Caring for Carers:

Investigating the Impact of an 8-week MI-via-CALC Intervention on the Health and Experiences of Caregivers of Children with a Disability

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By Jonathon P. Racine
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Abstract

Background: Caregivers provide immeasurable and unmatched support to children with a disability (CWD), assisting with instrumental activities of daily living, often across the lifespan. Caregiver demands and unhealthy coping behaviours likely contribute to large and unfavourable health disparities experienced among caregivers of CWD (CCWD). To reduce the occurrence of preventable health conditions and increase caregiver ability, it is vital to intervene as early as possible to encourage health-promoting behaviours and promote wellness in this at risk population.

Purpose: The purpose of this mixed-methods pre-experimental pilot study was to investigate the impact of an 8-week telephone-based Motivational Interviewing via Co-Active Life Coaching (MI-via-CALC) intervention on the health of CCWD living in Northwestern Ontario. Psychosocial, physical, and behavioural health constructs were assessed. Caregiving and study-related experiences were also explored to contextualize the population and understand their intervention involvement.

Method: Upon receipt of ethical approval, CCWDs were recruited to complete three assessments (pre- mid- and post-intervention) and eight 30- to 45-minute unscripted telephone-based MI-via-CALC sessions with one of three volunteer Certified Professional Co-Active Coaches (CPCC). Psychosocial variables, including parental self-efficacy (PSE), family quality of life (FQOL), and perception of health (POH), were collected via self-report questionnaires at pre-, mid-, and post-intervention; anthropometrics and body composition were collected in-person at the baseline assessment only; and physical activity, smoking, sleep, and self-care behaviours were collected at pre- and post-intervention. Caregiving and study related-experiences were explored qualitatively via a self-report entrance survey and one-on-one telephone-based semi-structured exit interview. Clinical significance via Cohen's *d* was examined among the pre-post differences for the quantitative variables measured. Inductive content analysis was used to analyze the qualitative data.

Results and Findings: In total, six female CCWD completed all intervention procedures. Anthropometric and body composition values at baseline indicated a sample with Class II Obesity and a significantly increased risk for developing weight-related health risks. Results for the psychosocial variables indicated clinically significant improvements from pre- to post-intervention for PSE (i.e., efficacy and satisfaction subscales); FQOL (i.e., parenting, physical/material wellbeing, and disability related supports subscales); and POH (i.e., physical functioning, pain, role functioning, and mental health subscales). Additionally, health behaviours including physical activity engagement, sleep, and self-care increased from pre- to post-intervention for most CCWD participants. Qualitatively, caregivers described their role as unique and unlike that of a caregiver to a typically developing child. Caregivers noted how CPCCs helped to provide tools, an alternative perspective, and a source of accountability regarding personal changes, which in turn, led to participants experiencing heightened self-prioritization and self-care.

Conclusion: As the first MI-via-CALC study to assess the psychosocial, physical, and behavioural health of CCWD, during a worldwide pandemic no less, this type of intervention appears to be a promising avenue to promote these dimensions among CCWD: an important implication for a population identified as a public health priority. Future MI-via-CALC research with CCWDs should examine alternative intervention durations and larger sample sizes, include a control group, explore CCPC experiences in parallel, and assess the fidelity of the intervention.

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Introduction

According to Statistics Canada (2018), more than one in five Canadian youth have at least one disability, including a range of physical or mental conditions that can profoundly limit one's ability to carry out typical daily activities (Human Resources and Skills Development Canada, 2013; Ontario Human Rights Commission, 2016; World Health Organization [WHO], 2011). Physical disabilities, including amputations or limb disfigurement, muscular dystrophy, acquired spinal injury, and spina bifida restrict an individual's physical functioning, mobility, dexterity, and stamina (Inner Melbourne VET Cluster, 2018; Reuben & Siu, 1990). Mental disabilities, including autism spectrum disorder, cerebral palsy, Down syndrome, and traumatic brain injury, more often known as intellectual and developmental disabilities, are neurodevelopmental conditions characterized by significantly impaired cognitive and adaptive functioning, including conceptual, social, and practical skills (American Psychiatric Association, 2013; Inner Melbourne VET Cluster, 2018; Schalock et al., 2010). Often, restrictions due to physical limitations may be mitigated with the use of aids, assistive devices, or environmental adaptations, whereas restrictions due to intellectual and developmental disabilities are generally more difficult to overcome due to their conceptual nature (American Speak-Language-Hearing Association, 2018; Statistics Canada, 2018).

Caregivers can be defined as individuals who are responsible for the general safety and well-being of another while in a temporary or permanent position of power (Isa et al., 2016; Savage & Bailey, 2004). Formal caregivers such as doctors, nurses, and personal support workers, and informal caregivers including family members and friends, provide support to individuals, often across the entire lifespan (National Alliance for Caregiving, 2009; Raina et al., 2004). Specifically, informal caregivers of people with disabilities are responsible for providing long-term unpaid physical, emotional, social, and financial support while assisting with the basic tasks of everyday life, including activities of daily living (Kottorp et al., 2003; National Alliance for Caregiving, 2009; Raina et al., 2004). Parents in particular, have been found to be the most enduring source of informal caregiving (who will herein be referred to as *caregivers*; Gilson et al., 2017). In fact, parents have the most influence on the personal health and wellness of a child with a disability (CWD) when compared to any other single individual or healthcare provider (Elliott & Mullins, 2004).

Over time, a shift in health care has occurred for people with disabilities from a medical towards a socially inclusive model (Sloper, 1999). This shift has resulted in people with disabilities becoming increasingly reliant on informal caregivers; that is, social inclusion is favoured over out-of-home placement and institutionalization (Levine, 2000). Caring for a CWD often requires a significant amount of time, can be physically and emotionally demanding, disrupt familial and social relationships, and adversely affect caregiver overall health (Brannan & Heflinger, 2006; Seltzer & Heller, 1997). Families are asked to shoulder heavy care burdens for increasing periods of time due to medical advances, shorter hospital stays, and expansion of home care technology (Levine, 2000). Thus, it is not surprising that caregivers have been described as a public health priority and an ‘at risk’ population in need of further investigation (National Alliance for Caregiving & American Association of Retired Persons, 2004; Shaji & Reddy, 2012).

Caring for a person with a disability can involve many variables and may have considerable implications on the entire family dynamic. Significant challenges associated with parental responsibilities and environmental constraints such as physical inaccessibility and transportation, financial, and educational barriers place caregivers at increased risk for excessive levels of personal distress (Resch et al., 2010). When experienced on a chronic basis, this caregiver distress can adversely affect the well-being of the child and the entire family unit (Plant & Sanders, 2007). Indeed, caregivers of CWD (CCWD) have been shown to experience poorer health outcomes when compared to caregivers of typically functioning children (Lee et al., 2017), including but not limited to: chronic stress, reduced emotional and physical health, and an increased risk for early mortality (Murphy et al., 2007; Schulz & Beach, 1999; Singer et al., 2007). Anxiety, depression, and stress are also prevalent in CCWD (Murphy et al., 2007). These trends are troubling since chronic stress has been linked independently to adverse health conditions such as cardiovascular disease, diabetes, and obesity, thereby resulting in further disparities experienced amongst CCWD (Lee et al., 2017). Given that the health of children is inextricably linked to that of their caregivers' (Lee et al., 2017), identifying avenues to foster health and wellness in this population is imperative.

Background

A review of the literature was conducted during 2018/2019 in which the student researcher accessed a range of disability-, caregiving-, and psychology-oriented peer-reviewed journals and research databases including ProQuest, PubMed, and Web of Science. Research that focused on health dimensions and/or behaviour change in a CCWD population was reviewed. Prior to exploring strategies that could be used to enhance the health of CCWD positively, it is important to understand the psychosocial, physical, and behavioural outcomes experienced often in this population.

Psychosocial Health of Caregivers

Caring for a CWD has been shown to elicit adverse psychosocial outcomes which may affect caregivers' well-being negatively (Schulz et al., 1990). One study examining the psychosocial functioning of families of 34 CWD found caregivers to experience more stress, less marital satisfaction, and less psychological well-being when compared to families without a CWD (Friedrich & Friedrich, 1981). Because of the strong link between the health and well-being of children and their caregivers, it is important to consider the psychological and social health of CCWD when designing an intervention, including: happiness, self-esteem, depression, and loneliness (Shiovitz-Ezra et al., 2009); and poverty and unemployment (Akhmat et al., 2014). More specifically, psychosocial concepts that play an important role in child development and have been recommended for further investigation when examining caregivers include parental self-efficacy (PSE) and family quality of life (FQOL; Coleman & Karraker 2003; Hohlfeld et al., 2018; Jones & Prinz, 2005; Kendall & Bloomfield, 2005; Montigny & Lacharité, 2005).

Parental Self-Efficacy

According to researchers, PSE plays an essential role in the development of a child (Coleman & Karraker 2003; Jones & Prinz 2005; Kendall & Bloomfield 2005; Montigny & Lacharité, 2005). Self-efficacy, as defined by Bandura's Social Cognitive Theory, is the internal state of confidence in one's own ability to arrange and carry out a behaviour or task, yielding a specific achievement or result (Bandura 1977, 1989, 1997; Bandura & Walters, 1977). In the context of CCWD, PSE is the confidence in one's own parenting ability to successfully facilitate positive developmental experiences for the CWD (Elder Jr., 1995; Rajan et al., 2016). Caregivers with a high level of PSE will act in ways that are expected to optimize the developmental outcomes of their children (Reichow et al., 2013). In contrast, caregivers with a low level of PSE will shy away from difficult tasks, and focus on personal deficiencies, obstacles, and adverse outcomes rather than how to perform successfully (Zimmerman & Bandura, 1994).

Socially, programs exist to support new parents, single mothers, and adoptive parents tasked with effecting positive changes in empowerment, stress, and competence (Barlow et al., 2002; Dunst, 2007; Guralnick, 2017). Indeed, there is a growing body of literature suggesting that training programs aimed at enhancing PSE can elicit positive outcomes in CCWD (Hohlfeld et al., 2018). For example, Hohlfeld et al. (2018) completed a systematic review of 25 parenting interventions that assessed PSE, representing 1697 caregivers. Included studies needed to be randomized controlled trials that evaluated parent training interventions delivered to caregivers of children ≤ 10 years of age with an established disability (e.g., autism spectrum disorder, cerebral palsy, Down syndrome, or attention deficit hyperactivity disorder). Analysis revealed that parental training programs were not standardized across the 25 studies assessed, and most used a variety of licensed commercial programs aimed at supporting and enhancing caregiving practices (e.g., Incredible Years, 2019; Stead Family Children's Hospital, 2019; Triple P, 2019; UC Davis MIND Institute, 2019). Among the studies examined, 17 used the Parental Sense of Competence Scale (PSOC) to assess PSE levels across domains including satisfaction and efficacy (Johnston & Mash, 1989), four used the Parenting Task Checklist which evaluates a caregiver's ability to successfully handle challenging behaviour in dependent children across varying activities of daily living (Parenting and Family Support Centre, 2001), and the remaining nine employed less commonly used assessment tools.

Overall, Hohlfeld et al. (2018) concluded that PSE is a robust parent outcome measure that can be used to evaluate the effectiveness of parenting programs. Specifically, parents of children younger than five, irrespective of diagnosis, had a significant increase in PSE (medium-large effect size [$d = 0.60$]) suggesting that developmental skills taught to parents of younger children may become more pronounced in response to these types of programs. That is, parents who can see the positive impact of enhanced parenting skills early on are more likely to experience heightened PSE (Ardelt & Eccles, 2001). Within the review, parent training programs were also shown to be effective regardless of whether they were administered by a psychologist or healthcare professional, emphasizing the importance of maximizing access where there is a scarcity of trained professionals or available resources (e.g., Flisher et al., 2010; Rahman et al., 2008; Reichow et al., 2013). Based on the evaluation of these 25 studies, Hohlfeld et al. (2018) concluded that parent training programs are effective at increasing PSE in CCWD, especially when caring for a younger CWD. Furthermore, the researchers suggested that future studies should investigate the ability of alternative cadre professionals to implement parental programming aimed at increasing levels of self-efficacy in CCWD.

In line with these findings and recommendations, Isa et al. (2016) also suggested that possessing internal coping mechanisms, such as self-efficacy, is essential for being a successful CCWD. Caregivers with high levels of PSE have favourable physical and mental health, less anxiety, and more satisfaction with their environmental relationship (Guillamón et al., 2013). Thus, it is not surprising that self-efficacy has been acknowledged as a predictor of caregiver quality of life (Guillamón et al., 2013; Rezendes & Scarpa, 2011): a related concept recommended for further investigation among CCWD (Coleman & Karraker 2003; Hohlfeld et al., 2018; Jones & Prinz, 2005; Kendall & Bloomfield, 2005; Montigny & Lacharité, 2005).

Family Quality of Life

Quality of life (QOL) is the perception of one’s position in life, within the context of their culture and value systems (WHO, 1997): a broad concept that relates to individual goals, expectations, standards, and concerns. It also incorporates physical health, psychological state, level of independence, social relationships, life situations, personal beliefs/spirituality, satisfaction with personal accomplishments, and relationship to the environment. Family QOL focuses on family interaction, parenting/caregiving, physical and material well-being, emotional well-being, and disability-related supports while examining the perceptions and dynamics of the family unit (Hoffman et al., 2006; Hu et al., 2012).

Typically, parenting a child can have considerable and profound implications on the family, which may impact the health and QOL of caregivers (Davis et al., 2009). Caregivers of CWD face heightened challenges and demands compared to those caring for children without a disability (Isa et al., 2016). For example, to explore issues impacting QOL, Davis et al. (2009) interviewed 24 mother- and 13 father-caregivers of children with cerebral palsy: the most common physical disability in children affecting both movement and posture (Blair et al., 2001; Davis et al., 2009). Caregivers reported varying levels of QOL, often attributing their experiences to their own personalities, social support, and outlook on life (Davis et al., 2009). More specifically, CCWD were impacted by: poor physical health; disrupted sleep; difficulty in maintaining social relationships; pressure on marital relationships; difficulty in taking family holidays; limited freedom and time; a child’s long-term dependence; difficulty in accessing funding; and insufficient support from services (Davis et al., 2009). Conversely, CCWD were positively impacted by building new social support networks and drawing inspiration from their children (Davis et al., 2009). In terms of avenues to enhance QOL, caregivers expressed that practical solutions, including having more money to meet the needs of the child, an environment more conducive to their child's needs, and personalized social support would be of benefit for themselves and their families (Davis et al., 2009). According to Davis et al. (2009), programs and services must endeavour to improve existing offerings while working with families to identify tailored avenues to address unmet needs.

