. Candle: Young carers give so much light and sometimes, their light gets diminished. There are times where young carers have to be on, burn a lot stronger, but then there are times when young carers	carers have a small amount of leisure time (that is, if we are drawing on dominant conceptualizations of leisure as non-obligatory and free time). Parents or adults pushing young carers to do certain activities during their small window of time may feel a lot more intense than if they had lots of time to themselves. Young carers do things for fun and to refresh both spontaneously and during scheduled time, although scheduled time is unpredictable. Caring is leisure. Young carers feel recharged by helping other people. Some young carers engage in caring to refresh. There are assumptions about what types of leisure are more healthy and	about young people. Why is there a certain speed that young people are supposed to mature at? Maturity is relative. Maturing faster than expected perpetuates the idea that you lost out on the maturity you were supposed to have had otherwise. Society doesn't view young caring as the same obligation when it is a parent caring for a child, even though it is almost completely similar. Just because the person is young, does not mean they are not supporting another person and thinking about that person all the time. That person is a part of everything they do. Sometimes parents and/or adults withhold information from young carers about their care partner even though they do not need to.	co-researchers see how another young carer might think about a situation very differently compared to them.

can rest. Young carers give a lot of their light and they do not have a lot of time to replenish. They try to let the candle burn as long as possible. <u>Pencil</u>: Sometimes young carers think about going back in time and erasing or changing something in the past. As they spend more time in their care roles, they are trying to write their own stories, express themselves, and develop their own identity. A pencil can be sharpened, can break, and become dull depending on how it is cared for.	helpful for young carers.		

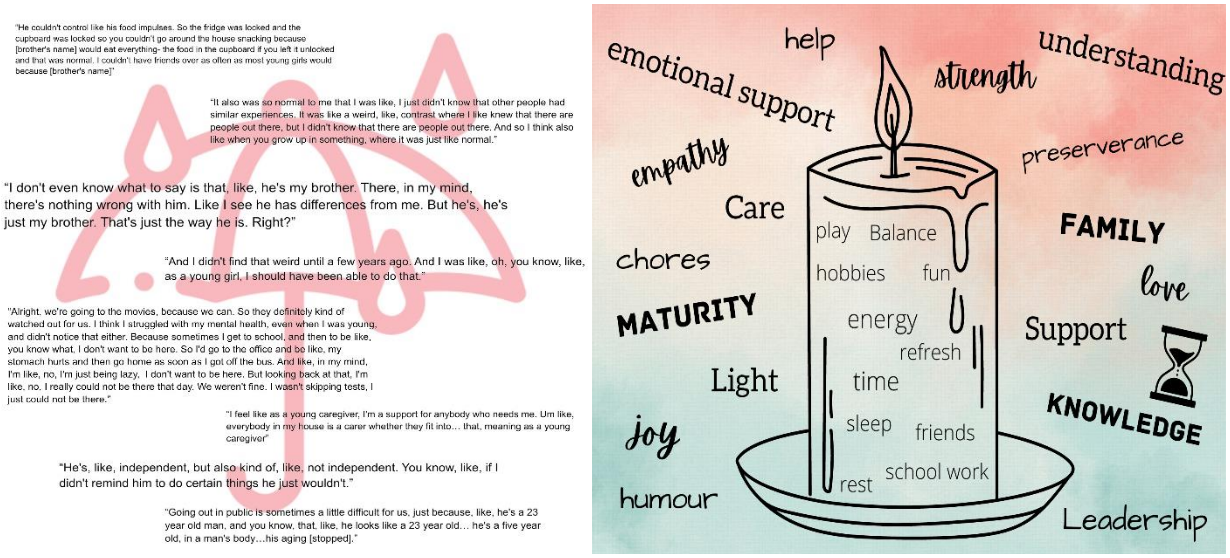
Phase 4: Expression.

Within the Expression phase, Lieshout and Cardiff suggest that co-researchers are "asked to express the 'essence' of the narratives in any creative way they feel comfortable" (p. 228). That is, they are asked to create a reflection that highlights the key messages that stand out for them after reading the text. Within the contemplation meeting, our team decided to design our creative expressions individually outside of a meeting. We began creating our expressions at the conclusion of our contemplation meeting.

I instructed co-researchers to create a creative piece that expressed the essence of what they read in their transcripts. This piece could be represented in any way they wanted (e.g., poem, a quote from the transcript, drawing, painting, symbol of what you saw in the transcript, collage, short story, etc.). Additionally, I asked for co-researchers to develop a description of their creative piece that expresses what the piece means to them, why they think it is important to represent, and why they feel the piece speaks to key ideas in their transcript. In the description of their creative piece, co-researchers added a substantial number of quotes from their assigned transcripts that they felt represented their ideas. Our creative expressions were due Thursday June 2nd, 2022; however, to give co-researchers more time, we landed on our expressions being due Wednesday June 8th, 2022, which was before our next meeting. Please see Figure 5 for two examples of creative expressions developed by co-researchers and Appendix M for examples of more co-researchers' creative expressions.

Figure 5.

Co-researchers' Initial Creative Expressions



"He couldn't control like his food impulses. So the fridge was locked and the cupboard was locked so you couldn't go around the house snacking because [brother's name] would eat everything- the food in the cupboard if you left it unlocked and that was normal. I couldn't have friends over as often as most young girls would because [brother's name]"

"It also was so normal to me that I was like, I just didn't know that other people had similar experiences. It was like a weird, like, contrast where I like knew that there are people out there, but I didn't know that there are people out there. And so I think also like when you grow up in something, where it was just like normal."

"I don't even know what to say is that, like, he's my brother. There, in my mind, there's nothing wrong with him. Like I see he has differences from me. But he's, he's just my brother. That's just the way he is. Right?"

"And I didn't find that weird until a few years ago. And I was like, oh, you know, like, as a young girl, I should have been able to do that."

"Alright, we're going to the movies, because we can. So they definitely kind of watched out for us. I think I struggled with my mental health, even when I was young, and didn't notice that either. Because sometimes I get to school, and then to be like, you know what, I don't want to be here. So I'd go to the office and be like, my stomach hurts and then go home as soon as I got off the bus. And like, in my mind, I'm like, no, I'm just being lazy. I don't want to be here. But looking back at that, I'm like, no, I really could not be there that day. We weren't fine. I wasn't skipping tests, I just could not be there."

"I feel like as a young caregiver, I'm a support for anybody who needs me. Um like, everybody in my house is a carer whether they fit into… that, meaning as a young caregiver"

"He's, like, independent, but also kind of, like, not independent. You know, like, if I didn't remind him to do certain things he just wouldn't."

"Going out in public is sometimes a little difficult for us, just because, like, he's a 23 year old man, and you know, that, like, he looks like a 23 year old… he's a five year old, in a man's body…his aging [stopped]."

Phases 5 to 7: Contestation and Critique, Blending, and Confirmation.

I have presented Phase 5 through Phase 7 of our CCHA process together to represent that these three phases were integrated. Specifically, Phase 6, which Lieshout and Cardiff (2011) describe as the blending phase of CCHA, happened organically and fluidly in our CCHA process and not necessarily as a fixed phase. Therefore, I will begin with a description of how blending unfolded in our CCHA process, then move to a discussion on Phase 5: Contestation and Critique and Phase 7: Confirmation.

Lieshout and Cardiff (2011) describe the blending phase of CCHA as a time where co-researchers "can expand their horizons through meeting with others, revealing shared understanding, and exploring divergent understandings" (p. 229). In our CCHA process, we started blending our ideas together during conversations in our contestation meeting and continued blending until the end of our confirmation phase. Please refer to Table 5, which outlines some of the questions that inspired blending in phases 5 and 7.

Table 5.

Questions that Inspired Blending

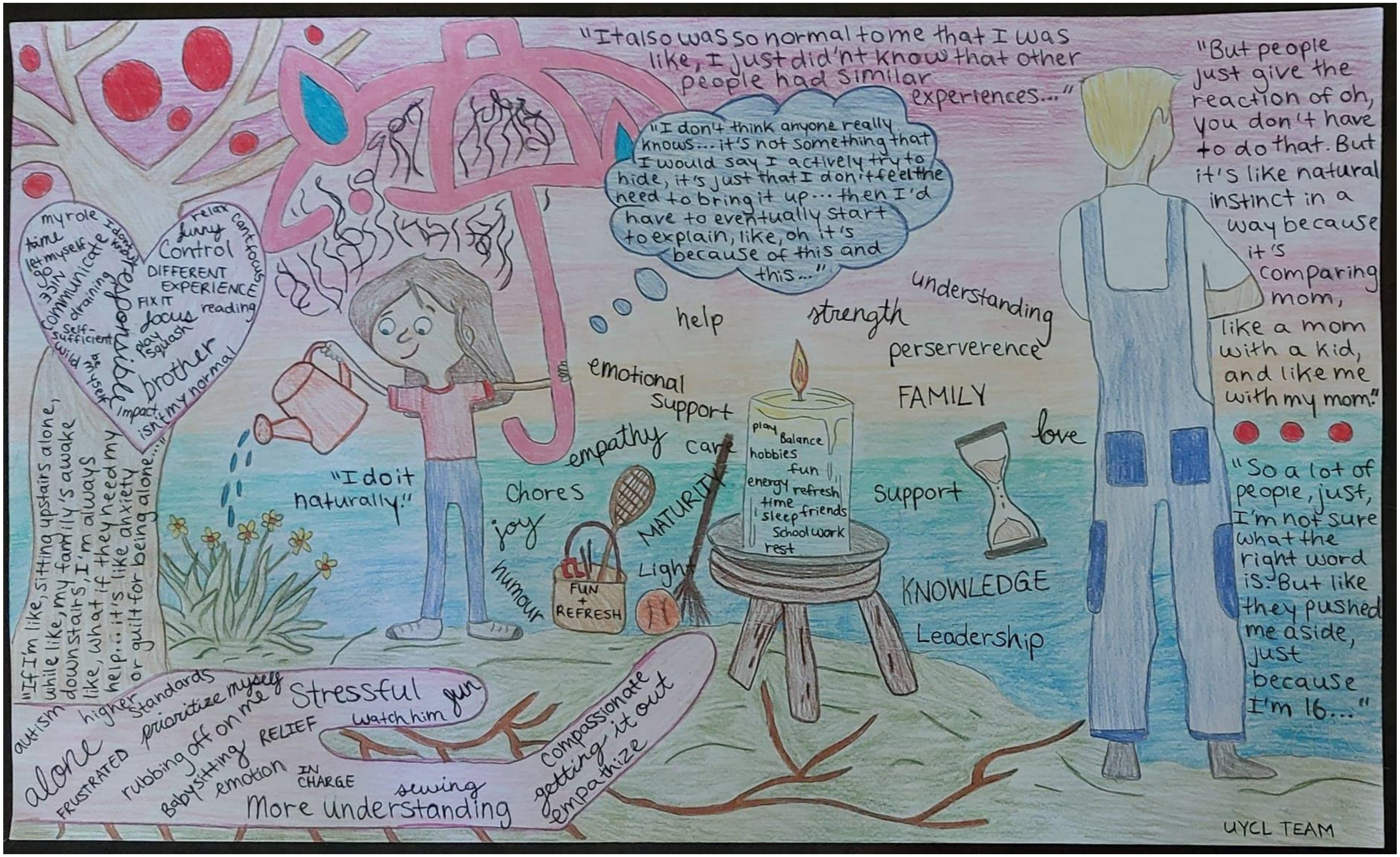
Phase 5: Contestation and Critique	Phase 7: Confirmation
• How did your transcript make you feel? • What were you excited about when reading the transcripts? What were you surprised about? • How was this experience for you? What would you have done differently? • What changes in society or for young carers did the transcripts make you think about? • How is power functioning in these transcripts (e.g., between young people, between adults, teachers, organization staff)? • How does this piece challenge the dominant understanding of young people (e.g., challenge that young people shouldn't be involved in decision-making, that young people are immature, that childhood is a time of innocence and dependency, etc.)? • What similarities (if any) can you see between your piece and the pieces of	• What are the key/important ideas that we feel we need to capture? • How does this piece help provide an alternative understanding/discourse of young carers? • How is young caring described? Why is caring described in a specific way? • What do the transcripts say about the experience of young caring? • What does this piece say about the experience of young caring? • How do these transcripts challenge the dominant understanding of young carers (e.g., challenge the idea that young carers are living a life they shouldn't be, that the caring experience is primarily negative, etc.)? • How does this piece challenge power dynamics (e.g., adults' power over young people)?

others? (Asked after each co-researcher presented their piece) • What differences (if any) can you see between your piece and the pieces of others? (Asked after each co-researcher presented their piece)	• What similarities (if any) can you see between our collaborative piece and your piece? • What differences (if any) can you see between your collaborative piece and your piece?

Phase 5 of CCHA, contestation and critique, is where collective interpretation can start, with co-researchers sharing their creatively expressed interpretation of the narratives (Lieshout and Cardiff, 2011). Critical questions, alterative interpretations, and contradictions help elicit more depth, detail, and clarity. In this phase, our contestation meeting was set for one hour and ended up being split into two smaller group meetings, both occurring on June 8th, 2022. In this meeting, we planned to share our creative pieces with each other and reflect on our contestation questions (see Appendix L and Table 5). Figure 5 and Appendix M shows that co-researchers' creative expressions were unique, with some including images, words, descriptions, and direct quotes from the transcripts. Since co-researchers spent much time sharing their rich descriptions of their creative expressions in our meeting, we did not end up having the time to approach our list of contestation questions until our next meeting, when we also focused on confirmation. Although not intentionally, we did address some of these questions more informally in our discussion. Within this phase, we primarily focused on explaining our creative expressions and commenting on similarities and differences between our expressions. After establishing a description of each individual creative expression, our team decided that I would take all co-researchers' creative pieces and blend them together into an integrated collaborative expression of the data. This blended creative reflection of the data acted as a guide for us to develop our themes, as each image and quote in the creative piece had a specific meaning and connection to each transcript. Please refer to Figure 6 for our collaborative creative expression of the data.

Figure 6.

Our Collaborative Creative Expression of the Data


"It also was so normal to me that I was like, I just did'nt know that other people had similar experiences..."
"I don't think anyone really knows... it's not something that I would say I actively try to hide, it's just that I don't feel the need to bring it up... then I'd have to eventually start to explain, like, oh it's because of this and this..."
"But people just give the reaction of oh, you don't have to do that. But it's like natural instinct in a way because it's comparing mom, like a mom with a kid, and like me with my mom."
"So a lot of people, just, I'm not sure what the right word is. But like they pushed me aside, just because I'm 16..."
"If I'm like, sitting upstairs alone, while like, my family's awake downstairs, I'm always like, what if they need my help... it's like anxiety or guilt for being alone...."
"I do it naturally."
my role
time
let myself go
I don't know
NICE
communicate
draining
responsible
self-sufficient
wild
be myself
relax
funny
can't focus
Control
DIFFERENT EXPERIENCE
FIX IT
reading
focus
play squash
brother
impact
isn't my normal
help
strength
understanding
perserverence
emotional support
empathy
care
FAMILY
love
Chores
joy
humour
MATURITY
Light
FUN + REFRESH
play
Balance
hobbies
fun
energy
refresh
time
sleep
friends
School work
rest
support
KNOWLEDGE
Leadership
autism
higher standards
prioritize myself
Stressful
fun
watch him
alone
FRUSTRATED
rubbing off on me
RELIEF
Babysitting
emotion
IN CHARGE
sewing
More understanding
Compassionate
getting it out
empathize
UYCL TEAM

Confirmation is the final phase of the CCHA process where themes are well established together (Lieshout & Cardiff, 2011). After we had our collaborative creative piece with all our loosely developed key themes, we participated in a meeting to discuss the piece and our contestation and critique questions, which we were not able to directly touch on in our previous meeting (see Appendix L and Table 5). This meeting was split into two smaller group meetings occurring on Thursday June 23rd, 2022, and Friday June 24th, 2022. Both group meetings were one hour in length. This combined contestation/critique and confirmation meeting helped to confirm the importance of key themes represented within our creative expression piece. We also worked collaboratively during these meetings to develop descriptions for each of the key themes identified within our creative expression piece. Since we had individually collected participant quotes from our transcripts to support our individual creative expressions, we had a substantial number of quotes that supported our key themes.

Lieshout and Cardiff (2007) mention that, in the confirmation phase, researchers can "return to the original narratives, retrieving the raw data that supports the developed thematic framework" (p. 229). After our confirmation meeting had ended, I went back to the raw data to ensure the quotes that each co-researcher pulled for their individual creative expression matched our key themes in the collaborative creative expression. Additionally, I began to build on our theme descriptions with additional quotes I found in the data. After strengthening our themes, I brought them back to the team for confirmation in our next team meeting. Information on our next team meeting, which is named 'UYCL Team Celebration Meeting,' and the results from our CCHA process are presented in the next chapter.

SECTION THREE

Chapter Four: Challenging and Expanding Understandings of Young Carers and their Leisure

In our confirmation meeting, we talked about how our collaborative expression piece might look to people who were not involved in our CCHA analysis process. Although we wanted our creative expression to be open to multiple interpretations, I begin this chapter with a breakdown of our creative expression of the data and discuss how each image and quote connects to key themes in Table 6. Next, I provide a multivocal and integrated discussion on the results of our CCHA process. Last, I outline our team celebration meeting and how I attended to authenticity throughout this research process.

Reflect

Table 6.

A Breakdown of our Collaborative Creative Expression of the Data

Key Theme	Subtheme	Corresponding Component in Creative Expression
There is Nothing Unnatural About Being a Young Carer: It's About Just Being Human	Young Caring as Natural and Widespread	-Participant quote to the left of the young carer: *"I do it naturally"* -Participant quote at the top and in the middle: *"It also was so normal to me that I was like, I just didn't know that other people had similar experiences..."* -On the bottom of the image, roots are spreading which represents young carers' care roles extending towards other people in their lives. -Towards the right and at the top, the young carer is holding an umbrella which represents that some young carers often shield and protect their care partner(s). The umbrella does not decide to shield the young carer from bad weather in this image which is similar to many young carers who do not choose to engage in care roles, it is instinctual. -Participant quote to the far left and at the top: *"But people just give the reaction of oh, you don't have to do that. But like its natural instinct in a way because*

		its comparing mom, like a mom with a kid, and like me with my mom." -The young carer is watering the flowers, nurturing them and helping them grow. This represents how some young carers help support the growth of people in their lives by developing a greater understanding of them and their life experiences. The young carer is smiling while doing this, which represents that some young carers are grateful for developing a newfound sense of empathy and understanding towards the people around them.
	Young Carers Hiding in Plain Sight	-Young carer multitasking in plain view, but the adult looking away does not see all that she is doing. This is based on dominant discourses that suggest young people should not be carers. Therefore, the adult in this image is not able to recognize the role of the young carer because it is not compatible with assumptions about the roles and abilities of young people. -Participant quote in thought bubble: *"I don't think anyone really knows...it's not something I would say I actively try to hide, it's just that I don't feel the need to bring it up...then I'd have to eventually start to explain, like, oh it's because of this and this"* -Participant quote in bottom right: *"So a lot of people, just, I'm not sure what the right word is. But like pushed me aside, just because I am 16..."* -Another participant quote that reflects this theme: *"Yeah, I personally, like don't discuss it. But if I, if I were to ask for like an extension, based on like, if, if it had to do with my caregiving, I feel like they would give me an extension. But I'm always scared that, you know, it'll be seen as I'm just making excuses. And I'm like, you know, I'm just bluffing. And I'm not actually doing all the things that I'm saying I need to do."*
Tensions in Understandings and Experiences of Young Carers	Navigating Assumptions about Maturity	-In the middle, the word maturity is written in capital letters and is surrounded by multiple other words that were pulled from participant quotes. This represents that maturity is only a part of what makes up a young carer as a whole person. -The word "maturity" being surrounded by multiple other words represents that not all young carers

		identify with or want to identify with the word maturity, but instead describe themselves with different words such as *strength, knowledge, empathy, and humour.* -Participate quote about navigating the concept of maturity: *"I think as of right now, at the top of my head, it's the expectation from my parents. I have a few conversations with my mom and it's like, your brother's like this so you should be more mature. You should be more understanding, more compassionate, you should dedicate more time to him. "*
	Navigating Challenges Associated with Mental Health	-Above the young carer, there are squiggly lines that look like lightening bolts. This represents the mental health challenges that young carers experience in their care roles. This also represents that young carers often navigate mental health challenges on their own but are not recognized in doing so. -In addition, stigma sometimes creates or enhances young carers' mental health challenges. Particularly, young carers mentioned having constant worries that other people might not understand their care partner in the same way that they do. -In the middle, there is a candle that holds words of importance to young carers that were pulled from participant quotes This candle represents that when young carers are not able to take time to engage in the things that help them navigate their mental health, they do not burn as brightly as before. -All the words in the candle are things that young carers need to navigate in their care roles. -One participant quote that represents this image is: Um because I don't always want to be in the mindset of, I have to be doing something to help someone right now. I want to be somewhat thinking about how I can take care of myself.
Leisure as Relational Moments of Rejuvenation in Everyday Life	The Entanglement of Leisure and Care	-The young carer is smiling, enjoying caring, with the traditional ways of engaging in leisure to the side. -Participant quote inside the tree to the far right about feeling uncomfortable when leisure is separate from caring: *"If I'm like, sitting upstairs alone, while like, my family's awake downstairs, I'm*

		always like, what if they need my help...it's like anxiety or guilt for being alone" -Sometimes leisure in the lives of young carers looks like spontaneous and fun activities with their care partner(s). For instance, here is a participant quote that reflects this theme: *"Sometimes my free time is just hanging out with [brother's name]. Because like, we'll do fun activities. Like over the summer, my parents like to take us out a little bit more just because like, I'm not in school, and we have that time. So, we were gonna do mini golfing on Saturday, but it was the end of March Break. So, we got there and there was a whole lot of kids. He's like, no, we're not doing that. So, we went to Walmart instead, and like, that was fun."*
	Resisting Youth Discourses Through Leisure	-All the objects in and around the bucket such as the music note, the basket-baseball, the pencils, the broom, and the squash racquet represent young carers taking ownership over their lives through deciding what leisure means to them and how they want it to look in their lives. -The broom to the right of the bucket represents that leisure depends on context in which it is experienced rather than the activity itself. The image of a broom came from a young carer quote about cleaning her room as leisure: "*I think to refresh for me, like I didn't think much of cleaning my room as something I do for me. Like mom would usually say [participant name] go clean your room. And it was like a chore. But I think I'm now grateful for the time I have to even clean my room. Some days. I'm so busy. I don't even have 20 minutes to clean my room."* -Bucket beside young carer that says *"Fun + Refresh"* represents leisure as something that can be for fun, to refresh, or both, depending on young carers' context and how they are feeling in that moment.
Being Acknowledged as Relational Beings	Having Relational Opportunities and Spaces	-At the bottom, the roots coming from the tree represent the important relationships present (or not present) in young carers lives.

		-Participant quote at the top and in the middle: *“It also was so normal to me that I was like, I just didn’t know that other people had similar experiences...”* -Words such as family, understanding, alone, love, and friends. -Another participant quote that reflects this theme is about the value of having older young carer in programs: “*We had a summer camp program, I think when I was in grade nine, so I was like, still not worrying about this at all. But I was like, oh, what happened to so and so- I feel like she was here like every year, she was here all the time, whatever. Like, I actually was able to have people who are older than me in my program. So, when I was like, I think, like ten, they were like four years older than me. So, there were people- I didn't really talk to them that much, but they took care of you in your programs. And now I'm like, where are all these people, like I had so much fun talking to them, whatever. And then someone told me like, oh, you know, the age limit is like 18, right? Like, they're not here anymore and I was like, what?”*
	Raising Awareness and Being Recognized	-Young carer is not hiding her role but still she is not noticed by the adult who is standing so close to her. -The adult’s body language shows that he is closed off which represents how powerful perceptions lead adults to misunderstand young carers. -Participant quote in bottom right: *“So a lot of people, just, I’m not sure what the right word is. But like pushed me aside, just because I am 16...”* -A participant quote that reflects this theme is: *“I think if young carers- just young carers as a whole, were more known about, like, when people think about disabilities, they think about all of the people who have disabilities, they’re so affected by this, we should be more compassionate towards them. But no one really talks about people who are affected by them, like firsthand, siblings and their family members.”* -Young carers mentioned that being recognized by society would support them in feeling like they do not have to hide their care roles from others

		-A participant quote that reflects young carers' call for awareness: *"I think it's just like, awareness. I think to be supportive just for people to know what I'm going through. And like just so I'm no-t because right now, I feel like when I go to school and talk to my friends, I'm like, hiding, I'm like living two lives. Because I have like life at school with my friends and then I have a life when I come home and I have my mom and none of them know about it."*

A Multivocal Discussion on our CCHA Results

Before I begin the discussion on our CCHA results, I would like to outline my decision to present our results as a multivocal and integrated narrative. Our CPAR process did not unfold in a clean and uniform way, but rather each phase of our process was entangled with the next in an integrated way. I feel that presenting my discussion separate from our results does not accurately represent how our entire process was designed, which was to include multiple perspectives and voices together. Since our entire CPAR process involved the blending of multiple voices, I felt it was suitable to present our CCHA results as a multivocal narrative. In this way, the following discussion will bring in young carers' voices, my own voice, and relevant literature to illustrate the story that is reflected in our collaborative creative expression of the data.

There is Nothing Unnatural About Being a Young Carer: It's About Just Being Human

Our first theme deconstructs dominant conceptualizations of young carers and young people as innocent, dependent, and in need of protection. Through representing caring as a natural and instinctual part of being human, young carers' own words challenge underlying and pervasive assumptions about their own lived experiences. Within this theme, there are two subthemes: Young Caring as Natural and Widespread and Young Carers Hiding in Plain Sight.

Young Caring as Natural and Widespread.

Young carer participants described their caring as normal, natural, and instinctual. Johnny, a young carer participant, supports his parent who lives with MS. In our research conversation, Johnny said:

> *I don't really think about it. I just do it. Because I'm so used to doing it. That I don't even think about what I did- that I was just helping somebody.*

In Johnny's experience, caring is not premediated but rather '[he] just [does] it.' Like Johnny, Rose described caring as a reflex. Specifically, she talked about supporting her mom:

> *I don't really think about doing it. It's just something that is just like a reflex kind of. You can- I like, I care for my mom, and I can see when she needs help. Or just like, it's just obvious. And I don't ask I just do it. Yeah.*

Both Johnny and Rose described caring as instinctive; it is not something they think about doing but simply something they just do. It is natural to them, yet in the young caring literature, caring at a young age is depicted quite negatively and as an unnatural circumstance that young people must be rescued from (Chojnacka & Iwanski, 2021; Frederick et al., 2020; Hendricks et al., 2021; Kavanaugh & Stamatopoulos, 2021; Parys et al., 2014). This literature draws on social constructions of child and adult roles, supporting dominant discourses that suggest young people can not or should not care for others, again denying their relational being. In this way, young carers' care roles are represented as problematic and in turn, young carers as vulnerable and at-risk (Aldridge, 2018; Kavanaugh, 2014; Stamatopoulos, 2016). Although many young carers' experiences are complex and involve challenges, Johnny and Rose describe young caring in a positive, innate way. Through mentioning that 'they do not think about caring' but rather ‘just do it,’ Johnny and Rose suggested that caring can be a natural phenomenon in the lives of young people.

Young carers expressed that their care roles helped them develop a deeper understanding of the different experiences young people may go through in their lives. Matthew, a young carer participant who cares for his parent living with MS, spoke about how his care role led him to develop a greater understanding of other young people:

> *Like understanding that people, like everybody goes through something different. So, it’s not like, oh, you can’t do this- but why?*

Matthew mentioned that ‘everybody goes through something different,’ whether they are young carers or not. In this way, Matthew challenged discourses that draw on ‘norms’ to dictate what young people should experience in their lives. Specifically, Matthew mentioned that his care role helped him understand that all people have different experiences in their lives, meaning there is not one way of experiencing life. Not only did Matthew talk about understanding everyone’s different lived experiences, but also, he discussed probing deeper into what those different experiences are. For instance, Matthew said “it’s not like, oh, you can’t do this-but why?” In this sentence, Matthew exposed common first reactions to different experiences as ‘oh, you can’t do this?’ This statement reads as being judgemental, misunderstanding, and surprised. Given that some experiences in childhood, such as young caring, challenges dominant narratives that suggest there are a specific range of experiences acceptable in childhood (Robson, 2004; Smith, 2015; Wihstutz, 2017; Wyn, 2015), society’s initial reaction to ‘non-traditional’ experiences is misunderstanding and in turn, judgement. Matthew took his understanding of the different lived experiences of young people one step further when he suggested that society should ask ‘but why’ instead of settling on misunderstanding and judgement. Through stating that ‘everybody goes through something different,’ Matthew brought attention to the importance of questioning *why* some young people are pushed aside and misunderstood in society. Perhaps, if all people go through something different and may experience caring in all kinds of unique ways, why aren’t all people considered carers and recognized for the contributions they make to others’ lives, whether they are young carers or not?

In research conversations, young carer participants talked about how their care roles were essential to their growth and how those roles emphasised the importance of helping others. Specifically, Johnny said:

> *Um because I was helping my father at such a young age, I have learned how to deal with people and help them in their scenarios. Which is why most people come to me when they have questions.*

Johnny expressed that being knowledgeable about helping people in their specific experiences was a direct result of caring for his parent at a young age. He went on to mention that people gravitate towards him for help, suggesting that he supports both his parent at home and other people outside of home. In this way, Johnny’s young caring extends beyond supporting his parent. It is here that we used the image of tree roots in our creative expression to represent that young caring is widespread.