More recently, Isa et al. (2016) investigated the challenges faced by CCWD that can impact their health and wellbeing. In a review of the literature, the researchers included 31 articles examining factors affecting QOL among CCWD (Isa et al., 2016). Sociodemographic indices, child disability-related variables, and psychosocial factors were investigated across both qualitative and quantitative studies published in peer-reviewed journals between 2009 and 2014. Analysis indicated that in comparison to caregivers of healthy children, CCWD reported poorer general- and mental-health, chronic conditions, activity limitations, elevated depressive symptoms, and increased levels of stress (Brehaut et al., 2009; Gallagher et al., 2009; Gallagher & Hannigan, 2014; Guillamón et al., 2013; Ha et al., 2011; Hoffman et al., 2009; Ong et al., 2011). Additionally, CCWD reported having poorer sleep quality which was predicted by increases in parental stress (Gallagher et al., 2009). It was also found that families with a CWD faced more significant financial burdens than families without (Xiong et al., 2011), and increased pressure to provide basic necessities while experiencing difficulty in maintaining employment (Davis et al., 2009; Nimbalkar et al., 2014). In light of these findings, Isa et al. (2016) emphasized the impact of caring for a CWD on the health outcomes and related QOL of caregivers, suggesting that appropriate assistance need to be in place, including emotional and social support, as well as educational, financial, and respite-related resources.

In addition to the many factors that can influence QOL among CCWD, the nature and severity of the child's disability can also play a significant role (Isa et al., 2016; Rezendes & Scarpa, 2011; Shobana & Saravanan, 2014; Werner & Shulman, 2013). Child functioning, including the degree of care dependency, duration of child sleep, and daytime diapering have been found to be significant predictors of QOL in CCWD (Isa et al., 2016). Furthermore, parental education level and social supports have been specifically identified as factors influencing QOL in CCWD and their families (Ha et al., 2011; Hatzmann et al., 2009; Isa et al., 2016; Marchal et al., 2013; Werner & Shulman, 2013).

Taken together, these findings suggest that the health and well-being of CCWD vary within each family unit and are dependent on many factors which can contribute towards QOL negatively. Identifying ways to optimize this variable is essential to enable success in the caregiver role for CWD and CCWD alike. Isa et al. (2016) advised that social support should not be overlooked when developing interventions for caregivers, suggesting that practical assistance tends to be a major concern for CCWD. Additionally, programs designed to involve CCWD in the development and implementation could help to enhance their sense of self-efficacy, while providing education on positive coping strategies (Isa et al., 2016). Supports and resources need to match caregiver needs to maximize potential and efficacy (Isa et al., 2016). That is, tailoring interventions to individual situations and unmet needs is an important consideration and could serve to reduce the long-term negative impacts on health and QOL in a CCWD population (Isa et al., 2016). Given that the mind and body are intimately intertwined when it comes to health, in addition to examining the psychosocial sequelae experienced among CCWD, physical health has also been recommended for investigation (Lee et al., 2017; Schulz & Beach, 1999).

Physical Health of Caregivers

Indeed, CCWD have poorer physical health outcomes than those of typically developing children (Lee et al., 2017). Studies have shown CCWD report a greater variety and number of chronic conditions, as well as more physical health complaints when compared to caregivers of children without a disability (Brehaut et al., 2004; Lovell et al., 2012). Additionally, a relationship between diminished immune response and caregiving has been reported (Kiecolt-Glaser et al., 1996). As a result, CCWD may experience compromised health associated with spending so much time providing care; they may have little time or energy to engage in a healthy lifestyle for themselves (Lee et al., 2017).

In 2017, Lee et al. compared the prevalence rates of various health conditions between CCWD and caregivers of children without a disability using the 2015 National Health Interview Survey (National Center for Health Statistics, 2016). This annual dataset of cross-sectional questionnaires and in-person interviews, based on non-institutionalized civilians living in the general US population, is administered by the Centres for Disease Control and Prevention (National Center for Health Statistics, 2016). Caregivers of CWD (*n* = 1436) were at least 18 years of age, living within a household which included a CWD, and identified themselves as family of the CWD. Caregivers of children without a disability (*n* = 8599) were at least 18 years of age, living with a child without a disability, and identified themselves as family of the child. Results indicated that CCWD fared worse than caregivers of children without a disability, reporting statistically significant increases in obesity (41 % vs. 31.4 %), joint symptoms (35.7 % vs. 24.3 %), back pain (35.2 % vs. 26.7 %), hypertension (24.7 % vs. 19.1 %), and migraine/headaches (24.1 % vs. 16.6 %).

Similarly, Lee et al. (2003) analyzed data from the Nurses Health Study which focused on a cohort of female registered nurses residing in 11 US states and their caregiving responsibilities and coronary heart disease risk between 1992 and 1996. Findings revealed that high levels of care provision were associated with an increased risk of coronary heart disease among adult female caregivers of families that included a person with a disability (Lee et al., 2003). Similarly, in a study examining caregiving demands and all-cause mortality among older (aged 66 to 96) spousal caregivers and non-caregivers, providing care while experiencing chronic strain was associated with mortality risks that were 63% higher among caregivers (Schulz & Beach, 1999).

Cumulatively, these results pertaining to caregivers and physical health are both troublesome and span several decades suggesting that interventions to attenuate this burden are still needed. It has been suggested that future interventions for caregivers should investigate behaviours that may be associated with developing chronic conditions (Lee et al., 2017). Avenues to reduce experienced health disparities, such as asthma, arthritis, chronic bronchitis, heart conditions, and joint symptoms may be critical in supporting caregivers while enhancing existing levels of health (Lee et al., 2017).

Caregiver Health Risk Behaviours

Health behaviours such as dietary intake, physical activity, substance use, uptake of social support, and personal safety practices (e.g., medical check-ups) can be described as actions that influence health outcomes (Mahalik et al., 2007; Stimson et al., 2003). Scientists believe that modifiable health behaviours are the most important influence with regards to health and longevity (Mahalik et al., 2007). In fact, researchers estimate that 50% of morbidity and mortality risk is due to such behaviours (Mokdad et al., 2004). The degree to which health behaviours are performed can often be predicted using sociodemographic variables. For example, having more education, being married, and having a high income are correlated with more health-promoting behaviours (Calnan & Rutter, 1986; Delva et al., 2006; Joung et al., 1995; Kaplan et al., 2001). Given that CCWD are said to be at an increased risk of belonging to a lower socioeconomic demographic, have lower formal educational attainment, and experience reduced overall health, further investigation in this context is paramount for determining ways to optimize their well-being (Bourke-Taylor et al., 2013; Lee et al., 2017).

Lee et al. (2017) investigated behaviours associated with an increased risk of developing adverse health among caregivers of children with and without a disability. Behaviours investigated included heavy drinking, cigarette smoking, physical inactivity, and sleep. Results indicated that when compared to caregivers of children without a disability, CCWD experienced increased physical inactivity (53.6 % vs. 48.8 %), smoking (22.2 % vs. 14.0 %), and unhealthy sleep patterns (47.7 % vs. 41.1 %), with the latter two being statistically significant ($p < 0.001$). According to Lee et al. (2017), unhealthy behaviours are often preferred methods to alleviate symptoms of stress experienced by CCWD due to their socially accessible nature among adults. Based on these findings, Lee et al. (2017) advised that future research is needed to investigate intervention approaches that can mitigate these behavioural disparities amongst CCWD. These suggestions have been echoed by other researchers emphasizing that novel approaches are needed to enhance health in this population (Bishop et al., 2018; Racine et al., 2018).

Client-Centred Health Behaviour Change Intervention Approaches

Various programs aimed at addressing how caregivers can positively affect the psychosocial development of a child via parent support, training, and education exist (e.g., Triple P Positive Parenting Program, Incredible Years Program, Early Start Denver Model, Project ImPAC; Hohlfeld et al., 2018; Incredible Years, 2019; Stead Family Children’s Hospital, 2019;

Triple P, 2019; UC Davis MIND Institute, 2019). Among those aspects intended to enhance caregiver health and abilities, education and cognitive behavioural techniques are among the most common (National Center for Biotechnology Information, 2016). Early intervention programs for parents of young children that integrate education and behavioural modelling can lead to an increase in developmental, social, and functional outcomes for children, and improvements among empowerment, stress, and self-efficacy for caregivers (Barlow et al., 2002; Dunst, 2007; Guralnick, 2017).

Yet, despite these benefits, an existing criticism of these types of interventions is that they are often group-based and do not incorporate the tailoring some CCWD need given the diversity of diagnoses and circumstances faced (Isa et al., 2016). Moreover, it has been found that interventions intended to promote health behaviour change (HBC) among CCWD rely heavily on providing education and information sharing practices (Gaume et al., 2009; Wiley et al., 2012), whereby caregivers are given advice and persuaded to act a certain way: strategies that have been shown to increase resistance to change and reduce participant engagement (Silva et al., 2010; Skouteris et al., 2012). Furthermore, existing studies aiming to improve PSE among CCWD seem limited to those with children five years and under (Hohlfeld et al., 2018), suggesting that a more diverse age range and tailored type of programming is needed for this population, irrespective of child age: a client-centred approach may be one way to address these shortcomings.

A client-centred approach includes striving to understand individuals as a whole, developing a partnership between the client and practitioner, listening, and exploring concerns (Little et al., 2001; Wiley et al., 2012). Evidence indicates that HBC interventions should address not only individual behavioural changes, but psychological indices that are known to affect the maintenance of change in the long-term (Clark et al., 2009; Rallis et al., 2007). For example, self-efficacy has been recommended for investigation among CCWD, as individuals with higher levels concomitantly have greater participation in positive health behaviours such as physical activity (McAuley et al., 2005).

Client Centred Needs Assessment

An important step when preparing to develop a client-centred HBC intervention is conducting a needs assessment with a subset of the target population (Racine et al, 2018). As part of a recent qualitative study involving 10 CCWD living in Northwestern Ontario (Racine et al., 2018), participants discussed effective caregiving barriers, personal health promoting practices, accessing services, and avenues for personal and family health promotion. Caregivers also described a typical day for them and their children while discussing what they valued regarding caregiving supports. A number of themes and sub-themes emerged from the data relating to low PSE, QOL, and perceptions of confidence and skill in their caregiver role, highlighting the need for positive change. For example, these CCWD stated that they experience a range of personal health challenges, including obesity, cardiovascular disease, diabetes, Multiple Sclerosis, anxiety, and depression; social support was also identified as important to alleviate caregiver burden. Specifically, future programming for CCWD with individual supports that could increase caregiver efficacy while helping to reduce preventable health conditions was recommended by participants. According to these caregivers, individual supports need to: (1) encourage and guide access to resources that are effective and align with unmet needs; and (2) consider caregiver health and feelings of guilt associated with self-care to affect the caregiving role positively (Racine et al., 2018).

The findings of Racine et al. (2018) echo previous research confirming that CCWD need additional supports, services, and programming specifically aimed at improving their health and wellness. It is important that future HBC interventions take these CCWD views into account. One such tailored approach that has been shown to enhance well-being, personal functioning, and increase goal attainment via motivation and behaviour change, is life coaching (Grant & O'Hara, 2006; Green et al., 2006; Newnham-Kanas et al., 2012): a client-driven counselling style.

Life Coaching

An innovative and cross-disciplinary industry that has separated itself from traditional counselling is life coaching (Newnham-Kanas et al., 2010, 2012). Unlike traditional counselling, where the counsellor is considered an expert who gives advice, a life coach takes the role of a 'thought partner' (Newnham-Kanas et al., 2011a). In this relationship, the coach does not give advice, but trusts that the client is an expert in their own life and capable of generating personally meaningful solutions (International Coach Federation [ICF], 2019). According to Jarosz (2016), life coaching is "a long-term efficient relationship that allows clients to maximize their potential" (p. 40). It assumes that issues of most importance to the client are self-identified and self-prioritized, while focusing on the client's whole life rather than any one pathology (Whitworth et al., 1998; Williams & Davis, 2007).

The goal of life coaching is sustainable cognitive, emotional, behavioural change via goal attainment and performance enhancement (Stober, 2006). Instead of focusing on past issues, life coaches focus on the present and future outcomes (ICF, 2019). It has been suggested that life coaching is a powerful and efficient approach to enhance life experience (Grant, 2003; Newnham-Kanas et al., 2012). Moreover, life coaching has been described as a thought-provoking and creative process that leads to increased competence, commitment, and confidence while maximizing a client's personal and professional potential (Hudson, 1999; ICF, 2019). Because coaching is not associated with a regulatory body, the number of coaching oriented styles and practices are varied. One style being applied increasingly within HBC interventions is Motivational Interviewing via Co-Active Life Coaching (MI-via-CALC; Kimsey-House et al., 2011; Miller & Rollnick, 2002, 2012; Newnham-Kanas et al., 2010).

Motivational Interviewing via Co-Active Life Coaching

Motivational Interviewing (MI) is a directive, goal-oriented, client-centred counselling style which focuses on resolving a client's ambivalence about change (Miller & Rollnick, 2002, 2012; Rollnick et al., 2008; Westra & Dozois, 2006). Specifically, MI is a style of collaborative conversation designed to strengthen a person's own motivation and commitment to modifying some aspect of behaviour (Miller & Rollnick, 2012). It is done in partnership "for" and "with" rather than to a person (Miller & Rollnick, 2012, pg. 15). The client is the expert in their own life; no one knows them better than they do (Miller & Rollnick, 2012). Metaphorically, Miller and Rollnick (2012) refer to MI as dancing: moving in partnership with, rather than against. While MI has been investigated as an HBC modality with some success in contexts such as weight management, substance use, physical activity engagement, and oral health (e.g., Borrello et al., 2015; Naidu et al., 2015), drawbacks of use often relate to inconsistent training approaches, and uncertainty as to how MI tenets can be put into practice (Hettema et al., 2005; Mantler et al., 2013; Mesters, 2009; Newnham-Kanas et al., 2010). Fried and Irwin (2016) noted that a standardized application of MI is essential to ensure reliability and adherence to its principles. In line with this notion, Co-Active Life Coaching (CALC; Kimsey-House et al., 2011), an accredited coaching model, has been recommended as an adjunct to support individuals looking to implement lifestyle and HBC. This approach includes explicit tools and practices, such as asking open-ended meaningful questions, reflective listening, self-management, and acknowledgements that can be used to convert MI tenets into action (Irwin & Morrow, 2005; Newnham-Kanas et al., 2010, 2011a).

Overcoming criticisms of MI and its use in isolation, becoming a Certified Professional Co-Active Coach (CPCC) requires a standardized and rigorous training program that includes five, three-day in-person experiential workshop courses equalling 100 hours, and a 25-week group-based, supervised certification process combining hands-on coaching, ongoing ‘pod’ work, and skills training(Co-Active Training Institute [CTI], 2019a, 2019b; Fried & Irwin, 2016; Kimsey-House et al., 2011). The certification process culminates in the completion of both an oral and written examination (CTI, 2019b). A pictorial representation of the Co-Active model can be found in *Figure 1* and is explained in detail below.