Similarly, Evelyn talked about how her care role had influenced her career goal, which is to help transform the accessibility of the tourism industry:

> *Yeah, I want to like, I want to be the person at the front desk that makes sure I know, to come around the counter to see somebody in a wheelchair instead of leaning over the counter. Or, like, just making the small changes in making sure things are accessible. Cuz like, I've seen so many people who go about it, like, the wrong way, like working at Tim Hortons for four years, I watched somebody come in, like, I think they were hearing impaired. And the cashier was like yelling at them, or like talking really- like talking to them like they were stupid. Like really enunciating the word almost in like a really rude way and I'm like, no that's not at all what you're supposed to do. So, like, I want to be that person that like, knows what to do and make sure your vacation is comfortable.*

In our research conversation, Evelyn spoke about multiple instances when she witnessed persons with disabilities being discriminated against, including her brother who lives with autism. Through these experiences, Evelyn has developed a greater understanding of accessibility and how to treat persons with disabilities with respect and dignity. Evelyn mentioned that she 'wants to be that person that knows what to do and makes sure your vacation is comfortable.' In other words, Evelyn's desired career in the tourism industry is to support the travel experiences of persons with disabilities.

Statements made by Evelyn and Johnny express that young caring does not only occur in private spaces. Specifically, both Evelyn and Johnny spoke about supporting or having a desire to support other people in their lives. In this way, Evelyn and Johnny represent caring as widespread and challenge the notion that caring is predominantly a hidden, private matter (Stephen et al., 2017). It is through Rose, Johnny, Matthew, and Evelyn's representations of caring that I turn to a discussion on relational caring to propose that young caring is indeed natural and widespread.

Relational caring is a philosophy of care that prioritizes relationships as the core of care processes (Engell, 2020). Dupuis et al. (2016) suggests that relational caring upholds interdependence, compassion, and growth promoting relationships as being "at the core of human wellness" (p.1). In addition to depictions of relational caring as a philosophy and practice, some scholars describe relational caring as a model that transcends a focus on the individual to include their entire social network (e.g., family, carers, community) (Rockwell, 2012). It is here that I find relational caring particularly applicable to dominant representations of care in the lives of young carers as it challenges the notion that caring is localized and unnatural. Young carer participants described the caring process as instinctive and existing within a broad web of connections. This leads me to wonder if models of relational caring may support young carers' representations of caring processes as intrinsically human experiences and in turn, expand surface-level understandings of young caring as unnatural and private.

Young Carers Hiding in Plain Sight.

Despite caring being a natural part of being a human and important part of young carers lives, young carers talked about feeling pushed aside and undermined by adults in their care roles. Specifically, young carers talked about their care roles being dismissed and unrecognized, feeling the need to hide away due to the assumption that caring at a young age is unnatural. One young carer participant, Rose, supports her mom who is living with ALS. Although initially she is hesitant about sharing her experience, she proceeds by expressing how adults make her feel in her care role:

> *I think, oh, actually, a big one, I'm not sure if- well I'm just going to say it. I'm like, I'm mom's primary caregiver. And then she's in the hospital. And it's like, her friend or my grandfather getting the news and being told everything, and I don't get told anything. Like well she had surgery and like, I have no idea. But I'm her main caregiver. So, a lot of people, just, I'm not sure what the right word is. But like they like, pushed me aside, just because I'm 16. Like, I'm a 16-year-old girl. That's like, I'm not seen as like mom's caregiver in a way. I'm just seen as her daughter who helps a mom. So that annoys me very much.*

As Rose indicated, she is her mom's main carer, yet the adults in her life undermine her role through withholding important information from her and not including her in important conversations and decisions. This clearly annoys Rose and causes her to feel unnecessary stress and frustration. Rose mentioned that adults 'pushed her aside, just because she is 16' and that 'she's just seen as a daughter who helps a mom.' In this way, the caring responsibilities that Rose takes on in her life are undermined, leading to a lack of recognition of her role altogether. The lack of recognition about Rose's experiences in her care role is consistent with dominant narratives that represent young people as dependent, innocent, and care-free (O'Dell et al., 2010; Wyn, 2015). Rose, however, challenges this perspective by identifying herself as her mother's primary carer and engaging in significant care responsibilities. Although Rose is her mom's main carer, CYS scholars would suggest that her age allows adults to feel the need to shield her from the dangers of the adult world, or in other words, experiences that involve responsibility and sometimes hardship (Wihstutz, 2017). In this way, adults maintain the view that caring at a young age is unnatural and unacceptable during childhood (O' Dell et al., 2010)

Rose's story suggests that adults' understandings of young carers are rooted in assumptions about the competence and abilities of young people and the need to only protect. These misunderstandings have the power to hide the reality of young carers' care roles through uncovering only specific parts of the whole story. In this way, the adults in Rose's life only see that she is 'a daughter who helps a mom' but not that she is her mom's main carer; that being a caring daughter also means providing the care her mother needs. It is here that Rose's care role is not seen nor accepted for what it truly is and means to her. As a result, our team thought it was necessary to feature Rose's quote in our creative expression piece.

Young carer participants also talked about keeping their experiences to themselves in fear of adults' downplaying or rejecting their care roles. Maya, another young carer participant, supports her younger brother with autism. When asked about if she speaks to any teachers at school about her care role, Maya said:

> *Yeah, I personally, like don't discuss it. But if I, if I were to ask for like an extension, based on like, if, if it had to do with my caregiving, I feel like they would give me an extension. But I'm always scared that, you know, it'll be seen as I'm just making excuses. And I'm like, you know, I'm just bluffing. And I'm not actually doing all the things that I'm saying I need to do.*

Although Maya believes that teachers would provide her with an extension, she mentioned feeling 'scared' that they will downplay her role or reject it completely. Maya specifically addressed a fear that her teachers will not believe she is 'actually doing all the things she is saying she needs to do.' The responsibilities that Maya takes on in her care role transcend taken-for-granted assumptions about what experiences are acceptable in childhood (Robson, 2004; Smith, 2015; Wyn, 2015). Given that her experience does not fit within a childhood characterized by learning and play (Wihstutz, 2017), Maya feels as though adults will think she is 'bluffing.' In fear of misunderstanding or lack thereof, Maya mentioned that she 'does not discuss her care role' with teachers at school.

Rose and Maya expressed feelings and fears regarding adults misunderstanding and downplaying or rejecting their care roles and experiences. Adults' misunderstandings stem from the dominant casting of young people, which includes young carers, as 'becomings' rather than 'beings' (Wihstutz, 2017), essentially relying on adults to develop and educate them toward adulthood and denying their being-ness from the start. In this way, adults' perceptions of young carers are clouded by their assumptions that young people cannot and should not care for others or be carers, resulting in missed opportunities to acknowledge young carers' humanness as demonstrated in their care roles.

In my own experiences as a young carer, I rarely confided in adults about my care roles in fear of them assuming the role I had in childhood was not safe or acceptable. As a young carer to my parent who lives with a rare schizoaffective condition and is recovering from substance misuse, many of my experiences did not align with societal expectations of childhood (e.g., dependence, innocence, absence of hardship, etc.) (O' Dell et al., 2010; Earley & Cushway, 2002). Specifically, as much as my siblings and I engaged in learning and play throughout our childhood, we also participated in a lot of serious conversations and took on significant responsibilities. I remember confiding in a teacher at school about my role and at one point, being required to speak to the children's aid society and a school counselor to explain my situation more. I felt very uncomfortable in that moment, because I had to almost 'prove' to adults that I was safe and that my care role was normal to me and a natural part of my life. Since I already felt that there was a lack of misunderstanding about my role, I sometimes wanted to withhold the truth or downplay my own experience when speaking with adults to protect my role from being made out to be something abnormal. As a result of adults' reactions to my care role, I remember thinking there must not be many young people with similar roles to me. I left that encounter feeling relatively alone in my situation, leading me to question if my role was in fact, 'unnatural.'

The discourses of what it means to be young are pervasive, so it is not surprising that young carers themselves come to adopt discourses that are used to define and describe who they should be and how they should behave. For instance, Evelyn cares for her older brother who lives with autism. When describing her experience, she said:

> *Maybe like, it's not supposed to be our responsibility to take care of our siblings. The adults should be in charge of that.*

Through suggesting that 'it's not supposed to be' young peoples' responsibility to care for their siblings but instead that 'adults should be in charge of that,' Evelyn draws on dominant assumptions that suggest young people should not be carers. It is here that I turn to literature on the rights of children, often referred to as childism, to further contextualise Rose, Maya, and Evelyn's experiences.

According to Prilleltensky et al. (2001), adults often ignore the social and political contexts in which children's problems occur. In other words, childism scholars describe childhood as an apolitical space created and dominated by scientific formulas of child development (Mayall, 2000). In this way, developmental models are challenged for promoting universal claims about how a ‘normal’ child feels and acts, and how a ‘normal’ childhood looks. Unfortunately, representations that draw on developmental approaches to understanding young people are pervasive and deeply embedded in education and healthcare (Gladstone et al., 2006), often resulting in young carers, like Evelyn, internalizing problematic assumptions about their lives and what it means to be a relational being.

Childism scholars bring attention to the term social competence, which is about young peoples’ rational, purposeful interactions in a variety of social contexts (Gladstone et al., 2006). Due to models of development, adults reserve social competence for those who have transitioned into adulthood, restricting young people from actively contributing to the world during childhood (Hutchby, 2005). According to Malorni (2022), “adults, the main actors of this limitation of agency, can normalize this disenfranchisement by judging youth on the premise of developmental immaturity” (p. 2). When young carers like Rose, Maya, and myself then come forward with their roles and responsibilities, it is seen as incompatible with the dominant developmental understanding of young people and their abilities. The inability to acknowledge young people as carers is driven by the faulty developmental perspective carried by adults, and has serious consequences for young carers, making them feel like they are hiding in plain sight or that they have to hide important aspects of their lives from others. Therefore, even when young carers’ responsibilities are evident and are a natural part of their lives, adults overlook and undermine the reality of their lived experiences.

Tensions in Understandings and Experiences of Young Carers

Our second theme refers to the complexities involved in the understandings and experiences of young carers. Young carer participants expressed contradictions that they consistently navigate in their lives to try to understand their own lived experiences and the experiences of others. Within this theme, there are two subthemes: Navigating Assumptions about Maturity and Navigating Challenges Associated with Mental Health.

Navigating Assumptions about Maturity.

The concept of maturity was mentioned multiple times throughout our research conversations. Particularly, young carer participants discussed being described as mature by adults in their lives, identifying as mature in relation to the positives involved in young caring, and times when they felt the concept of maturity was pushed on them. Rose, a young carer who supports her parent living with ALS, spoke about how she feels more mature as a result of her care role:

> *Um, I think I'm more mature. I like- I actually, not just people telling me, like a lot of people tell me, but I actually see it like when dealing with situations. Because I can talk to mom about MaiD [Medical Assistance in Dying] and, like, just, like, just have a conversation about it. But my mom's friend who has a grandmother wants to do MAID, and they're, like, 45-year-old daughters can't talk about it civilly while, I can. And that just kind of shows me how, like, I'm more mature than I actually thought I was. So, I think being a young carer has, like, just made me more mature, I guess, to put it in simple terms.*

Rose mentioned that 'a lot of people' tell her that she is mature; however, there are certain instances, such as speaking with her mom about MAID (Medical Assistance in Dying), where she personally identifies with the concept of maturity. She is able to compare herself with adults much older than she is and see her maturity. Rose continuously used the phrase 'more mature,' suggesting that she is positioning her maturity in comparison to someone who is ‘less mature’, and she associated this maturity, in part, to her caring role. Given dominant understandings of young people as ‘immature’ and ‘innocent’ (O’ Dell et al., 2010), Rose draws on assumptions that young people are generally ‘immature’ unless they have experiences outside the ’norm’ in which case they become more mature than their inexperienced counterparts. It is important to note that I am not intending to invalidate Rose’s maturity, but instead bringing attention to the flaws of using a concept such as maturity due to its connection to taken-for-granted assumptions about the competence of young people.

Like Rose, I often used the concept of maturity to describe myself in relation to the positives of my care role. In fact, it is one of the first descriptions I use in this thesis to describe the strengths I have developed because of my care role. During research conversations, I started to notice how much the concept of maturity came up when we discussed the rewards associated with caring at a young age. Since going back to the literature, I noticed that the concept of maturity was often used by scholars to explain the benefits of caring at a young age (Matzka & Nagl-Cupal, 2020; McDougall et al., 2018; Rose & Cohen, 2010). Upon reflection, I often used the concept of maturity to balance out the positives and challenges of young caring when I described my role to others. In doing so, I drew on the narrative that young caring has resulted in me losing out on a ‘normal’ childhood (Aldridge & Becker, 1993). To justify that this ‘loss’ was not for nothing, I relied on the notion of maturity to express to others that I have indeed gained something from the perceived sacrifice of caring at a young age (O’ Dell et al., 2010). In this way, I do identify with the concept of maturity when I think about the skills I have gained as a result of my care role; however, in doing so, I am also suggesting that I lost out on a childhood where I would have been ‘less mature.’ I view this tension as problematic because my identity is tied up with assumptions that being ‘less mature’ or not caring at a young age is preferred, leading me to feel the need to justify that my care experiences have an underlying, positive silver-lining, which in this case, is maturity.

Young carer participants, Johnny, and Matthew, also draw on dominant narratives about the abilities of young people as a result of descriptions about their competence placed on them by adults. In our research conversation, Johnny said:

> *I had to grow up a little faster than most kids. So, like, I have been told I’m mature for my age, or whatever.*

In this statement, Johnny described a hierarchical, stage-like transition into adulthood when he says that he “had to grow up a little faster than most kids.” Specifically, he compares himself to ‘norms’ that suggest young people are accorded specific strengths and abilities at particular ages (Smyth et al., 2011; Wihstutz, 2017). When Johnny talked about being ‘told he’s mature for his age,’ he brought attention to assumptions about development that dictate how a young person should behave at specific ages (Rose & Cohen, 2010). In this way, Johnny’s understanding of maturity is based on a model of childhood that does not accommodate young carers since they take on specific responsibilities ‘earlier’ than socially accepted (Charles et al., 2008; O’Dell, 2010).

Matthew, a young carer who supports his parent with MS, talked about feeling like he was “More mature, younger. As opposed to acting like a child.” In this statement, Matthew’s foundation for his maturity is based on descriptions of how children act. Specifically, maturity is positioned in opposition to ‘acting like a child,’ which then positions Matthew as ‘not acting like a child.' This representation presents young carers as being different than dominant constructions of children (e.g., immature); however, it maintains that all other young people fall within these same constructions. Therefore, young carers like Rose, Johnny, Matthew, and I understand ourselves as different (or more mature) compared to all other young people who are not young carers or have not had similar experiences.

Although many young carer participants were described as mature by adults and identified with that description, some young carers mentioned that the concept of maturity put added pressure on them to be someone that they felt they were not. Specifically, Alice, who cares for her brother living with autism, talked about challenges regarding the expectation that she should be more mature given her care responsibilities:

> *I think as of right now, at the top of my head, it's the expectation from my parents. I have a few conversations with my mom and it's like, your brother's like this so you should be more mature. You should be more understanding, more compassionate, you should dedicate more time to him. And I'm graduating so I am like yes and yes, [laughs]. I know, I could probably do better. But there's just so much I have to take in like school, like school alone. And with all the stuff that's happening, COVID on top of that, like I just, there's so much I have to think about and I know, like, I know, inside I'm kind of neglecting my duties as a young carer. But I'm trying.*

Alice mentioned that the expectation from her parents to be 'more mature, more understanding, more compassionate, and dedicate more time to her brother' adds additional pressure in her life. In this way, the expectation for Alice to be 'more mature' leads her to feel as though she is 'neglecting her duties as a young carer.' This statement suggests that Alice views concepts such as maturity, understanding, and compassion as descriptions that must be achieved in young caring. This is problematic because Alice, who already takes on significant responsibilities in her life, feels as though she needs to achieve specific traits to be considered a 'better' young carer. In this way, Alice is also comparing herself to an idealized norm, such as a 'typical young carer' who is always 'mature, understanding, and compassionate' (Matzka & Nagl-Cupal, 2020; McDougall et al., 2018). Young carers are predominantly described as mature, compassionate, and resilient in the young caring literature (Banks et al., 2002; Fives et al., 2013; Nagl-Cupal et al., 2014; McDonald et al., 2009), which may lead to the assumption that all young carers identify with these descriptions. As a result, young carers are held up to a standard that they feel may not represent their lived experiences and what traits they want to identify with at different moments in their life. In the young caring literature, some young carers were "concerned about being labelled as 'angels' or 'heroes,' as it left them with no room for failure or need for support (Rose & Cohen, 2010, p. 478; see also: Moore & McArthur, 2007). Perhaps then, relying on concepts such as maturity to describe all young carers results in both comparisons between young carers and young people, and comparisons between young carers themselves. This leads young carers, like Alice, to feel as though they 'could do better' compared to another young carer, even though their experiences are likely very different.

In research conversations, young carer participants experienced tensions whereby they challenged dominant assumptions about young people through their significant responsibilities *and* supported dominant assumptions of young people through understanding their own maturity in relation to a 'normal' child counterpart who is not mature. Further, some young carers felt the concept of maturity added additional pressure to their lives, since they felt they must measure up to dominant representations of who young carers should be and the traits they should have. It is here that I suggest troubling the pervasive use of maturity to describe young carers in the young caring literature. Although describing young carers as mature may seem positive and harmless, it perpetuates underlying and problematic assumptions about young people and young carers that cause tensions in understanding the real lived experiences of young carers.

Navigating Challenges Associated with Mental Health.

In research conversations, young carer participants shared challenges within their care roles that were related to their mental health; however, many young carers mentioned that their mental health challenges were either created or enhanced by the stigma associated with their care partners' lived experiences. Layla, a young carer participant, supports her brother who lives with autism. Layla talked about feeling like she needed to be in control all the time due to the responsibility of her care role:

> *And then like people like notice that like [participant name] your kind of a control freak. I'm like, oh, sorry. I just like, that's like the way that I'm like, wired now, because it's like, if I'm not in control- in control of it, then who is, you know?*

Layla expressed that she feels a constant need to be in control. She mentioned that the people around her notice her need to be in control, which suggests that her tendency to maintain control extends beyond her relationship with her care partner. Layla talked about how she is now 'wired' to remain in control out of fear that if she is not, nobody else will be. In this way, Layla expressed that she is in a state of long-term stress where she needs to constantly stay in control.

In the young caring literature, scholars often describe young carers' mental health challenges, bringing attention to feelings such as stress and anxiety (Becker & Sempik, 2019; Stamatopoulos, 2016; Stephen et al., 2019); however, this literature tends to focus on intervention and prevention (Purcal et al., 2012; Gray et al., 2008), both of which are informed by assumptions about the emotions and responsibilities accepted in childhood. In other words, it is not necessarily that intervention and prevention services do not have their place in supporting young carers but rather, that they are based on a web of assumptions that suggest caring, and the complexities that come with it, should not be taken up in childhood (O' Dell et al., 2010). For instance, in Gray et al.'s (2008) study, a social worker talks about how young carers care responsibilities should ultimately be the responsibility of the parent. In this way, the social worker draws on assumptions about what roles are acceptable during childhood and adulthood. Instead of supporting young carers through assisting them in navigating their own mental health challenges, scholars and health professionals advocate for interventions that place young carers into roles that they deem more 'suitable' in childhood (e.g., challenge free) (Aldridge, 2018; Gray et al., 2008; O'Dell et al., 2010).

In our research conversation, Johnny talked about navigating his own mental health challenges though identifying how to support himself in his care role. Specifically, Johnny spoke about how he feels when he goes for walks: "I calm myself down because I get into the right mindset." When I asked Johnny why he goes for walks, he said:

> *Um because I don't always want to be in the mindset of I have to be doing something to help someone right now. I want to be somewhat thinking about how I can take care of myself.*

Johnny expressed his efforts in navigating his mental health when he spoke about taking walks to ‘calm down’ and get into the ‘right mindset.’ Through identifying that he ‘wants to be thinking about how he can take care of himself’ sometimes, Johnny challenges assumptions that young people are ‘dependent’ and ‘in need of protection’ from others (Bolas et al., 2006; Cooklin, 2010; Frank & Slatcher; 2008; Kavanaugh, 2014). Specifically, Johnny determined how to navigate his own mental health, without interference from adults. Within the young caring literature, scholars often make decisions and recommendations for young carers, assuming they know what is best for them (Joseph et al., 2019). This contrasts Johnny’s experiences; he is the one who determined how to navigate his own mental health effectively. Perhaps then, scholars should focus less on discussing amongst themselves how to address young carers’ mental health challenges and simply ask young carers directly about what they already do to navigate their mental health (Joseph et al., 2019).

In research conversations, some young carer participants talked about experiencing mental health challenges as a result of worrying about how other people might react or respond to their care partners. Maya, a young carer who supports her brother living with autism, talked about being over-protective because of a fear that people might not understand her brother like she does:

> *Me personally, sometimes I can be a bit too protective. Like this happens a lot when we go outside, like, he will be wandering off...But I think it's like my personal anxiety about him getting hurt or like somebody getting mad at him because like, you know, people might not be as understanding. People might not understand why he's touching their car or touching their purse. So, I always like try to keep him back and hold him. And I feel*

> *like, you know, that's just- it's a lot in my mind constantly watching him making sure he doesn't touch anything or do anything. But it's also like not great for him because he needs to, like have freedom. So that can be a challenge.*

Maya discussed that she experiences 'anxiety' and 'a lot in her mind' when she is supporting her brother. These feelings are not necessarily due to Maya's care role directly, but more so because she is worried about her brother's safety. Maya mentions that she has a 'personal anxiety' that 'somebody will get mad' at her brother because of misunderstanding his actions. In this way, Maya is concerned about the way other people might respond to her brother, which leads her to experience mental health challenges in her care role. Further, Maya feels guilty about 'being a bit too protective' of her brother since she suggested he also needs his 'freedom.' This adds another layer of challenges to Maya's experiences, since she feels her fear that other people will not respond kindly to her brother is pushing her to keep him from experiencing life.

Fear of stigma is consistently mentioned in the young caring literature, particularly in the lives of young carers who support a parent with mental health challenges (Gray et al., 2008; Gray & Robinson, 2009). According to Rose and Cohen (2010), stigma was often mentioned by young carers who support a parent with mental health challenges, alcohol or drug misuse, and/or learning difficulties. In the context of young carers who support siblings, there is much less attention brought to how stigma influences young carers' mental health. Although the young caring literature mentions stigma as an element that influences young carers (Frank et al., 2009; Gray & Robinson, 2009; Smyth et al., 2011), there is little literature that focuses on exploring the extent to which stigma causes and/or enhances young carers' mental health challenges. Of this literature, there is an underrepresentation of young carers' own voices and stories, resulting in simplified understandings of stigma and the role it may have in influencing young carers' mental health. Therefore, given that Maya's mental health challenges are exacerbated by her fear that other people may stigmatize her brother, I suggest that we need more research that both emphasizes young carers' own perspectives of stigma in their lives and brings attention to the complexities involved in young carers' mental health challenges, especially as they interact with stigma. Further, Maya's experience emphasises the relational nature of care, bringing attention to how experiences of one person influence the experiences of another. In this way, there is a crucial need for more relational understandings of young carers' lives and experiences, especially in relation to young carers' mental health challenges and how they interact with stigma.

Leisure as Relational Moments of Rejuvenation in Everyday Life

Our third theme encompasses young carers' representations of leisure as relational moments of rejuvenation in everyday life. Young carer participants described leisure in their lives as complex, malleable, relational, and context-dependent, and challenged simplified, contemporary conceptualizations of leisure in the lives of young people. Within this theme, there are two subthemes: The Entanglement of Leisure and Care and Resisting Youth Discourses Through Leisure.

The Entanglement of Leisure and Care.

In our research conversations, young carers described leisure and care synonymously in that they did not always exist in isolation from each other. Evelyn, a young carer who supports her brother living with autism, described leisure as spending time with her brother:

> *Sometimes my free time is just hanging out with [brother's name]. Because like, we'll do fun activities. Like over the summer, my parents like to take us out a little bit more just because like, I'm not in school, and we have that time. So, we were gonna do mini golfing on Saturday, but it was the end of March Break. So, we got there and there was a whole lot of kids. He's like, no, we're not doing that. So, we went to Walmart instead, and like, that was fun.*

In Evelyn's experience, leisure is not separated from her care role. Specifically, Evelyn mentioned that her leisure time is sometimes 'just hanging out with her brother.' In this context, Evelyn does not stop her care role to engage in leisure with her brother, but instead leisure and care are entangled together. Through her discussion of jumping from mini golfing to Walmart, Evelyn described leisure in her life as spontaneous and flexible, as it depended on how her care partner felt in that moment. Further, Evelyn mentioned that leisure in her life often takes the shape of fun activities with her brother, suggesting that the entanglement of leisure and care positively impacts her leisure experiences.

Evelyn suggested that she understands and experiences leisure through her relationship with her care partner. In this way, care becomes a mechanism for learning and development for both Evelyn and her care partner. For Evelyn, leisure is not necessarily defined by an activity or 'what' leisure might look like but rather, by the relationship or the 'who' leisure is experienced with. I could not find any literature that explores the relationality of leisure in the lives of young carers; however, Aitchison (2009), a critical disabilities scholar, emphasizes that young people with disabilities in her study demonstrated that "leisure was not defined so much by when they took part (leisure time), what they did (leisure activities) or where their leisure took place (leisure spaces), but by who they encountered and interacted with as part of their leisure" (p. 383). In this way. Aitchison suggests that leisure may be influenced by and contingent upon the extent to which meaningful social interaction is experienced. It is here that "the 'who' aspect of leisure is as significant as the 'when,' 'where,' 'what,' and 'how' or leisure" (p. 383). Given that young carer participants emphasized the relational nature of leisure, I suggest that more leisure research privilege the 'who' when exploring leisure in the lives of young carers. This includes finding a range of ways to connect young carers with others, such as through leisure-related technologies.

Literature that explores leisure in the lives of young people prioritizes conventional understandings of leisure as a non-obligatory activity, free-time, or a state of mind (Russel, 2013; Lopez et al., 2021). Amongst the two studies that explore leisure and play in the context of young carers, neither discuss the complexity of leisure in that it transcends boundaries of care in young carers' lived experiences. Lopez et al. (2021) introduces alternative conceptualizations of leisure as amorphous, "transcending segmentation and binaries of time, role, and place" (p. 4). Still, I could not find any literature that represents leisure as messy in the lives of young people and young carers. I view this as problematic since traditional representations of leisure in the lives of young people do not bring attention to the complexities that exist in leisure-care experiences. This is especially concerning for young carers like Evelyn, whose lived experiences of leisure-care are not represented or understood. Given that leisure professionals draw on contemporary conceptualizations of leisure, it is likely that young carers, who have the time and opportunity to participate in leisure services and programs, are learning about and trying to engage in leisure in a way that may not reflect their real lived experiences or meanings of leisure.

Maya, a young carer supporting her brother who lives with autism, talked about feeling emotions such as anxiety and guilt when she engages in leisure separate from her care role. Specifically, in a quote we featured in our creative expression piece, Maya expressed tensions in trying to engage in contemporary conceptualizations of leisure:

> *Um, I like, it's very limited to what I can do during the day, because I need to be home most of the time to help out. And it's just I feel like, I don't know if it's like separation anxiety. But if I'm like, sitting upstairs alone, while like, my family's awake downstairs, I'm always like, what if they need my help, or if I need to do something, like they're gonna call me down to help any minute. So, I kind of, it's like, anxiety and guilt for being alone during the day when other people could be using my help. Or like, I could be helping other people. But I feel like, like watching movies and TV shows and stuff, if I'm just sitting in the living room with everyone, I could do that. But things like going out a lot and things like that. I like- it's not that I can't, but I just get this like anxiety around and guilt around it for not being more present that it kind of just yeah.*

Maya discussed contemporary descriptions of leisure such as 'being alone' or 'going out a lot' as challenging to participate in. Specifically, she talked about experiencing separation anxiety and guilt when leisure time was separated from her care role. To mitigate the challenge of participating in binaries of leisure/care, Maya indicated that she could 'watch movies and TV shows and stuff in the living room with everyone.' In doing so, Maya suggested that her negative feelings of anxiety and guilt may be reduced if she was to participate in leisure and care synonymously. Although Maya would still be watching a movie or TV, she would be doing so with her family and care partner, causing her to feel more at ease than if they were separated. Maya and Evelyn's experiences of leisure and care speak to the need for alternative conceptualizations of leisure in the lives of young carers. Given her feelings of anxiety and guilt, when Maya experiences leisure in the way it is traditionally taken up in the literature, it may be harmful to her and exacerbate the challenges she may already experience in her care role.

Of the two studies that explore leisure in the lives of young carers, both suggest that young carers view leisure as obligation-free time and use it to distract themselves from challenges in their lives (Jonzon & Goodwin, 2012; Matzka & Nagl-Cupal, 2020); however, in Maya and Evelyn's experiences, leisure is heavily embedded in care roles, which may or may not be viewed as obligatory. It is here that more notions of leisure as messy, complex, and entangled within experiences of care are needed to better represent leisure in the lives of young carers.

Resisting Youth Discourses Through Leisure.

Young carers described leisure as being something that they liked to do for fun, to refresh, or both, depending on the context in which it was experienced. Through taking ownership over their meanings and experiences of leisure, young carers resisted dominant understandings about what leisure should look and feel like in the lives of young people and young carers. Rose, a young carer who supports her mom, described what she likes to do to refresh:

> *I think to refresh for me like I didn't think much of cleaning my room as something I do for me. Like mom would usually say [participant name] go clean your room. And it was*

> *like a chore. But I think I'm now grateful for the time I have to even clean my room. Some days. I'm so busy. I don't even have 20 minutes to clean my room.*

Rose described cleaning her room as 'something she now does for her.' What once was a 'chore,' has now become something that Rose is grateful to have the time to engage in. Although the activity of cleaning her room has not changed, Rose's context has changed, leading her to experience the activity in different ways. Largely missing from literature on leisure in the lives of young people, including young carers, is representations of leisure as defined by the situational context in which it is experienced rather than the activity itself (Dupuis, 2000; Dupuis & Smale, 2000). In Rose's experience, one of the ways she understands leisure is as something that helps her to refresh. As a result, when Rose was pushed to clean her room, she did not view it as refreshing; however, when cleaning her room became something that she actively chose to do, that is when she viewed the activity as refreshing. It is here that we used the image of a 'broom' in our creative expression piece to represent that leisure is defined by the context in which it is experienced rather than the activity itself.

Through her discussion of leisure, Alice brings further understanding to leisure as contextual and complex:

> *Yeah, if I am going to take on piano, for example if I had to bring something else in. Piano can be both a fun thing to do, like I can learn this new like song and its so fun, like I like this anime and I am going to learn the theme song- or it can be a refresher. Like, oh, I like playing the same songs. I'm gonna play it for a little bit. But it could also be like a stressor. So, like, do the repertoire and I like, I hate this so much. My moms like you need to practice this. It can be like all of that into one.*

Alice explained how the same activity can be ascribed to different meanings of leisure. Specifically, she talked about how piano can be both fun and refreshing, but also a stressor in different contexts. In this way, leisure in the lives of Rose and Alice is defined according to the situational context in which they experience it. Like Rose, Alice's interactions with the same activity are only defined as leisure when she has active control over her participation in that activity. In Alice's experience, piano becomes a stressor when her mom pushes her to practice the repertoire. In contexts where she is in control of how she experiences piano such as when she is learning a new anime song or playing what she wants to play, piano is considered fun and/or refreshing (e.g., Alice defines piano as leisure).

Literature that explores leisure in the lives of young people predominantly draws on developmental models to understand how young people experience leisure (Caldwell & Witt, 2011; Fredriksson et al., 2018). In this way, leisure is conceptualized by its role in transitioning young people towards adulthood in specific and preferred ways (Cassidy, 2005). Specifically, Cassidy (2005) suggests that "it is important to understand the patterns of child leisure behaviour which predict constructive leisure attitudes and engagement in adulthood" (p. 65). In this way, 'constructive leisure attitudes' such as resilience and competence, are encouraged through specific leisure-type activities in childhood as they are preferred in adulthood (Caldwell & Witt, 2011; Matzka & Nagl-Cupal, 2020). Lopez et al. (2021) suggests that leisure can be a vehicle for resistance. Through taking ownership over how they understand, take up, and experience leisure, young carers resist dominant assumptions that suggest young people do not have the capacity to make decisions about their own lives, including their leisure. In her discussion on leisure, Layla talked about navigating what leisure means to her:

> *I think it's kind of, okay. So, when it comes to specifically like, sewing, boxing, and squash, so, okay, so my old, my old main sport used to be tennis, because my parents loved it. And I was like, pushed into it. I hate tennis. I'm so bad at tennis. It was a, it was a shit show, let's be honest if I'm being honest, anyways. And then I got into squash and that was like, kind of my own thing. And I like I don't really, I think it was like a kind of a combo of the sport. And also like, just like, I got to do something that like was my own thing, if that makes sense.*

Layla discussed being 'pushed into' tennis because her parents love it. Although her parents consider tennis to be one of their preferred leisure activities, Layla mentioned that she 'hates it' and described herself as performing badly at it. She then transitions into participating in squash, an activity she chose for herself, and suggested that it was 'her own thing.' Through moving away from tennis and towards squash, Layla created a space where she could use her power to set boundaries on how she experienced leisure in her life. In Layla's situation, she did not consider tennis leisure since she did not actively choose to participate in it. Once Layla found a sport that was 'her own thing,' she ascribed meanings of leisure to it. Like Rose and Alice, Layla represents leisure as complex and defined in relation to the situational context in which it is experienced. Through taking control of their own meanings and experiences of leisure, Rose, Alice, and Layla challenge dominant conceptualizations of young people as lacking the ability to make decisions about their own leisure experiences (Ibrahim et al., 2014; Smith, 2015; Wright, 2020; Wyn, 2015). In choosing and defining leisure on their own terms, they not only challenge dominant conceptualizations of leisure, but also dominant discourses of what it means to be young.

Being Acknowledged as Relational Beings

Our final theme brings attention to supports that young carers' identified as being important to assisting them in their care roles. Within this theme, there are two subthemes: Having Relational Opportunities and Spaces and Raising Awareness and Being Recognized.

Having Relational Opportunities and Spaces.

In research conversations, young carers spoke about the value of relationships and being able to talk to others about themselves and their experiences. Specifically, Alice, a young carer who supports her brother, talked about the support that comes with having relationships with friends:

> *Hanging out with my friends just kind of grounds me a little bit it. Yeah, I think it allows me to be a bit more in the moment because like, oh, there is this group of people, and I just have to think about them right now. I don't have to think about schoolwork or this and that. It's like, I get to hang out with these people that I like. And it's yeah, it's refreshing. And I just get to hear what they're going through. And even if it's something that's stressing them, it's like a refresher for me, because like, oh, yeah, we're not like completely different. Like, it's not just me in this world kind of thing.*

Alice talked about how 'grounding' it is to be 'in the moment' with friends. She mentioned that, even when her friends are sharing their challenges with her, it is 'refreshing' because she can see how they are not 'completely different.' In this way, Alice identified developing and maintaining friendships as an important support, since it helped her to recognize that 'it's not just her in this world.' In addition to helping Alice feel refreshed, learning more about her friends encouraged her to challenge dominant conceptualizations of young people that perpetuate representations of childhood as a time free from challenge or hardship (Wihstutz, 2017). After 'hanging out' with her friends and 'hearing what they are going through,' Alice recognized that other young people also experience challenges in their lives, leading her to feel less alone in her experiences.

Like Alice, I have found immense support through the relationships I have with my friends. Given my care experiences, it took a while for me to feel comfortable enough to share the intimacies of my life with others. Although I spent most of my life thinking that there were very few young people with similar experiences to me, I have come to realize that almost all my friends are young carers in some way. It was only through developing relationships over a long period of time that I was able to come to this realization, since I did not often have a lot of opportunities where my care role would organically come up in conversation. In addition to not having many opportunities to bring up my care role, I was not aware of the term 'young carer' until well after my undergraduate studies. In this way, I can relate to young carer participants who discussed wanting more opportunities to connect with other young carers. Although young carer participants were connected with either the YCA or YCP, many of them expressed a desire for more opportunities to talk with young carers who have similar roles to them. Matthew, a young carer who supports his parent, said:

> *I think I need just clarity that there are people that are like- you know that there are people that are going through what I'm going through.*

Matthew's statement suggests that it helps him to know there are other people who are going through similar experiences to him. Therefore, Matthew indicated that he would feel supported through having more opportunities to talk to other young carers who 'are going through what he is going through.' Like Matthew's desire for more opportunities to talk with young carers, Alice, a young carer participant, described the feeling that comes with establishing valuable relationships with young carers:

> *But then you realize a lot of people out there who have similar situations, and who might even be going through like, other difficult things as well. So, it's easy to feel like you're alone. But I feel like, having other young carers around you, and hearing their stories, makes you feel like a lot more accepted, and less alone in your situation.*

Alice mentioned that having opportunities to have other young carers around helps her feel less isolated in her experiences. Specifically, she talked about how 'hearing young carers stories' makes her feel 'accepted,' as she is able to realize that there are 'a lot of people out there going through difficult things as well.' In this way, Alice suggested that having relationships with other young carers supports her through helping her feel less alone in her situation.

In addition to establishing relationships with young carers in general, young carer co-researchers discussed the potential of developing relationships with older young carers at the YCA and YCP. Specifically, one young carer co-researcher talked about her appreciation for having older young carers at the young carer organization she was a part of:

> *We had a summer camp program, I think when I was in grade nine, so I was like, still not worrying about this at all. But I was like, oh, what happened to so and so- I feel like she was here like every year, she was here all the time, whatever. Like, I actually was able to have people who are older than me in my program. So, when I was like, I think, like ten, they were like four years older than me. So, there were people- I didn't really talk to*

> *them that much, but they took care of you in your programs. And now I'm like, where are all these people, like I had so much fun talking to them, whatever. And then someone told me like, oh, you know, the age limit is like 18, right? Like, they're not here anymore and I was like, what?*

This young carer co-researcher mentioned that she had become familiar with some of the older young carers in her program. Although she stated that she 'didn't really talk to them that much,' she discussed missing their presence because when she did talk to them, it was 'so much fun.' Given this young carer co-researcher's disappointment when hearing that the older young carers who used to 'take care of her in her program' were gone, she suggested that she may have wanted more opportunities to establish relationships with older young carers in her program. Through vocalizing that she was 'actually able to have people who are older than her in her program,' this young carer co-researcher indicated that it is not very common to have relationships with older young carers at the young carer organization she is connected to. Similarly, Matthew, a young carer participant, spoke about feeling more comfortable in programs with older young carers compared to young carers that were closer in age to him:

> *I just find it a lot easier to talk to some older kids. Like I find it a lot easier to talk to, like, older kids than ten-year-olds and eight-year-olds.*

Matthew talked about being in programs where almost all the young carers were younger than him. Through mentioning that he finds it 'a lot easier to talk to some older kids,' Matthew suggested that he would value opportunities to speak with older young carers. It is through this desire to connect with older young carers that I wonder how mentorship relationships might introduce new possibilities for establishing connections between young carers. According to

Ellis et al. (2007), mentorship opportunities have the potential to provide reciprocal conditions such as nurturance, and shared knowledge, values, and culture; however, McNeven et al. (2020) states that relational quality is fundamental to ensuring these conditions are possible in mentorship relationships. Therefore, I turn to literature on relational theories and approaches to understanding and working with young people, to further understand the possibilities for relational mentorship opportunities in the lives of young carers.

Freeman and Garfat (2014) suggested that a "relational practice involves much more than just 'having a relationship'" (p. 14). Instead, a "relational practice shifts the focus from the actors engaged in some form of interaction to the *experience of interacting* regardless of the specific actors" (Gharabaghi, 2014, p. 8; emphasis added). From this relational approach to working with young people, Freeman and Garfat (2014) established a relational child and youth care approach that mobilizes 25 characteristics within three categories: being, interpreting, and doing. For the purposes of this discussion, I will focus on the category named 'being' which Fewster (2004) describes as:

> "Being in relationship means that we have what it takes to remain open and responsive in conditions where most mortals – and professionals – quickly distance themselves, become 'objective' and look for the external 'fix.'" (as cited in Freeman & Garfat, 2014, p. 18).

Freeman and Garfat (2014) suggested that 'being in relationship' means interacting with another person in an intimate and profound manner, which is often achieved through 'hanging out' and 'hanging in.' Hanging out refers to spending time doing things with people and hanging in refers to committing to hanging out even when times are tough. Hanging out, particularly, takes time due to the requirement of "investing in building relationships of trust, safety, connectedness, and professional intimacy" (p. 23).

It is through 'hanging out' that I suggest mentorship relationships may support young carers in their care roles. Specifically, our research provided us with a space to essentially 'hang out' over a long period of time. As a result, our team was able to establish the conditions necessary for 'being in relationship' with each other. Given that there were young carers of different ages on our team, our research provided a unique opportunity for mentorship relationships to flourish. For instance, multiple young carer co-researchers would come to Chelsea, Cayleigh, and/or I for support, advice, or just to talk about their experiences. In this way, the relationships that have developed within our research suggest that relational spaces have the potential to establish mentorship opportunities for young carers, which may support them in navigating their care roles.

Since young carers have unpredictable schedules, programming for young carers is not often provided as a series of small hangouts but instead as drop-in events or activities for larger groups (Stamatopolous, 2016; Young Caregivers Association, 2020). In this way, programming is less concerned with facilitating intimate, authentic relationships like Freeman and Garfat (2014) suggest but rather, is predominantly focused on supporting the perceived needs of young carers, including peer support groups, workshops for developing self-help tools, and activity-based life skills programming. When reflecting on her time at a young carer organization, Maya talked about how she enjoyed activity-based programming when she was younger:

> *But I feel like when you're young, that's like a really good place because I would just go, they would pick me up. I would go do some fun activities. Come back, it would be a great*

> *time. But yeah, I just- the things that I really liked about it was the interactive-ness. And the just like community, you kind of get out of it and just being able to like, have somewhere to go for something to do.*

Maya brought attention to the sense of 'community' that she felt when attending programs at the young carer organization she is connected to. Specifically, she talked about how the programs were very interactive and activity-based, allowing her to connect with others through engaging in fun activities. Maya talked about how the programs were a 'good place when you are young,' because they allowed for opportunities to interact with others through various activities.

Although programming at the YCA and YCP support many young carers, there may be additional ways to support young carers who are interested in developing relationships with others. While commenting on her experience with the young carer organization she is connected to, Alice discussed how she would prefer supports that are more relational instead of activity-based:

> *Yeah. And I think in young carers program I am in right now, they have a lot of fun activities, and like, kind of chill activities, but they aren't- up to my knowledge, as much like group talk, like, we all have this thing in common. So, let's talk about it. It's more like we all have this in common, let's do like fun things together. And I like the fun things together, but I would like to know about their situations as well, which would kind of help me. I think I enjoyed the fun activities a lot more when I was younger, I think those fun activities were geared towards younger ones. But now that I'm a bit older, I'd like a few more conversation type, go into depth about what we're going through kind of talks.*

In her reflection on the programming at the young carer organization she is connected to, Alice suggested that, as she had grown older, she has come to want to engage in 'more conversations' that go 'into depth' about her experiences. In this way, Alice brought attention to a need for programming that places authentic relationships at its center, in addition to activity-based programs.

Although programming at young carer organizations is making enormous strides in supporting young carers, young carer participants expressed continuing to feel uncomfortable talking about their experiences and reaching out for help. Maya, a young carer who supports her brother, said:

> *I think it's still pretty uncomfortable and like, to get you to- yeah, to get out of yourself to talk to somebody or admit that you might need help with something.*

Maya mentioned that she still feels uncomfortable talking to others about her care role and admitting that she may need support to do so. Although there are outlets at young carer organizations for Maya to express herself, the conditions necessary for 'being in relationships,' such as 'hanging out' and 'hanging in' are missing. Perhaps then, relational practices may provide young carer organizations with important insights in supporting relationships between young carers.

Raising Awareness and Being Recognized.

Young carer participants expressed that there needs to be greater awareness, recognition, and understanding of young carers and their care roles. Specifically, Layla talked about how she wished her friends had a better understanding of how her care role influences her:

> *Yeah, it's like I know, it looks like a bad day. But I think they just think like, oh, she didn't get enough sleep last night or something like that. Or like, oh, really, she over- like she might have like overslept this morning and had to get up really quickly. But it's like, kind of, I'm like, kind of trying to communicate with you that like, it's more than that. And like, I just wish they would like understand any of it.*

Layla talked about trying to communicate with her friends about how her care role has a direct influence on her day; however, her friends are not able to fully understand how her care role affects her. Similarly, Rose called for more awareness through expressing that she wanted her friends to understand her more:

> *I think it's just like, awareness. I think to be supportive just for people to know what I'm going through. And like just so I'm no-t because right now, I feel like when I go to school and talk to my friends, I'm like, hiding, I'm like living two lives. Because I have like life at school with my friends and then I have a life when I come home and I have my mom and none of them know about it. And I'm just like, if only you knew, but I just wish without me saying- going up to them saying here this is what I do, this is what I do, and listing all the things trying to make myself 'ound like, like I do a lot but just somehow for everyone to know, but I don't know how they would do that.*

Rose mentioned that she lives 'two different lives,' one at school and one at home. In our research conversation, she suggested that awareness may help support her in feeling like she can be herself completely at school with her friends. Both Layla and Rose discussed wanting their friends to understand their experiences more without them having to explain their experiences in too much detail. Another young carer participant, Alice, talked about how she would feel more supported if people knew more about young carers, especially in schools:

> *I think if young carers- just young carers as a whole, were more known about, like, when people think about disabilities, they think about all of the people who have disabilities, they're so affected by this, we should be more compassionate towards them. But no one really talks about people who are affected by them, like firsthand, siblings and their family members. And I don't think anyone really consciously thinks about that. But they're everywhere. And people don't know that they are one as well, they think like, oh, I have to do this and oh, well, it's okay. Stuff like that. I think if young carers, like, as a group, were more known as mental health is, I know, schools are trying to push towards mental health being like, a normal thing, like you should get help and stuff like that. Young carers should also be more known at least to schools- I think at the start, like, these students aren't lazy, like we have other things in their life to do. If they can't do this homework by this deadline, you shouldn't be so hard on them.*

Much of the young caring literature brings attention to awareness and recognition as an important step in supporting young carers (Aldridge, 2018; Stamatopolous, 2015; Stamatopolous, 2018); however, much of this literature draws on problematic assumptions about young people, including young carers. Alice calls for young carers 'as a whole to be more known about,' which suggests that awareness about the complexities involved in young carers' lived experiences is generally missing from society. This results in understandings of young carers that only take into consideration specific parts of a whole experience (O Dell et al., 2010). Wyn (2015), a CYS scholar, suggests that adult-centric spaces, such as schools, often take up assumptions that separate childhood from adulthood, which allow for the representation of young people as being without insight and agency (O' Dell et al., 2010; Smith, 2015). As Alice mentioned, teachers generally assume that young carers are 'lazy' when they cannot complete homework due to time spent in their care roles. In this way, Alice suggested that teachers 'shouldn't be so hard' on young carers because they have 'other things in their life to do.' Layla, Rose, and Alice described their experiences at school negatively, suggesting that they have to hide certain parts of their identity due to misunderstanding from friends and teachers.

Although the YCA has begun to integrate their powerhouse programming to support young carers in local schools (Young Caregivers Association, 2020), there are no policies that intentionally bring awareness to young carers within the broader Canadian education system (Aldridge, 2018). Given that most of the current young caring literature is grounded in problematic assumptions about young people, any new policies that are intended to support young carers in the education system may work to reinforce misunderstandings that in turn, maintain inaccessible spaces, opportunities, and resources (O' Dell et al., 2010; Wright, 2020; Wyn, 2015). CYS scholars suggest that when schools, which are intended for growth and exploration, draw on assumptions that make universal statements about the lives of young people, they become oppressive spaces (Carey et al., 2020; Wyn, 2015). Therefore, in addition to a call for greater awareness and recognition of young carers' care roles in schools, I suggest that we need more complex understandings of young peoples' lived experiences, including young carers. Given that young carers are experts on their own lives, having young carers be directly involved in describing their own experiences in awareness and recognition initiatives is vital.

UYCL Team Celebration Meeting

Our team came together on Thursday July 21st, 2022, to celebrate the wrapping up of our analysis phase and the completion of our decision-making and data collection phases. We used this meeting as an opportunity to check in with each other, discuss our collaborative creative expression and key themes, reflect on the research process, and loosely plan the resource we intend to create from the results of this research. In this meeting we also reflected on the transitional events that many of us had experienced throughout the year. For instance, Chloe, Emaan, and Saige graduated and are moving into their next year of high school. Bernadette graduated grade 12 and will be attending university soon, and I got engaged, soon to be married, and am moving from my hometown to a different city. Young carer co-researchers talked about wanting to continue to stay in touch beyond our research, specifically sharing pictures with each other of exciting events (e.g., co-researchers requested that I send the team a picture of my wedding dress and of the wedding). Although we still have plans to develop our resource in future meetings, I started to feel a little emotional in this meeting. It was in this meeting that I could really see the strong relationships that have developed over the last year between team members. Not only were research meetings a place to discuss our research, but a space to establish the trust and comfort needed to share stories with each other. Bernadette, one of our young carer co-researchers, described our team meetings:

> *I think that [the team meetings] always felt like a safe space to kind of share what we wanted to. And you've always made it a like no pressure kind of thing. And that really helped me to feel comfortable to open up and say stuff about my experience, even though I would think like, maybe I don't really want to share this because it feels private,*

> *but then I can- just the environment, like the atmosphere of the meetings like this is very inviting, to kind of say whatever you want to.*

Beyond providing a space to celebrate our accomplishments, our celebration team meeting motivated all co-researchers to speak openly and honestly about their experiences throughout the research process. Specifically, for the latter half of our meeting I prepared a list of questions that would encourage us to think about if and how I facilitated specific tenets of authenticity throughout the research process. The conversations co-researchers and I had about if and how I attended to authenticity within this research is the discussion I turn to next.

Attending to Authenticity

Given the importance of personal and social change to critical CPAR processes, Manning (1997) argues for the need to attend to authenticity. Specifically, Manning outlines that authenticity involves a specific set of criteria: fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity. Each of these criteria commits a researcher to a set of actions to maintain the integrity of the research. In the following paragraphs, I bring specific attention to co-researchers' perspectives as I discuss how I attended to authenticity throughout our research process. Co-researchers felt confident about their identities being connected to their statements regarding authenticity.

Fairness

Fairness refers to the balance of voices throughout the process. In this way, fairness asks: Who speaks? For whom? To whom? For what purpose? And how? To attend to fairness, I began by continuously attaining informal consent from co-researchers throughout the research process. Manning (1997) suggests that researchers have an obligation to invite co-researchers to express their desires about distribution restrictions, authorship, and the use of their words and experiences. To maintain informal consent, I made sure to communicate with co-researchers anytime their words or experiences were going to be used. During these conversations, co-researchers were continuously made aware that they owned their own words and could always decide whether they wanted them used in this research. Saige spoke about being informed throughout the process:

> *I think you made it very clear, like, and especially, to know what we were comfortable with, to each person about when our names would be used and even when our like- we say one word, when that word would be used. And like, I know, I feel comfortable with using it, but I know others don't, but you made it very like it's okay if you don't want this- like not pressured. Yeah, you didn't like pressure us which made it way easier.*

In addition, conversations about authorship were engaged in continuously throughout the process. Specifically, I consistently asked all co-researchers if they wanted to be identified as co-researchers in this research and any materials that came from it, with all co-researchers indicating an interest throughout the entirety of the research process. As a result, young carer co-researchers were aware that having their names attached to this research would identify them as young carers. Co-researchers were verbally made aware that they could participate during the research is any way that felt comfortable to them and that they did not have to identify as a co-researcher to participate in the research. In our celebration meeting, Chelsea with the YCP reflected on the different levels of participation and sharing that was present throughout our research process:

> *Yeah, I was just going to say I think you explained all the- I think you also gave options, so people didn't feel like either they had to participate or not. I think you did a really good job of explaining that and then also giving different options too for the level of participation or like the level of which they're sharing.*

Using a CPAR process, I intentionally worked hard to ensure that young carers voices were privileged in all phases of the research process. During the decision-making phase, that meant ensuring that young carer co-researchers were provided with a meeting outline a week or more in advance of our meetings. Providing the meeting outline prior to our meetings helped prepare young carer co-researchers for meeting topics and questions, encouraging them to feel confident in sharing their voices and perspectives in our meeting. Emaan talked about how she felt her voice was heard throughout the process:

> *Um, for me, I feel like my voice was definitely heard because I think through every step of the research, it was just, there was such an openness to, you know, hear us out on whatever we had to say. And I felt really involved because there were a lot of questions that we got to, you know, be involved with, as well throughout the entire process, we kind of embedded or input into every single part of the entire project, I guess.*

Along with preparing meeting outlines in advance, clarifying meanings, what others call member checking, was important throughout our process. Specifically, Manning (1997) suggests that member checking, or clarifying meanings, helps researchers represent perspectives in all their complexity, assures that the themes emerging throughout the project arise from participants and co-researchers, and that the researcher is clear on the meanings intended. In addition to checking in with my co-researchers often, I also debriefed regularly with my supervisor and colleagues, to ensure that I was doing as much as possible to prioritize co-researchers' voices throughout our research.

Throughout our collaborative analysis process, I worked hard to consistently involve co-researchers in the development of key themes. Saige spoke about her contributions to our collaborative creative expression:

> *I think, like, when I saw the creative piece, I was like, really happy, because I could like, point out what I did. And I felt really, like, proud, I guess.*

Bernadette also discussed our collaborative creative expression piece and how it reflected her own voice:

> *I felt like my voice was also heard through other people and their experiences. So yeah, and yeah, during the final piece, I could see like, all these different things that I was saying.*

Although each co-researcher had a role in establishing key themes during our collaborative analysis, I checked in with young carer co-researchers during our confirmation meeting and celebration meeting to ensure key themes were developed in collaboration with them.

In addition to attending to fairness during our collaborative analysis and the development of our key themes, it was important that I ensured a diversity of voices were represented in our discussion of the research findings. In this way, I tried to make sure that all participants had an opportunity to contribute to the story we were trying to tell. Recognizing my own role in this story, I also worked hard to integrate my own voice into our discussion without overpowering the voices of young carer participants.

To attend to fairness, Manning (1997) also brings attention to prolonged engagement, which is assessed by determining if the researcher has engaged with co-researchers for a sufficient among of time to build any understanding of their perspectives, stories, and lives. Our research team has been meeting for approximately one year, leading us to develop close relationships with each other. Our conversations in meetings often extended beyond research topics, allowing us to get to know each other in a more intimate way over a long period of time. I intentionally built time for reflection into our process in the form of check-ins at the beginning of every team meeting and team meetings specifically reserved for sharing stories. The time we had for reflection throughout the process helped me develop a greater understanding of co-researchers' lives as well as my own life as a young carer. In our celebration meeting, I asked the team: 'Do you feel that I have a good understanding of your experiences?' Saige said:

> *Um, I think, personally, for me, you did. And also, you made it, like, important not to learn about my experience, but like to make sure I was okay. Which made me like - I like eventually shared a lot with you.*

Emaan also discussed how she felt understood throughout the research process when she said:

> *Oh, me personally, I also feel like throughout the entire thing, whenever I talked about an experience, you did a really good job kind of like relating to it. When you feel like you relate to someone, it kind of helps you feel more understood. And you know, even if you didn't have similar experiences, I feel like you were very respectful throughout the whole thing. So, I just, it felt like a safe place to talk about my experiences, and I did feel understood.*

In addition to co-researchers feeling understood throughout the research process, Manning (1997) recommends that researchers engage in reflexivity, which includes being explicit about their own opinions, personal attributes, and values. To ensure that I facilitated reciprocity and trust throughout this project, I shared stories about myself as a young carer and researcher with co-researchers. For instance, Saige reflected on a time during the research process where we shared stories with each other:

> *I think I learned about you because you- not like asked about me but because I shared my experiences with you. In return, you shared some of yours back so we could like connect. I remember one like one call. We were just talking. And then I learned a lot about you but like, in a way because you connected it to my experience. So, it made me realize I guess we're not so different.*

Participating in safe conversations with co-researchers helped me share my opinions and perspectives openly and provided me with a way to maintain accountability throughout the process. I believe that if I am asking young carers to trust me with their stories, I should also be trusting them with mine.

Ontological Authenticity

Manning (1997) calls for ontological authencity, which asks if team members have grown because of the process. To attend to ontological authenticity, I prioritized dialogical conversations with co-researchers and participants, providing a space for reciprocal conversations and learning. Dialogical conversations require the researcher to relinquish control, realizing that co-researchers and participants are the experts on the topic of discussion. To do so, I actively listened to the voices of co-researchers and participants, recognizing that I held no prior knowledge of their stories and the meanings that would emerge from their stories. It is through facilitating open and honest conversations that Manning (1997) suggests co-researchers and participations have the space to create and discover new perspectives. This was the case for Chelsea from the YCP who spoke often throughout the research process about how her perspective of leisure had changed over time as a result of hearing about young carers' experiences of leisure in their lives:

> *Yeah, I think like even how like to look at like leisure as well. I think I've always seen it as something more like kind of scheduled or planned. And like, I think this really made me aware of just how like, random it can be. And then like how important it is to also like, emphasize the little, like five-minute breaks that happen during your day, that can just be like looking at your phone, and that's okay and that is leisure too.*

Dialogical conversations were also present in our narrative research conversations. Through our team's decision to structure the research conversations as informal, free-flowing, and reciprocal, I was able to reduce uneven power imbalances that often privilege researchers' perspectives over co-researchers' and participants'. Specifically, I worked hard to relinquish control during research conversations in hopes of encouraging participants to take conversations in the directions they wanted. At times, this required us to move away from the questions on our research conversation guide and towards conversations that participants felt were important to engage in. In this way, participating in the narrative research conversations allowed young carer participants to story their own experiences, transforming them personally and relationally as they reflected on their own lives and the lives of other young carers. Specifically, during the research conversations, multiple young carers mentioned thinking about an experience in their life differently. As previously mentioned, this may be because of the informal and unstructured design of the narrative research conversations, as they encouraged young carers to speak openly and safely about their experiences. For instance, when speaking about helping peers who live with a disability, Alice, one of our young carer participants, said:

> *But when I, when I do have a chance, I try to just provide support to them. Because I know, I didn't really think about it in this way. But now that I'm talking about it, I know if that was my brother, I would want someone to be there for him. So.*

Through having the space to speak about how her care role influences other domains of her life (e.g., peers at school), Alice reflected on how her actions are influenced by her care role in a way she had not thought of before.