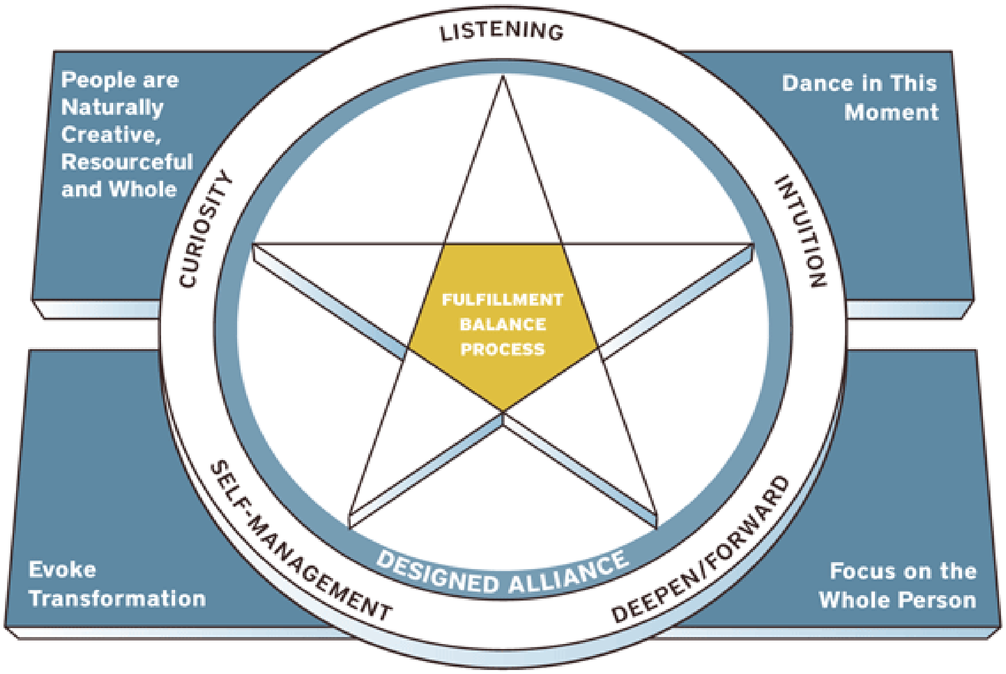

Figure 1: The Co-Active model. This figure illustrates Co-Active Life Coaching (Kimsey-House et al., 2011a).

The Co-Active model. Co-Active Life Coaching focuses heavily on the coach-client relationship, referred to as the designed alliance (CTI, 2019b). Within this relationship, the coach is viewed as the catalyst and the client is responsible for setting the agenda (Kimsey-House et al., 2011). This designed alliance exists only to serve the goals of the client (Kimsey-House et al., 2011). Similar to MI, the role of the coach is to view the client as a whole person and act in a thought-provoking and supportive manner (Kimsey-House et al., 2011). The Co-Active model is grounded in four *cornerstones* that serve to guide the coach in their interactions with the client, and based around the use of five *contexts* (Kimsey-House et al., 2011). The coach applies one or a combination of three *principles* during each session in service of assisting the client in achieving their agenda and related goals (Kimsey-House et al., 2011). Typically, trained Co-Active coaches deliver their sessions with clients over the telephone (Harvey et al., 2018; Pearson et al., 2012).

Co-Active cornerstones. The four cornerstones form a “container” that holds the Co-Active conversation (Kimsey-House et al., 2011, p3). A fundamental belief of the Co-Active approach is that the client is not broken or in need of fixing, but that people are *naturally creative, resourceful, and whole* (Kimsey-House et al., 2011). This means that the coach recognizes that clients, as the experts in their own lives, are capable of finding their own answers, based on their own agendas. *Focus on the whole person*, another cornerstone, refers to the fact that the person being coached is made up of heart, mind, body, and spirit (Kimsey-House et al., 2011). Thus, the areas they bring forth are not necessarily neatly isolated but inexorably entwined in the clients' whole life (Kimsey-House et al., 2011). The coach also strives to *dance in this moment*, a third cornerstone, responding to stimuli and the dialogue in real time, rather than a master plan (Kimsey-House et al., 2011). Collaboratively, the coach and client take turns dancing, moving the conversation forward. In a truly Co-Active conversation, it may feel like the coach is leading, the client is leading, or there is no clear leader (Kimsey-House et al., 2011). To *evoke transformation*, the fourth cornerstone, is to express an inner conviction meaning that the client has taken purposeful steps to achieve some goal or task, and/or has some deeper meaning or appreciation for the issue at hand based on their whole life (Kimsey-House et al., 2011).

Co-Active coaching contexts. According to Kimsey-House et al. (2011), the easiest way to understand the application of coaching skills is to view them within the context of the coaching relationship. For example, one of the most important contexts is *listening*: a skill that can be learned and developed through training. Internal listening (level 1) is the action of listening to the words, but attention is on what it means to the listener personally. Focused listening (level 2) includes a sharper focus and expending a great deal of attention on the client, and not much on the outside world. Global listening (level 3) is when one listens as if the client is the centre of the universe, receiving information from everywhere at once; it is fully immersive across sight, sound, touch, and smell, along with incorporating tactile and emotional sensations. Global listening is the most powerful type of listening used within coaching and gives the coach the greatest access to their *intuition*. Along with listening, intuition is another important skill in which the gathering of nonempirical information, usually in response to a question, gives depth and perspective to any issue (Kimsey-House et al., 2011). *Curiosity* is a different way of discovering, and often starts with a question. Unlike conventional questions that are deductive in nature or looking to fill in the blank, curious questions, like “What is it like to be you?” are open-ended and thought-provoking.

According to Kimsey-House et al. (2011), the most visible outcome and primary reason clients want coaching is action. However, a second complementary and just as important outcome, is learning. All of the coaching skills are used with the intention of forwarding the action and deepening the client's personal learning (Kimsey-House et al., 2011). In relation to this process, it is essential that coaches engage in *self-management*: a practice that involves heightened self-awareness to serve the client better. Specifically, coaches are trained to notice when their own thoughts stray, how a topic affects them personally, and how to get back and reconnect with the client (Kimsey-House et al., 2011). Within the coaching relationship, the coach employs these contexts dynamically in service of assisting the client in achieving their agenda and related goals (Kimsey-House et al., 2011).

Principles of Co-Active coaching. Central to the Co-Active model are three principles of coaching experienced by clients: fulfillment, balance, and process (Kimsey-House et al., 2011). *Fulfillment coaching* is about working with clients in their quest toward a fulfilled life which can include external measures of success, such as earning more money and getting promoted, while also incorporating personal beliefs and values (Kimsey-House et al., 2011). Fulfillment coaching focuses on the present and is not concerned with some future date. During fulfillment coaching, clients' personal values are used to facilitate life choices; coaches inspire clients to live a more satisfying life while encouraging choices that align with their values (Kimsey-House et al., 2011).

Balance coaching is about opening up client perspectives in order to generate choices and in turn, action (Kimsey-House et al., 2011). In society today, it is easy to become overwhelmed as life tends to revolve around responsibilities and distractions. Responsibilities may increase as some clients are driven to say yes often, which can lead to an unbalanced life and disservice to themselves. Balance is a dynamic and continually changing construct, wherein clients are constantly moving either toward or away from a balanced life (Kimsey-House et al., 2011).

Coaches may use geography, including awareness of the physical self and/or surrounding environment, where clients can explore other perspectives of an object, action, or thought, allowing them to discover other choices (Kimsey-House et al., 2011).

Finally, *process coaching* is about living each experience fully and being in the present moment (Kimsey-House et al., 2011). As an antecedent to behaviour change, process coaching involves a curious exploration of what is going on within oneself. Using an analogy of the river, process coaching can flow in various directions and speeds at different times throughout life. During this experience, the coach's role is to 'be with' the client and to notice where they are in the process while encouraging and supporting their emotional journey (Kimsey-House et al., 2011). Process coaching may involve feelings of discomfort as clients develop the capacity to be with conditions/feelings they have been denying or avoiding. The coach uses techniques such as offering reflective summaries and asking meaningful questions to help clients stop avoiding, pretending, and denying, so they might be more empowered and able to make better decisions for themselves (Irwin & Morrow, 2005; Kimsey-House et al., 2011).

Fulfillment, balance, and process coaching are used interchangeably and sometimes simultaneously while the coach and client dance in the moment in service of goal attainment (Kimsey-House et al., 2011). By combining the tenets of MI and the methodology of CALC, a unique and promising intervention supporting health improvements has emerged and been tested empirically (Goddard & Morrow, 2015; Mantler et al., 2014; Pearson et al., 2012). A brief overview of the literature in this regard has been provided below.

MI-via-CALC interventions

Motivational Interviewing via Co-Active Life Coaching has been described as an evidence-based, theoretically grounded cognitive behavioural change technique inclusive of all aspects of an individual's life (Irwin & Morrow, 2005; Newnham-Kanas et al., 2008, 2010, 2011a; Pearson, 2011; Pearson et al., 2012, 2013a; van Zandvoort et al., 2008, 2009; Whitworth et al., 2007). Previous research has investigated the efficacy of MI-via-CALC as an HBC technique in areas that relate and could be of benefit to a CCWD population, including physical activity, obesity, dietary intake, and smoking cessation (Gorczynski et al., 2008; Mantler et al., 2014; Newnham-Kanas et al., 2008, 2011a; Pearson et al., 2013b). It should be noted that due to the pandemic and a leave of absence taken during the research reporting period, the literature reviewed herein was conducted prior to 2019 and may therefore not be reflective of the most recent advances in the field.

In one such study, Goddard and Morrow (2015) assessed the impact of a 12-week telephone-based MI-via-CALC intervention on physical activity engagement in 25 sedentary women between the ages of 30-55. A pre-post intervention design with repeated measures was used to assess self-efficacy, self-esteem, physical activity, body mass index (BMI), waist-to-hip ratio, and waist circumference (WC) using the Exercise-Specific Self Efficacy Scale, the Barrier Specific Self-Efficacy Scale, the International Physical Activity Questionnaire-Short Form, and the Rosenberg Self-Esteem Scale. Ultimately, 19 women completed the study that included 12-weekly 30- to 45-minute MI-via-CALC sessions with a CPCC and related assessment components. Results indicated a significant ($p < 0.05$) mean decrease for participants' weight, WC, and waist-to-hip ratio. The researchers attributed these changes, in part, to increases in barrier-specific exercise self-efficacy and self-esteem, suggesting that participating in a 12-week MI-via-CALC intervention may be an effective way to elicit positive changes to psychological constructs. It was also posited that these changes could serve as an antecedent to favourable future changes in participant anthropometrics. The researchers recommended that future researchers explore MI-via-CALC as a modality to promote HBC within a health promotion framework that includes dimensions such as self-care and social support (Goddard & Morrow, 2015).

In the context of obesity, Pearson et al., (2012) examined the impact of a 12-week telephone-based MI-via-CALC intervention on participant anthropometrics, QOL, and self-esteem among young adults attending university. More specifically, the researchers compared MI-via-CALC to the Lifestyle, Exercise, Attitudes, Relationships, Nutrition (LEARN) Program for Weight Management (Brownell, 2004), a well-validated and thoroughly tested behaviour change program. Measurements were collected at pre-, mid-, and post-intervention, as well as 3- and 6-months following the intervention. Forty-five participants completed the study ($n = 25$ [MI-via-CALC]; $n = 20$ [LEARN]). The young adults randomized to the MI-via-CALC group worked with CPCCs to achieve goals through dialogue, whereas those in the LEARN group engaged in a prescriptive lifestyle modification program delivered by trained research assistants.

Analysis indicated that both conditions elicited significant changes between pre- and post-intervention and up to the 6-month follow-up. For example, a significant effect for time occurred between baseline and 6-months across QOL subscales including general physical health ($p < .001$, $\eta^2 = .53$), general mental health ($p < .01$, $\eta^2 = .52$), and overall health ($p < .01$, $\eta^2 = .55$). A significant time effect was also observed between baseline and 6-months for self-esteem with significant improvements occurring between 6- and 12-weeks ($p < .001$, $\eta^2 = .30$). Furthermore, analysis of participant weight identified a significant effect of time between baseline and 6-months ($p = .01$, $\eta^2 = .27$), with additional analysis revealing changes occurring specifically between baseline and 6-weeks ($p < .01$, $\eta^2 = .19$), and 6- and 12-weeks ($p = .01$, $\eta^2 = .13$). Based on the results, the researchers concluded that MI-via-CALC appears to be on par with LEARN as a viable obesity treatment option. Additionally, positive effects were seen in as little as 6-weeks for the dependent measures suggesting that this timeline may be sufficient for evoking meaningful change. The researchers recommended that future researchers investigate MI-via-CALC as a viable treatment for obesity due to its dynamic alignment with participant needs.

Similar to obesity, cigarette smoking has been linked to numerous, well-documented, and widely accepted health consequences, costing Ontario nearly $7 billion dollars, both directly and indirectly, in 2018 alone (Ontario Tobacco Research Unit, 2018). The most effective way in which smokers can improve their health is through cessation (Edwards, 2004); however, success rates are low, especially in individuals with low levels of self-efficacy for quitting. As such, Mantler et al. (2014) investigated MI-via-CALC and its effects on smoking cessation behaviours, personal competence, and changes in smoking-related perceptions over one year among young adults. More specifically, a mixed-methods, MI-via-CALC intervention delivered over 8-10 coaching sessions among 40 young adult smokers was completed. Coaching sessions with a CPCC were 30 minutes in duration and occurred over telephone or Skype. Thirty-five participants completed the intervention, which included assessments at baseline, immediately following the last coaching session, and at 3-, 6-, and 12-months post-intervention. Variables assessed included the number of cigarettes smoked per day, cigarette dependency, and cessation. The Cigarette Dependency Scare (Etter, 2008) was utilized to assess addiction, whereas cessation was verified via a saliva cotinine test at 12-months (Zevin et al., 1997). The Rosenberg Self-Esteem scale and the Smoking Self-Efficacy Questionnaire were used to measure levels of self-efficacy for sustaining cessation and self-esteem (Etter et al., 2000; Rosenberg, 1989). Lastly, semi-structured interviews were completed at each assessment, either in person or over the telephone, investigating participants' perceptions of identity, smoking, quitting, and the intervention, including questions like: What is it like being you now compared to the start of the intervention?; What is a barrier to quitting?; What is a facilitator to quitting?; What is important to you about quitting smoking?; and What was your experience being in the study? (Mantler et al., 2014).

Significant findings related to the reduction of smoking behaviours and increased personal competence occurred following the intervention. The most notable result was the cessation rate at the 12-month follow up: 27.5 % of participants were verified via saliva cotinine testing. This is much higher than pharmacotherapy (15 %), or pharmacotherapy combined with behavioural support (23 %; Mantler et al., 2014). Qualitative findings were consistent with the quantitative results and highlighted that study participation helped participants deal with smoking triggers. Re-shaping identity, increasing personal competence, and altering perceptions of smoking and quitting behaviours were also noted as valuable outcomes, as well as an overwhelmingly positive experience of participating in the intervention (Mantler et al., 2014).