Additionally, Evelyn, another one of our young carer participants, reflected on a time in their life where they navigated their mental health. Specifically, Evelyn said:

> *Because sometimes I get to school, and then to be like, you know what, I don't want to be here. So, I'd go to the office and be like, my stomach hurts and then go home as soon as I got off the bus. And like, in my mind, I'm like, no, I'm just being lazy,*
> *I don't want to be here. But looking back at that, I'm like, no, I really could not be there that day.*

In this research conversation, Evelyn had the opportunity to reflect on an experience in her life, changing her perspective of that experience. During research conversations with all participants, it was really important for me to create a space that encouraged young carers to share their stories freely and openly. Manning (1997) discusses a caring and trustful researcher/participant relationship, which comes from sufficient effort to establish a trusting relationship with respondents. Through sharing my own story with participants during research conversations, participants and co-researchers felt comfortable enough to discover a new perspective as they began to give their story a voice.

Educative Authenticity

Educative authenticity ponders if team members understandings of others' experiences have expanded. It addresses the question: "Did the experience of the research process broaden the respondent's understanding, not only of [themselves] (i.e., ontological authenticity), but of the expressed constructions of other participants?" (Manning, 1997, p. 108). Like ontological authenticity, prioritising dialogical conversations and facilitating caring and trustful relationships helped co-researchers expand understandings of themselves and deepen their understanding of other young carers. In our celebration meeting, Bernadette shared how participating in this research impacted her understanding of other young carers in a way that encouraged her to take on more responsibilities in her care role:

> *Doing this research helped me to see like all the other young carers and their different experiences. And I'm not my brother's primary caregiver, as I've said, and my mom is the one who takes care of him the most. So, it made me feel like I want to get more involved in caring for my brother in like the usual everyday things. And I know that I obviously have a lot more to do with my brother's condition than like, my friends who have like 'regular' siblings. But it makes me feel like, it kind of gives me more of a sense of responsibility, because it's really easy, when you don't know what everyone else is going through to kind of feel like, 'Oh, why is it me?' You know like 'why is my situation like*

> *this.' But seeing how other people also have similar experiences makes me feel like, kind of like I'm now more mature in that kind of sense.*

Through being directly involved in research conversations and in our data analysis process, co-researchers were able to hear and share stories with other young carers. As a result, co-researchers, especially young carer co-researchers, were able to expand understandings of themselves and young carer participants simultaneously. Emaan reflected on developing a new understanding of other young carers and, through that process of understanding, learning more about herself:

> *I feel like the experience really helped me understand other people's situations and kind of compare them to my own. And I really, like gained a new understanding of like, like how other people have their own struggles and how I have my own. And it was just really interesting to, you know, see how many people have similar and different experiences. And yeah, it's like made me more empathetic, and more understanding, and grateful. And also, like, I don't know what the opposite of grateful is, I don't know, it's just really been eye opening, I guess.*

Young carers rarely have opportunities to share stories with each other. Although the YCA and YCP facilitate activities where young carers can interact with each other, there are not many chances where young carers can establish the type of relationships necessary to feel comfortable sharing personal stories. Since our team had multiple team meetings, we had a unique opportunity to get to know each other quite well and learn about each other's care roles. When reflecting on what she learned during the research process, Saige mentioned learning more about who young carers may support in their lives:

> *Um, I know I learned, because I guess I tend to do this, like when it's my situation, I really think that's the only way it can be. So, for young carers, I only thought like about caring for a parent. Then I learned it can be like, literally anything and not just like someone with an illness, just a whole different variety of things. So, I've learned that.*

Manning (1997) mentions caring and trustful relationships in the authenticity criteria many times. Specifically, Manning suggests that establishing caring and trustful relationships requires a sufficient investment of effort and time. I tried to facilitate caring and trustful relationships throughout the research process through asking young carers about themselves at the beginning of every meeting. For instance, I would ask co-researchers: How are you today? How has your week been? Do you have any special plans for the weekend? Are you looking forward to winter/summer break? What are your plans for your break? I would also share new and fun facts about myself such as stories about movies or TV shows I had recently watched to help spark conversations where co-researchers could get to know each other more informally. During a team discussion about understanding the diverse experiences of young carers, Emaan reflected on understanding the collective experience of being a young carer:

> *I also just wanted to add that I think I've kind of understood that, even though we do have different experiences, we all have these kind of collective emotions that not a lot of others do. It's like things that I guess, not only but mostly young caregivers experience, like guilt and anxieties that others wouldn't understand. But even though young carers have different experiences, we all kind of have those like same understandings of those certain emotions.*

Through providing a space for mutual trust and understanding over a long period of time, this research provided young carer co-researchers with the opportunity to learn and relate to each other in a more intimate way, which helped expand their understandings of the young care experience beyond their own individual experiences.

Catalytic Authenticity

Catalytic authenticity asks if the insights and interpretations of data facilitate and stimulate action. Working with my partners, we plan to develop an engaging and accessible way to share our findings, so they inspire changes in others. Specifically, we intend to create a resource from our collaborative creative expression and the key themes within it. We hope that this resource will challenge dominant discourses of young carers and young people, bringing awareness to young carers unique experiences and the different ways to better support them in their care roles, including in their leisure. Within our team, we have had various conversations about who we wanted to share our resource with. During one of these discussions, Saige suggested: *"I think any audience because the more the better"* which aligned well with Manning's (1997) recommendation for the research findings and product to be widely accessible. To add to Saige's suggestion, Bernadette spoke about who she felt the resource would apply to:

> *Yeah, I feel the same way. I also think it should, I think, just with exposure, I guess, like more people should know. I think it should be- my first thought was like, it should be like general public, like we need more people to know about this, but also people who it would apply to, like young carers or like a relative of young carers so that we can get young carers who might not know we exist, to kind of feel the same sort of calmness and*

> *community that we feel knowing there are young carers, so I think, both like people who aren't young carers and who are young carers.*

Although our plans for our collaborative resource are still in the making, our team decided that one of our main priorities with our resource is to spread awareness about young carers to young carers. We have established that becoming part of a community of young carers is very powerful. Young carer co-researchers were especially adamant that our resource show young carers that they are not alone in their care roles. As Saige mentioned to me in our celebration meeting: "Because look what happened once you figured out that you were a young carer. Look where we got to."

Tactical Authenticity

Tactical authenticity asks whether the team members were empowered to act on findings. I attended to this criterion through careful negotiation of the research data and outcomes, and upholding confidentiality. Specifically, Manning (1997) states that I must be fully aware that co-researchers' and participants' meanings are not mine for the taking. Not only do I need to be aware that co-researchers and participants have complete ownership over their data and the meanings they attribute to them, but co-researchers and participants also need to be aware of this. Taking guidance from Manning (1997), I ensured that co-researchers and participants were made aware of our negotiations regarding data use, interpretations, confidentiality, and cooperation through providing them with formal consent forms and continuously obtaining their informal consent throughout the research process. To guarantee that I was clear with co-researchers about confidentiality and the use of their data and meanings, I asked co-researchers: “Have discussions throughout the research explained that the data about you ultimately and always belongs to you?” Emaan responded by saying:

> *I feel like yeah, because a lot of the times we were really like um reminded that you only have to say what you want to say and it’s all up to you about how much you want to share and how much you don’t want to share. And I think we’ve been reminded a lot that we do have a substantial role in the project, I guess. And that yeah, that the things that we say are not like, I guess traced back to us, kind of. Yeah, I feel like we definitely have been taught that what we say is like, I guess I don’t really know the word but our words, I guess.*

Manning (1997) mentions that the research process meets the standards of tactical authenticity when co-researchers understand themselves as knowing subjects with the power to transform their world. When speaking with our team about transforming how organizations work with young carers, Chelsea from the YCP said:

> *I guess I can share specifically that I already told, like in a meeting, everybody about the creative pieces [laughs]. Yeah, I’ve definitely felt like a co-researcher and like echoing what we said before- I really want to share everything we learned and share specifically, I think about the- this process specifically, as well as the results like how well this can work, and what happens and what you can create when you include, like the voices of young carers as well and have like a full team like this.*

Cayleigh from the YCA added to Chelsea’s comment by sharing that she taught her colleagues about this research at a board meeting:

> *I agree too. I, even in the beginning, I think it was maybe like, four- three or four months ago, I was to go to a board meeting and talk about research and I think I had like 15 minutes, and I probably talked about this one for like, eight [laughs]. I was like, this one was just a really cool opportunity and like it gives, like our young caregivers, like a chance to grow and learn and like it's just like a really unique way to kind of do things. And it was- my purpose was to show like the different types of research that we were doing. But I found that this one was the one that I was most passionate about and being like, "we're like fully integrated into the team and like, our kids get to be a part of it and it's not just like kind of static, it's like ongoing and a creative process, which is very different and unique." So, I feel like yeah, like our board of directors are well aware of our research [laughs].*

In addition to changing how organizations view and do research with young carers, co-researchers talked about wanting to continue conversations about this research with others. While talking about how she wanted to act on this research, Bernadette talked about tailoring her post-secondary courses to topics related to our research:

> *I really like this project. And I'm going to university next year, and I was kind of like, looking over the different programs and like the hundreds of different programs and like classes they offer is so overwhelming. And I was like looking at the minors and stuff. And I was like considering taking up like, I forget what it's called, but it was a disability course. And I was thinking of taking some classes on like, disability, or at least psychology classes because of this like, project was so interesting to me.*

In our celebration meeting, co-researchers expressed that they were all very passionate about this research. Since our research centered around topics that were very intimately meaningful to all of us, the process was very special. As our celebration meeting came to a close, young carer co-researchers expressed how grateful they were to be partners in this research and made it clear that we would all make an effort to stay in touch beyond the completion of our resource and use our findings to make changes for the better for young carers.

Chapter Five: A Starting Point for Expanding Supports and Understandings of Young Carers

In this chapter I provide a discussion on implications of doing CPAR as it relates to theory, methodology, and practice.

Theoretical and Conceptual Implications of our UYCL Project

In chapter two of this thesis, I explored representations of young carers and their leisure in the existing young caring literature. In doing so, I found that diverse understandings of young carers and their leisure are generally lacking in the young caring literature. Very few studies emphasize the voices and perspectives of young carers and I could find only two studies that explore leisure in the lives of young carers. It is here that I discuss how our CPAR process and collaborative findings contribute alternative conceptualizations of young carers and their leisure to the young caring literature.

Looking back on the young caring literature, it was evident to me that young caring is predominately represented using a deficit-based approach. Specifically, literature primarily emphasizes the challenges and consequences of caring at a young age, compared to the rewards or complexities of the role. Through over-representing challenges and consequences, the young caring literature depicts young caring as unnatural and outside the range of experiences acceptable in childhood (Wihstutz, 2017). For instance, Aldridge and Becker (1993) depict young carers' care roles as disrupting the 'normal' process of transitioning into adulthood. This view has spawned a rationale for terms like 'parentification' (Borchet et al., 2021; Boumans & Dorant, 2018; Charles et al., 2009; Chojnacka & Iwanski, 2021; Frederick et al., 2020; Hendricks et al., 2021), which perpetuate the perspective that caring in childhood is abnormal and dangerous (Chojnacka & Iwanski, 2021; Earley & Cushway, 2002; Frederick et al., 2020; Hendricks et al., 2021; Kavanaugh & Stamatopoulos, 2021; Parys et al., 2014). Through promoting the adoption of a risk-oriented approach to understanding young caring, most of the existing young caring literature underestimates young peoples' abilities and simplifies the young caring experience (Heyman & Heyman, 2013). Findings from our project normalise young caring as instinctive and represent caring as natural – part of being human – in the lives of young carers. Our collaborative expression piece intentionally represents caring as a natural phenomenon, challenging discourses that young people should not care for others. While depicting young caring as natural and instinctual, our research suggests that young caring is widespread, often influencing young carers' broader social circles and the ways they care for others in their lives. Specifically, young carers mentioned that their care roles helped them recognize and understand that young people have diverse experiences. In doing so, young carers felt prepared and encouraged to support people in their unique situations. In this way, our research provides an alternative conceptualization of young caring as a natural process both within and beyond care roles. Through taking guidance from young carers' own voices and perspectives, our project critiques dominant narratives that misunderstand, downplay, and reject the normalisation of care in the lives of young carers. Our findings do not intend to disregard the challenges that young carers experience in their care roles but rather, shed light on the complexities involved in young caring to break down restrictive frameworks that dictate what experiences are appropriate, or not, during childhood.

In addition to normalizing caring in the lives of young carers, our findings emphasize the tensions that young carers navigate in their care roles. Particularly, through prioritizing young carer's own voices and perspectives, our research challenges dominant representations of young people as ‘dependent’ and without agency or insight (Wyn, 2015). Stemming from the perception that there are preferred ways of experiencing childhood, the young caring literature describes young carers as being ‘in need of protection’ (Ibrahim et al., 2014) and ‘children-first’ (O’ Dell et al., 2010; Rose & Cohen, 2010; Smith, 2015; Smyth et al., 2011; Wyn, 2015). As a result, young carers are often described in comparison to their non-caring counterparts. Words such as resilience, maturity, and adversity are frequently used in the young caring literature to represent the benefits of caring at a young age (Banks et al., 2002; Fives et al., 2013; Matzka & Nagl-Cupal, 2020; McDougall et al., 2018; Rose & Cohen, 2010). I would like to note that many young carers do experience responsibilities in their roles that facilitate resilience, maturity, and adversity; however, when these concepts are consistently used to describe young carers, they reproduce singular understandings of young people and young carers. Specifically, in the young caring literature, young carers are often described as being more mature because of their care roles (Banks et al., 2002; Fives et al., 2013; Nagl-Cupal et al., 2014; McDonald et al., 2009). This phrase is so common when describing young carers that I have caught myself using it to describe my own care experiences multiple times. Our findings suggest that consistently describing young carers as ‘more mature’ positions them in opposition to taken-for-granted assumptions about the competence of young people. Although young carers take up significant responsibilities in their care roles that result in a variety of valuable skills, our research represents the concept of maturity as problematic, since it draws on assumptions that young people are generally not mature (O’ Dell et al., 2010). Our project and findings challenge these assumptions through recognizing and appreciating that young people, including young carers are experts on their own lives and possess the power and agency to make decisions about their lives.

Literature on leisure in the lives of young carers is severely lacking. With only two studies that explore experiences of leisure and play among young carers (Jonzon & Goodwin, 2012; Matzka and Nagl-Cupal, 2020), our research provides necessary insight into the ways leisure is understood and taken up in young carers' lives. In the context of leisure in the lives of young carers and young people, literature draws on developmental models of growth, representing leisure as a non-obligatory activity, free time, or state of mind (Russel, 2013). Our findings suggest that these representations may not accommodate all young carers' experiences and meanings of leisure.

Our project and findings represent leisure as relational moments of rejuvenation in everyday life. In doing so, we describe leisure in the lives of young carers as messy, relational, and influenced by the context in which they experience it. Young carers in our research ascribed words such as fun and refresh to their meanings of leisure; however, young carers mentioned that what they liked to do for fun or refresh depended on how they felt in that moment and given their time constraints, was very valuable to them. Additionally, our findings suggest that when traditional leisure-type activities are chosen *for* young carers instead of *by* them, those experiences are described as being harmful. Specifically, young carers described the same activity as being fun and refreshing when they chose how to engage in it, but also as stressful in situations when the activity was forced on them. Most of the young caring literature draws on developmental approaches to understanding young people and leisure (Caldwell & Witt, 2011; Fredriksson et al., 2018; O'Dell et al., 2010), which over-simplifies young carers' leisure experiences. Through bringing attention to leisure as defined by the situational context in which it is experienced rather than the activity itself, our findings contribute to the lack of young caring literature that explores leisure as messy and contextual.

In her study with adult carers, Dupuis (2000) suggests that "the qualities and characteristics of a specific context as a whole influence individuals' perceptions of that context as leisure" (p. 260). Our findings suggest that young carers experience leisure in activities beyond traditional leisure-type activities, such as cleaning and within caring itself. Specifically, within the two studies that focus on leisure and play in the lives of young carers, neither explore the entanglement of leisure and care. Our findings suggest that young carers' care roles are often entangled with their leisure experiences. Particularly, young carers in our research described leisure as time with their care partners. In situations where young carers had to participate in traditional leisure-type activities without care partners, they experienced feelings such as anxiety and guilt. As a result, our findings bring attention to representations of leisure and care as synonymous. Although there are no studies in the young caring literature that explore the relationship between leisure and care, Weinblatt and Navon (1995) found that some adult carers perceived leisure as threatening to their health and well-being. Our findings suggest that young carers experience similar feelings of anxiety and guilt compared to adult carers when they are only supported in experiencing leisure separate from their care partner(s). As a result, our research calls for more scholars in the young caring literature to explore diverse understandings of leisure in the lives of young carers and subsequently, how to better support experiences where leisure and care are entangled. This may require thinking about how to support family leisure experiences that include the young carer and the family member they support.

The young caring literature has begun to move away from prioritizing supports aimed at intervening or preventing young carers from taking on care roles; however, much of the literature that discusses supporting young carers does not include the voices and perspectives of young carers. In response to this, Joseph at al. (2019) critiques the young caring literature for making claims about young carers' perceived needs instead of directly involving them in exploring how they can be better supported in their care roles. As a result of growing research that recommends assistance and mitigation-based supports for young carers, organizations such as the YCA and YCP have made significant strides in developing programs "aimed at assisting youth in their care roles (via counselling, information on other services or self-help techniques and access to peer support groups) and/or mitigating some of the negative consequences experienced (via respite-based services, educational assistance and training and employment assistance)" (Stamatopoulos, 2016, p. 190). Although many young carers suggest that they receive significant support from these programs, I believe it is problematic that young carers' voices are predominantly missing from conversations and decisions about their own lives. In this way, our research upholds young carers' own perspectives about the supports that they feel would assist them in their care roles. Through doing research in partnership with young carers and recognizing the valuable insights they have into their own lived experiences, our team suggests actively involving young carers in future research that explores how to better support them in their care roles.

Methodological Implications and Considerations

Reflections on an Authentic Partnership Approach

In all the young caring literature, our research is the first to draw on an authentic partnership approach when doing research in partnership with young carers. Through making decisions *with* young carers and not *for* them (Dupuis et al., 2012b), our research brings attention to the value of young carers' own knowledge and life experiences. The authentic partnership approach provided our team with a moral compass which we used to establish deep connections with each other throughout the CPAR process. To establish and maintain meaningful relationships, we positioned a 'genuine regard for self and others' (Dupuis et al., 2012b, p. 436) at the center of our process. This meant taking time throughout our process to tell stories that were not always related to research-level decisions. As a new CPAR researcher, I was challenged in being open to the ambiguity and 'messiness' of participatory processes. To 'focus on the process' and uphold a 'genuine regard for self and others' (Dupuis et al., 2012b, p. 436), it was important that co-researchers and I trust the process and where it would naturally take us. Oftentimes it was very challenging for me to shed concerns about meeting specific outcomes in our research; however, it was only through prioritizing time to value and learn from co-researchers that I was able to navigate my own agendas in a way that maintained an environment of trust and respect. Much of our challenge as a team was navigating deeply rooted assumptions about the lives of young people and the ways leisure should be experienced in childhood. In this way, an authentic partnership approach ultimately provided us with the foundation to creatively interpret young carers' meanings and experiences, which we were able to reflect in our collaborative expression piece and hope to reflect in our future resource.

Challenges In and Implications of Doing CPAR with Young Carers

After being introduced to participatory research, I quickly started to outline the intentions I had for our PAR project. I planned to follow the seven features of PAR that I previously outlined by Kemmis and McTaggart (2005) and looked forward to collaborating with staff from young carer organizations and young carers themselves as partners in the research process. As a young carer myself, I was very excited to share stories with other young carers as I had never had the opportunity to do so. Although I passionately prepared for this research, the explorative journey was not without its challenges and considerations. Especially through doing CPAR entirely virtually, our process required careful navigation of barriers, and my own personal and professional reflections. Although this thesis may present itself as a clean, stage-like process, it almost always unfolded in a messy and complex way. Therefore, to bring attention to the complexities involved in our CPAR process, I reflect on challenges related to the overall process, in facilitation and in navigating disengagement, ending on considerations for future research with young carers.

Participatory Process Challenges.

Doing participatory research for the first time in a Master's program was not easy. I was fortunate enough to learn about the challenges of PAR during coursework and from my supervisor and colleagues who are well experienced in doing PAR. Although I felt prepared to jump into participatory research, I quickly learned that every detail of CPAR cannot and should not be planned out. It was important for me to come to team meetings prepared with our meeting outlines of course, but I never would have been able to anticipate exactly how our process would play out.

The phrase, ‘trust in the process’ led me to engage in deep reflection often. As it turned out, I found it quite difficult to embrace the ambiguity of our CPAR process when I had specific deadlines to make as a Master’s student. Specifically, throughout our entire CPAR process, I had to work hard to navigate partnerships in a way that accounted for the tenets of CPAR and my own timelines. Oftentimes, navigating partnerships in a way that prioritized both myself and others, required trusting that our process and our team would get our CPAR project where it needed to go. For instance, there were multiple times when one team meeting would not accommodate all the changing schedules of co-researchers. Given my experience as a young carer, I could recognize that time is very valuable in the lives of young carers. In this way, it was essential that I let go of the idea that we had to meet as a full team in every meeting. If I had proceeded with our original meeting times instead of being flexible, I would have restricted opportunities for all co-researchers to share their voices and perspectives, which is one of the important features of PAR.

Navigating partnerships also required that I support young carers in being as involved in our CPAR process as they wanted to be. In this way, different co-researchers were more involved at different times throughout the process. To ensure participation could exist on a continuum, it was important for me to regularly check in with co-researchers to determine if they were comfortable with their role in the process at that moment, and support changes where necessary. For instance, one of our young carer co-researchers decided to take a lesser role during data collection and analysis to prioritize herself and her care role. Conversations about participation were ongoing and constantly negotiated within our team.

Facilitation Challenges.

Facilitating a CPAR process is challenging, but doing it online comes with even more barriers and challenges. There is a certain feeling of community when people come together in person to share in a collective experience. Although I have never met any of our co-researchers in person, I felt an enormous sense of community through meeting with the same people for over a year. Navigating CPAR in an online environment proves that not only CPAR with young carers is possible, but CPAR online with young carers is also possible.

Throughout our CPAR process, I had to learn how to facilitate an online environment where young people felt welcomed and safe. Although young people can contribute to research in the same meaningful way as adults, they are often left out of decision making, especially in a research context (Joseph et al., 2019). Therefore, it was my responsibility to ensure that there was a balance of voices throughout our CPAR process. This meant that Cayleigh, Chelsea, and I needed to be mindful that we did take away or impede on young carer co-researchers' opportunities to share their voices and perspectives with us. Within our process, it was important that we establish an understanding of young carers' experiences through getting to know them better. Young carer co-researchers specifically wanted time built into our process to talk about their lives in ways that were not always connected to research topics. This encouraged all co-researchers to be open to learning and sharing which in turn, led us to better understand and support each other as partners in the process.

Challenges in Disengagement.

As our CPAR process started to end, I realized that I had not really considered what would happen when our UYCL project was over. I had been so involved in moving through the process and in supporting co-researchers, that I hadn't truly considered how relationships within our team would continue (or not). Although our time together is not yet over, our celebration meeting held bitter-sweet moments that jolted me into considering what would happen to our UYCL team as we came to the end of my thesis. Since most co-researchers on our team are young carers, including myself, our research created a rare space where we could come together to share stories about a collective experience. For me, this project was a personal exploration of my own experiences as a young carer, which led me to reflect on and challenge assumptions about my life and the lives of other young carers. In our celebration meeting, young carer co-researchers talked about how special our project was as it provided an opportunity for them to realize the similarities and differences between themselves and other young carers. Since very few people are aware of young carers' experiences, there are not a lot of opportunities or spaces to establish relationships with young carers. This made our research special since it provided us with an opportunity and space to create important friendships with each other. Young carer co-researchers expressed that they wanted to stay in touch with our team beyond the completion of my thesis and our collaborative resource. Knowing that co-researchers want to continue the relationships our team worked hard to build and maintain makes disengagement much easier for me.

Considerations for Future PAR Research with Young Carers

CPAR with young carers is extremely rewarding. Each member of our team adds unique and valuable insight to understanding the lived experiences of young carers. As a researcher who was drawn to CPAR, I had never really considered how critical participatory action research might look to researchers who drew on more traditional methodologies and ways of exploring phenomena. In this way, I realized that it was difficult for me to see both the strengths and challenges of participatory research from co-researchers' perspectives early in the process. I predominantly viewed CPAR for its strengths and in retrospect, communicating with co-researchers more about what challenges might arise in participatory research would have been very useful for a new CPAR researcher such as myself. Cayleigh, one of our co-researchers with the YCA, shared her newfound perspective on doing participatory research with young carers:

> *I would say it's helped me grow to see kind of the potential of what a team like this can look like. And also, like how to be more creative with research and not so kind of traditional, and kind of seeing the value in having multiple voices. And that it's not like too many cooks in the kitchen and actually really adds a lot of value through unique perspectives, but still creates that kind of common ground that we all can kind of connect in, in a very unique way.*

Hearing Cayleigh reflect on the value of doing CPAR was powerful. As I previously mentioned, there is no young caring literature that draws on participatory approaches to understanding young carers, despite a call for it (Joseph et al., 2019). Our research suggests that working *with* young carers instead of *for* them yields important insight into the experiences of young carers. Since our project upholds that young carers are experts on their own lives and should be involved in the decisions that influence them, I believe that it is crucial for more research to be conducted in partnership with young carers.

To support future research that intends to partner with young carers, I provide the following additional recommendations:

1. Be prepared. Provide clear (but flexible) agendas to all partners with enough time to review those resources before meetings.
2. Make sure to clarify with partners often about the level of participation they would like to commit to at various times in the process. Not every partner will be able to commit to the same level of participation.
3. Be flexible in terms of how meetings are structured. Sometimes not all team members may be able to attend the same meeting. Therefore, having multiple options for meeting times will support co-researchers in having the opportunity to contribute. Ask and explore with team members what will support them in actively contributing throughout the process.
4. Don’t be afraid to engage co-researchers in the facilitation of research conversations. Not only does this often help establish an informal environment where participants are more comfortable speaking openly but engaging co-researchers in research conversations also helps them to be more engaged with participants’ meanings and experiences.
5. Although many PAR projects involve partners in decision-making, there are few that actively engage participants in the analysis process. CCHA provided a creative collaborative process that supported co-researchers in contributing to the analysis

process. The use of the creative expressions was particularly powerful in opening up dialogue around the stories shared by participants.

6. Intentionally plan time for reflection into the process, creating a safe space for partners to honestly and openly talk about their experiences and provide suggestions for changes to the process.

Practical Policy and Practice Implications of our UYCL Project

In the young caring literature, young carers and their leisure are represented in ways that do not take into consideration their real lived experiences and contexts. Through partnering with young carers in this research, we determined that problematic assumptions about young people and leisure inform most of the young caring literature. Since these assumptions are embedded so deeply in society's understanding of young people, our team was not surprised to see negative constructions of young carers as different, problematic (Aldridge and Becker, 1993), and in need of protection (Ibrahim et al., 2014; Quijada Cerecer et al., 2013). Young carers in our research challenge this dominant understanding of young caring as producing a loss of opportunity to be a 'normal' child (O' Dell et al., 2010; Rose & Cohen, 2010; Smith, 2015; Smyth et al., 2011; Wyn, 2015) when they represent young caring as natural, instinctive, and an important part of their daily interactions within their broader social circles.

O' Dell et al. (2010) demonstrated that when policies and practices draw on normative understandings of young carers, they promote the idea that the life of a 'normal' young person is free from disability and any form of difficulty. This representation of young people simply does not reflect the lived experiences of young carers and reproduces dominant discourses that compare young people with different experiences, "holding up one version against which all whom are different fail" (O' Dell, 2010, p. 653). Our research brings attention to the messiness and complexities in young carers lives, challenging dominant discourses that simplify all young peoples' lives and experiences. Rather than compare young carers to idealized norms, I suggest that policymakers and practitioners acknowledge the diversity and complexities that exist within young peoples' lives and support them for the differences that they so readily want to embrace.

Our research brings attention to the supports that young carers' feel would help them better navigate their care roles. Both young carer co-researchers and young carer participants in this project brought attention to the importance of relationships in their lives. Opportunities and spaces for young carers to learn and share stories are widely unavailable and inaccessible. Our research is unique, as it provided young carers with a space to come together and critically examine their situations to change them for the better. As our UYCL project and findings suggest, young carers are experts on their own lives and have important insights to share. Therefore, we urge policymakers and practitioners to involve young carers in the decisions that influence their lives. Besides the YCA, who has implemented a youth advisory council to include the voices and perspectives of young carers in decision making, few organizations that provide supports and services to young carers have addressed this call. In part, this is due to a lack of funding and resources available to organizations, which aid them in creating opportunities for young carers to be actively involved in decision-making. Currently, the YCA is the only young carer organization in Canada with the funding and resources to develop initiatives that actively include young carers in decisions about their lives and experiences.

Beyond including the voices and perspectives of young carers, our research suggests that relational practices are central to understanding the complexities involved in the young caring experience. As mentioned in our discussion, Fewster (2004) suggests that professionals quickly distance themselves, become ‘objective’ and look for the external ‘fix’, when young people expose the challenges and complexities in their lives. In this way, our research suggests that relationships be at the heart of young carer supports and services, as they provide young carers with acceptance, understanding, and a space to embrace their differences.

In research conversations and conversations within our process, young carers brought attention to a specific type of relationship that was missing from the services available to them: mentorship relationships. In addition to wanting a safe and trustworthy space to share their stories meaningfully with others, young carers talked about the benefits of having someone guide them through all the complexities of the young caring experience. When discussing youth mentorships, Lester et al. (2018) states that “the presence of an older mentor who has ‘been there’ and can both emphasize and normalize [youths’] experiences is vital” (p. 158). Like an authentic partnership approach which provided our research with a foundation for the establishment of meaningful relationships (Dupuis et al., 2012a), mentorship relationships foster empathy and authenticity through drawing on relational processes that build closeness among young people (Lester et al., 2018). Given that our research represents young caring as relational and extending beyond young carers’ immediate social circles, our research suggests that mentorship relationships should also transcend the young person-mentor dyad to include multiple relations between young person, mentor, parent/guardian, and the wider context of the community or program (Smith et al., 2016). Despite connections to young carer organizations, our findings suggest that many young carers feel uncomfortable sharing stories about their care experiences with others and reaching out for help when they most need it. It is here that our research recognizes the important role that mentorship relationships may have in the lives of young carers through establishing opportunities for young carers to connect with each other authentically and meaningfully.

In our research, young carers called for more recognition and awareness of the complexities involved in their care roles, including in their leisure. Specifically, young carers mentioned schools as a primary location where they wanted better recognition of their care roles. CYS scholars mention that schools often take up assumptions that mark the "child as being separate from the adult world (society), who in early childhood does not have the cognitive capacity or lived experiences to make rational and reasonable decisions about what is or could happen to them" (Wyn, 2015, p. 22; see also: Ibrahim et al., 2014; Quijada Cerecer et al., 2013). Since young carers transcend taken-for-granted assumptions about young people (O' Dell et al., 2010), schools have the potential to become oppressive spaces that silence young carers' voices and perspectives. In this way, our research suggests that schools develop awareness campaigns that bring attention to the lives of young carers. In keeping with our perspective that young people are experts on their own lives, our team recommends that schools actively involve young carers in these awareness campaigns, to ensure that young carers' lived experiences are represented in complex and diverse ways. In our analysis conversations, co-researchers suggested that schools integrate awareness campaigns into their curriculum that normalise caring at a young age. Perhaps then, through normalising young caring, young carers may feel more comfortable sharing their stories with others and advocating on behalf of themselves about the ways to better support them in their care roles.

In addition to awareness campaigns, our research brings attention to the need for leisure programming that supports different meanings and experiences of leisure. In our project, we found that leisure in the lives of young carers is often messy and complex. For instance, young carers described leisure as being dependent on the context in which they experienced it rather than the activity itself. Oftentimes, young carers prioritized the 'who' of leisure, rather than the 'what.' In this way, young carers discussed meanings of leisure that were entangled with experiences of care; young carers suggested that they experienced leisure by simply just being in the presence of their care partner(s). Therefore, our research recommends that leisure programming at schools support young people, including young carers, in leisure experiences that speak to their own meanings and experiences of leisure. To do so, it is imperative that adult staff in schools (teachers, counselors, principals, etc.) actively involve young carers in influencing decisions about their own leisure experiences. Further, our findings call for young carer organizations to represent leisure in the lives of young carers as contextual and complex. Through drawing on young carers own voices and knowledge about their meanings and experiences of leisure, our team suggests that young carer organizations support young carers in experiencing leisure as it is entangled with care.

Limitations of our CPAR Project

In this section, I bring attention to a variety of limitations that our project was not able to address. After discussing each point, I summarize with a recommendation for future research to attend to.

Most co-researchers on our CPAR team were Caucasian; however, we have one co-researcher who identifies as Pakistani and another who identifies as Pilipino. Our project did not focus on reaching out to young carers from diverse racialized identities and thus, our findings may not reflect the experiences and meanings of young carers from diverse backgrounds. It is quite likely that young carers who are most marginalised due to time pressures, financial, and other circumstances may have faced additional challenges to participating in our research. This may explain the lack of diversity in young carers' who expressed an interest in participating in our research. Given that the young caring literature has only begun to explore the cultural differences in understandings and conceptualizations of young caring and young carers, more research is needed that focuses on understanding the experiences of young carers from diverse racialized identities.

Our research specifically excluded young people under the age of 12. Co-researchers who work with the YCA and YCP suggested that young people over the age of 12 may be able to navigate the online structure of our project and speak more comfortably in informal environments, such as our narrative research conversations. Therefore, future research that explores the experiences of young carers under the age of 12 is needed.

In our project, we engaged in an arts-based method of analysis online. As a result, I took all team members' creative expression pieces and blended them all together. If we had been able to meet up in person, we may have had the opportunity to create the collaborative expression simultaneously in a way that allowed all team members to blend their ideas together. In this way, I recommend that research explore the different ways arts-based methods can be used to support collaborative analysis with young people, both online and in person.

Most of our young carer co-researchers and participants supported a sibling or parent with similar diagnoses. For instance, all young carers who did not support a parent, supported a sibling living with autism. In this way, our project was limited in exploring the experience of young caring for a diverse range of relationships (e.g., sibling, parent, grandparent, relative, etc.). Therefore, in future research I suggest broadening our understanding of the different types of caring relationships through exploring young caring in different contexts (e.g., sibling, parent, grandparent, relative, friend, etc.).

All our young carer participants and co-researchers were recruited through young carer organizations, suggesting that all young carers in this research identified as young carers and had access to the supports that the YCA and YCP already provide. In future research, I suggest exploring a range of ways to reach out to young carers who are not already connected with the YCA and/or YCP.

Given my own experience supporting a parent living with schizoaffective condition and recovering from substance misuse, I hoped to reach out to participants who were caring in a similar situation. In our project we were not able to do so and therefore, I hope to focus my future research on connecting with young carers who support a family member living with a mental health concern and/or substance misuse.

Project Conclusions and Moving Forward

The purpose of our CPAR study was *to partner with young carers to expand our understandings of young carers' experiences of care and how those care experiences shape* *leisure.* To get there, we aimed to provide a platform to privilege the voices of young carers; challenge dominant perspectives of young carers through bringing awareness to their unique experiences; and ensure young carers are better supported in their roles by identifying specific ways to support young carers, including in their leisure. I believe that through collaboration and commitment, our team achieved each of our objectives. Through involving young carers in all stages of our CPAR process, our research prioritized a space for young carers' voices and stories to be effectively heard. We challenged dominant discourses by representing young people as experts on their own lives with the capacity to engage in active decision-making with others; young carers as dynamic beings with lived experiences that produce unique skills; and young caring as natural, intrinsic, and widespread. Young carers identified that relationships were the key to helping them feel better supported in their care roles. They called for a deeper awareness and recognition of their lived experiences in all its complexity and brought attention to the benefits of relational opportunities and spaces. Our findings contributed an alternative conceptualization and meaning of leisure as messy, complex, and contextual in the lives of young carers. Particularly, we determined that leisure and care are often synonymous in the lives of young carers, and that in certain situations, separating the two may result in harmful leisure experiences.

Through meaningful and authentic relationships, our team represented young carers experiences of care and leisure in a creative, unique way. Our collaborative expression piece and future resource will help provide the young caring literature with an alternative conceptualization of young carers and their lived experiences. Drawing on CYS and an authentic partnership approach facilitated opportunities for us to challenge dominant discourses of young caring and leisure while bringing attention to the power of working in collaboration with young people. We learned that our CPAR process required elements of creativity, flexibility, and relationality to ensure that all co-researchers voices were heard and incorporated into the process effectively. Additionally, our project and findings emphasize the potential of CPAR with young carers, to better understand and support them in the complex ways they experience care and leisure. It is my hope that researchers, policymakers, and professionals recognize the value in different lived experiences and embrace young peoples' capacity to meaningfully contribute to their lives and the lives of others.

References

Aeyelts, R., Marshall, S., Charles, G., & Young, R. (2016). How care is negotiated between a young carer and a parent experiencing mental illness and addiction. *International Journal of Child, Youth, & Family Studies*, *7*(1), 65–80. https://doi.org/10.18357/ijcyfs.71201615417

Aitchison, C. (2009). Exclusive discourses: leisure studies and disability. *Leisure Studies*, *28*(4), 375–386. https://doi.org/10.1080/02614360903125096

Aldridge, J. (2018). Where are we now? Twenty-five years of research, policy and practice on young carers. *Critical Social Policy, 38*(1), 155–165. https://doi.org/10.1177/0261018317724525

Aldridge, J., & Becker, S. (1993). *Children who care: Inside the world of young carers*. Loughborough, England: Loughborough University.

Ali, L., Ahlström, B. H., Krevers, B., Sjöström, N., & Skärsäter, I. (2013). Support for young informal carers of persons with mental illness: a mixed-method study. *Issues in Mental Health Nursing*, *34*(8), 611-618. https://doi.org/10.3109/01612840.2013.791736

Anderson, C., & Kirkpatrick, S. (2016). Narrative interviewing. *International Journal of Clinical Pharmacy*, *38*(3), 631-634. 10.1007/s11096-015-0222-0

Banks, P., Cogan, N., Riddell, S., Deeley, S., Hill, M., & Tisdall, K. (2002). Does the covert nature of caring prohibit the development of effective services for young carers? *British Journal of Guidance and Counselling, 30*(3), 229–246. https://doi.org/10.1080/030698802100002281

Banks, P., Cogan, N., Deeley, S. W., Hill, M., Riddell, S., Tisdall, K. (2001). Seeing the invisible children and young people affected by disability. *Disability and Society, 16*(6): 797–814.

Barry, M. (2011). 'I realised that I wasn't alone': the views and experiences of young carers from a social capital perspective. *Journal of Youth Studies*, *14*(5), 523-539. https://doi.org/10.1080/13676261.2010.551112

Bean, C. N., Kendellen, K., & Forneris, T. (2016). Examining needs support and positive developmental experiences through youth's leisure participation in a residential summer camp. *Leisure/Loisir*, *40*(3), 271-295. https://doi.org/10.1080/14927713.2016.1252938

Becker, F. & Becker, S. (2008). *Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16–24*. The Princess Royal Trust for Carers, London, UK.

Becker, S. (2007). Global perspectives on children's unpaid caregiving in the family: research and policy on "young carers" in the UK, Australia, the USA and Sub-Saharan Africa. *Global Social Policy, 7*(1), 23–50. https://doi.org/10.1177/1468018107073892

Becker, S., & Sempik, J. (2019). Young adult carers: the impact of caring on health and education. *Children & Society, 33*(4), 377–386. https://doi.org/10.1111/chso.12310

Becker, S., Aldridge, J. & Dearden, C. (1998) *Young Carers and their Families*. Blackwell Science, Oxford, UK.

Bedim, L. A., & Guinan, D. M. (1996). "If I could just be selfish ...": Caregivers' perceptions of their entitlement to leisure. *Leisure Sciences, 18*(3), 227–239. https://doi.org/10.1080/01490409609513284

Bedini, L. A., Labban, J. D., Gladwell, N. J., & Dudley, W. N. (2018). The effects of leisure on stress and health of family caregivers. *International Journal of Stress Management, 25*(S1), 43–55. https://doi.org/10.1037/str0000072

Blake-Holmes, K. (2020). Understanding the needs of young carers in the context of the COVID-19 global pandemic. Norwich: University of East Anglia.

Bolas, H., Wersch, A. V., & Flynn, D. (2007). The well-being of young people who care for a dependent relative: An interpretative phenomenological analysis. *Psychology and Health*, *22*(7), 829-850. https://doi.org/10.1080/14768320601020154

Borchet, J., Lewandowska-Walter, A., Połomski, P., Peplińska, A., & Hooper, L. M. (2021). The relations among types of parentification, school achievement, and quality of life in early adolescence: an exploratory study. *Frontiers in psychology*, *12*(635171), 1-10. https://doi.org/10.3389/fpsyg.2021.635171

Boumans, N. P., & Dorant, E. (2018). A cross-sectional study on experiences of young adult carers compared to young adult noncarers: Parentification, coping and resilience. *Scandinavian Journal of Caring Sciences*, *32*(4), 1409-1417. https://doi.org/10.1111/scs.12586

Butler, A.H. and Astbury, G. (2005), The caring child: an evaluative case study of the Cornwall Young Carers project. *Children & Society, 19*, 292-303. https://doi-org.proxy.lib.uwaterloo.ca/10.1002/chi.851

Caldwell, L. L., & Faulk, M. T. (2013). Adolescent leisure from a developmental and prevention perspective. In T. Freire (Ed.), Positive leisure science: From subjective experience to social contexts (pp. 41–60). Dordrecht, The Netherlands: Springer Science Business Media.

Caldwell, L. L., & Witt, P. A. (2011). Leisure, recreation, and play from a developmental context. *New Directions for Youth Development*, 130, 13-27. https://doi.org/10.1002/yd.394

Carey, R. L., Akiva, T., Abdellatif, H., & Daughtry, K. A. (2020). "And school won't teach me that!' Urban youth activism programs as transformative sites for critical adolescent learning. *Journal of Youth Studies, 24*(7), 941-960. https://doi.org/10.1080/13676261.2020.1784400

Cass, B. (2007). Exploring Social Care: Applying a New Construct to Young Carers and Grandparent Carers. *The Australian Journal of Social Issues, 42*(2), 241–254. https://doi.org/10.1002/j.1839-4655.2007.tb00052.x

Cassidy, T. (2005). Leisure, coping and health: The role of social, family, school and peer relationship factors. *British Journal of Guidance & Counselling*, *33*(1), 51-66. https://doi.org/10.1080/03069880412331335830

Chadi, N., & Stamatopoulos, V. (2017). Caring for young carers in Canada. *Canadian Medical Association Journal*, *189*(28), E925–E926. https://doi.org/10.1503/cmaj.170145

Chalmers, H., & Lucyk, L. (2012). The impact of caregiving: Is it who I am or what I do? *Relational Child & Youth Care Practice*, 25, 37–46.

Charles, G., Stainton, T., & Marshall, S. (2008). Young carers in Canada: An invisible population. *Relational Child and Youth Care Practice*, *21*(4), 5-12.

Charles, G., Stainton, T., & Marshall, S. (2009). Young carers: Mature before their time. *Reclaiming Children and Youth*, *18*(2), 38-41. https://doi.org/info:doi/

Chattillion, E. A., Mausbach, B. T., Roepke, S. K., Von Känel, R., Mills, P. J., Dimsdale, J. E., Allison, M., Ziegler, M. G., Patterson, T. L., Ancoli-Israel, S., & Grant, I. (2012). Leisure activities, caregiving demands and catecholamine levels in dementia caregivers. *Psychology & Health, 27*(10), 1134–1149. https://doi.org/10.1080/08870446.2011.637559

Chikhradze, N., Knecht, C., & Metzing, S. (2017). Young carers: growing up with chronic illness in the family-a systematic review 2007-2017. *Journal of Compassionate Health Care*, *4*(1), 1-16. https://doi.org/10.1186/s40639-017-0041-3

Chiu, Y.-C., Liao, H.-C., Li, C.-L., Lin, C.-H., Hsu, J.-L., Lin, C.-Y., & Hsu, W.-C. (2020). The mediating effects of leisure engagement on relationships between caregiving stress and subjective wellbeing among family caregivers of persons with cognitive impairment: A cross-sectional study. *Geriatric Nursing, 41*(2), 124–131. https://doi.org/10.1016/j.gerinurse.2019.08.017

Chojnacka, B., & Iwański, R. (2021). Young Carers and Parentification–Between Support and Responsibility: Involving the Child in the Functioning of the Family. *Journal of Family Issues, 0*(0), 1-23. https://doi.org/10.1177/0192513X211038072

Cluver, L., Operario, D., Lane, T., & Kganakga, M. (2012). “I Can’t Go to School and Leave Her in So Much Pain” educational shortfalls among adolescent ‘Young Carers’ in the South African AIDS epidemic. *Journal of Adolescent Research, 27*(5), 581–605. https://doi.org/10.1177/0743558411417868

Cohen, S. A., Cook, S., Kelley, L., Sando, T., & Bell, A. E. (2015). Psychosocial factors of caregiver burden in child caregivers: Results from the new national study of caregiving. *Health & Quality of Life Outcomes*, *13*(1), 120-125. 10.1186/s12955-015-0317-2

Collins, J., & Bayless, S. (2013). How caring for a parent affects the psychosocial development of the young. *Nursing Children & Young People*, *25*(10), 16-21. 10.7748/ncyp2013.12.25.10.16.e351

Cooklin, A. (2010). “Living upside down”: being a young carer of a parent with mental illness. *Advances in Psychiatric Treatment: The Royal College of Psychiatrists’ Journal of Continuing Professional Development*, *16*(2), 141–146. https://doi.org/10.1192/apt.bp.108.006247

Cree, V. E. (2003). Worries and problems of young carers: issues for mental health. *Child & Family Social Work*, *8*(4), 301-309. https://doi.org/10.1046/j.1365-2206.2003.00292.x

Cunningham, L. C., Shochet, I. M., Smith, C. L., & Wurfl, A. (2017). A qualitative evaluation of an innovative resilience-building camp for young carers. *Child & Family Social Work*, *22*(2), 700-710. https://doi.org/10.1111/cfs.12286

Dearden, C. & Becker, S. (2000) Growing up Caring: Vulnerability and Transition to Adulthood - Young Carers Experiences. Youth Work Press for the Joseph Rowntree Foundation, Leicester, UK.

Dearden, C., & Becker, S. (2004). Young carers in the UK: the 2004 report. London: Carers UK.

Dharampal, R., & Ani, C. (2020). The emotional and mental health needs of young carers: What psychiatry can do. *BJPsych Bulletin, 44*(3), 112-120. 10.1192/bjb.2019.78

Doutre, G., Green, R., & Knight-Elliott, A. (2013). Listening to the voices of young carers using interpretative phenomenological analysis and a strengths-based perspective. *Educational & Child Psychology, 30*(4), 30–43.

Dupuis, S. L & Whyte, C. (2017). Participatory approaches to research with marginalized individuals and groups: ensuring relevancy. In Stumbo, N. J., Wolfe, B. D., & Pegg, S. (Eds.)., *Professional Issues in Therapeutic Recreation* (pp. 543-556). Sagamore Publishing.

Dupuis, S. L, Kontos P., Mitchell G., Jonas-Simpson C., & Gray J. (2016a). Re-claiming citizenship through the arts. *Dementia, 15*(3) 358-380. 10.1177/1471301216637206

Dupuis, S. L., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L., & Sadler, L. (2012a). Moving beyond 'patient' and 'client' approaches: Mobilising authentic partnerships in dementia care. *Dementia: The International Journal of Social Research and Practice*, *11*(4), 428-450. https://doi.org/10.1177/1471301211421063

Dupuis, S. L., Whyte, C., Carson, J., Genoe, R., Meshino, L., & Sadler, L. (2012b). Just dance with me: an authentic partnership approach to understanding leisure in the dementia context. *World Leisure Journal, 54*(3), 240–254. https://doi.org/10.1080/04419057.2012.702454

Dupuis, S. L., & Smale, B. J. A. (2000). Bittersweet journeys: Meanings of leisure in the institution-based caregiving context. *Journal of Leisure Research*, *32*(3), 303-340. https://doi.org/10.1080/00222216.2000.11949919

Dupuis, S. L. (2000). Institution-based caregiving as a container for leisure. *Leisure Sciences*, *22*(4), 259-280. https://doi.org/10.1080/01490409950202294Earley, L., & Cushway, D.

(2002). The parentified child. *Clinical Child Psychology and Psychiatry, 7*(2), 163–178. https://doi.org/10.1177/1359104502007002005

Earley, L., Cushway, D., & Cassidy, T. (2007). Children's perceptions and experiences of caregiving: A focus group study. *Counseling Psychology Quarterly*, *20*(1), 69-80. 10.1080/09515070701217830

Early, L., Cushway, D., & Cassidy, T. (2006). Perceived stress in young carers: Development of a measure. *Journal of Child and Family Studies*, *15*(2), 169-180. 10.1007/s10826-005-9011-z

Eley, S. (2004). "If they don't recognize it, you've got to deal with it yourself": Gender, young caring and educational support. *Gender and Education*, *16*(1), 65-75. :10.1080/0954025032000170345

Ellis, J., Da Costa, J. L., Leroy, C., & Janzen, C. A. (2007). Mentors for students in elementary school: the promise and possibilities. In *International Handbook of Student Experience in Elementary and Secondary School* (pp. 233–261). Springer Netherlands. https://doi.org/10.1007/1-4020-3367-2_9

Engell, K. (2020). Reconceptualising relationships in the dementia context: Imagining the caring process as fertile ground for friendship between persons living with dementia and paid care partners. *UWSpace.* http://hdl.handle.net/10012/16025

Fewster, G. (2004) Making contact: personal boundaries in professional practice.' *Relational Child and Youth Care Practice, 17*(4), 8-18.

Fives, A., Kennan, D., Canavan, J., & Brady, B. (2019). Why we still need the term "Young Carer." *Critical Social Work, 14*(1). https://doi.org/10.22329/csw.v14i1.5872

Fogel, S. J. (2004). Risks and opportunities for success: Perceptions of urban youth in a distressed community and lessons for adults. *Families in Society, 5*(1), 26–43.

Fortune, D., McKeown, J., Dupuis, S., & de Witt, L. (2015). "It was like reading a detective novel": Using PAR to work together for culture change. *Journal of Aging Studies, 34*, 38-47. https://doi.org/10.1016/j.jaging.2015.04.002

Fox, M. (2016). On Research, Art, and Transformation: Multigenerational Participatory Research, Critical Positive Youth Development, and Structural Change. *Qualitative Psychology, 3*(1), 46–58. https://doi.org/10.1037/qup0000053

Fox, M. (2020). In the space between us: reflections for adult audience members of youth-centered participatory research. *International Journal of Qualitative Studies in Education*, *33*(1), 98–114. https://doi.org/10.1080/09518398.2019.1678780

Frank, J., & Mclarnon, J. (2008). Young carers, parents and their families: Key principles of practice. Supportive guidance for those who work directly with, or commission services for, young carers and their families. London: The Children's Society.

Frank, J., & Slatcher, C. (2009). Supporting young carers and their families using a whole family approach: children and young people who act as carers of family members are often isolated and unsupported. *Journal of Family Health Care*, *19*(3), 86-89.

Frank, J., Tatum, C., & Tucker, S. (1999). *On small shoulders: Learning from the experiences of former young carers*. London, England: The Children's Society.

Frederick, T., Vitopoulos, N., Stamatopoulos, V., & Kidd, A. S. (2020). Brief Report: Youth homelessness, youthful caregiving, and resilience. *Journal of Child and Family Studies*. https://doi.org/10.1016/j.childyouth.2021.106177

Fredriksson, I., Geidne, S., & Eriksson, C. (2018). Leisure-time youth centres as health-promoting settings: experiences from multicultural neighbourhoods in Sweden. *Scandinavian journal of public health*, *46*(20), 72-79. https://doi.org/10.1177/1403494817743900

Freeman, M. (1998). The sociology of childhood and children's rights. *The International Journal of Children's Rights*, *6*(4), 433–444. https://doi.org/10.1163/15718189820494175

Freeman, J., & Garfat, T. (2014). Being, interpreting, doing: A framework for organizing the characteristics of a relational child and youth care approach. *Child & Youth Care Online, 17*(9), 23-27.

Freire, T. (Ed.). (2012). *Positive leisure science: From subjective experience to social contexts*. Springer Science & Business Media.

Fullagar, S., E. Rich, and J. Francombe-Webb. 2017a. New Kinds of (ab) Normal?: Public Pedagogies, Affect, and Youth Mental Health in the Digital age. *Social Sciences, 6*(3) 1-12. https://doi.org/10.3390/socsci6030099

Fullagar, S., E. Rich, J. Francombe-Webb, and A. Maturo. 2017b. Digital Ecologies of Youth Mental Health: Apps, Therapeutic Publics and Pedagogy as Affective Arrangements. *Social Sciences, 6*(4): 1-14. https://doi.org/10.3390/socsci6040135

Gahagan, J., Loppie, C., Rehman, L., Maclellan, M., & Side, K. (2007). "Far as I get is the clothesline": The impact of leisure on women's health and unpaid caregiving experiences in Nova Scotia, Canada. *Health Care for Women International, 28*(1), 47–68. https://doi.org/10.1080/07399330601003408

Genoe, M. R., & Dupuis, S. L. (2011). “I’m just like I always was”: a phenomenological exploration of leisure, identity and dementia. *Leisure/Loisir, 35*(4), 423-452. https://doi.org/10.1080/14927713.2011.649111

Gharabaghi, K. (2014) Relationships and relational practice. *CYC-OnLine, 185*, 6-9.

Gladstone, B. M., Boydell, K. M., & McKeever, P. (2006). Recasting research into children’s experiences of parental mental illness: Beyond risk and resilience. *Social Science & Medicine, 62*(10), 2540–2550. https://doi.org/10.1016/j.socscimed.2005.10.038

Grant, A., Leigh-Phippard, H., & Short, N. P. (2015). Re-storying narrative identity: a dialogical study of mental health recovery and survival. *Journal of Psychiatric and Mental Health Nursing, 22*(4), 278-286. 10.1111/jpm.12188

Gray, B., & Robinson, C. (2009). Hidden children: Perspectives of professionals on young carers of people with mental health problems. *Child Care in Practice*, *15*(2), 95-108. https://doi.org/10.1080/13575270802685369

Gray, B., Robinson, C., & Seddon, D. (2008). Invisible children: Young carers of parents with mental health problems-the perspectives of professionals. *Child and Adolescent Mental Health*, *13*(4), 169-172. https://doi.org/10.1111/j.1475-3588.2007.00477.x

Griffin, C. (1993). Representations of youth: The study of youth and adolescence in Britain and America. Cambridge, MA: Polity Press.

Grimwood, B. S. R. (2015). Participatory action research: Democratizing knowledge for social justice. In Johnson, C.W. & Parry, D. (Eds.), *Fostering Social Justice through Qualitative Inquiry* (pp. 217- 250). Routledge.

Grobe Schlarmann, J., Metzing-Blau, S., & Schnepp, W. (2008). The use of health-related quality of life (HRQOL) in children and adolescents as an outcome criterion to evaluate family oriented support for young carers in Germany: an integrative review of the literature. *BMC Public Health*, *8*(1), 1-10.

Groundwater-Smith, S. (2012). Living ethical practice in qualitative research. In Higgs, J., Titchen, A., Horsfall, D., & Bridges, D. (Eds.). *Creative spaces for qualitative researching: Living research (Vol. 5)* (pp. 201-210). Springer Science & Business Media.

Grose, J. (2022, April 16). On Japan's Adorable 'Old Enough!' Show and the State of American Childhoods**.** *The New York Times. https://www.nytimes.com/2022/04/16/opinion/old-enough-kids-parents.html*

Hamilton, M. G., & Adamson, E. (2013). Bounded agency in young carers' life course-stage domains and transitions. *Journal of youth studies*, *16*(1), 101-117. https://doi.org/10.1080/13676261.2012.710743

Hansen, D. M., Larson, R. W., & Dworkin, J. B. (2003). What adolescents learn in organized youth activities: A survey of self-reported developmental experiences. *Journal of research on adolescence*, *13*(1), 25-55. https://doi.org/10.1111/1532-7795.1301006

Harrison, P. A., & Narayan, G. (2003). Differences in behavior, psychological factors, and environmental factors associated with participation in school sports and other activities in adolescence. *Journal of school health, 73*(3), 113-120. https://doi.org/10.1111/j.1746-1561.2003.tb03585.x

Haworth, J. T., & Hill, S. (1992). Work, leisure, and psychological well-being in a sample of young adults. *Journal of Community & Applied Social Psychology, 2*(2), 147–160. https://doi.org/10.1002/casp.2450020210

Hendricks, B., Vo, J., Dionne-Odom, J., & Bakiatas, M. (2021). Parentification among young carers: A concept analysis. *Child and Adolescent Social Work Journal*. https://doi.org/10.1007/s10560-021-00784-7

Heyman, A., & Heyman, B. (2013). "The sooner you can change their life course the better": the time-framing of risks in relationship to being a young carer. *Health, Risk & Society, 15(6-7),* 561–579. *https://doi.org/10.1080/13698575.2013.830080*

Heywood, C. (2018). *A history of childhood: children and childhood in the west from medieval to modern times* (Second edition.). Polity Press.

Hill, T., Smyth, C., Thomson, C., & Cass, B. (2009). *Young carers: Their characteristics and geographical distribution*. Canberra, Australia: Social Policy Research Centre.