Taken together, these studies show that MI-via-CALC can elicit significant changes across various health-related constructs, including physical activity engagement, smoking cessation, self-efficacy, QOL, body weight, and WC, in as little as six weeks using a combination of in-person, over the telephone, or Skype-based communications. Given MI-via-CALCs demonstrated utility and the fact that CCWD have been shown to experience poor health and health risk behaviours in comparison to caregivers of typically functioning children (Davis et al., 2009; Goddard & Morrow, 2015; Hohlfeld et al., 2018; Isa et al., 2016; Lee et al., 2017; Mantler et al., 2014; Pearson et al., 2012; Rajan et al., 2016), it stands to reason that MI-via-CALC may be a viable health promoting strategy in this population.

Summary and Study Qualifiers

Caregivers of CWD have a unique role to play in the lives of CWD; they provide immeasurable and unmatched care, sometimes across the lifespan, as well as emotional, financial, and social support, often assisting with instrumental activities of daily living (Kottorp et al., 2003; National Alliance for Caregiving, 2009; Raina et al., 2004). It has been shown that CCWD experience large and unfavourable health disparities when compared to caregivers of typically developing children (Lee et al., 2017). This differential may be due to the effect of stressful caregiver demands combined with unhealthy coping behaviours (Gardner & Harmon, 2002; Lee et al., 2017). In addition to providing the basic necessities of life and core elements of care, including clothing, nutrition, shelter, and healthcare, CCWD are central to optimizing well-being and development for themselves and their children alike. To reduce the occurrence of preventable health conditions, delay institutionalization and out-of-home placement of the CWD, and increase caregiver ability, it is vital to intervene as early as possible to encourage health-promoting behaviours in this population (Brodaty et al., 2003; Lee et al., 2017).

Recent research has shown that there seems to be no ‘one size fits all’ solution to meeting the expansive and variable needs of CCWD (Racine et al., 2018). Existing caregiver-oriented interventions often incorporate advice giving and persuasion, which have been shown to increase resistance to change and reduce participant engagement (Silva et al., 2010; Skouteris et al., 2012). This is troublesome, given that modifiable health behaviours are the most important factors known to influence health and longevity (Mahalik et al., 2007). According to the literature, MI-via-CALC has been shown to elicit positive improvements in various contexts resulting in positive changes to health behaviours and psychosocial constructs in as little as six weeks (Goddard & Morrow, 2015; Mantler et al., 2014; Pearson et al., 2012). While MI-via-

CALC has been assessed in populations including university students, youth, young adults, and older adults (Goddard & Morrow, 2015; Mantler et al., 2014; Newnham-Kanas et al., 2008, 2010, 2011a; Pearson et al., 2012, Whitworth et al., 2007), no studies to date have assessed its utility in CCWD. Indeed, Fried and Irwin (2016), have recommended that MI-via-CALC be assessed further in various populations.

Interestingly, CCWD living in Northwestern Ontario have expressed their desire and need for client-centred approaches in addition to intervention tailoring when attempting to ameliorate undesirable health outcomes (Racine et al., 2018). Furthermore, CCWD also expressed that they may find it challenging to attend assessments outside of the home or commit to lengthy interventions due to unique caregiver demands associated with caring for a CWD (Racine et al., 2018). Through its use of the designed alliance and whole-person approach, MI-via-CALC may be ideal for supporting CCWD in this regard (Racine et al., 2018).

Purpose

The purpose of this mixed-methods pre-experimental pilot study was to investigate the impact of an 8-week MI-via-CALC intervention on the health of CCWD living in Northwestern Ontario. Psychosocial, physical, and behavioural health constructs were assessed including: parental self-efficacy (PSE), family quality of life (FQOL), and perception of health (POH); anthropometrics and body composition; and physical activity, smoking, sleep, and self-care. In addition, participants' caregiving and study-related experiences were explored qualitatively to contextualize the population and uncover insights related to intervention involvement (Merriam & Tisdell, 2016).

Hypotheses

It was hypothesized that CCWDs would experience clinically significant improvements in the quantitative variables examined over time, as observed in other MI-via-CALC studies focused on adult populations (e.g., Fried & Irwin, 2016; Goddard & Morrow, 2015; Gorczynski et al., 2008; Harvey et al., 2018; Newnham-Kanas et al., 2011a; Thompson, 2002; van Zandvoort et al., 2008, 2009). More specifically, it was hypothesized that:

i) Participants' levels of PSE, including satisfaction and efficacy subscales, would increase for CCWD from pre- to post-intervention (Mejia et al., 2012).

ii) Participants' FQOL, including family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support subscales would increase for CCWD from pre- to post-intervention (Pearson et al., 2012).

iii) Participants' POH, including physical functioning, pain, role functioning, social functioning, mental health, and current health perception subscales would improve for CCWD from pre- to post-intervention (Isa et al., 2016; Lee et al., 2017).

iv) Participant anthropometrics, including WC and BMI, and body composition, including fat mass (FM) and lean dry mass (LDM), would each improve for CCWD from pre- to post-intervention (Goddard & Morrow, 2015; Pearson et al., 2012).

v) Participant health behaviours, including physical activity engagement, smoking, sleep quality, and self-care activities would each improve for CCWD from pre- to post-intervention (Gardner & Harmon, 2002; Isa et al., 2016; Lee et al., 2017; Mantler et al., 2014).

With regards to caregiving and study-related experiences, it was expected that the qualitative findings would complement the quantitative results, highlighting the impact and utility of MI-via-CALC as an empirically sound and effective modality to enhance indices of health in the CCWD population, while also informing future MI-via-CALC and CCWD-oriented interventions (Merriam & Tisdell, 2016).

Method

Study Design

An 8-week mixed-methods pre-experimental pilot study with repeated measures was implemented between February and May, 2020 to examine quantitative changes in psychosocial health, physical health, and behavioural constructs from pre- and post-intervention (e.g., baseline, 4-, and 8-weeks). The psychosocial data were collected at each assessment time-point (pre-, mid-, and post-intervention), while the health behaviour data were collected at the pre- and post-intervention assessments. A qualitative open-ended survey was intended to capture caregiving and study-related experiences at pre- and post-intervention. Due to the onset of COVID-19 which required that all data be collected remotely, and lower than anticipated sample size, participant anthropometric and body composition data were measured in person at the baseline assessment only, and the post-intervention exit-survey was delivered as a telephone-based one-on-one semi-structured interview.

Participants

It was anticipated that approximately 20 CCWD from Northwestern Ontario would be recruited to participate: a sample size in line with other pilot studies (Billingham et al., 2013), similar MI-via-CALC interventions (e.g., Fried & Irwin, 2016; Goddard & Morrow, 2015; Gorczynski et al., 2008; Harvey et al., 2018; Newnham-Kanas et al., 2011a; van Zandvoort et al., 2009), and recommended for research targeting the experiences of specialized populations like CCWD (Creswell, 1998; Mason, 2010; Morse, 1994). Interested caregivers were required to be:

at least 18 years of age; able to speak and read English fluently; the live-in legal parent/guardian and primary caregiver to a child under the age of 21 with a disability; able to attend three in-person assessments for completion of questionnaires, body composition measures, and a survey; and committed to participating in eight weekly 30- to 45-minute telecommunication-based MI-via-CALC sessions, using telephone or platforms such as FaceTime, Skype, or Zoom. Caregivers of children with a primary diagnosis of a learning disability (e.g., auditory processing disorder, attention deficit hyperactivity disorder, dyslexia) or complex health condition (e.g., cancer, multiple sclerosis, arthritis, uncontrolled diabetes) were excluded from participation to reduce the variability in the types of caregiving while also streamlining the degree of caregiving required in relation to the severity of diagnosis.

Certified Professional Co-Active Coach Criteria

Approximately seven CPCCs were expected to be recruited to provide confidential coaching services in line with the research purpose. Interested coaches were required to: be at least 18 years of age, have completed the certification program through the CTI (2019b), be living in North America to avoid major time differences and costly phone calls, speak and read English fluently, and voluntarily coach at least two CCWDs weekly throughout the 8-week study. Enrolled coaches were asked to employ skills learned through their CPCC training only, and not any alternative approaches or skills that they may have acquired, to ensure that the coaching intervention delivery was standardized (van Zandvoort et al., 2008). Additionally, CPCCs enrolled as the study coaches had no other role in the study beyond delivery of the coaching sessions. That is, the CPCCs were not involved in the participant assessments or data analysis.

Recruitment Procedures

Upon receiving ethical approval from the Lakehead University Research Ethics Board (Appendix A), CCWD participants were sought through a combination of word of mouth, reaching out to peers and colleagues, displaying recruitment posters, and having existing participants refer their peers and friends (Coolican & Kelly, 2014). To further aid in the recruitment of caregiver participants, the student researcher (J.R.) contacted, via phone or in person, local agencies often accessed by CCWD including George Jeffrey Children's Centre, Thunder Bay Family Network, Thunder Bay Children's Centre, March of Dimes Thunder Bay, and Special Olympics Ontario Thunder Bay. These agencies provide local programming and services to families of individuals with a disability including: early intervention; education; physical, speech, and mobility therapy; as well as social and respite services. If interested and willing, the agency was provided printed copies of the Caregiver Participant Recruitment Poster (Appendix B) and Caregiver Participant Information Letter (Appendix C) for display. Furthermore, the student researcher requested that if an agency had an electronic dissemination platform, such as internal and external mailing lists, social media accounts such as Facebook, Twitter, or Instagram, and was willing, that the information letter and/or recruitment poster be added/shared, without alteration. The student researcher also used other means to contact prospective participants such as in-person presentations within the community, including staff meetings for the agencies listed above, and attending events commonly accessed by caregivers such as day programming at the March of Dimes. Finally, the student researcher posted the recruitment poster on his own personal Facebook, Twitter, and Instagram pages in the hopes of reaching other potential participants within the community.

Interested individuals contacted the researcher through email or phone to discuss possible participation. Once initial contact with the interested individual was made, they were informed of the study purpose and procedures, inclusion and exclusion criteria, and that as a volunteer participant they could withdraw at any time, for any reason, without repercussion. When speaking with an interested individual in person, they were provided with a printed copy of the information letter. When speaking to a potential participant over the telephone or via other electronic means, including Skype, FaceTime, Facebook Messenger, and text message, they were provided with an electronic copy of the information letter via email. Potential caregiver participants were screened using the Caregiver Participant Eligibility Form (Appendix D) which was created for the study. Those who met the criteria and were willing to participate were then scheduled for the initial baseline assessment (Neuman, 2013). Throughout the recruitment process, the student researcher verbally explained the research purpose and procedures while also giving the potential participant opportunities to ask questions before providing consent. Informed consent (Appendix E) was obtained for each eligible participant prior to commencing the initial baseline assessment.

Certified Professional Co-Active Coach Recruitment

In conjunction with the recruitment of CCWD, CPCCs were recruited, screened, and enrolled in the study. Using techniques similar to other MI-via-CALC interventions (e.g., Fried & Irwin, 2016; Goddard & Morrow, 2015; Gorczynski et al., 2008; Harvey et al., 2018; Newnham-Kanas et al., 2011a; van Zandvoort et al., 2009), CPCCs were recruited via an online poster (Appendix F) uploaded through the Co-Active Network (CTI, 2019a), a web-based platform affiliated with the CTI, and through connections established via former coaching-based studies (e.g., Harvey et al., 2018; Pearson et al., 2013a). The coach recruitment poster included a brief synopsis of the intervention and contact information for the student researcher, supervisor, and research ethics board. If interested, prospective CPCCs were asked to contact the student researcher via email or telephone. Upon receiving contact information, the student researcher then sent a copy of the Coach Information Letter (Appendix G) to prospective coaches, which included a detailed description of the study purpose and procedures, expectations associated with involvement, and inclusion criteria. Prior to enrolling within this study as a coach, they had to sign the Coach Consent Form (Appendix H), acknowledging that they had read the Coach Information Letter, and agreed to coach caregiver participants on a voluntary basis in line with, and limited to, their CTI training. They also acknowledged that coaching was to be provided in accordance with the ethical guidelines as set out by the ICF (CTI, 2019b).

Procedures

As revealed in a study conducted by Racine et al. (2018), CCWDs may find it challenging to attend assessments at locations away from home due to difficulties associated with finding appropriate childcare, or because of unexpected behavioural challenges that can occur for the CWD. Because a unique feature of this pilot study was its focus on tailoring the intervention for the CCWD population, the student researcher aimed to be adaptive to the needs of the participants. That is, he met when and where it worked best for the caregivers to complete the in-person assessments. Indeed, recent research investigating the impact of a parent-focused intervention for childhood obesity revealed that home-based assessments can be a viable avenue for collecting caregiver data (Reilly et al., 2018). All baseline assessments were conducted in-person at the host institution. Due to COVID-19 restrictions put in place on March 17, 2020, three of the mid-point assessments were conducted online, while three were in-person in the lab before this date. All final assessments were conducted remotely. The location of each in-person assessment was recorded during data collection for the purposes of assessing utility and reproducibility.

Two days prior to the baseline assessment, participants were reminded by the student researcher about the upcoming meeting via their preferred contact method. Prior to commencing the initial baseline assessment, informed consent was obtained for each eligible participant. At baseline, participants completed an open-ended paper-based entrance survey, followed by a demographic information form and series of quantitative questionnaires. Anthropometric measures, including height, weight, and WC, and body composition values were then collected. At the end of the baseline assessment, participants were provided with contact information for their assigned CPCC in writing and via e-mail (Appendix I). Lastly, the student researcher gave participants a brief explanation of MI-via-CALC and asked them to think about area(s) in their life where they wished to make a change prior to their first coaching session (Harvey et al., 2018; Pearson et al., 2013a). All baseline participant assessments ($n = 6$) were completed on the Lakehead University campus (i.e., CJ Saunders Fieldhouse, NOSM) during daytime hours (i.e., 10:00 am to 9:00 pm) and lasted approximately 45 to 60 minutes.

To accommodate schedules and timelines associated with study enrollment, coaches and participants were matched by the student researcher based upon time preferences for coaching sessions and coach availability (Goddard & Morrow, 2015; Harvey et al., 2018). Once a match was made, the student researcher contacted the assigned CPCC via email to advise them to expect a phone call or email from a participant (Harvey et al., 2018; Pearson et al., 2013a). In line with the Co-Active method (Whitworth et al., 2007) and previous studies (Goddard & Morrow, 2015; Mantler et al., 2014; Pearson et al., 2013a), participants were responsible for initiating contact with their assigned coach within one week following the initial assessment.

The quantitative questionnaires were completed again at the mid-point of the study (i.e., between sessions four and five; in-person [*n*=3]; online [*n*=3]) and took 15 to 30 minutes. At post-intervention (i.e., within 7 days of completing session eight; online [*n*=6]), the baseline procedures were repeated minus the body composition analysis due to COVID-19 restrictions. Within four days of completing the post-intervention assessment, the exit survey (*n*=6) was administered via a telephone-based one-on-one semi-structured interview.