Hill, T., Thomson, C., & Cass, B. (2011). Young carers: Location, education and employment disadvantage. *Australian Journal of Labour Economics*, *14*(2), 173-198.

Hopper, T. D., Iwasaki, Y., Walker, G. J., & McHugh, T.-L. F. (2019). "I feel like we finally matter": the role of youth-led approaches in enhancing leisure-induced meaning-making among youth at risk. *Leisure = Loisir, 43*(4), 419–444. https://doi.org/10.1080/14927713.2019.1697351

Hopper, T. D., Iwasaki, Y., Walker, G. J., & McHugh, T.-L. F. (2019). The Role of Relationships in Meaningfully Engaging Youth at Risk in Recreation and Leisure Contexts. *Child & Youth Services, 40*(3), 245–266. https://doi.org/10.1080/0145935X.2019.1568235

Hutchby. (2005). Children’s talk and social competence. *Children & Society*, *19*(1), 66–73. https://doi.org/10.1002/chi.858

Ibrahim, A., Steinberg, S. R., & Hutton, L. (Eds.). (2014). *Critical youth studies reader*. New York, NY: Peter Lang.

Iwasaki, Y., & Hopper, T. (2017). Leisure, engagement, and meaning-making among high-risk youth. *Loisir Et Société/Society and Leisure*, *40*(3), 324-339. https://doi.org/10.1080/07053436.2017.1378504

Jennings, L. B., Parra-Medina, D. M., Hilfinger-Messias, D. K., & McLoughlin, K. (2008). Toward a critical social theory of youth empowerment. *Journal of Community Practice, 14*(1-2), 31–55. https://doi.org/10.1300/J125v14n01_03

Johnson, C. W., & Parry, D. (2015). Fostering social justice through qualitative Inquiry. Routledge.

Jonzon, A. J., & Goodwin, D. L. (2012). Daughters of mothers with multiple sclerosis: Their experiences of play. *Adapted Physical Activity Quarterly*, *29*(3), 205-223.

Joseph, S., Becker, S., Becker, F., & Regel, S. (2009). Assessment of caring and its effects in young people: Development of the multidimensional assessment of caring activities checklist (MACA-YC18) and the positive and negative outcomes of caring questionnaire (PANOC-YC20) for young carers. *Child: Care, Health & Development, 35*(4), 510-520. Doi:10.1111/j.1365-2214.2009.00959.x

Joseph, S., Sempik, J., Leu, A., & Becker, S. (2020). Young carers research, practice and policy: An overview and critical perspective on possible future directions. *Adolescent Research Review*, *5*(1), 77-89. https://doi.org/10.1007/s40894-019-00119-9

Kavanaugh, M. (2014). Children and Adolescents Providing Care to a Parent with Huntington's Disease: Disease Symptoms, Caregiving Tasks and Young Carer Well-Being. *Child & Youth Care Forum, 43*(6), 675–690. https://doi.org/10.1007/s10566-014-9258-x

Kavanaugh, M. S., & Stamatopoulos, V. (2021). Young Carers, The Overlooked Caregiving Population: Introduction to a Special Issue. *Child and Adolescent Social Work Journal.* 10.1007/s10560-021-00784-7

Kavanaugh, M. S., Noh, H., & Studer, L. (2015). "It'd be nice if someone asked me how I was doing. Like, 'cause I will have an answer": Exploring support needs of young carers of a parent with Huntington's disease. *Vulnerable Children and Youth Studies*, *10*(1), 12-25. https://doi.org/10.1080/17450128.2014.980370

Kemmis, S., & McTaggart, R. (2005). Participatory action research: communicative action and the public sphere. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage Handbook of Qualitative Research* (pp. 559–603). Sage Publications Ltd.

Kemmis, S., McTaggart, R., & Nixon, R. (2014). Introducing critical participatory action research. In *The action Research Planner* (pp. 1-31). Springer, Singapore.

King, G., Petrenchik, T., Law, M., & Hurley, P. (2009). The enjoyment of formal and informal recreation and leisure activities: A comparison of school-aged children with and without physical disabilities. *International Journal of Disability, Development and Education*, *56*(2), 109-130. https://doi.org/10.1080/10349120902868558

King, T. L. (2021). Young carers in the COVID-19 pandemic: Risks for mental health. *The Lancet Regional Health–Western Pacific*, *16*. https://doi.org/10.1016/j.lanwpc.2021.100307

Kleiber, & McGuire, F. A. (2016). *Leisure and human development*. Sagamore Publishing.

Kumar, S., & Cavallaro, L. (2017). Researcher self-care in emotionally demanding research: A proposed conceptual framework. *Qualitative Health Research, 28*(4), 648–658. https://doi.org/10.1177/1049732317746377

Lackey, N. R., & Gates, M. F. (2001). Adults' recollections of their experiences as young caregivers of family members with chronic physical illnesses. *Journal of Advanced Nursing*, *34*(3), 320-328. 10.1046/j.1365-2648.2001.01761.x

Lakman, Y. (2015). Profiling young carers' lives: An examination of individual, family, and social contexts (Master's thesis). Brock University, St. Catharines, ON. Retrieved from https://dr.library.brocku.ca/handle/10464/7156

Larson, R. W., Hansen, D. M., & Moneta, G. (2006). Differing profiles of developmental experiences across types of organized youth activities. *Developmental psychology*, *42*(5), 849. https://doi.org/10.1037/0012-1649.42.5.849

Lavie-Ajayi, & Krumer-Nevo, M. (2013). In a different mindset: Critical youth work with marginalized youth. *Children and Youth Services Review, 35*(10), 1698–1704. https://doi.org/10.1016/j.childyouth.2013.07.010

Lee, L., Currie, V., Saied, N., & Wright, L. (2020). Journey to hope, self-expression and community engagement: Youth-led arts-based participatory action research. *Children and Youth Services Review*, 109, 1-10. https://doi.org/10.1016/j.childyouth.2019.104581

Lieshout, F. V., & Cardiff, S. (2011). Innovative ways of analysing data with practitioners as co-researchers. In Higgs, J., Titchen, A., Horsfall, D., & Bridges, D. (Eds.), *Creative Spaces for Qualitative Researching: Living Research (Vol. 5)* (pp. 223- 234). Springer Science & Business Media.

Lesko, N. (1996). Denaturalizing Adolescence: The Politics of Contemporary Representations. *Youth & Society, 28*(2), 139–161. https://doi.org/10.1177/0044118X96028002001

Lester, A. M., Goodloe, C. L., Johnson, H. E., & Deutsch, N. L. (2019). Understanding mutuality: Unpacking relational processes in youth mentoring relationships. *Journal of Community Psychology, 47*(1), 147–162. https://doi.org/10.1002/jcop.22106

Leu, A., Wepf, H., Sempik, J., Nagl-Cupal, M., Becker, S., Jung, C., & Frech, M. (2020). Caring in mind? Professionals' awareness of young carers and young adult carers in Switzerland. *Health & Social Care in the Community*, *28*(6), 2390–2398. https://doi.org/10.1111/hsc.13061

Leu, A., & Becker, S. (2017). A cross-national and comparative classification of in-country awareness and policy responses to 'young carers'. *Journal of Youth Studies*, *20*(6), 750-762. https://doi.org/10.1080/13676261.2016.1260698

Liebenberg, L. (2018). Thinking critically about photovoice: Achieving empowerment and social change. *International Journal of Qualitative Methods, 17*(1), 1-9. 10.1177/1609406918757631

Lloyd, K. (2013). Happiness and well-being of young carers: Extent, nature and correlates of caring among 10 and 11 year old school children. *Journal of Happiness Studies*, *14*(1), 67-80. https://doi.org/10.1007/s10902-011-9316-0

Lopez, K. (2018). "We are not a machine": Personal support workers' (ante)narratives of labour, leisure, and hope amidst politics of genderacialised care in long-term care homes [Doctoral dissertation, University of Waterloo]. *UWSpace.* http://hdl.handle.net/10012/12850

Losada, A., Pérez-Peñaranda, A., Rodriguez-Sanchez, E., Gomez-Marcos, M. A., Ballesteros-Rios, C., Ramos-Carrera, I. R., ... & García-Ortiz, L. (2010). Leisure and distress in caregivers for elderly patients. *Archives of Gerontology and Geriatrics*, *50*(3), 347-350. https://doi.org/10.1016/j.archger.2009.06.001

Mahoney, J. L., & Stattin, H. (2000). Leisure activities and adolescent antisocial behavior: The role of structure and social context. *Journal of adolescence, 23*(2), 113-127. https://doi.org/10.1006/jado.2000.0302

Mannell, R. C., & Kleiber, D. A. (2013). Psychology of leisure. In *Routledge Handbook of Leisure Studies* (pp. 62-73). Routledge.

Manning, K. (1997). Authenticity in constructivist inquiry: methodological considerations without prescription. *Qualitative Inquiry, 3*(1), 93–115. https://doi.org/10.1177/107780049700300105

Mansfield, L. (2021). Leisure and health – critical commentary. *Annals of Leisure Research, 24*(3), 283–294. https://doi.org/10.1080/11745398.2020.1767664

Marsh, L., Leamon, J., Robinson, A., & Shawe, J. (2018). LEARNS: A creative approach to analysing and representing narrative data incorporating photo-elicitation techniques. *Journal of Research in Nursing, 23*(4), 334–343. https://doi.org/10.1177/1744987117750218

Martin, S. (2021). Young Carers and COVID-19: The Invisible Front-Line Workers (Master's Thesis). University of Guelph, Guelph, ON. Retrieved from https://atrium.lib.uoguelph.ca/xmlui/handle/10214/25695

Matzka, M., & Nagl-Cupal, M. (2020). Psychosocial resources contributing to resilience in Austrian young carers—A study using photo novella. *Research in Nursing & Health, 43*(6), 629–639. https://doi.org/10.1002/nur.22085

Mayall. (2000). The sociology of childhood in relation to children's rights. *The International Journal of Children's Rights, 8*(3), 243–259. https://doi.org/10.1163/15718180020494640

McAndrew, S., Warne, T., Fallon, D., & Moran, P. (2012). Young, gifted, and caring: A project narrative of young carers, their mental health, and getting them involved in education, research and practice. *International Journal of Mental Health Nursing, 21*(1), 12–19. https://doi.org/10.1111/j.1447-0349.2011.00762.x

McDonald, J., Cumming, J., & Dew, K. (2009). An exploratory study of young carers and their families in New Zealand. *Journal of Social Sciences*, *4*(2), 115-129. Doi:10.1080/1177083X.2009.9522448

McDonald, J., Dew, K., & Cumming, J. (2010). Change and Adaptation in Families with Young Carers. *The Australian Journal of Social Issues, 45*(4), 459–475. https://doi.org/10.1002/j.1839-4655.2010.tb00192.x

McDougall, E., O'Connor, M., & Howell, J. (2018). "Something that happens at home and stays at home": An exploration of the lived experience of young carers in Western Australia. *Health & Social Care in the Community*, *26*(4), 572-580. https://doi.org/10.1111/hsc.12547

McNeven, S., McKay, L., & Main, K. (2020). The lived experience of professional mentorship and its implications for school-based mentoring programs. *Journal of Education (Boston, Mass.), 200*(2), 89–96. https://doi.org/10.1177/0022057419875129

Mirra, N., Garcia, A., & Morrell, E. (2015). *Doing youth participatory action research: Transforming inquiry with researchers, educators, and students*. Routledge.

Miskovic, M., & Hoop, K. (2006). Action research meets critical pedagogy: theory, practice, and reflection. *Qualitative Inquiry, 12*(2), 269–291. 10.1177/1077800405284367

Moore, T., McArthur, M., & Morrow, R. (2009). Attendance, achievement and participation: young carers' experiences of school in Australia. *The Australian Journal of Education, 53*(1), 5–18. https://doi.org/10.1177/000494410905300102

Morelli, G. A., Rogoff, B., & Angelillo, C. (2003). Cultural variation in young children's access to work or involvement in specialised child-focused activities. *International Journal of Behavioral Development, 27*(3), 264–274. https://doi.org/10.1080/01650250244000335

Nagl-Cupal, M., & Hauprich, J. (2018). Being we and being me: Exploring the needs of Austrian families with caring children. *Health & Social Care in the Community, 26*(4), e532-e540. https://doi.org/10.1111/hsc.12567

Nagl-Cupal, M., Daniel, M., Koller, M. M., & Mayer, H. (2014). Prevalence and effects of caregiving on children. *Journal of Advanced Nursing*, *70*(10), 2314-2325. https://doi.org/10.1111/jan.12388

Nap, H. H., Hoefman, R., de Jong, N., Glimmerveen, L., Lovink, L., Lewis, F., Santini, S., D'Amen, B., Socci, M., Boccaletti, L., Casu, G., Manattini, A., Brolin, R., Sirk, K., Hlebec, V., Rakar, T., Hudobivnik, T., Leu, A., Berger, F., … Hanson, E. (2020). The awareness, visibility and support for young carers across Europe: a Delphi study. *BMC Health Services Research, 20*(1), 921–921. https://doi.org/10.1186/s12913-020-05780-8

O'Dell, L. O., Crafter, S., de Abreu, G., & Cline, T. (2010). Constructing "normal childhoods": Young people talk about young carers. *Disability & Society, 25*(6), 643-655. https://doi.org/10.1080/09687599.2010.505734

Obadina, S. (2010). Parental mental illness: Effects on young carers. *British Journal of School Nursing*, *5*(3), 135-139. https://doi.org/10.12968/bjsn.2010.5.3.47459

Pakenham, K. I., Chiu, J., Bursnall, S., & Cannon, T. (2007). Relations between social support, appraisal and coping and both positive and negative outcomes in young carers. *Journal of Health Psychology*, *12*(1), 89–102. https://doi.org/10.1177/1359105307071743

Pederson, S. N. (2013). To be welcome: A call for narrative interviewing methods in illness contexts. *Qualitative Inquiry, 19*(6), 411-418. https://doi.org/10.1177/1077800413482099

Phelps, D. (2012). Commissioning services for young carers and their families. Carers Trust.

Phelps, D. (2017). The voices of young carers in policy and practice. *Social Inclusion, 5*(3), 113-121. https://doi.org/10.17645/si.v5i3.965

Pienaar, L., & Reynolds, F. (2015). 'A respite thing': A qualitative study of a creative arts leisure programme for family caregivers of people with dementia. *Health Psychology Open*, 1-11. https://doi.org/10.1177/2055102915581563

Pölkki, P., Ervast, S.-A., & Huupponen, M. (2004). Coping and resilience of children of a mentally ill parent. *Social Work in Health Care, 39*(1-2), 151–163. https://doi.org/10.1300/J010v39n01_10

Purcal, C., Hamilton, M., Thomson, C., & Cass, B. (2012). From Assistance to Prevention: Categorizing Young Carer Support Services in Australia, and International Implications. *Social Policy & Administration, 46*(7), 788–806. https://doi.org/10.1111/j.1467-9515.2011.00816.x

Quijada Cerecer, D. A., Cahill, C., & Bradley, M. (2013). Toward a Critical Youth Policy Praxis: Critical Youth Studies and Participatory Action Research. *Theory into Practice, 52*(3), 216-223. https://doi.org/10.1080/00405841.2013.804316

Quinney, L., Dwyer, T., & Chapman, Y. (2016). Who, where, and how of interviewing peers: Implications for a phenomenological study. *Sage Open, 6*(3), 1-10. 10.1177/2158244016659688

Remtulla, Y., Charles, G., & Marshall, S. (2012). An Analysis of Responsibility, Attachment Security, and Relationship Efficacy among Young Carers. *Relational Child & Youth Care Practice*, *25*(2).

Rhodes, J., & Spencer, R. (2005). Someone to watch over me: Mentoring programs in the after-school lives of children and adolescents. In *Organized activities as contexts of development* (pp. 431-448). Psychology Press.

Richardson, K., Jinks, A., & Roberts, B. (2009). Qualitative evaluation of a young carers' initiative. *Journal of Child Health Care*, *13*(2), 150-160. https://doi.org/10.1177/1367493509102475

Robison, O. M. E. F., Inglis, G., & Egan, J. (2020). The health, well-being and future opportunities of young carers: A population approach. *Public Health*, *185*, 139-143. https://doi.org/10.1016/j.puhe.2020.05.002

Robson, E. (2004). Hidden child workers: young carers in Zimbabwe. *Antipode*, *36*(2), 227-248. https://doi.org/10.1111/j.1467-8330.2004.00404.x

Rockwell, J. (2012). From Person-Centered to Relational Care: Expanding the Focus in Residential Care Facilities. *Journal of Gerontological Social Work, 55*(3), 233-248. 10.1080/01634372.2011.639438

Rogers, N. B. (2001). Family obligation, caregiving, and loss of leisure: The experiences of three caregivers. *Activities, Adaptation, & Aging, 24*(2), 35-49. https://doi.org/10.1300/J016v24n02_03

Romero-Moreno, R., Losada, A., Marquez, M., Laidlaw, K., Fernández-Fernández, V., Nogales-González, C., & López, J. (2014). Leisure, gender, and kinship in dementia caregiving: psychological vulnerability of caregiving daughters with feelings of guilt. *The Journals of Gerontology*, 69(*4),* p. 502–513. https://doi.org/10.1093/geronb/gbt027

Russell, R. (2013). Pastimes: The context of contemporary leisure (5th ed.). Sagamore.

Rose, H. & Cohen, K. (2010). The experiences of young carers: A meta-synthesis of qualitative findings. *Journal of Youth Studies*, *13*(4), 473-487. 10.1080/13676261003801739

Roulston, K. (2010). Reflective Interviewing: A Guide to Theory and Practice. Sage Publications.

Sahoo, R., & Suar, D. (2010). Influence of social environment on young carers, assistance and consequences of caregiving. *Psychological Studies, 55*(4), 323-329. 10.1007/s12646-010-0041-2

Sauerwein, M., Theis, D., & Fischer, N. (2016). How youths' profiles of extracurricular and leisure activity affect their social development and academic achievement. *International*

Journal for Research on Extended Education, *4*(1), 103-124. https://doi.org/10.3224/ijree.v4i1.24778

Sawatzky, J. E., & Fowler-Kerry, S. (2003). Impact of caregiving: Listening to the voice of informal caregivers. *Journal of Psychiatric and Mental Health Nursing, 10*(3), 277–286. 10.1046/j.1365-2850.2003.00601.x

Schryer, E., Mock, S. E., Hilbrecht, M., Lero, D., & Smale, B. (2016). Use of leisure facilities and wellbeing of adult caregivers. *Leisure Sciences, 38*(1), 17-33. 10.1080/01490400.2015.1038373

Sexton, C. (2018). Caregiver Stress: An Exploration of Stressors and Coping Strategies Among Young Carers (Master's Thesis). Brock University, St. Cathrines, ON. Retrieved from https://dr.library.brocku.ca/handle/10464/13297

Shamrova, D. P., & Cummings, C. E. (2017). Participatory action research (PAR) with children and youth: An integrative review of methodology and PAR outcomes for participants, organizations, and communities. *Children and Youth Services Review*, *81*, 400-412. https://doi.org/10.1016/j.childyouth.2017.08.022

Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family – caregivers of people with mental illnesses. *World journal of psychiatry*, *6*(1), 7–17. https://doi.org/10.5498/wjp.v6.i1.7

Shin, K., & You, S. (2013). Leisure Type, Leisure Satisfaction and Adolescents' Psychological Wellbeing. *Journal of Pacific Rim Psychology*, *7*(2), 53–62. https://doi.org/10.1017/prp.2013.6

Skovdal, Ogutu, V. O., Aoro, C., & Campbell, C. (2009). Young carers as social actors: Coping strategies of children caring for ailing or ageing guardians in Western Kenya. Social *Science & Medicine, 69*(4), 587–595. https://doi.org/10.1016/j.socscimed.2009.06.016

Smith, K. (2015). Deconstructing discourses to rupture fairytales of the "ideal" childhood. In: J. Wyn & H. Cahill (Eds.). *Handbook of children and youth studies* (pp. 21-33). Singapore: Springer.

Smith, B, M., Brown, D. M., & Van Blerk, L. (2016). 'It's good but it's not enough': the relational geographies of social policy and youth mentoring interventions. *Social & Cultural Geography, 17*(7), 959–979. https://doi.org/10.1080/14649365.2016.1147059

Smyth, C., Blaxland, M., & Cass, B. (2011). 'So that's how I found out I was a young carer and that I actually had been a carer most of my life': Identifying and supporting hidden young carers. *Journal of Youth Studies, 14*(2), 145–160. https://doi.org/10.1080/13676261.2010.506524

Smyth, P. (2017). Working with high risk youth: A relationship-based practice framework. New York, NY: Taylor & Francis Group.

Stallard, P., Norman, P., Huline-Dickens, S., Salter, E., & Cribb, J. (2004). The effects of parental mental illness upon children: A descriptive study of the views of parents and children. *Clinical Child Psychology and Psychiatry*, *9*(1), 39-52.

Stamatopoulos, V. (2015). One million and counting: the hidden army of young carers in Canada. *Journal of Youth Studies, 18*(6), 809–822. https://doi.org/10.1080/13676261.2014.992329

Stamatopoulos, V. (2016). Supporting young carers: A qualitative review of young carer services in Canada. *International Journal of Adolescence and Youth, 21*(2), 178-194. https://doi.org/10.1080/02673843.2015.1061568

Stamatopoulos, V. (2018). The young carer penalty: Exploring the costs of caregiving among a sample of Canadian youth. *Child & Youth Services, 39*(2-3), 180–205. https://doi.org/10.1080/0145935X.2018.1491303

Stanfors, M., Jacobs, J. C., & Neilson, J. (2019). Caregiving time costs and trade-offs: Gender differences in Sweden, the UK, and Canada. *SSM – Population Health*, *9*, 1-9. https://doi.org/10.1016/j.ssmph.2019.100501

Statistics Canada. (2012) *Young Canadians providing care.* Statistics Canada. Retrieved from https://www150.statcan.gc.ca/n1/pub/89-652-x/89-652-x2014003-eng.htm

Stephen, J., Sempik, J., Leu, A., & Becker, S. (2019). Young carers research, practice and policy: an overview and critical perspective on possible future directions. *Adolescent Research Review*, 1-13. https://doi.org/10.1007/s40894-019-00119-9

Stevens, A. B., Coon, D., Wisniewski, S., Vance, D., Arguelles, S., Belle, S., ... & Haley, W. (2004). Measurement of leisure time satisfaction in family caregivers. *Aging & Mental Health*, *8*(5), 450-459. https://doi.org/10.1080/13607860410001709737

Stevens, K., McGrath, R., & Ward, E. (2019). Identifying the influence of leisure-based social circus on the health and well-being of young people in Australia. *Annals of Leisure Research*, *22*(3), 305-322. https://doi.org/10.1080/11745398.2018.1537854

Theriault, D. (2017). Implementation of promising practices for LGBTQ inclusion: A multilevel process. *Journal of Park and Recreation Administration*, *35*(3), p. 122-134. https://doi.org/10.18666/JPRA-2017-V35-I3-7702

Theriault, D. (2014). Organized Leisure Experiences of LBGTQ Youth: Resistance and Oppression. *Journal of Leisure Research, 46*(4), 448–461. https://doi.org/10.1080/00222216.2014.11950336

Thomas, N., Stainton, T., Jackson, S., Cheung, W. Y., Doubtfire, S., & Webb, A. (2003). 'Your friends don't understand': Invisibility and unmet needs in the lives of young carers. *Child and Family Social Work, 8*(1), 35-46. https://doi.org/10.1046/j.1365-2206.2003.00266.x

Toolis, E. E., & Hammack, P. L. (2015). The lived experience of homeless youth: A narrative approach. *Qualitative Psychology, 2*(1), 50. https://doi.org/10.1037/qup0000019

Trainor, S., Delfabbro, P., Anderson, S., & Winefield, A. (2009). Leisure activities and adolescent psychological well-being. *Journal of Adolescence*, *33*(1), 173–186. https://doi.org/10.1016/j.adolescence.2009.03.013

Trenberth, L., & Dewe, P. (2002). The importance of leisure as a means of coping with work related stress: An exploratory study. *Counselling Psychology Quarterly*, *15*(1), 59-72. https://doi.org/10.1080/09515070110103999

Ungar, M. (Ed.). (2005). *Handbook for working with children and youth: Pathways to resilience across cultures and contexts*. Sage Publications.

Unger, L. S., & Kernan, J. B. (1983). On the meaning of leisure: an investigation of some determinants of the subjective experience. *Journal of Consumer Research, 9*(4), 381–392. https://doi.org/10.1086/208932

Vacchiano, M., & Bolano, D. (2021). Online and offline leisure, relatedness and psychological distress: a study of young people in Switzerland. *Leisure Studies*, *40*(3), 338-351. https://doi.org/10.1080/02614367.2020.1862282

Van Parys, H., Smith, J. A., & Rober, P. (2014). Growing up with a mother with depression: An interpretative phenomenological analysis. *The Qualitative Report*, *19*(29), 1-18. 10.46743/2160-3715/2014.1245

Vizard, P., Obolenskaya, P., & Burchardt, T. (2019). Child Poverty Amongst Young Carers in the UK: Prevalence and Trends in the Wake of the Financial Crisis, Economic Downturn and Onset of Austerity. *Child Indicators Research, 12*, 1831–1854. 10.1007/s12187-018-9608-6

Warren, J. (2007). Young carers: Conventional or exaggerated levels of involvement in domestic and caring tasks? *Children & Society*, *21*(2), 136-146. 10.1111/j.1099-0860.2006.00038.x

Warren, J., & Ruskin, A. (2008). Young carers: still 'hidden' after all these years. *Research, Policy and Planning*, *26*(1), 45-56.

Watkins, M., & Shulman, H. (2008). Toward psychologies of liberation. UK: Palgrave MacMillan.

Weinblatt, N., & Navon, L. (1995). Flight from leisure: A neglected phenomenon in leisure studies. *Leisure Sciences, 17*(4), 309-325. 10.1080/01490409509513265

Weybright, E. H., Son, J. S., & Caldwell, L. L. (2019). "To have healthy leisure is to have balance:" Young adults' conceptualization of healthy and unhealthy leisure. *Journal of Leisure Research*, *50*(3), 239-259. https://doi.org/10.1080/00222216.2019.1588694

Wihstutz, A. (2017). From Objects of Care to Citizens- Young Carers' Citizenship. In H. Warming & K. Fahnoe (Eds.), *Lived Citizenship on the Edge of Society: Rights, Belonging, Intimate Life and Spatiality* (pp. 175-197). 10.1007/978-3-319-55068-8

Wiersma, E., & Dupuis, S. L. (2010). Becoming institutional bodies: Socialization into a long-term care home. *Journal of Aging Studies, 24*(4), 278-291. 10.1016/j.jaging.2010.08.003

Williams, K. L., Morrison, V., & Robinson, C. A. (2014). Exploring caregiving experiences: Caregiver coping and making sense of illness. Aging & Mental Health, 18(5), 600–609. http://dx.doi.org.proxy.library.brocku.ca/10.1080/13607863.2013.860425

Wilson, D. M., Gottfredson, D. C., Cross, A. B., Rorie, M., & Connell, N. (2010). Youth development in after-school leisure activities. *The Journal of Early Adolescence*, *30*(5), 668-690. https://doi.org/10.1177/0272431609341048

Wong S. (2016). Young carers in schools: How many do you know? *British Journal of School Nursing,* 11(8), 380–383. 10.12968/bjsn.2016.11.8.380

Wright, D. E. (2020). Imagining a more just world: critical arts pedagogy and youth participatory action research. *International Journal of Qualitative Studies in Education*, *33*(1), 32–49. https://doi.org/10.1080/09518398.2019.1678784

Wyn J. (2015). Thinking about childhood and youth. In: J. Wyn & H. Cahill (Eds.). *Handbook of children and youth studies* (pp. 3-20). Singapore: Springer.

Young Caregivers Association (2020). *Powerhouse.* Young Caregivers Association. Retrieved from https://youngcaregivers.ca/who-are-young-caregivers/

Young Carers Program (n.d.). *What we do.* Young Carers Program. Retrieved from https://www.ycptoronto.com/what-we-do.html

Young, J., R. McGrath, and C. Adams. 2018. “Fresh air, Sunshine and Happiness: Millennials Building Health (Salutogenesis) in Leisure and Nature.” *Annals of Leisure Researc,21*(3), 324–346.

Appendix A: Young Carer Co-Researcher Informal Research Summary Sheet

Following is the research summary sheet that was provided to each young carer co-researcher prior to them joining the PAR team. The study title in this form has since been changed by our team to 'Understanding Young Carers and their Leisure (UYCL): A Critical Participatory Action Research (CPAR) Initiative.'

Research Summary Sheet

Study Title: ***Exploring the Leisure Experiences of Young Carers***

Co- researchers:

Rebekah Norman, Master of Arts (MA), University of Waterloo
Email: [redacted]
Cayleigh Sexton, Director of Programs and Services, The Young Caregivers Association
Email: [redacted]
Chelsea-Anne Alex, Young Carers Program Coordinator, Young Carers Program
Email: [redacted]

Informed Consent:

You are being asked to participate in a research study as a co-researcher. This form explains the purpose of this research study and provides details about what your role would be during this decision-making phase if you choose to participate. This consent is requested by The Young Caregivers Association and The Young Carers Program who will be recruiting young carers to be co-researchers in this project. The University of Waterloo does not require consent from co-researchers during this decision-making phase of the research process. Please read this form carefully and ask any of the listed co-researchers to clarify anything you do not understand or would like to know more about.