MI-via-CALC Sessions

The MI-via-CALC intervention involved eight weekly 30- to 45-minute unscripted coaching sessions held between the participant and CPCC. For mutual convenience, all coaching sessions were limited to telecommunications-based technology, such as telephone or other digital internet technology, and restricted to audio communication only (e.g., voice calls on FaceTime, Skype, or Zoom). Limiting the sessions to this technology was intended to support ecological validity (e.g., using methods employed in the real world), while also ensuring a standardized delivery of the coaching intervention (Goddard & Morrow, 2015). During the first coaching session as part of designing the alliance, the coaches answered any questions that the participants had about coaching, explained the nature of coaching, and identified the client's primary agenda (van Zandvoort et al., 2009). All coaching sessions typically began with the stem "What would you like to focus on today?" or some derivative thereof.

Following the second coaching session, the student researcher checked in with each caregiver participant to inquire as to how the coaching relationship was progressing (e.g., Were there communication challenges being experienced? Was the duo mismatched? Did they wish to be reassigned to another CPCC?). It is important to note that the caregiver participants were not asked by the student researcher about the content of their coaching sessions. Rather, the purpose of the check-in was to ensure that the client and coach were developing a positive coaching relationship, and that both parties were interested in moving forward together (Harvey et al., 2018).

Instrumentation

During the baseline assessment, participants completed an entrance survey (Appendix J), demographic questionnaire (Appendix K), the PSOC (Appendix L), the Beach Centre FQOL scale (Appendix M), and the 20-Item Short-Form Health Survey (SF-20; Appendix N). At the end of the assessment, anthropometrics and body composition values were measured and recorded (Appendix O). During the mid- and post-intervention assessment, participants again completed the PSOC, FQOL and SF-20 questionnaires. An exit interview (Appendix P) was held after participants completed the post-intervention measures. Each of the instruments are described below.

Entrance Survey and Exit Interview

A self-report entrance survey (Appendix J) was completed by participants at the beginning of the baseline assessment to enable sharing of their caregiving experiences and study-related expectations. A semi-structured one-on-one telephone-based interview based on the exit survey (Appendix P) was completed within four days of the post-intervention assessment for each participant.

The survey and interviews were developed by the student researcher in line with the research purpose and other MI-via-CALC studies (e.g., Harvey et al., 2018, Newnham-Kanas et al., 2011a; Pearson et al., 2012), including a combination of open- and close-ended questions. More specifically, the entrance survey asked participants questions such as “What is it like to be you?”. Additionally, the entrance survey explored challenges to and supports for their roles as caregivers, asking “At present, what (if any) would you say is the greatest challenge/[support] you are facing within your role as a CCWD?”. The exit interview similarly explored participant study goals, challenges, and supports in their role, as well as questions related to logistical elements of the program, such as delivery mode and number of coaching sessions completed. Lastly, study specific experiences, including “What did you find most/[least] helpful about the study and why?” were also explored.

Demographic Questionnaire

Caregiver participants were asked to complete a demographic questionnaire (Appendix K) during their initial baseline assessment which included several closed- and open-ended questions pertaining to age, sex, formal educational attainment, employment status, household income, health insurance coverage, family composition, disability information, and community services accessed; Lee et al., 2017; Racine et al., 2018). The purpose of this questionnaire was to provide additional contextualization of the sample population in relation to the quantitative data and survey findings.

Parental Self-Efficacy

The Parental Sense of Competence scale (PSOC; Appendix L; Johnston & Mash, 1989) is a self-administered, 17-item Likert scale questionnaire commonly used to assess PSE (Elder Jr., 1995). The measure includes two subscales: satisfaction and efficacy. The satisfaction subscale assesses enjoyment, motivation, and satisfaction in the parenting role, whereas the efficacy subscale assesses perceived knowledge, confidence, and competence in parenting (Giallo et al., 2013; Johnston & Mash, 1989). Individual questions anchor across a six-point scale ranging from strongly agree [1] to strongly disagree [6].

The PSOC was originally designed to measure PSE in first-time parents of infants (Johnston & Mash, 1989). Since then, the scale and associated sub-scales have become commonly used across many parenting interventions, including assessments of burden and sleep disturbances in caregivers (Mol et al., 2012; Park et al., 2007), suggesting that this tool is an appropriate measure when investigating the intervention impact on PSE in CCWD. The scale has been well-validated across varying populations, including parents of children with hyperactive disorders and seizure disorders (Fowles & Horowitz, 2006; Park et al., 2007; Sonuga-Barke et al., 2001). Furthermore, the PSOC has been shown to consistently demonstrate moderate levels of reliability via Cronbach's alpha coefficient for both the Satisfaction scale ($\alpha = 0.75$) and the Efficacy scale ($\alpha = 0.76$; Giallo et al., 2013).

Family Quality of Life

The Beach Centre FQOL scale (which will herein be referred to as the *FQOL scale*; Appendix M; Beach Center on Disability, 2012) is a self-administered 25-item Likert scale questionnaire commonly used to assess family perceptions of satisfaction with different aspects of family-related QOL. This includes individual's perceptions of their position in life, within the context of their culture and value systems in which they live, and focuses on the interactions and dynamics of the family unit (Hoffman et al., 2006; Hu et al., 2012). The FQOL scale is comprised of five subscales: 1) family interaction, which includes relationships that family members have with each other, and the emotional climate within which the relationships exist; 2) parenting, which includes providing guidance, structure, and teaching to children and youth; 3) emotional well-being, which includes the 'feeling aspects' of life; 4) physical/material well-being, which includes having dependable financial and transportation resources, along with feeling safe in their surrounding environment; and 5) disability-related support, which includes their ability to achieve goals, develop social connections, and have positive engagement with service providers. Individual questions anchor across a five-point scale from very dissatisfied [1] through to very satisfied [5].

The FQOL scale was originally developed to quantify perceptions of satisfaction among families that include a CWD (Beach Center on Disability, 2012). The reliability scores have been found to be high via Cronbach's alpha α, 0.94 and 0.88, respectively (Hoffman et al., 2006).

Perception of Health

The 20-Item Short-Form Health Survey (SF-20; Appendix N; Ware et al., 1992) is a self-administered, 20-item health survey commonly used to assess perceptions of functional health and wellbeing. The SF-20 is a shortened version of one of the most widely used health-related QOL measures (e.g., SF-36; RAND Corporation, 2019; Ware et al., 1992) and includes six domains: 1) physical functioning, which addresses the presence and extent of physical limitations; 2) pain, which includes intensity of bodily pain, and extent of interference with normal work activities; 3) role functioning, which encompasses physical health-related role limitations such as difficulty performing work; 4) social functioning, which includes the ability to develop, maintain, and nurture major social relationships; 5) mental health, which involves anxiety, depression, loss of behavioural/emotional control, and psychological wellbeing; and 6) health perception, which is their rating of health from excellent to poor (RAND Corporation, 2019; Ware et al., 1992).

The validity of the SF-20 has been supported across varying populations (Stewart et al., 1988), and the measure has been shown to have adequate reliability, with coefficients ranging from 0.81 to 0.88 for the subscales. Subscales of the SF-20, including current health perceptions, have been correlated substantially with many of the SF-36 subscales, and have been found to have an empirical validity ranging between 80% and 90% (Rodrigue et al., 2001; Ware Jr, 2000). Other MI-via-CALC studies have also included short-form health surveys, including the SF-36, thereby allowing for comparative discussion regarding the results.

Anthropometrics

Participants had their height (cm), and weight (kg) measured using a tape and weight scale, and results were recorded on the anthropometric collection sheet (Appendix O). The participants BMI (kg/m^2; Heart and Stroke Foundation, 2021) was calculated by dividing the participants weight (kg) by the square of their height (m^2). Participants with a BMI within 18.5 kg/m^2 and 24.9 kg/m^2 are at the lowest risk for developing weight-related health problems. Individuals with a BMI between 25 kg/m^2 and 29.9 kg/m^2 are considered to have overweight, and individuals with a BMI of 30 kg/m^2 or more are considered to have obesity; the latter two categories are associated with an increased risk for developing weight-related health problems (Heart and Stroke Foundation, 2021).

Waist circumference (cm; Heart and Stroke Foundation, 2021), a minimally invasive measure used to assess weight-related health risks, was taken at the top of the iliac crest. Importantly, centrally distributed fat has been shown to increase health risks such as high cholesterol, high blood pressure, cardiovascular disease, and diabetes (Biesmans et al., 2013; Gunderson, 2004; Heart and Stroke Foundation, 2021). According to the Heart and Stroke Foundation (2021), the risk for developing weight-related health conditions is increased for females with a WC greater than 80 cm (31.5 inches), and substantially increased if greater than 88 cm (35.0 inches). Similarly, males with a WC greater than 94 cm (37.0 inches) are at increased risk, and substantially increased if greater than 102 cm (40.0 inches), respectively.

In line with the guidelines of the Heart and Stroke Foundation (2021), participants were asked to have their WC measured by the student researcher. The student researcher asked participants to raise their shirts to just above the iliac crest so the measure could be taken against the skin. If they so chose, the test was completed overtop of clothing to accommodate varying comfort levels. Waist circumference was quantified and recorded on the anthropometric collection sheet by the student researcher during the baseline assessment as a measure of weight-related health risk and to provide additional contextualization of the participant population.

Body Composition

Bioelectric Impedance Analysis (BIA; RJL Systems, 2013) is a fast, safe, and non-invasive method for assessing body composition and weight-related health risk. The Quantum IV BIA System (RJL Systems, 2013) used by the student researcher during each baseline assessment, calculates body composition variables such as FM (e.g., total body fat) and LDM (e.g., fat-free mass without water), using accompanying software and validated empirical equations (e.g., NHANES-III) developed from relationships between body fluid compartments (Chumlea et al., 2002; Kyle et al., 2004a; RJL Systems, 2013). The device measures the resistance (Ω) and reactance (Ω; at 50 kHz) to a low-voltage current passed between surface electrodes on both the hand and foot (Kyle et al., 2004a). Specifically, an electrical current passes through intra- and extra-cellular fluid, varying proportionally across different tissues (Kyle et al., 2004a). Because varying hydration levels can introduce increased variability in the BIA results, participants were asked to refrain from performing activities that could easily affect personal hydration levels such as exercising, taking a sauna within eight hours, and consuming alcohol or other diuretics within 12 hours of performing the assessment measures (RJL Systems, 2013).

During analysis, the participant had surface electrodes placed on the right hand and foot. Participants were asked to remove any jewelry, the sock and shoe from the body's right side, then to lay down on a flat surface. The student researcher cleaned the sites where the electrodes were placed using an alcohol swab, removing any lotions or skin oils that could affect the results (RJL Systems, 2013). While the Quantum IV BIA device was turned on, the participant was asked to lay still to allow the resistance and reactance values to stabilize. Once the displayed values were stable, the student researcher recorded the displayed resistance and reactance values on the anthropometric collection sheet, turned off the BIA device, and then gently removed and discarded the surface electrodes (Kyle et al., 2004b). The BIA, including the placement and removal of electrodes, took at most five minutes, with the actual analysis taking less than one minute (RJL Systems, 2013).

Health Behaviours

As part of the entrance survey (Appendix J) and exit interview (Appendix P), participants completed four questions asking them to quantify: 1) the number of minutes of moderate-to-vigorous physical activity performed within the last seven days; 2) the average number of cigarettes smoked within a 24-hour period; 3) the average number of hours slept within a 24-hour period within the last seven days; and 4) the number of minutes of self-care activities performed within the last seven days. Additionally, an open-ended self-care activity question asked participants to describe any self-care activities participated in.

Data Analysis

All quantitative data were inputted into Statistical Package for the Social Sciences Version 25. Participant demographic information, including: age; sex; formal educational attainment; employment status; household income; health insurance coverage; family composition; disability information; and community services accessed, was analyzed using descriptive statistics to determine frequencies and measures of central tendency, such as mean (*M*) and standard deviation (*SD*) where appropriate, thereby allowing for the data to be summarized and described in a meaningful way (Laerd Statistics, 2018).

Prior to analyzing the dependent variables, steps were taken to create the subscales associated with each measure (i.e., PSOC, FQOL, SF-20). For the PSOC, to calculate the efficacy subscale (*Min* = 7, *Max* = 42), the scores for items 1, 6, 7, 10, 11, 13, and 15 were summed. To calculate the satisfaction subscale (*Min* = 9, *Max* = 54), the scores for items 2, 3, 4, 5, 8, 9, 12, 14, and 16 were reverse coded and then summed. The overall PSOC composite score (*Min* = 17, *Max* = 102) was calculated by adding together the efficacy subscale score, the satisfaction subscale score, and the score of item 17. Scores were then transformed linearly to 0-100 scales, with 0 and 100 representing the lowest and highest possible scores, respectively. Higher values of each factor indicate stronger scores of the associated characteristic.

For the FQOL scale, subscale scores were calculated by summing the value of each related item, including: 1) family interaction, items 1, 7, 10, 11, 12, 18 (*Min* = 6, *Max* = 30); 2) parenting, items 2, 5, 8, 14, 17, 19 (*Min* = 6, *Max* = 30); 3) emotional well-being, items 3, 4, 9, 13 (*Min* = 5, *Max* = 25); 4) physical/material well-being, items 6, 15, 16, 20, 21 (*Min* = 5, *Max* = 25); and 5) disability-related support, items 22, 23, 24, 25 (*Min* = 4, *Max* = 20). The overall FQOL composite score (*Min* = 25, *Max* = 125) was calculated by adding each subscale score together. Scores were then transformed linearly to 0-100 scales, with 0 and 100 representing the lowest and highest possible scores, respectively. Higher values of each factor indicates higher measures of the associated family-related QOL components.

For the SF-20 [POH], item 1 was rescored (i.e., 1 = 5, 2 = 4.36, 3 = 3.43, 4 = 1.99, 5 = 1) and items 8, 10, 12b, and 12c were reverse scored (i.e., 1 = 5, 2 = 4, 3 = 3, 4 = 2, 5 = 1) before items were summed according to their value and related subscale, including: 1) physical functioning, items 2a, b, c, d, e, and f (*Min* = 6, *Max* = 18); 2) pain, item 3 (*Min* = 1, *Max* = 6); 3) role functioning, items 4 and 5 (*Min* = 2, *Max* = 6); 4) social functioning, item 6 (*Min* = 1, *Max* = 6); 5) mental health, items 7, 8, 9, 10, and 11 (*Min* = 5, *Max* = 30); and 6) health perception (*Min* = 5, *Max* = 25), combines overall health, item 1 (*Min* = 1, *Max* = 5), and current health perception, items 12a, b, c, and d (*Min* = 4, *Max* = 20). Scores were then transformed linearly to 0-100 scales, with 0 and 100 representing the lowest and highest possible scores, respectively. Higher values of each factor indicate higher measures of the associated health related FQOL components; increases among components indicates a favourable change, except for pain, where a decrease, indicating less of the component, is favourable.