Introduction:

This research is being completed as part of my (Rebekah) MA Thesis under the supervision of Dr. Sherry Dupuis at the University of Waterloo. Throughout my (Rebekah) experiences as a young carer supporting a loved one, not only did I feel unheard due to the lack of awareness of my situation and resources available to me, but I also was never provided with the opportunity to share my story to create change. Often in adult-centered institutions such as schools, it is adults who share young peoples' stories and make decisions that effect the lives of young people. When young carers are not provided with the space to share their stories and inform decisions, they continue to remain unheard and unsupported. Not only does this situation exist in schools, but in leisure settings as well. Since many studies have found how important leisure is for young people, it is especially concerning that leisure settings are not accessible to young carers and that their voices do not inform these leisure settings.

This research aims to explore how young carers think about and experience leisure to bring awareness to their unique situations and to further understand the role that leisure plays in their lives. We recognize that young carers hold deep knowledge about their lives and experiences and because of this, should help shape the decisions that influence them. In this research, we take guidance from participatory action research (PAR) which is a process that involves researchers and participants working together to examine a problematic situation or action to change it for the better. As part of the PAR team, you will be considered a co-researcher who will have an active role in sharing your voice and influencing decisions about each stage of the research process. Through taking guidance from PAR, we respect each member of the PAR team as authors and experts of their own lives and recognize that each co-researcher brings unique knowledge and strengths that are vital to this research.

Who is eligible?

To be involved you should identify as a young carer between the ages of 12 to 24. The Young Caregivers Association defines young carer as a child, youth, or young adult who provides care for a family member due to a chronic illness, disability (physical or intellectual), mental health concern, substance misuse, or socioeconomic factor (language barrier, etc.).

What will happen during this research?

Participation in this research is voluntary and you may discontinue your position as co-researcher at any time. As a member of the PAR team, you are being asked to engage in ongoing collaboration, participation, and decision-making with the PAR team until May 2022. This will involve monthly or bi-monthly meetings, depending on the availability of the team members. We recognize that you are committing to a long process, and we greatly appreciate your willingness to be a co-researcher. We acknowledge that you may be very busy at certain times throughout the research and are more than willing to accommodate your schedule.

This research involves meeting with the PAR team to make decisions about the research process. This may include developing research questions, exploring how information might be collected from other young carers, working with me (Rebekah) to collect information from other young carers, analysing all the information provided, and deciding how to share that information with others. You will have the opportunity to indicate what aspects of the project you feel more comfortable participating in. We will be working hard to make sure that you feel supported and confident when making decisions throughout this research and it is not expected that you have any research experience when you join this team.

What are the risk or harms of participating as a co-researcher?

There are no anticipated risks in participating in this research as a co-researcher during the decision-making phase, but you may experience some short-term emotions due to topics related to your experiences as a young carer in PAR team meetings. If you experience any feelings of discomfort, please contact Rebekah Norman, Cayleigh Sexton, and/or Chelsea-Anne Alex for support.

As all co-researchers have the option to share their stories and experiences, we require that information shared within the PAR team remain confidential. Although you will be provided with the option for your identity to be kept confidential outside the PAR team, members of the PAR team will know your identity. If you would like to contact a fellow young carer co-researcher on the team, please contact Cayliegh Sexton or Chelsea-Anne Alex. At all times, you can share as much or as little information as you feel comfortable. Again, the focus of our team meetings will be on making decisions about the research project.

For participating in meetings using an online video call, it is important for you to understand that when information is transmitted over the internet confidentiality cannot be guaranteed. This research will use a zoom platform for PAR team meetings. Participating in the online call can be done with or without video, depending on what you are comfortable with.

What are the benefits of participating as a co-researcher?
You will be considered a co-researcher throughout this research. You will be provided with the option to identify yourself as a co-researcher or to not be identified. If choosing to be identified as a co-researcher on this PAR team, you will be given credit as a co-researcher on all research-related documentation. By participating in this project, you will have the opportunity to have a voice in decisions made about research on young carers, something that has rarely happened in the past. Your participation in this research may help spread awareness about young carers and inform future research, programming, and policy related to young carers.

I have read the information presented in the Research Summary Sheet about a project being conducted by Rebekah Norman through the University of Waterloo. I understand that this Research Summary Sheet provides information about my role as a co-researcher during the decision-making phase of the research process. I am aware that I am being asked to become a co-researcher for this research and to commit to participation until May 2022. I am aware that, if I chose, I will be identified as a co-researcher on all research-related documentation. I am also aware that other members of the PAR team will know my identity. I understand that if I have any questions or need additional support throughout this research, I can contact Rebekah Norman, Cayleigh Sexton, and/or Chelsea-Anne Alex. I have been told that I can share as much or as little information as I feel comfortable. I was informed that I may withdraw my consent at any time without penalty by advising Rebekah Norman.

With full knowledge of all information provided to me in the Research Summary Sheet, I agree to participate as a co-researcher on the PAR team.

☐YES ☐NO

I agree to be identified as a co-researcher in this study on presentations, reports and publications related to the project.

☐YES ☐NO ☐Would Like to Decide Later

I would like Rebekah Norman to communicate with me through (please write contact details):

☐EMAIL: ____________________ ☐TEXT: ____________________ ☐BOTH

Co-Researcher Name and Signature: _____________________________ Date: _______________

Appendix B: Team Guidelines

TEAM Guidelines

- Be honest with team members
- Embrace vulnerability and trust the team
- Show team members the respect you would like to receive
- Listen to team members and lend a hand when you can
- Be a friend
- Show empathy to all team members
- Use all our power to understand each other and demonstrate solidarity
- Maintain confidentiality within the team
- Providing team members with the space to share their voices, opinions, perspectives
- Show kindness and patience
- Be open to different opinions and perspectives

Appendix C: Team Meeting Outlines

Outlined below are eight PAR team meeting outlines. Within each outline is the topic, activity, agenda, and questions.

TEAM MEETING PLAN – July 19th 1 hour

TOPIC: Introduction and Purpose of Research

Activity:

- Two truths and one untruth
- Strengths you bring to the team (See List)
- Open discussions

YOUR NOTES

-

AGENDA

- Introduce ourselves.
- Learn about participatory action research (PAR) and critical youth theory (CYT).
- Talk about the strengths of all co-researchers.
- Explore and share leisure experiences.
- Talk about research purpose.

TODAY'S QUESTIONS:

- What strengths do you bring to this research?
- What decisions do you make about the type of leisure you are involved in? If you do not choose your leisure, who does?
- How do you feel about the purpose of this research?
- What questions do you have?
- When are you available for meetings?

NEXT STEPS

NEXT MEETING IS: ____________________ AT __________________

TEAM MEETING PLAN –

TOPIC: Purpose, Leisure, Research Questions, Participatory Action Research (PAR)

Activity:

- Roll the dice & answer the question (Each number on the dice will either be a question about yourself or your opinions about the research)

YOUR NOTES

AGENDA

- Check in: How are you today?
- Talk about confidentiality and meeting guidelines.
- Talk about and break down the research purpose.
- Explore definition of leisure and leisure experiences.
- Develop research questions.
- Learn more about the methodology: PAR

TODAY'S QUESTIONS:

- How are you? Do you have any questions or thoughts about last meeting?
- How do you feel about the purpose of this research?
- Do you participate in leisure? What do you do? Is it easy to participate in?
- What are important questions to ask young carer participants about their leisure that will help us learn more about their experience?
- Do you have any questions about PAR?

NEXT STEPS

NEXT MEETING IS:

TEAM MEETING PLAN –

TOPIC: *Purpose, Research Objectives, Research Questions, Methods of Data Collection*

Activity:

- Brainstorm + Pros/Cons of Methods

Purpose: To partner with young carers to expand our understanding of young carers' experiences of care and the influence of those experiences on leisure.

Objectives:

- To explore how young carers think about and experience their care roles
- To bring awareness to the unique experiences of young carers
- To understand the meaning and experiences of leisure in the lives of young carers
- To identify specific ways to better support young carers

***What questions do we need to ask young carers to answer these objectives?**

YOUR NOTES

-

AGENDA

- Check in: How are you today?
- Talk about the research purpose and the research objectives
- Begin to develop research questions based on each objective
- Learn about and choose methods of data collection

TODAY'S QUESTIONS:

- How are you? Do you have any questions or thoughts about last meeting?
- How do you feel about the research purpose and objectives?
- What questions do we need to ask to answer each of the research objectives?
- What else might we need to ask young carers?
- What are the pros and cons of each data collection method?
- What type of data collection method do you prefer? Why?
- Do you have any additional questions or thoughts?

NEXT STEPS

NEXT MEETING IS:

TEAM MEETING PLAN –

TOPIC: *Recap + Reflect on team meetings, Plan next meeting time*

Activity:

- Guess the birthday!
- Brainstorm + Discussion

Purpose: To partner with young carers to expand our understanding of young carers' experiences of care and the influence of those experiences on leisure.

Objectives:

- To explore how young carers think about and experience their care roles
- To bring awareness to the unique experiences of young carers
- To understand the meaning and experiences of leisure in the lives of young carers
- To identify specific ways to better support young carers

YOUR NOTES

-

AGENDA

- Check in: How are you today?
- Reflect on team meetings
- Plan next meeting time/date

TODAY'S QUESTIONS:

- How are you? Do you have any questions or thoughts about last meeting?
- What do you want this research to do?
- What resources if any would you want this research to contribute to/develop?
- What (if anything) would you like to talk about more?
- Do you feel supported/heard/valued in these meetings?
- How can we make these meetings better?
- What time/date is best for you to meet in the future?
- Do you have any additional questions or thoughts?

*How we want to represent our data will change as we begin to analyse what the young carers say in their interviews.

NEXT STEPS

- NEXT MEETING: We will discuss Data Analysis and Representation

NEXT MEETING IS:

TEAM MEETING PLAN –

TOPIC: *Simplify research objectives + next steps/updates + reflection on our own experiences*

Activity:

- Same and Different Activity
- Brainstorm + Discussion

Purpose: To partner with young carers to expand our understanding of young carers' experiences of care and the influence of those experiences on leisure.

Objectives:

- Provide a platform to privilege the voices of young carers
- Challenge the dominant perspectives of young carers - **COMBINE**
- **Bring awareness** to the unique experiences of, and discrimination faced by, young carers -**COMBINE**
- **Challenge the dominant perspectives of young carers through bringing awareness to their unique experiences**
- **Ensure young carers are better supported in their roles by identifying specific ways to support young carers, including in their leisure**

AGENDA

- Check in: How are you today?
- Simplify research objectives
- Plan next meeting time/date + discuss next steps
- Reflect on care experiences

TODAY'S QUESTIONS:

- How are you? Do you have any questions or thoughts about last meeting?
- What are the key objectives we want to achieve through this research?
- How do you feel about the update on data analysis (mentioned in this meeting)?
- How do you feel about the plans for data collection (mentioned in this meeting)?
- Do you have any additional questions or thoughts?

NEXT STEPS

- NEXT MEETING:

NEXT MEETING IS:

TEAM MEETING PLAN –

TOPIC: *Research Conversations + Research Conversation Guide, Data Analysis, Next Steps*

Activity:

- Pictionary Online
- Brainstorm + Discussion

Purpose: To partner with young carers to expand our understanding of young carers' experiences of care and the influence of those experiences on leisure.

YOUR NOTES

AGENDA

- Check in: How are you today?
- Reflect on care experiences
- Talk about research conversations (interviews) and analysis
- Go over research conversation guide
- Plan next meeting time/date + discuss next steps

TODAY'S QUESTIONS:

- How are you? Do you have any questions or thoughts about last meeting?
- What can we do to better support you?
- What role would you like to have in research conversations and analysis?
- How do you feel about the research conversation guide and structure?
- How do you feel about our data analysis plan moving forward?
- Do you have any additional questions or thoughts?

NEXT STEPS

NEXT MEETING IS:

TEAM MEETING PLAN –

TOPIC: *Check In, Reflection, Next Steps*

Activity:

- Pictionary Online
- Discussion + Reflection

Purpose: To partner with young carers to expand our understanding of young carers' experiences of care and the influence of those experiences on leisure.

YOUR NOTES

AGENDA

- Check in: How are you today? How was your holiday?
- Where we are now in this process!
- Reflect on care experiences.
- Talk about next steps.

TODAY'S QUESTIONS:

- How are you? Do you have any questions or thoughts about last meeting?
- What supports or resources do we need to participate in the capacity we want?
- How are the opinions and perspectives of all partners shared?
- I have learned thus far that….
- How have our understandings of others changed over time?
- What actions are needed to move forward?
- Do you have any additional questions or thoughts?

NEXT STEPS

NEXT MEETING IS: TBA

TEAM MEETING PLAN –

TOPIC: *Check in, Timelines, Research Conversations, Analysis, Scheduling*

Activity:

- Two truths and one untruth
- Discussion + Reflection

Purpose: To partner with young carers to expand understandings of young carers' experiences of care and how those care experiences shape leisure.

YOUR NOTES

AGENDA

- Check in: How are you today? What are your plans for march break?
- Discuss timelines for this project
- Reflect on care experiences.
- Talk about research conversations, go over conversation guide
- Talk about next steps for scheduling

TODAY'S QUESTIONS:

- Do you have any questions or thoughts?
- What supports or resources do we need to participate in the capacity you want? What role would you like to have moving forward?
- How do you feel about research conversations/participating in them?
- What questions do you have about analysis?
- Do you have any additional questions or thoughts?

NEXT STEPS

NEXT MEETING IS: TBA

Appendix D: Co-Researcher Formal Consent Form

Co-Researcher Informed Consent to Participate in a Research Study

Study Title: ***Understanding Young Carers and their Leisure (UYCL): A Participatory Action Research (PAR) Initiative***

Lead Student Researcher:

Rebekah Norman, Master of Arts (MA), Recreation and Leisure Studies, University of Waterloo
Email: [redacted]

Faculty Supervisor:

Dr. Sherry Dupuis, PhD, Recreation and Leisure Studies, University of Waterloo
Email: [redacted]

Co-Researchers:

Cayleigh Sexton, Director of Programs and Services, The Young Caregivers Association
Email: [redacted]
Chelsea-Anne Alex, Young Carers Program Coordinator, Young Carers Program
Email: [redacted]
Emaan Fatima, Young Carer
Chloe Chomos, Young Carer
Saige Johnston, Young Carer
Bernadette Sarmiento, Young Carer

Informed Consent:

You are being asked to participate in a research study as a co-researcher. This form explains the purpose of this research study and provides details about what your role would be during this process if you choose to participate. Please read this form carefully and ask Rebekah Norman to clarify anything you do not understand or would like to know more about. Young carers can also reach out to Cayleigh Sexton and/or Chelsea-Anne Alex if they have questions.

The study you are about to read about has received ethics clearance from a University of Waterloo Research Ethics Board (ORE #44039).

Introduction:

My name is Rebekah Norman and I am completing this research as part of my MA Thesis under the supervision of Dr. Sherry Dupuis at the University of Waterloo. I am also a young carer and throughout my experiences as a young carer supporting a loved one, not only did I feel unheard due to the lack of awareness of my situation and resources available to me, but I also was never provided with the opportunity to share my story so I could inform needed changes. When young carers are not provided with the space to share their stories and inform decisions, they continue to remain unheard and unsupported. This research aims *to partner with young carers to expand our understanding of young carers' experiences of care and how those care experiences shape their leisure and recreation.*

In this research, I am using a participatory approach called participatory action research (PAR). What this means is that I am partnering with staff from young carer organisations and young carers themselves in determining how best to approach this research. You are being invited to participate as a member of the PAR team. In this role, you will be considered a co-researcher who will have an active role in making decisions with other team members about the research, including, data collection, data analysis, and data representation phases of the research.

Who is eligible?

To be involved as a co-researcher you should identify as a staff person working with young carers or a young carer between the ages of 12 to 25. The Young Caregivers Association defines young carer as children, youth, and young adults under the age of 25 who have extra responsibilities and offer support to a family member due to a chronic illness, disability (physical or intellectual), mental health concern, substance misuse, parental absence, or other social or cultural factors (e.g., language barrier, etc.).

What will happen during this research?

As a member of the PAR team, you are being asked to engage in ongoing collaboration, participation, and decision-making with the PAR team until the completion of the analysis for the project, likely June 2022. This will involve continued monthly or bi-monthly meetings, depending on the availability of the team members. These meetings are not recorded; however, I will be manually documenting discussions, decisions made, ideas shared, reflections on the process, and select quotes made during the meetings. No names will be identified in the documented notes. I recognize that you are committing to a long process, and we greatly appreciate your willingness to be a co-researcher. I acknowledge that you may be very busy at certain times throughout the research and are more than willing to accommodate your schedule.

This research involves meeting with the PAR team to make decisions about the research process. This will also include working with me when available to collect information from other young carers in research conversations (interviews), analysing the information collected, and deciding how to share that information with others. In research meetings, we will also regularly participate in conversations about your experience as a co-researcher that will be used to enhance the research process for everyone involved and may be used to inform future participatory processes with young people. You will have the opportunity to indicate what aspects of the project you feel more comfortable participating in. We will be working hard to make sure that you feel supported and confident if you choose to be involved in research conversations (interviews) with me and young carer participants and in data analysis. It is not expected that you have any research experience to participate as a co-researcher.

What are the risk or harms of participating as a co-researcher?

This project is meant to provide young carers with an opportunity to share their experiences and play a role in determining what is needed to better support young carers in their care roles. We do not anticipate major risks associated with participating as a co-researcher in this research. However, you may experience some short-term emotions when speaking about topics related to your experiences as a young carer or hearing about the experiences of other young carers. Should this happen, you can discontinue your involvement in the project. If you are a young carer and feel you need support, you are encouraged to contact Rebekah Norman, Cayleigh Sexton, and/or Chelsea-Anne Alex.

What are the benefits of participating as a co-researcher?

Very little research on young carers includes the voices and perspectives of young carers themselves. Your participation in this research will assist us in making sure the research is relevant and accessible to young carers and captures their voices. It will also ensure that our understanding of young carers is based on their perspectives and may help spread awareness about young carers and inform future research, programming, and policy related to young carers.

You will be considered a co-researcher throughout this research. You will be provided with the option to identify yourself as a co-researcher or to not be identified. If choosing to be identified as a co-researcher on this PAR team, you will be given credit as a co-researcher on all research-related documents, publications, and presentations based on the research and gain knowledge and experience as a participatory researcher. By participating in this project, you will have the opportunity to have a voice in decisions made about research on young carers, something that has rarely happened in the past.

Finally, you also have access to volunteer hours for all time spent as a co-researcher in this study. Please connect with Rebekah Norman, Cayleigh Sexton, and/or Chelsea-Anne Alex for more information about this benefit.

How do I maintain confidentiality and keep participants' information secure?

You will have the opportunity to indicate if you wish to be identified as a co-researcher outside of this project. You should be aware that other members of the research team will know your identity and should you participate in co-facilitating research conversations with young carer participants, those individuals will also know your identity. Thus, it will be impossible to completely protect your identity in these situations.

As a co-researcher, you will be asked to sign an agreement indicating that you will not share participant and co-researcher identities and any information shared in research team meetings and in research conversations outside this research project. All identities and information are to remain confidential. Participants in research conversations will also be asked to keep in confidence information that identifies or could potentially identify any researchers and/or their comments. If you are a young carer, we will work in partnership with Cayleigh Sexton and Chelsea-Anne Alex to ensure that you do not know the young carer participants when you are co-facilitating research conversations, if this is something you agree to do. Participants and co-researchers will also be told that they should not make any recordings or take photos of research conversations and research meetings. Despite this request, we cannot guarantee that all participants or other co-researchers will respect this request. Thus, in research meetings and research conversations, we ask co-researchers to only share comments that they would be comfortable making in a public setting and to hold back making comments that they would not say publicly.

Once the research conversations are completed, a text version of the conversation will be created from the video or audio recordings. During this process, all names and identifying information will be removed. Once all identifying information has been removed, some quotations from the research conversations may be shared with the research team via Sendit, a protected platform at the University of Waterloo, for analysis purposes. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

Quotations from research conversations or captured during research meetings may be used when consent is provided to do so, but pseudonyms will be used in place of real names. Only I will have access to study forms/files that identify co-researchers and participants (i.e., participant consent forms, video and audio recorded Zoom conversations) and these will be stored separately from the research transcripts.

The written electronic information that is collected for the study, including consent forms and transcripts of the video/audio-recordings, will be kept on a personal, password protected computer for a minimum of 1 year, after which time they will be destroyed as required by, and in a way that is consistent with, University of Waterloo policy. All audio and video recordings will be permanently deleted as soon as they are transcribed and transcripts have been checked with the audio/video files, likely within three months of the research conversation. No data collected during this research project will be saved to a cloud platform.

When participating in a research conversation or research meeting using an online video call, it is important for you to understand that when information is transmitted over the internet confidentiality cannot be guaranteed. This study will use the Zoom videoconferencing platform for all team meetings and to collect data, which is an externally hosted cloud-based service. A link to their privacy policy is available here (https://zoom.us/privacy). Please note that there is a small risk with any platform such as this of data that is collected on external servers falling outside the control of the research team. If you are concerned about this, we would be happy to make alternative arrangements for you to participate in another way, perhaps via telephone. Please talk to me if you have any concerns.

What are the rights of participants in a research study?

You have the right to have this form and all information about this study explained to you. Participating in this study is your choice (voluntary). You have the right to choose not to participate, or to stop participating in this study at any time without having to provide a reason. Even if your parent/guardian consents on your behalf, we will seek your (young carer) consent prior to participation. Your decision to participate (or not) or to discontinue your participation will have no affect on your involvement with and the support you receive from the young carer organisations partnering with me on this project. The data we collect from a participant or co-researcher who chooses to withdraw will be removed from our research unless the participant or co-researcher gives us permission to use what they have already contributed. Once we have submitted the research for publication it will not be possible to remove data. Should you choose to withdraw from the study you are encouraged to contact me.

During research meetings and research conversations you co-facilitate, you have the right to participate and share only what you feel comfortable sharing. You can share as much or as little as you feel comfortable.

You have the right to receive all the information you need to help you make an informed decision about participating in this study. You also have the right to ask questions about this

study and your rights as a co-researcher, and to have them answered, before you make any further decision. If you have any questions about this study, please contact me.
You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please provide your name, address and telephone number to me, Rebekah Norman at [redacted]

Who do I go to if I have questions or concerns?

Any questions with regard to this research should be directed to Rebekah Norman at [redacted] If you are a young carer, Cayleigh Sexton ([redacted]) and Chelsea-Anne Alex ([redacted]) are also available to answer any of your questions.

I want to remind you that this study has received ethics clearance through a University of Waterloo Research Ethics Board (ORE #44039). Should you have any comments or concerns resulting from your involvement in this study, please contact the Office of Research Ethics at the University of Waterloo at 519-888-4567, ext. 36005 or reb@uwaterloo.ca.

If you are willing to participate in this research, please complete the appropriate consent form attached. If you are under the age of 17, you will also need your parent/guardian to sign their consent form as well. Signed consent forms should be sent to me, Rebekah Norman at [redacted].

Consent of Co-Researchers

By signing this consent form, you are not waiving your legal rights or releasing the researcher(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the Co-Researcher Informed Consent Form about a project being conducted by Rebekah Norman through the University of Waterloo. I understand that this Co-Researcher Informed Consent form provides information about my role as a co-researcher during the research process. I am aware that I am being asked to become a co-researcher for this research and to commit to participation until June 2022. I am aware that, if I choose, I will be identified as a co-researcher on all research-related documentation. I am also aware that other members of the PAR team and some participants involved in research conversations I co-facilitate will know my identity. I understand that if I have any questions or need additional support throughout this research, I can contact Rebekah Norman at [redacted]. Young carers can also reach out to Cayleigh Sexton and/or Chelsea-Anne Alex should they have questions or concerns, or if they need support. I have been told that I can share as much or as little information as I feel comfortable. I was informed that I may withdraw my consent at any time without penalty by advising Rebekah Norman. A photo of this completed consent form is acceptable. Please send the photo of the completed form to Rebekah Norman, email: [redacted].

Permissions:

With full knowledge of all information provided to me in the Co-Researcher Informed Consent Form, I consent to participating as a co-researcher on the UYCL PAR team.

☐YES ☐NO

I consent to the audio/video recording of the research conversations for this study.

☐YES ☐NO

I have been made aware that I am required to keep identities of other co-researchers and participants and all information shared throughout the project completely confidential and agree to do this.

☐YES ☐NO

I agree to be identified as a co-researcher in this study on presentations, reports and publications related to the project.

☐YES ☐NO ☐Would Like to Decide Later

I consent to the use of anonymous quotations in any presentations, reports and publications related to the project.

☐YES ☐NO

Co-Researcher Name ______________________________

Co-Researcher Signature: _________________________ Date: ____________________________

Consent of Parent/Guardian (If required)

By signing this consent form, you are not waiving your legal rights or releasing the researcher(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the Co-Researcher Informed Consent Form about a project being conducted by Rebekah Norman through the University of Waterloo. I understand that this Co-Researcher Informed Consent form provides information about my child's role as a co-researcher during the research process. I am aware that they are being asked to become a co-researcher for this research and to commit to participation until June 2022. I am aware that, if my child wishes and consent is provided, they will be identified as a co-researcher on all research-related publications, documents and presentations resulting from the research. I am also aware that other members of the PAR team and some research participants will know my child's identity. I understand that if I or my child have any questions or need additional support throughout this research, we can contact Rebekah Norman, Cayleigh Sexton, and/or Chelsea-Anne Alex. My child has been told that they can share as much or as little information as they feel comfortable. We have also been informed that I/we can withdraw consent at any time without penalty by advising Rebekah Norman. A photo of this completed consent form is acceptable. Please send the photo of the completed form to Rebekah Norman, email: [redacted].

Permissions:

With full knowledge of all information provided to me in the Co-Researcher Informed Consent Form, I consent to my child participating as a co-researcher on the UYCL team.

☐YES ☐NO

I consent to the audio/video recording of the research conversations for this study.

☐YES ☐NO

I have been made aware that my child is required to keep identities of other co-researchers and participants and all information shared through the project completely confidential and agree to support my child in complying with this responsibility.

☐YES ☐NO

I agree for my child to be identified as a co-researcher in this study on presentations, reports and publications related to the project.

☐YES ☐NO ☐Would Like to Decide Later

I consent to the use of anonymous quotations made by my child in any presentations, reports and publications related to the project.

☐YES ☐NO

Co-Researcher Name _______________________ Parent/Guardian Name____________________

Parent/Guardian Signature: ____________________________ Date: ________________________

Appendix E: Recruitment Details Form

Recruitment Details

Criteria:

- Four to six young carers (ex. 2-3 from each: YCA and YCP)
- Young carers between the ages of 12-25, identify as a young carer
- Preferably look for diversity in gender, race, ethnicity if possible

Instructions for Participant Ethics Documents:

- Please see email template for initial recruitment of young carers
- After you have determined young carers who are interested in participating: I will send you the Information Letter and Consent Form to be signed (by themselves and guardian if necessary) (or other options can be arranged, ex. email reply) and returned to you (virtually- a photo is also acceptable).
- I will then ask that you send the Information Letters/Consent Forms to me, where I will keep them secure.

Instructions for Co-researcher Ethics Documents:

- I will send out the Information Letter and Consent Form with our next meeting invitation
- At our meeting, I will set aside time for co-researchers to ask any questions about the Information Letter and Consent Form
- I will then ask co-researchers (and guardians if necessary) to sign said forms as soon as possible and email directly to me, and ask that you check in with co-researchers to make sure they are comfortable and able to sign the form

Appendix F: Invitation Email Template for Participant Recruitment

Dear <<NAME>>,

The Young Carers Association and the Young Carers Program have partnered with Rebekah Norman, an MA student at the University of Waterloo and a young carer, on a participatory research project. The purpose of the research is to partner with young carers to expand our understanding of young carers' experiences of care and how those care experiences shape their leisure. Information generated from this research will help spread awareness about young carers and inform future research, programming, and policy related to young carers.

You are receiving this message of invitation to participate in this study because either Cayleigh Sexton or Chelsea-Anne Alex has identified you as a young carer or parent/guardian of a young carer. Participation in this study will include one research conversation (interview) with a young carer that will take approximately one hour or less. The research conversation will be held using Zoom videoconferencing (requires a computer with an internet connection and microphone). Conversations will audio and/or video recorded to allow the research team to engage in analysis. You can find more details about the study in the attached consent form.

Your233helsea233n to participate or not participate in this study will not affect your ability to participate in future research projects, your relationships with the researchers and co-researchers, or your ability to access resources from the Young Carers Association, the Young Carers Program, or that may come from this study.

If you have further questions before you make a decision about your participation in the study, please contact Cayleigh Sexton (Co-researcher, email: [redacted]), Chelsea-Anne Alex (Co-researcher, email: [redacted]), and/or Rebekah Norman (Lead Student Researcher, email: [redacted]).

If you are willing to participate, please complete the attached consent form and forward it to Rebekah Norman. If you are under the age of 17, you will also need your parent/guardian to sign their consent form as well.

We would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board [ORE #44039].