For each psychosocial measure (e.g., PSOC, FQOL, POH), participants change scores from pre- to post-intervention were calculated, including the M_{diff} (SD_{diff}) for each sub- and composite-scale. A combination of visual inspection via line-graphs and Cohen's *d* effect size (Cohen, 1988) was used to assess all dependent variables from pre- to post-intervention. Cohen's *d* is the standardized difference between two means (Cohen, 1988), and can indicate the strength of relationships between two or more variables or groups (Levine & Hullett, 2002). Effect sizes (*d*) were calculated to provide a standardized measure of the size of the effect between two time points (Field, 2009).

Effect size (*d*) was selected for data analysis given the smaller than anticipated sample size. Due to the fact that significance tests are dependent on sample size, research with small sample sizes can still report non-significance of strong and important effects (i.e., a type 2 error;

Levine & Hullett, 2002). Further, effect size provides an indication of the clinical significance; that is, whether the intervention makes a practical difference in the everyday life of the participants (Thompson, 2002). When interpreting Cohen's *d*, a small effect is considered 0.20, a medium effect is considered 0.50, and a large effect is considered 0.80 (Bakeman, 2005; Cohen, 1988). The effect size via Cohen's *d* was calculated for each composite and subscale to provide an indication of clinical significance from pre- to post-intervention (Laerd Statistics, 2018; Thompson, 2002).

Participant health behaviour data, including physical activity engagement, smoking, sleep quality, and self-care activities, were analyzed by using change scores to examine changes from pre- to post-intervention. Differences indicated an increase, decrease, or no change [-]. Means and standard deviations of the change scores were also calculated. This allowed for comparison to health behaviour recommendations from governing bodies, such as: 150 minutes per week of moderate-to-vigorous physical activity (Canadian Society of Exercise Physiologists, 2016; Centers for Disease Control and Prevention, 2008); and at least 7 hours of sleep per day (Buxton & Marcelli, 2010; Krueger & Friedman, 2009). The open-ended responses were also available for participants to supplement physical activity engagement and specific self-care activity quantitative responses.

The anthropometric characteristics of the caregiver participants, including height (cm), weight (kg), BMI (kg/m^2), and WC (cm), were analyzed and group means were categorized according to recommendations from the Heart and Stroke Foundation (e.g., BMI, [Underweight, < 18.5 kg/m^2 ; Normal, 18.5 - 24.9 kg/m^2; Overweight 25.0 - 29.9 kg/m^2; Obese {Class I}, 30.0 - 34.9 kg/m^2; Obese {Class II}, 35.0 - 39.9 kg/m^2; Obese {Class III, ≥ 40.0 kg/m^2}]; WC, [Female: increased risk, ≥ 80 cm; and substantially increased risk, ≥ 88 cm; Male: increased risk,

≥ 94 cm; and substantially increased risk, ≥ 102 cm]; 2021). Additionally, body composition values, including FM and LDM, were measured using the Quantum IV bioelectrical impedance analysis equipment from RJL Systems providing an indication of overall body composition. Normative data indicative of adult female FM percentages, including athletic (8 - 15 %), good (16 - 23 %), acceptable (24 - 30 %), overweight (31 - 36 %), and obese (≥ 37 %; Jeukendrup & Gleeson, 2018) were used to categorize participant group means.

Lastly, a combination of deductive and inductive content analysis was used to analyze the qualitative findings via identifying common emergent themes (Charmaz, 2006; Patton, 1989; Strauss & Corbin, 1990, 1998), and aligning these themes in categories related to the study purpose. To become emersed within the data, the student researcher read through the survey responses and interview data several times. A list of codes was then created inductively. Common words and phrases present in the data were derived using a constant comparative open coding method (i.e., developing names and classifications by segmenting data and describing them; Strauss & Corbin, 1990, 1998). Based on participant responses, as understood by the student researcher, categories of related codes were then created via axial coding (e.g., the breaking down and relating of core themes; Strauss & Corbin, 1990, 1998). As an iterative process, the codes and categories were then grouped and organized into a hierarchical coding frame consisting of main themes and associated subthemes (Lewins & Silver, 2007).

The trustworthiness of the data was maintained throughout data collection and analysis, and included elements of credibility, dependability, and transferability (Lincoln & Guba, 1985). Credibility can be defined as the confidence in how well the data address the intended focus of the measures, and involves accurately describing participants (Elo et al., 2014; Lincoln & Guba, 1985; Polit & Beck, 2004). Credibility was addressed by using a mixed-method approach to corroborate the results and findings. Member checking techniques, such as paraphrasing and summarizing to confirm understanding of participant responses and providing participant quotes when reporting on the findings were used. Dependability refers to the stability of the data over time and across different contexts (Elo et al., 2014; Lincoln & Guba, 1985). Dependability was addressed by preparing a detailed and thorough summary of the method and analysis. Transferability can be defined as the potential for extrapolation to other contexts (Elo et al., 2014; Lincoln & Guba, 1985). By providing detailed results related to participant inclusion criteria, demographics, and instruments used, the data representative of the participants can be extrapolated to other like populations or measures.

Results

Recruitment and Enrollment

Despite a 10-week recruitment window (i.e., January to early March 2020), the student researcher was not able to reach the intended sample size. Nine female CCWD who matched the participant inclusion criteria expressed interest in the study; however, upon signing the consent form, one could not commit to the time required, a second dropped out after coaching session two due to personal reasons and a third withdrew after four coaching sessions due to a change in her child's medical condition. In total, six CCWD completed the entire intervention (i.e., three assessments; eight weekly MI-via-CALC sessions) and will be reported on for the purpose of this thesis.

In total, 13 individuals contacted the student researcher to enquire about CPCC participation. Seven did not reply after receiving information about the study, two indicated that they did not match the CPCC inclusion criteria, and one declined to participate due to the time commitment involved. Thus, three CPCCs were enrolled to provide coaching services to caregiver participants. Two of these coaches were recruited through connections established via former coaching-based studies (e.g., Harvey et al., 2018; Pearson et al., 2012) and the other via an online poster uploaded through the Co-Active Network (CTI, 2019a). Of the three participating CPCCs, all had private practices; two had a combination of paid and pro bono clients, and the other had unpaid clients only. All CPCCs had completed their Co-Active certification and were located in North America (US, *n* = 1; Canada, *n* = 2). Coaches committed to coaching participants in line with their availability and other commitments resulting in two CCWDs being assigned to each coach respectively. After each CPCC completed their final coaching session with their assigned clients, the student researcher contacted them to personally relay appreciation for their participation.

Participant Demographics

All participants (*n* = 6) were mothers to at least one CWD, ranged in age from 32 to 58 years (*Mean[M]* = 48.8 years, *Standard Deviation [SD]* = 9.5 years), were married to the father of the CWD, and reported having between one and three children (*M* = 2.0, *SD* = 0.9). Caregivers shared that the children had a range of co-diagnoses and severity. All participants had completed at least high school (high school, *n* = 2; college, *n* = 3; business college, *n* = 1), were employed part- or full-time in varying positions, and half reported a household income of at least $50,000 ($25,000 - $49,999, *n* = 3; $50,000 - $74,999, *n* = 2; $75,000 - $99,999, *n* = 1). All CWD and five CCWDs were actively covered under a health insurance policy used to pay for medical services, devices, and medications. Lastly, various services were noted by participants as being accessed in the community, including respite and financial supports (i.e., Passport funding through Disability Service Ontario), health professionals (i.e., counsellor, mental health nurse, psychologist, and psychiatrist), and programming through local service providers.

Quantitative Results

Psychosocial Health

Parental Self-Efficacy

Participants raw change scores from pre- to post-assessment indicated a M_{diff} of 2.7 (SD_{diff} = 2.9) for the satisfaction subscale, a M_{diff} of 3.0 (SD_{diff} = 5.9) for the efficacy subscale, and a M_{diff} of 5.5 (SD_{diff} = 7.0) for overall sense of competence composite scale; an average increase of 13.4 %, 15.1 %, and 12.7 % respectively. Visual inspection revealed that the PSOC composite and related subscales showed an upward trend from pre- to post-intervention. With regards to clinical significance, participant change scores showed a large effect size for the satisfaction (d = .93) domain, and a medium effect size for the efficacy (d = .51) and overall PSOC composite (d = .78) domains. Therefore, the related hypotheses were accepted. Refer to *Figure 2* for a visual

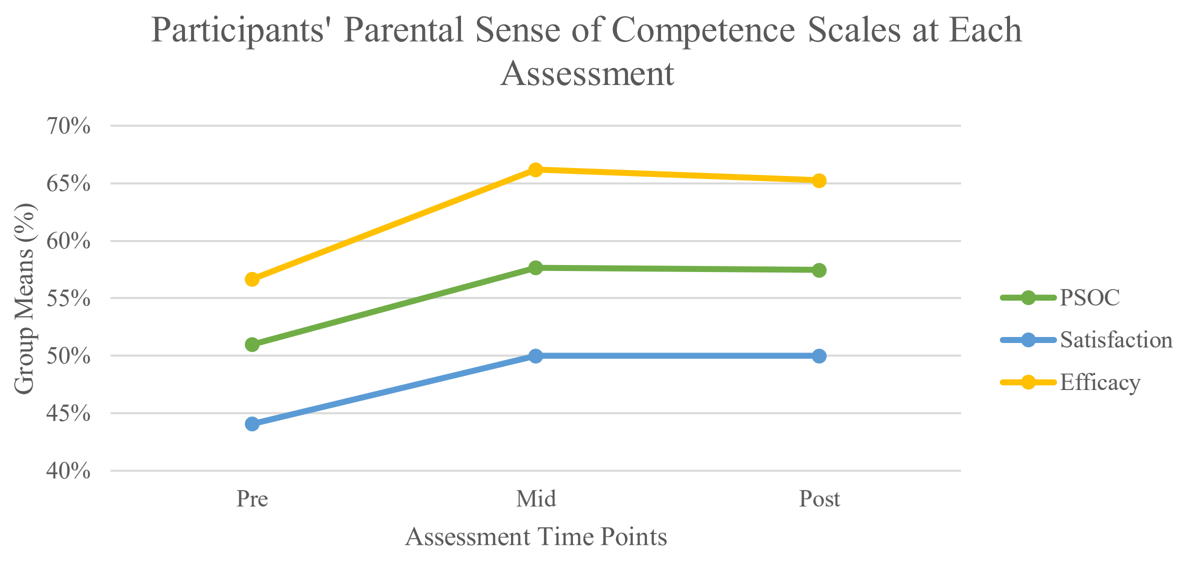

Figure 2: Grouped Means of the Participants' Parental Sense of Competence Scores. This figure provides the graphed data for group means of participants parental sense of competence and related subscale scores at each assessment.

representation of participants' PSOC and associated subscale scores across all time points. Individual scores by participant over time can be found in *Table 1.*

Family Quality of Life

Participants raw change scores from pre- to post-intervention indicated a M_{diff} of -1.2 (SD_{diff} = 2.6) for the parenting subscale, a M_{diff} of 0.7 (SD_{diff} = 1.9) for the physical/material well-being subscale, and a M_{diff} of 0.3 (SD_{diff} = 1.5) for the disability related support subscale: all of which showed clinical significance. Analysis revealed a small effect size for the parenting (d = .44), physical/material well-being (d = .36), and disability related support (d = .22) domains. Thus, the related hypothesis for physical/material wellbeing and disability related support were accepted while those associated with the parenting and remaining subscales were rejected. Combined, these results suggest a decrease for parenting (-7.1 %), and an increase for the

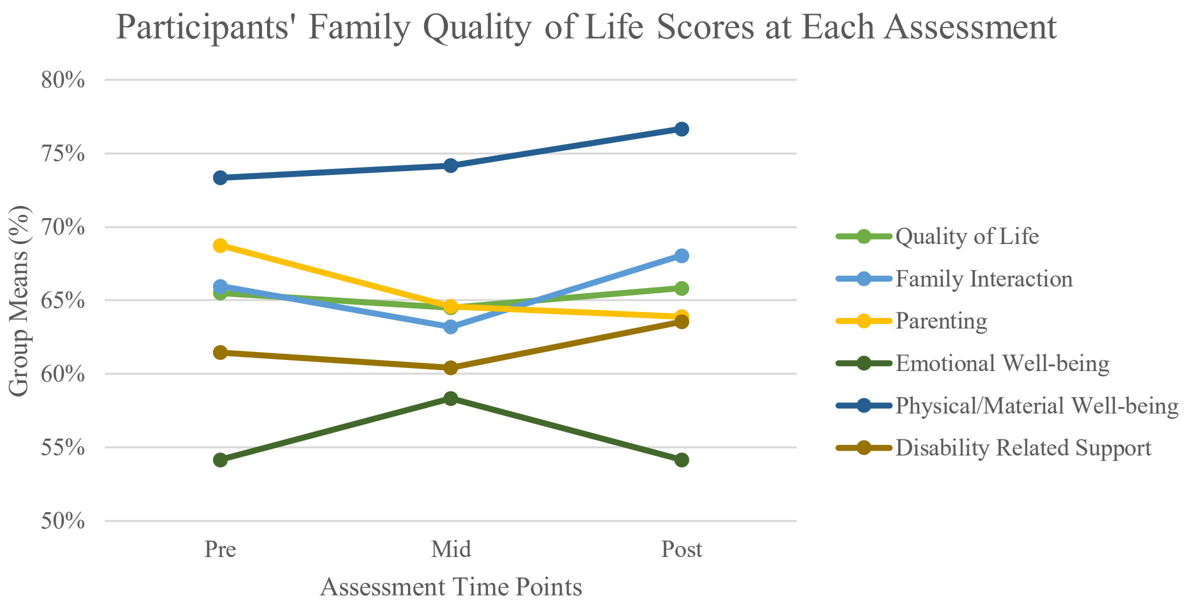

Figure 3: Grouped Means of the Participants' Family Quality of Life Scores. This figure provides the graphed data for group means of participants family quality of life and related subscale scores at each assessment.

physical/material well-being (+4.5 %) and disability related support (+3.4 %) domains from pre- to post-intervention: all of which are supported by visual inspection. Refer to *Figure 3* for a visual representation of participants' FQOL scores across all assessment time points. Individual results by participant can be found in *Table 2.*

Perception of Health

Participants raw change scores from pre- to post-intervention indicated a M_{diff} of 0.7 ($SD_{diff} = 2.1$) for physical functioning, a M_{diff} of -0.3 ($SD_{diff} = 0.5$) for pain, a M_{diff} of 0.2 ($SD_{diff} = 0.4$) for role functioning, a M_{diff} of -1.0 ($SD_{diff} = 2.2$) for social functioning, and a M_{diff} of 2.8 ($SD_{diff} = 4.0$) for mental health. Participants change scores for the pain ($d = .65$) and mental health ($d = .71$) domains had a medium effect size, whereas participants change scores for the physical functioning ($d = .32$), role functioning ($d = .41$), and social functioning ($d = .46$) domains had a small effect size. Physical functioning, pain, role functioning, social functioning, and mental health were all clinically significant ($d > 0.2$); therefore, the hypotheses related to the clinically significant increases were accepted, while those associated with social functioning and health perception were rejected. Collectively, these results suggest an increase for physical functioning (+7.1 %), role functioning (+4.8 %), and mental health (+20.2 %), and a decrease in pain (-13.3 %) and social functioning (-20.7 %) from pre- to post-intervention. Visual inspection

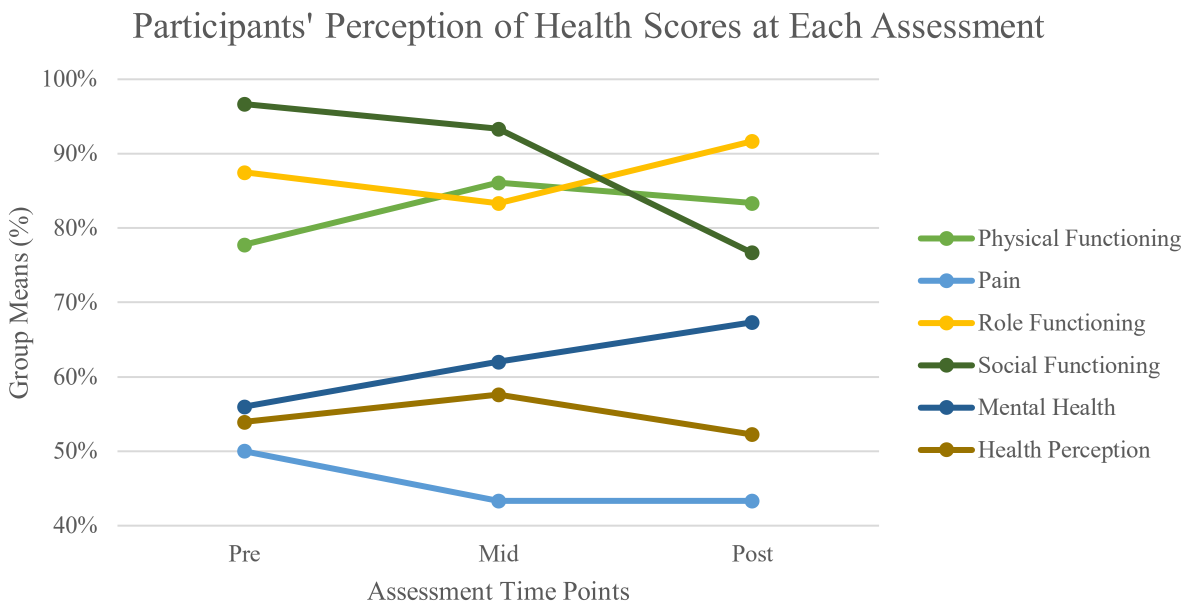

Figure 4: Grouped Means of the Participants' Perception of Health Scores. This figure provides the graphed data for group means of participants perception of health scores at each assessment.

supports the changes from pre- to post-intervention and reflected effect sizes observed. Refer to *Figure 4* for a visual representation of participants' POH scores across all assessment time points. Composite and subscale POH scores by participant can be found in *Table 3*.

Physical Health

Due to the onset of the COVID-19 pandemic, participant anthropometric and body composition data were collected at the in-person baseline assessments only. The participants mean BMI of 36.9 kg/m^2 (*SD* = 5.1 kg/m^2) and WC of 120 cm (*SD* = 10.9 cm) would categorize the sample as having Obesity, Class II (BMI ≥ 35.0 kg/m^2), and significantly increased risk (WC ≥ 88 cm) for developing weight-related health conditions. Further, participants FM of 48.6 % (*SD* = 3.0 %) and LDM of 13.2 % (*SD* = 0.9 %) revealed means in excess of what would be considered a healthy range (Jeukendrup & Gleeson, 2018). Participant baseline anthropometric and body composition data are represented in *Table 4*.

Health Behaviours

Participants raw change scores by group from pre- to post-assessment indicated a M_{diff} of 271.7 minutes (SD_{diff}= 246.4 minutes) for physical activity engagement, a M_{diff} of 0.8 hours (SD_{diff} = 1.3 hours) for sleep duration, and a M_{diff} of 205.0 minutes (SD_{diff}= 242.9 minutes) for engagement in self-care activities: an average increase of 281.0 %, 12.6 %, and 246.0 % respectively. These results indicate that: most participants either met or exceeded recommendations of 150 minutes per week of moderate- to vigorous-physical activity at post-intervention (Canadian Society of Exercise Physiologists, 2016; Centers for Disease Control and Prevention, 2008); less than half the participants met the daily recommended amount of at least 7 hours of sleep per 24-hour period after completing the intervention (Buxton & Marcelli, 2010; Krueger & Friedman, 2009). Most caregiver participants' experienced an increase of self-care activities post-intervention of between 40- to 570-minutes, with one participant showing a decrease of 30 minutes post-intervention. No participants noted smoking any cigarettes at pre- or post-intervention. Overall, positive trends were observed for each health behaviour from pre- to post-intervention, supporting the hypotheses. Participant health behaviour results and responses are included in *Tables 5 and 6.*

Qualitative Findings

Qualitative findings that emerged from the participant baseline survey and post-intervention interview responses were summarized into three main themes, some with related subthemes: (1) Caregiving Identity (What It's Like to be a CCWD; Challenges and Supports for the CCWD); (2) The Coaching Experience (Session Logistics; Expectations; Goals; Changes Made; Coaching Strategies); and (3) Future Study-related Recommendations from CCWD.

Caregiving Identity

What It's Like to Be a CCWD

Collectively, participants discussed how being a caregiver to a CWD is unique, and unlike that of a typically developing child. Common experiences pertaining to managing multiple roles, such as employee, parent, and advocate, feeling misunderstood, and related feelings of overwhelm and fear were noted. For example, when sharing what it was like to be them, two participants identified themselves specifically as "special-needs parents"(P1), commenting that "[T]his is what we have to do, so we do it." Another caregiver stated "[W]e're always having to try and advocate. And unfortunately, it should be easier for us."(P3) She explained further that as a CCWD, they are already the ones going through so much. One caregiver noted that "It is difficult being [a CCWD]. I am always panicked and stressing and worrying about everything. I do the most stupid things sometimes. I am always rushing to get everything done."(P2) Another self-described "hockey-mom"(P1) shared that "I'm stretching myself pretty thin" stating that "when I'm not at work, I'm travelling to appointments, or advocating for autism awareness and services at rallies… [and] … researching ways to help my autistic son."(P1) Two caregivers expressed how non-CCWDs do not understand what their lives are like. One felt "isolated"(P5) because she does not have "a lot of people around who totally get what I live with.” The second (P6) explained how she feels as if she is perceived by others as complaining while highlighting what other people do not get about their lives:

> People are funny in the sense that they don’t want to listen to other people bitch. And, when they ask about how your life is, and your life primarily revolves around your child, they start to think of that as just complaining all the time. ‘What did you do?’ ‘Oh well, [CWD] and I did this’ … And they go, … ‘[W]hy do you have to whine about it?’ ‘I wasn’t whining. I said we went bowling, I said we did this’ . … I find it very amazing that people don’t … understand that life. That change that comes when your kids hit teen years and you suddenly get back, slowly but surely, you gain back your freedom so to speak … and then, you know, they are in their 20s. You can do whatever you want. Your kids are off, you’ve raised them, you’ve taken care of them, they’re good. You can do whatever the hell you want… ahhh, yeah, no [we don’t get that]! So, a lot of people have a really hard time grasping that. So they look at it as complaining or whining ‘cause all you’re doing is talking about your kids, when in fact that’s your life. (P6)

Collectively, most CCWDs shared an underlying sense of fear of who will care for their CWD once they are no longer able to - something they feel sets themselves apart from other caregivers, while also uniting them to feel not alone. As one CCWD revealed, “[M]y biggest fear is what is going to happen to those boys when I am not around to look after them anymore? Or if I am too sick to do it?”(P2) with another saying, “I worry all the time about my son’s future.”(P4) A third participant shared how her son relies on her for everything, and she cannot picture not having that role in his life. Another explained that “we’re just in a different boat.”(P3)

Challenges and Supports for the CCWD

Throughout the findings, most participants shared that limited time, a loss of self-care, and difficulty fostering meaningful social connections were common within their roles as a CCWD. For example, all participants frequently described a lack of time and related ability to meet the demands of life. For one participant, “Getting my child the services he needs to have the best chance at independence possible as an adult [and] balancing the attention he needs with my other children and work life”(P1) was noted as her greatest demand. Three caregivers identified similarly that making time for themselves and self-care activities such as exercise were their greatest hurdles. One caregiver noted feeling “paralyzed”(P5), as if she had given up her personal dreams, expressing her loss of self-care and self-control, due in part to her journey for her child to receive his eventual diagnosis. Another three caregivers described how finding time to spend with those important to them was very difficult, with one identifying “spending quality time with my husband,”(P3) and another, “sharing personal time [with my husband] without our son”(P4) as their greatest difficulty.

Conversely, all participants shared that partners, like husbands and spouses, are most important for enabling them to feel effective within their CCWD roles. Additionally, these CCWD identified social connections and respite as valuable supports. More specifically, four caregivers spoke about close relationships including “definitely my family and friends,”(P1) “my husband, and my mom,”(P3) and “spouse, son, dad, friends.”(P5) One participant shared that she is friends with a much younger CWD from her home community, and they talk over Facebook nightly to co-support one another. One caregiver shared similarly that it is often “parent to parent”(P6) supporting each other, adding that the constant feeling of having to advocate for her child against an unreceptive environment is “really kind of sad.”(P6) With regards to respite, one

CCWD described how she found the staff to be among her greatest supporters. She explained that her workers and child's host mother (i.e., staff from a local community-based respite home) were "amazing"(P6) because they listen, do not criticize, do not attack, are consistent, and are there whenever she needs them. This CCWD also shared that such a self-designed support network enabled her to feel safe while expressing her unmet needs. Ultimately, these participants expressed that their greatest supports as CCWD are found in the knowledge and experiences of others who understand what it is uniquely like to be them: one parent noted specifically that it is "one of the only places you can get it from."(P6)

The Coaching Experience

Session Logistics

Initially at baseline, some participants expected that difficulties associated with their CCWD roles such as "working full-time, helping my mom, [and] trying to find time to exercise"(P2) would impact study involvement. Although one participant commented that she was "quite flexible,"(P4) two wondered if they would have enough time in the day for the sessions, noting that finding a quiet place to talk might be a "challenge."(P6) Overall, following program completion these CCWD identified that participation was primarily impacted by their surroundings and status of childcare arrangements at the time of the sessions. For example, one participant specifically spoke about the environment during her sessions; she usually ended up "wandering around the house"(P6) so she could be present. One time she "sat in the car, in the front yard because [she] could not get anybody to leave [her] alone."(P6) In addition, a few caregivers noted the requirement for their child to be cared for, such as in school or supervised by a family member so that they could dedicate themselves to being present during the coaching sessions.

Some participants shared having to reschedule up to three sessions due to competing caregiver demands, issues with technology, and differences in time-zones. For example, one participant noted that "not having [childcare] at the time [she and her coach] committed to,"(P3) along with having "double-booked" herself because she has "a million things on [her] brain" as reasons. Another two participants identified work and having to unexpectedly shut down a children's camp due to local COVID-19 health orders as reasons. When reflecting on study involvement post-intervention, participants collectively noted how very flexible and agreeable to rescheduling their coaches were if something unexpected came up.

At the end of the exit interview, participants were specifically asked how the COVID-19 pandemic affected their study-related experiences. Overall, participants shared how COVID-19 affected participant coaching sessions in terms of content, duration, and scheduling. One participant noted that she and her coach would spend the first "10-15 minutes talking about COVID."(P6) She said they often talked longer than an hour, because they would first talk about the world and COVID-19 before they actually got into "just her."(P6)

Expectations

Initially, a few participants expected the study to be most helpful by facilitating new-skill development and their ability to work through personally meaningful life issues. Specifically, participants spoke about what they were hoping to get out of the study with regards to self-care and feelings associated with mental health. For example, as one caregiver described at baseline, "It will give me an opportunity to focus more on myself without feeling so much like I'm being selfish and taking time away from my [CWD]."(P1) For another, she hoped that she would be able to "find a way to relax, [and] have less anxiety."(P2) She explained further that "I stress and worry too much, and I need to get that under control before I become ill."(P2) One participant wanted to be a “stronger caregiver,”(P3) and to help herself and other friends going through the same CCWD-related challenges. In another case, a caregiver shared she hoped to “work through the grief and futility [she] feels,”(P4) while also finding something that “[she] has the confidence to do.”(P4) Further, her intention was to find ways to “live beyond [her] situation”(P4) as opposed to just giving to others; she wanted to find tools for herself to “analyze … and look at how [she] was kind of just existing.”(P4) In general, these caregivers expected that talking about their feelings and exploring issues in their lives could lead them to feel better and more like themselves.

Goals

At the outset of the intervention, the primary goal of the participants commonly focused on bettering themselves. For example, the main goal for three caregivers was to “become healthier in general,”(P1, P2, P3) while another two wanted “to feel better about themselves”(P5, P6). Additionally, one participant included the goal of being a “better help to her son,”(P5) and to feel “more confident in [her] decisions.”(P6) Another wanted to “gain peace about this new journey, acceptance, and the ability to refocus and make new life goals.”(P4). She also wanted to “lose weight and sleep better.”(P4)

After completing the intervention, participants were again asked to discuss their goals, which were less focused on general health, and more focused on continuing to work on themselves and not fall back into old habits (e.g., not delegating tasks or taking on too much, not putting herself first). One participant’s new goal was “remain a little calmer then what I have been,”(P2) describing herself as “a pretty sensitive person,” “a perfectionist,” and “hard on herself.” This CCWD explained that she just wants to be able to “let it go.”(P2) Another wanted “to continue on with what [she’s] been doing”(P5) based on ideas discussed with her coach to "help out with [her] stress levels." A third CCWD hoped to make more people aware of what caregivers go through in life, noting that as a CCWD, "[I]t's ok to ask for help."(P3) As she explained, "[I]t's okay to take time for myself because it's in-turn better for me, as a caregiver, and a partner, and you know, family member, and friend."(P3) Lastly, two participants felt as if their goals had not changed, but their "outlook"(P6) and ability to "process what is good in her life"(P4) had improved.