Sincerely,
<<Name>>
<<Title>>

Appendix G: Participant Consent and Confidentiality Form

Informed Consent to Participate in a Research Study

Study Title: ***Understanding Young Carers and their Leisure (UYCL): A Participatory Action Research (PAR) Initiative***

Lead Student Researcher:

Rebekah Norman, Master of Arts (MA), Recreation and Leisure Studies, University of Waterloo
Email: [redacted]

Faculty Supervisor:

Dr. Sherry Dupuis, PhD, Recreation and Leisure Studies, University of Waterloo
Email: [redacted]

Co-Researchers/Members of the PAR Team:

Cayleigh Sexton, Director of Programs and Services, The Young Caregivers Association
Email: [redacted]
Chelsea-Anne Alex, Young Carers Program Coordinator, Young Carers Program
Email: [redacted]
Emaan Fatima, Young Carer
Chloe Chomos, Young Carer
Saige Johnston, Young Carer
Bernadette Sarmiento, Young Carer

Informed Consent:

You are being asked to consider participating in a research study. This form explains the purpose of this research study and provides details about what you would be asked to do if you choose to participate. Please read this form carefully and ask Rebekah Norman, Cayleigh Sexton, and/or Chelsea-Anne Alex to clarify anything you do not understand or would like to know more about.

The study you are about to read about has received ethics clearance from a University of Waterloo Research Ethics Board (ORE #44039).

Introduction:

My name is Rebekah Norman and I am completing this research as part of my MA Thesis under the supervision of Dr. Sherry Dupuis at the University of Waterloo. I am also a young carer and throughout my experiences as a young carer supporting a loved one, not only did I feel unheard due to the lack of awareness of my situation and resources available to me, but I also was never provided with the opportunity to share my story so I could inform needed changes. When young carers are not provided with the space to share their stories and inform decisions, they continue to remain unheard and unsupported. This research aims *to partner with young carers to expand our understanding of young carers' experiences of care and how those care experiences shape their leisure and recreation.*

In this research, I am using a participatory approach called participatory action research (PAR). What this means is that I have partnered with staff from young carer organisations and young carers themselves in determining how best to approach this research. You are being invited to be a participant in this study and share your voice within research conversations (interviews). In this PAR project, we respect each participant as authors and experts of their own lives and recognize that each participant brings unique knowledge that is vital to this research.

Who is eligible?

To be involved you should identify as a young carer between the ages of 12 and 25. The Young Caregivers Association defines young carer as children, youth, and young adults under the age of 25 who have extra responsibilities and offer support to a family member due to a chronic illness, disability (physical or intellectual), mental health concern, substance misuse, parental absence, or other social or cultural factors (e.g., language barrier, etc.).

What will happen during this research?

If you choose to participate, you will be invited to participate in one research conversation facilitated by me, and when possible, one other co-researcher on the PAR team. The research conversation will take approximately one hour or less.

Research conversations will be conducted using the on-line platform Zoom on a date and time convenient for you. With your consent, and/or the consent of your parent or guardian, research conversations will be audio and/or video taped using Zoom technology. Zoom technology produces both a video and audio recording of the conversation. Participating in the online research conversation can be done with or without video, depending on what you are comfortable with. If you would like to participate in the research conversation but would not like your image to be captured, you are welcome to participate via audio only by either calling in with your phone or turning off your video on the online call. If you consent only to the audio-recording being used, the video recording will be deleted immediately following the conversation and only the audio recording will be used to create a text version (transcript) of the conversation. I will be the only one who will use the recording to create the conversation transcript.

There will be three guiding questions we will explore with you during the research conversation. These questions address: who participants are as young carers and how they experience their care roles; what they do in their leisure time, how they experience leisure, and what leisure means to them; and their perspectives of supports/services available to them as young carers. I acknowledge that you may be very busy at certain times and am more than willing to accommodate your schedule when planning a date/time for research conversations.

What are the risk or harms of participating?

This project is meant to provide young carers with an opportunity to share their experiences and play a role in determining what is needed to better support young carers in their roles. We do not anticipate major risks associated with participating in this research. However, you may experience some short-term emotions when speaking about topics related to your experiences as a young carer. Should this happen, you can discontinue your involvement in the project or ask to continue the research conversation at another time. Should you feel you need support, you are encouraged to contact Rebekah Norman, Cayleigh Sexton, and/or Chelsea-Anne Alex for support.

What are the benefits of participating?

Very little research on young carers includes the voices and perspectives of young carers themselves. Your participation in this research will ensure that our understandings of young carers is based on their perspectives and may help spread awareness about young carers and inform future research, programming, and policy related to young carers. You also have access to volunteer hours for all time spent as a participant in this study. Please connect with Rebekah Norman, Cayleigh Sexton, and/or Chelsea-Anne Alex for more information about this benefit.

How will my information be kept confidential and secure?

Your identity will be kept confidential and will not be passed to a third party. Only Rebekah, Cayleigh, Chelsea, and the members of the research team who co-facilitate your research conversation will know that you have participated in this research. All members of the research team have signed an agreement indicating that they have agreed not to share participant identities and information outside this research project. Although I trust the members of this research team, you should know that I cannot completely guarantee that all members will honor their agreement not to share identities and information. So, we are asking you to make only those comments that you would be comfortable making in a public setting and to hold back making comments that you would not say publicly.

Given that Rebekah Norman and another member of the research team will be present in, and may share information during research conversations with you, all participants will also be asked to keep in confidence information that identifies or could potentially identify any researchers and/or their comments. Participants should not make any recordings or take photos of research conversations.

Once the research conversations are completed, a text version of the conversation will be created from the video or audio recordings. During this process, all names and identifying information will be removed. Once all identifying information has been removed, some quotations from the research conversations may be shared with the research team via Sendit, a protected platform at the University of Waterloo, for analysis purposes. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated. Participant names will not appear in any paper, report, or presentation resulting from this study. However, with participants’ permission, quotations may be used with a pseudonym in place of participants’ real names. Only I will have access to study forms/files that identify participants (i.e., participant consent forms, video and audio recorded Zoom conversations) and these will be stored separately from the research conversation transcripts.

The written information that is collected for the study, including consent forms and transcripts of the video/audio-recordings, will be kept on my personal encrypted and password protected computer for a minimum of one year, after which time they will be destroyed as required by, and in a way that is consistent with, University of Waterloo policy. All audio and video recordings will be permanently deleted as soon as they are transcribed and transcripts have been checked with the audio/video files, likely within three months of the research conversation. No data collected during this research project will be saved to a cloud platform.

When participating in a research conversation using an online video call, it is important for you to understand that when information is transmitted over the internet confidentiality cannot be guaranteed. This study will use the Zoom videoconferencing platform to collect data, which is an externally hosted cloud-based service. A link to their privacy policy is available here (https://zoom.us/privacy). Please note that there is a small risk with any platform such as this of data that is collected on external servers falling outside the control of the research team. If you are concerned about this, we would be happy to make alternative arrangements for you to participate in another way, perhaps via telephone. Please talk to me if you have any concerns.

What are the rights of participants in a research study?

You have the right to have this form and all information about this study explained to you. Participating in this study is your choice (voluntary). You have the right to choose not to participate, or to stop participating in this study at any time without having to provide a reason. Even if your parent/guardian consents on your behalf, we will seek your (young carer) consent prior to participation. Your decision to participate (or not) or to discontinue your participation will have no affect on your involvement with and the support you receive from the young carer organisations partnering with me on this project. The data we collect from a participant who chooses to withdraw will be removed from our research unless the participant gives us permission to use what they have already contributed. Once we have submitted the research for publication it will not be possible to remove participant data. Should you choose to withdraw from the study you are encouraged to contact me, Rebekah Norman.

During your research conversation, you have the right to skip or not answer any questions you prefer not to answer. You can share as much or as little as you feel comfortable.

You have the right to receive all the information you need to help you make an informed decision about participating in this study. You also have the right to ask questions about this study and your rights as a research participant, and to have them answered, before you make any further decision. If you have any questions about this study, please contact me.

You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please provide your name, address and telephone number to me, Rebekah Norman at [redacted]

Who do I go to if I have questions or concerns?

Any questions with regard to this research should be directed to Rebekah Norman at [redacted]. Cayleigh Sexton ([redacted]) and Chelsea-Anne Alex ([redacted]) are also available to answer any of your questions.

I want to remind you that this study has received ethics clearance through a University of Waterloo Research Ethics Board (ORE #44039). Should you have any comments or concerns resulting from your involvement in this study, please contact the Office of Research Ethics at the University of Waterloo at 519-888-4567, ext. 36005 or reb@uwaterloo.ca.

If you are willing to participate in this research, please complete the appropriate consent form attached. If you are under the age of 17, you will also need your parent/guardian to sign their consent form as well. Signed consent forms should be sent to me, Rebeka Norman at [redacted].

Consent of Young Carer Participant

By signing this consent form, you are not waiving your legal rights or releasing the researcher(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the attached Informed Consent Form about a project being conducted by Rebekah Norman through the University of Waterloo. I understand that this Informed Consent Form provides information about my role should I choose to participate in this study. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I understand that if I have any questions or need additional support, I can contact Rebekah Norman, Cayleigh Sexton, and/or Chelsea-Anne Alex. I have been told that I can share as much or as little information as I feel comfortable. I was informed that I may withdraw my consent at any time without penalty by advising Rebekah Norman. A photo of this completed consent form is acceptable. Please send the photo of the completed form to Rebekah Norman, email: [redacted]

For all other questions, contact Rebekah Norman, email: [redacted].

Permissions:

With full knowledge of all information provided to me in the Informed Consent Form, I consent to participating in a research conversation for this study.

☐YES ☐NO

I consent to the video recording of the research conversation for this study.

☐YES ☐NO

I consent to the audio recording of the research conversation for this study.

☐YES ☐NO

I consent to the use of anonymous quotations in any presentations, reports and publications related to the project.

☐YES ☐NO

____
Printed Name of Young Carer Participant

____________________________________ ____________________________________

Signature of Young Carer Participant Date

Consent of Parent/Guardian

By signing this consent form, you are not waiving your legal rights or releasing the researcher(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the Informed Consent Form about a project being conducted by Rebekah Norman through the University of Waterloo. As the parent/guardian of a young carer, I understand that this Informed Consent Form provides information about the young carers' role should we consent to their participation in this study. We (me and/or the young carer) have had the opportunity to ask any questions related to this study, to receive satisfactory answers to our questions, and any additional details we wanted. I understand that if we have any questions or need additional support, I can contact Rebekah Norman, Cayleigh Sexton, and/or Chelsea-Anne Alex. I have been told that the young carer can share as much or as little information as they feel comfortable. I was informed that I may withdraw this consent at any time without penalty by advising Rebekah Norman. A photo of this completed consent form is acceptable. Please send the photo of the completed form to Rebekah Norman, email: [redacted]

For all other questions, contact Rebekah Norman, email: [redacted].

Permissions:

With full knowledge of all information provided to me in the Informed Consent Form, I consent to my child participating in a research conversation for this study.

☐YES ☐NO

I consent to the audio recording of the research conversation for this study.

☐YES ☐NO

I consent to the video recording of the research conversation for this study.

☐YES ☐NO

I consent to the use of anonymous quotations in any presentations, reports and publications related to the project.

☐YES ☐NO

______________________________	______________________________
Printed Name of Young Carer	Printed Name of Parent/Guardian
______________________________	______________________________
Signature of Parent/Guardian	Date

Appendix H: Narrative Research Conversation Guide and Script

Script:

Rebekah: Hi, my name is Rebekah Norman. I am currently pursuing my master's degree in Recreation and Leisure Studies at the University of Waterloo. I am the lead student researcher for this study, and I am also a young carer to my parent who experiences a mental health concern and is recovering from substance misuse. I am partnering with staff at the Young Caregivers Association and the Young Carers Program and four young carers who are all members with me of the participatory action research team.

Co-researcher: *Co-researcher(s) introduce themselves.*

Rebekah: How are you? Is this still a good time to talk with you?

Participant:

If no:

Is there a better time to speak with you? Thank you, goodbye.

If yes:

Great. Before we begin, I would like to quickly remind you of the information shared with you in the informed consent form you signed. As you know, this study is being used for research purposes at the University of Waterloo. The aim of this research study is partner with young carers to expand understandings of young carers' experiences of care and how those care experiences shape leisure. The purpose of doing this is to ensure young carers are better supported in their roles by identifying specific ways to support young carers, including in their leisure. The research conversation we are going to participate in now should take approximately one hour. You should share as much or as little as you feel comfortable. If you aren't comfortable with answering any of the questions, please feel free to skip it, and you may withdraw from the study at any point in time without any consequence. Your responses are confidential, and we ask that you please do not share anything that is said with anyone outside this conversation. While we can make this request, however, you should know that we can't guarantee no one will repeat what you said outside of this conversation. No information that discloses your identity will be released or published. The data from this research conversation will only be seen by our research team and identifying information will be removed from the transcripts. Do you still agree, of your own free will, to participate in this study?

If no:

Okay, thank you for your consideration. Goodbye.

If yes:

This research conversation will be video and/or audio recorded based on what you consented to. If you do not want your image to be captured on video, please turn your camera off or call in via your phone. The audio files will only be used by me to document your responses into a written transcript. Do you agree to being audio-recorded?

If no:

Okay. I will take detailed notes to try and accurately capture your answers.

If yes:

Okay, I will start the recording now. Do you have any questions for me before we begin?

If no:

Okay, great. Let's get started. -Begin with question 1-

If yes:

-Answer Questions then begin with question 1-

Questions:

1. **Tell me a little about yourself and you as a young carer.**
   - a) How old are you?
   - b) How would you describe yourself?
   - c) When did you become a young carer?
   - d) What does being a young carer mean to you?
   - e) What kinds of things do you do in your care role?
   - f) What is it like to be a young carer – what is that experience like? What, if any, challenges/difficulties do you experience as a young carer? What, if any, positive aspects do you experience as a young carer?
2. **Tell me about what you like to do for fun or to refresh.**
   - a) Can you give me an example?
   - b) What was the situation?
   - c) Who were you with?
   - d) How did it feel?
   - e) When was the last time you were able to do that?
   - f) How does your care role influence how you might experience this or other experiences like it? What gets in the way of you experiencing this or other experiences like it?
3. **How do you feel you could be better supported in your care role and in the things you enjoy doing?**
   - a) How are you supported in your care role now?
   - b) How are you supported in experiencing what you like to do for fun or to refresh now?
   - c) What would you change about the services/supports available to you?
   - d) What do you need to help you feel better supported in your care role?
   - e) What do you need to help you feel better supported in experiencing the things you enjoy doing in your life?

Probes:

- You mentioned ______; could you tell me more about that.
- You mentioned ____, and that _____ happened. Could you give me a specific example of that?
- Thinking back to that time, what was that like for you?
- You mentioned earlier that you _____. Could you describe in detail what happened?

Appendix I: Instructions for Research Analysis

Instructions for Data Analysis

You have until Wednesday May 19th to read through the data and make notes/comments.

1. Fill out the doodle poll in the email. Include all dates/times that work for you to meet online.
2. Once you receive your transcript:
   - Save it to your computer (in a safe place where only you will see/access it)

     OR
   - Print off the transcript and keep it in a safe, private place where only you can see/access it
3. Read through the transcript once. Write notes about your thoughts and highlight quotes that feel important to you (either on the transcript or in a notebook). Continue to check in with the 'Questions to Ponder' document as you read through the data and write down your thoughts relating to the questions.

   NOTE: You do not have to answer every question - they are to help you reflect on important concepts as you read.
4. Read through the transcript a second time and write notes about your thoughts. Pay special attention to the 'Sensory Questions' in the 'Questions to Ponder' document this second time around. Think about how this transcript makes you feel and why.
5. Have your notes/comments available for you to have with you during our next analysis meeting.

Important Points to Remember

- If you feel comfortable, feel free to write about yourself as you read. (ex. 'this is different then my experience because...,' 'this shocked me because...' 'this is similar to my experience because...''this made me feel___because...')
- Make sure to make comments on all the people speaking in the transcript (ex. I, I2, P).
- If you can, take breaks when you read the transcript. You can read it all in one go, but sometimes I feel it helps me digest the information if I take a step back and read in chunks (ex. 3 pages at a time).
- As always, if you are feeling overwhelmed, confused, or need to talk, you can always email or text/call me (705-329-8761).

Appendix J: Questions to Ponder- Research Analysis

Questions to Ponder

- What are some common things that you see? What keeps popping up?
- What are some differences/contradictions that you see?

Leisure

- What stories are young carers telling about their leisure? How are they telling (describing) these stories?
- What does leisure mean to young carers? How do they describe leisure?
- Are the stories about young carers experiences of leisure positive or negative? What is positive or negative about them?
- How do young carers control their leisure? If they do not have control over their leisure, why don't they?
- Who do young carers think can better support them in doing the things they like to do for fun or to refresh? How can those people (ex. professionals, family members, service providers) better support young carers in doing those things?

Young Carer Experience

- What stories are young carers telling about their care experience? How are they telling (describing) these stories?
- Are the stories about young carers experiences of caring positive or negative? What is positive or negative about them?
- How are young carers describing young people? What do young carers think about young people?
- How are young carers involved in decision making? If they aren't, how or why are they not involved?
- Who do young carers think can better support them in their care roles? How can those people (ex. professionals, family members, service providers) better support young carers in their care roles?

Sensory Questions

- What pictures come to your mind when you go through the data?
- What images do you see in the data?
- How does the data make you feel? What parts of the data make you feel this way?
- How did your body feel when you were reading the data? What parts of the data made your body feel this way?

Further Thoughts

- What surprised you about what you read/are reading?
- What did not surprise you about what you read/are reading?
- What is sticking with you as you are reading? What about that sticks with you?
- What metaphors are coming out as you read?
- What symbols are emerging as you read?

Appendix K: Contemplation Questions and Activity

<u>Contemplation Questions</u>

1. How has this experience been for you? What are your thoughts?
2. Find an object around you that says something about what you saw in the data and describe it

OR

Find an object that reflects how you think about being a young carer and describe it

3. What did you see in the data that supported or challenged dominant constructions of young carers and young people? (ex. too young to be providing care, not involved in decision making, etc.)

Appendix L: Contestation Questions

Contestation Questions 😊

Research Questions:

- How do young carers story their experiences of care and leisure in their unique contexts of caring?
- How do the stories of young carers' experiences of care and leisure contrast with the dominant constructions presented in the literature?
- How might service providers and leisure professionals better support young carers in their care roles, including in their leisure?
- What are the key/important ideas that we feel we need to capture?

Comparisons

- Are there any similarities or differences between the pieces?
- Are there any similarities or differences between the key ideas we brought from the transcripts?

Young Caring Experience

- What do the transcripts say about the experience of young caring?
- What does this piece say about the experience of young caring?

Critical Youth Studies

- How do these transcripts challenge the dominant understanding of young carers? (ex. challenge the idea that young carers are living a life they shouldn't be, that the caring experience is primarily negative, etc.)
- How does this piece challenge the dominant understanding of young carers?
- How does this piece challenge the dominant understanding of young people? (ex. challenge that young people shouldn't be involved in decision-making, that young people are immature, that childhood is a time of innocence and dependency, etc.)
- How do these transcripts support the dominant understanding of young carers?
- How does this piece help provide an alternative understanding/discourse of young carers?
- What contradictions did we see in the transcripts?
- How is power functioning in these transcripts? (ex. between young people, between adults, teachers, organization staff)
- How does this piece challenge power dynamics (ex. adults' power over young people)

Feelings

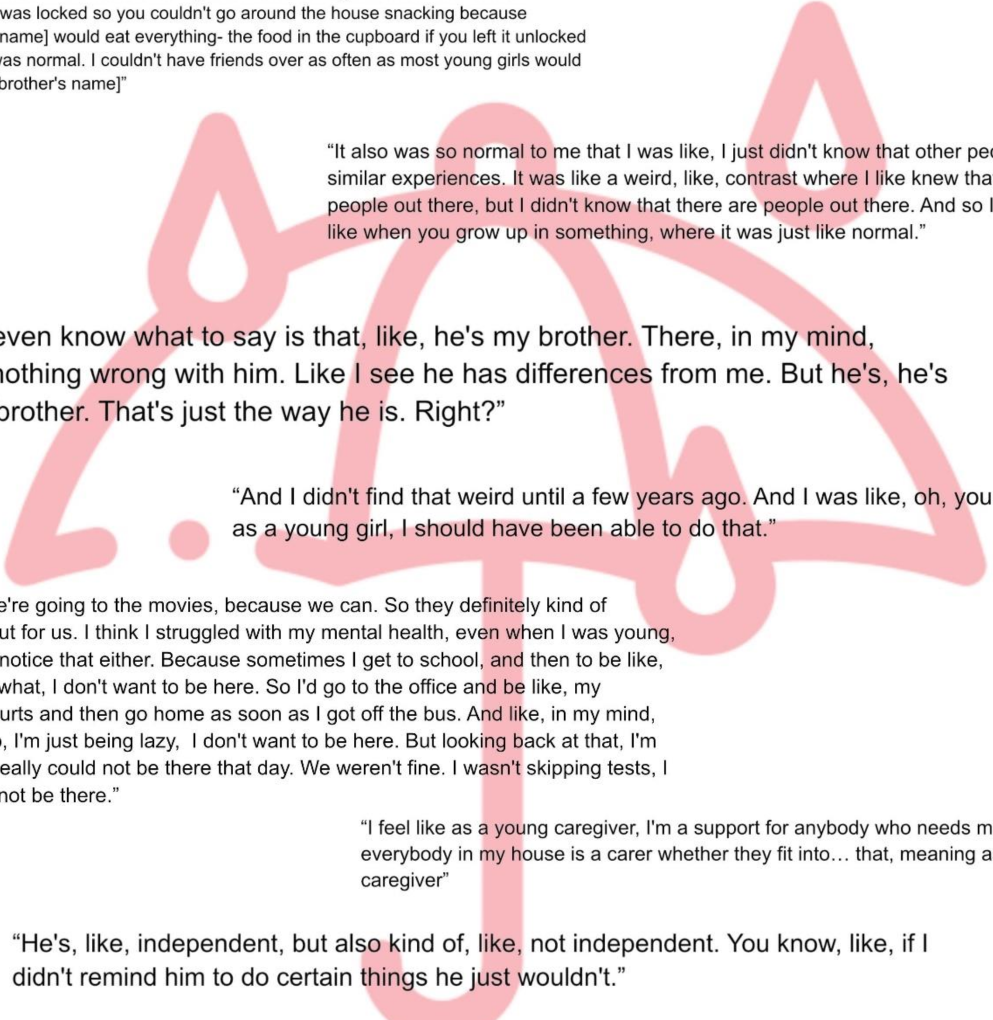
- How did your transcript make you feel?
- What were you excited about when reading the transcripts? What were you surprised about? What were you angry about? What were you sad about?
- What changes in society or for young carers did the transcripts make you think about?

Collaborative Creative Expression Piece

- How was this experience for you? What would you have done differently? What did you like?
- How does the collaborative piece make you feel? Does it represent what you read?

Appendix M: Co-researcher Creative Expressions

The following pages are some of our co-researcher creative expressions. One expression that is not included was provided verbally, and the other expression contains information that may identify the co-researcher who created it. Therefore, this expression was intentionally left out.



“He couldn't control like his food impulses. So the fridge was locked and the cupboard was locked so you couldn't go around the house snacking because [brother's name] would eat everything- the food in the cupboard if you left it unlocked and that was normal. I couldn't have friends over as often as most young girls would because [brother's name]”

“It also was so normal to me that I was like, I just didn't know that other people had similar experiences. It was like a weird, like, contrast where I like knew that there are people out there, but I didn't know that there are people out there. And so I think also like when you grow up in something, where it was just like normal.”

“I don't even know what to say is that, like, he's my brother. There, in my mind, there's nothing wrong with him. Like I see he has differences from me. But he's, he's just my brother. That's just the way he is. Right?”

“And I didn't find that weird until a few years ago. And I was like, oh, you know, like, as a young girl, I should have been able to do that.”

“Alright, we're going to the movies, because we can. So they definitely kind of watched out for us. I think I struggled with my mental health, even when I was young, and didn't notice that either. Because sometimes I get to school, and then to be like, you know what, I don't want to be here. So I'd go to the office and be like, my stomach hurts and then go home as soon as I got off the bus. And like, in my mind, I'm like, no, I'm just being lazy, I don't want to be here. But looking back at that, I'm like, no, I really could not be there that day. We weren't fine. I wasn't skipping tests, I just could not be there.”

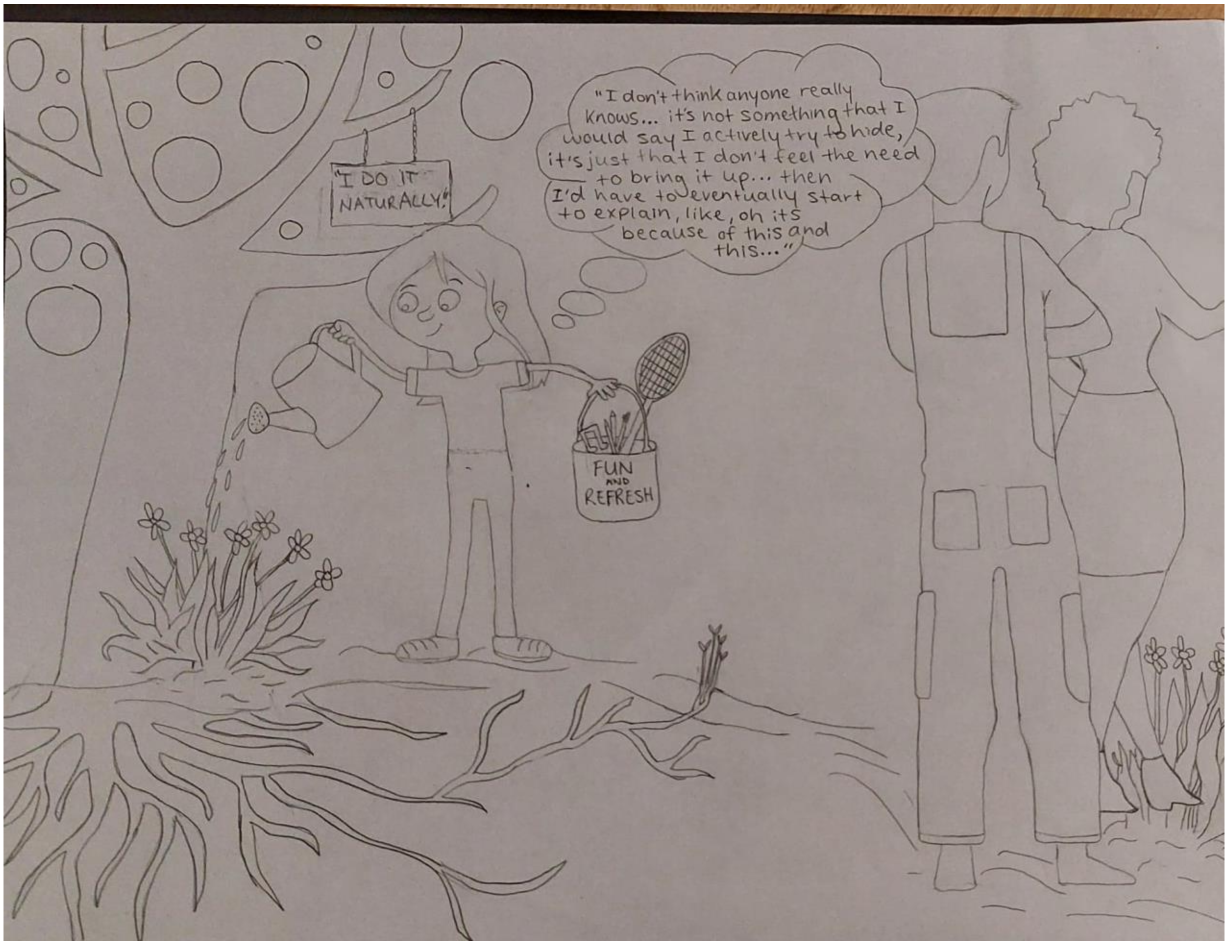
“I feel like as a young caregiver, I'm a support for anybody who needs me. Um like, everybody in my house is a carer whether they fit into… that, meaning as a young caregiver”

“He's, like, independent, but also kind of, like, not independent. You know, like, if I didn't remind him to do certain things he just wouldn't.”

“Going out in public is sometimes a little difficult for us, just because, like, he's a 23 year old man, and you know, that, like, he looks like a 23 year old… he's a five year old, in a man's body…his aging [stopped].”


communicate
control
different experience
responsible
my role
I don't know
fix it
time
different
reading
let myself go
good moment
brother
parents
nice
impact
relax
play squash
draining
self sufficient
difficult
can't focus
wild
be myself
funny
focus
isn't my normal
isn't
baking
control freak
higher standards
babysitting
getting it out
relief
empathize
boxing
alone
stressful
fun
frustrated
watch him
prioritize myself
autism
rubbing off on me
compassionate
in charge
emotion
sewing
more understanding


help
emotional support
strength
understanding
empathy
preserverance
Care
play
Balance
FAMILY
chores
hobbies
fun
love
MATURITY
energy
Support
refresh
Light
time
KNOWLEDGE
joy
sleep
friends
school work
rest
humour
Leadership


"I DO IT NATURALLY!"
"I don't think anyone really knows... it's not something that I would say I actively try to hide, it's just that I don't feel the need to bring it up... then I'd have to eventually start to explain, like, oh its because of this and this..."
FUN AND REFRESH