Changes Made

When describing changes made in relation to their study participation, responses varied and focused on what is possible, including a support system when solving problems, and dealing with stress in a healthier way. For example, one participant described putting herself "out of her comfort zone"(P1) as a result of her involvement. She explained that she began to "delegate tasks to [her] husband [that she] would never have done,"(P1) such as taking one of the children to get bloodwork or see a dietician. She acknowledged that by allowing someone else to do these types of things "the whole world didn't fall apart,"(P1) and that she could focus more on what is possible because of this delegating. A second participant shared that in comparison to before the study, she could now analyze her life to identify things that are good and things that are troublesome: a skill she felt would allow her to "change what does not bring her joy."(P4) For example, she noted:

> When I started the study…I was needing somebody to help me process and learn how to think for myself again. Like, what I had done was become this robot that just does what needed to be done. So, I need to get up at 6am, and get up at 6am, and I need to do the meds, and, and I was literally just felt robotic in everything I was doing. Like, just get everything done, and don't do anything for pleasure. And so, that caused me to have

> zero joy because, like, my knitting. I love knitting, but my knitting has been sitting in a bag for three years. You know? … After the first session … she'd [the coach] give me one thing and … [I would spend] the entire week like, meditating on that one thing. And [I learned] how I was in control of us, and how I could change things, you know? … So after that first week I like, picked up my knitting. Like, for the first half an hour, like I would rather not go to bed and at least finish three or four rows of my knitting, and then go to bed. So even if it caused me additional stress, I just kind of like, picked it up. (P4)

This participant explained further that she had learned to "verbalize to her support system."(P4) Through completing the study, "[she] speaks more about [her] concerns and [she] draws involvement and assistance from more people around [her] than [she] did before."(P4) Another caregiver learned to "self-soothe,"(P2) "not take everything to heart,"(P2) and "find a better way to deal with [her] stress."(P2) Another caregiver noted that she learned how "beneficial"(P3) it was to take time for herself, and how "it is okay to do so."(P3) In line with this notion, another participant expressed that the most helpful part of the study was how she learned to "not be so hard on [herself]."(P2)

Coaching Strategies

Throughout the post-intervention interviews, all participants shared views on the content of their coaching sessions. Specifically, these CCWD noted how their coaches helped them to help themselves by: 1) encouraging them to identify and explore personally meaningful issues within their own lives; 2) motivating and supporting them in developing behaviour change techniques focussed on addressing the identified issues; and 3) supporting their accountability and follow through for themselves. For one participant, her coach provided some "guidance and a little push."(P2) Similarly, another participant explained:

> She [the coach] would kind of bring me down to earth sometimes. Um, you know? Like, I'd be telling her about my week, or whatever. She would say, 'Ok, but you know… you didn't get this, and this, and this done, and this didn't go right, but this did, and you did this.' And like, she made me focus more on the stuff that went right, instead of the stuff that didn't… she made me change my way of thinking that way. (P1)

With regards to motivation and support, two participants described how their coach did not tell them what to do. Instead, the "[coach] would provide ideas"(P5) or the duo would work together to identify "another way of doing things."(P5) As one participant shared, "I've really enjoyed the way I've been dealt with respectfully and without judgement."(P4) Another participant expressed confidence in her coach's availability, stating that if she needed her, the coach was there. Another participant shared similarly that she looked forward to being able to "bounce a few things off of"(P3) and "looked forward" to speaking with her coach who could provide "a different perspective." This, in turn, allowed her to be more aware of herself and express things she may not have otherwise, such as what she was feeling and going through. For another participant, it was noted that the coach supported her to examine the way she was dealing with her CWD; this increased self-awareness enabled her to follow through with meaningful action. The caregiver noted how she would "go with the flow"(P5) and "pick their battles"(P5) in an effort to reduce stress – for herself and her CWD.

Future Study-Related Recommendations from CCWD

Overall, participants shared overwhelmingly positive experiences regarding their participation within the study while identifying the need to empower CCWDs and promote autonomy within their roles. When asked about future recommendations for similar research, many emphasized: the importance of programs and service providers being familiar with and receptive to people with a disability; identifying alternative populations that may benefit from similar programs; and ways to increase enrollment of CCWD. For example, one caregiver recommended that researchers and individuals running future programming understand what life is like for people with a disability to foster tailored and person-centred approaches. She suggested that a 30-minute home-visit prior to the start of a program would allow facilitators to "see"(P2) what the person's environment is like, and what a CCWD deals with on an ongoing basis. She noted further that this would assist with enhancing the context regarding her child, instead of them just being a "name."(P2) Another caregiver stated that there should be a larger program similar to the present study available to all CCWDs. She expressed how having someone to talk to was "great,"(P5) and how it made her understand herself and her role instead of just "doing what she had been told" by other health care providers. She also recommended that the program be further developed for "kids and young adults"(P5) alike so they could experience similar benefits, including a heightened sense of control, increased ability to express oneself, and learn to focus on what can be done, instead of what cannot. To increase participant enrollment within future CCWD studies, two participants recommended appealing to CCWDs willingness to try things that may benefit them or their child, specifically pointing out how taking time for self-care to better-oneself can lead to being a better CCWD and in turn benefit their CWD, and to express how through participating CCWD are helping others. Lastly, two caregivers commented that they would not make any changes, with one saying "I don't think I would really change anything. It went really well!"(P1) and the other: "It's been a really good study to participate in. I don't have anything that I would change."(P4)

Discussion

This was the first study to investigate the effects of MI-via-CALC on CCWD. More specifically, the purpose of this pilot research was to examine the impact of an 8-week MI-via-CALC intervention on psychosocial, physical, and behavioural health indices, as well as explore the caregiving role and study-related experiences of CCWD living in Northwestern Ontario. The quantitative results indicated favourable outcomes for domains of psychosocial health and behavioural indices. Qualitatively, participants shared how being a CCWD is unique, and unlike that of a typically developing child, noting common experiences pertaining to managing multiple roles while feeling misunderstood, overwhelmed, and afraid. Further, CCWD shared positive involvement experiences during the intervention, expressing how their CPCCs helped to provide tools, an alternative perspective, and a source of accountability, which in turn led to participants experiencing heightened self-prioritization and self-care. Taken together, these data suggest that MI-via-CALC holds promise as a health promoting strategy in CCWD.

Study participant demographic data indicated a sample of individuals having Obesity, Class II (e.g., BMI ≥ 35 kg/m^2, FM ≥ 37 %), and substantially increased risk (e.g., WC ≥ 88 cm) for developing weight-related health conditions. Overall, age, sex, household income, educational attainment, and baseline body composition data for those in the present study are similar to other MI-via-CALC intervention samples (Liu et al., 2015; Racine et al., 2018) which enables some comparisons to be made. Participant psychosocial health, including PSE, FQOL, and POH, revealed some noteworthy improvements along with enhancements in health behaviours, including increases in physical activity engagement, sleep quality, and self-care activities. Each are discussed below.

Changes to Psychosocial Health

Parental Self-Efficacy

Across the intervention, participant change scores revealed a large effect for the PSOC satisfaction subscale and a medium effect for the efficacy and composite subscales suggesting that participants' enjoyment of/motivation for the parenting role and confidence in their ability to successfully facilitate positive developmental experiences for themselves and their CWD improved during the intervention. This is not surprising given how the participants described that their coaches enabled them to use an alternative perspective. As part of a six-month, telephone-based MI-via-CALC intervention involving eight women with obesity, participants experienced similar clinically significant increases in self-efficacy for managing barriers to healthy nutrition (Newnham-Kanas et al., 2011a). The participants completed 18-weekly, 35-minute MI-via-CALC sessions. One CPCC who delivered the sessions was interviewed after the intervention and noted that balance coaching, which is about opening up the clients' perspective to generate choice and in turn, action, was used often with participants. Balance coaching can lead a client to envision new perspectives, to become aware, and learn how to generate new action plans and ways of looking at things (Newnham-Kanas et al., 2011a; Whitworth et al., 1998, 2007). In the present study, one CCWD noted that her coach would bring her "down to earth"(P1) and provide an alternative viewpoint, often focusing more on what went right versus wrong: an example of balance coaching. This new perspective, led her to "change her thinking."(P1) Another CCWD mentioned how she could "bounce a few things off of a different person who's not going through [her] everyday life"(P3) leading her to be more aware of herself and what she needs to do to care for herself, her family, and other priorities. In both cases, the coach supported the CCWD by expanding their understanding of their situation, encouraging more self-awareness, and challenging any negative self-talk. This may have enabled the participants to set more challenging goals and uncover new solutions, thereby leading to increases in self-efficacy for and satisfaction with parenting.

It may also be the case that CCWD possess heightened levels of PSE due to the hand they have been dealt – that is, having a CWD can force parents to be adaptive, innovative, and resilient (Racine et. al., 2018). In a cross-sectional analysis of 71 mothers of children with (n = 33) and without a disability (n = 38), Osmančević Katkić et al. (2017) investigated stress levels and parental sense of competence. Their results indicated that mothers without a CWD had significantly higher stress levels compared to CCWD, along with significantly lower levels of parental efficacy which could indicate that parenting a CWD can lead to positive outcomes, and that parents of CWD may perceive stress differently. Similarly, in a study conducted by Hung-Chu et al. (2018) investigating PSE among caregivers of children with Autism spectrum disorder, PSE was positively correlated with enrichment (i.e., satisfaction and personal growth resulting from experiencing hardships; $r = 0.32$, $p = 0.003$) and negatively correlated with stress (i.e., an adverse psychological response to the perceived imbalance between demand and ability in parenting; $r = -0.28$, $p = 0.005$). These results provide some insight into the PSE findings from the present study. The notion of stress was often discussed by CCWD wherein as a special needs parent, they struggle with self-care, are highly self-critical, and need to find ways to decrease stress, and in a healthy way.

Findings from these studies combined with the current intervention suggest that stress affects feelings of competence in parents, regardless of having a CWD or not (Osmančević Katkić et al., 2017). However, as most disabilities are present at birth or identified at a young age, CCWD often seek out early intervention strategies which leads to enhanced parental knowledge, skill, and performance (Hastings & Johnson, 2001; Osborne et al., 2008; Schwichtenberg & Poehlmann, 2007), which in turn, could impact their PSE positively. It is interesting to note that not all literature is in agreement with regards to this relationship. In some instances, it has been found that parents of a CWD experience higher parenting stress levels, a weaker sense of coherence, and reduced health when compared to those without a CWD (Bawalsah, 2016; Oelofsen & Richardson, 2006; Picci et al., 2015). These discrepancies highlight the need for further study related to the relationship between parental stress and self-efficacy among those with and without a CWD. Further, as the link between coaching and PSE among CCWD has been documented minimally, future research is warranted to explore causative mechanisms.

Family Quality of Life

From pre- to post-intervention, participant change scores for FQOL subscales indicated a small effect for parenting, physical/material wellbeing, and disability-related supports. These results suggest that while their satisfaction with providing guidance, structure, and teaching to their children decreased, satisfaction with dependable resources, such as finances, transportation, and feeling safe in their environment increased, as did satisfaction regarding disability-related supports, including goal achievement, developing social connections, and positive engagement with service providers. With the onset of the COVID-19 pandemic taking place during the intervention, these CCWD were home with their CWD and families more than before. Because of provincial emergency orders and associated service closures (Government of Ontario, 2020), CCWD were not able to provide the same degree of structure to their CWD and family compared to pre-pandemic. Thus, it is not surprising that a decrease was observed for the parenting subscale.

According to the definition of the parenting subscale, caregivers are responsible for providing guidance, structure, and teaching to their children; however, CCWD are generally not trained as educators. In fact, CCWD typically have less formal education and are less likely to be employed when compared to families of those without a CWD (Barros et al., 2019; Davis et al., 2009; Isa et al., 2016; Nimbalkar et al., 2014). With the closure of educational institutions at the onset of the COVID-19 pandemic, these caregivers were suddenly responsible for providing greater guidance, structure, and teaching to their CWD, along with any other dependents, and were likely ill equipped to do so (Irani et al., 2021). According to participants, everything in the community had come to a halt, the pandemic was keeping them home, and it was hard to explain COVID-19 to their CWD such as why they could not see their friends, go to school, or do their normal things. Further, the participants experienced a loss of control such that their schedules, routines, and normal daily activities were newly disrupted which might also explain this subscale decrease. Interestingly, increases in PSE were observed over the course of the intervention, suggesting that participants were prepared for and capable of parenting, yet possibly inexperienced and unable to predict acute changes to their individual and family needs due to the ongoing disruptions and stressors related to COVID-19. Coaching, by nature, endorses empowerment and goal attainment for clients through the promotion of autonomy and choice (Whitworth et al., 2007). Indeed, one participant noted that following the intervention, she experienced a heightened sense of control, increased ability to express herself, and learned how to focus on what can, versus what cannot be done.

In addition, CCWD have noted in previous research that it is important for delivery agents to consider the guilt many CCWD have associated with participating in self-care activities, as they view this as taking away from their CWD (Racine et al., 2018). In line with this notion, CCWD in the present study shared post-intervention that they were appreciative of the non-judgemental approach taken by the coaches, and that having an objective individual to provide an alternative perspective was beneficial for increasing self-awareness. According to Kimsey-House et al. (2018), being genuinely curious about clients and willing to "play with whatever shows up" (p. 75) is at the crux of the Co-Active relationship. Thus, it may be the case that participants felt a sense of safety within the coaching environment due to the non-judgemental and genuinely curious approaches taken by the coaches. This, in turn, could have contributed to the observed increase in physical/material well-being positively.

With regards to the improvements in disability-related support, the coaching relationship may similarly have played a role. For example, some participants described spending the first 10 to 15 minutes of their coaching sessions discussing COVID-19 and its impact with their coach, as opposed to diving directly into exploring other issues (Whitworth et al., 2007) as is typical in non-pandemic times. This extra check-in could have served to foster meaningful connection and relatability between the duo given they were both experiencing the pandemic simultaneously. Further, life coaching inherently involves setting and identifying ways to achieve goals in an autonomy promoting manner (Whitworth et al., 2007). Indeed, according to Grant (2007), the focus of coaching is to facilitate goal attainment. As one participant noted, "She didn't tell me what to do, she'd give me ideas of what to do."(P5) Grant and Palmer (2002) emphasized similarly that coaching is an approach that enhances performance and wellbeing in personal and work domains. This notion is supported by a recent study conducted by Williams and Palmer (2020) which provides preliminary evidence that solution-focused cognitive behavioural coaching can be useful in the context of a pandemic for enhancing individual mental health and well-being. Given the observed increases in both disability-related support and mental health (discussed below), it would seem that MI-via-CALC holds promise as a support for CCWD: especially during times of crisis.

Perception of Health

Along with PSE and FQOL, how participants perceived their functional health and wellbeing has important implications. Overall, from pre- to post-intervention, participant change scores indicated a medium effect size for the pain and mental health subscales, and a small effect size for the physical functioning, role functioning, and social functioning subscales. Combined, these results suggest that CCWDs perceived less bodily pain and enhanced psychological well-being, as well as improvements in physical and role-related limitations following the intervention. However, a decrease for social functioning was noted suggesting that participants felt less able to foster and maintain social relationships. This reduction is interesting given that CCWD often depend on family and friends to be effective within their caregiving role (Pfeifer et al., 2014; Racine et al., 2018). For example, in one cross-sectional study examining 50 caregivers of children with cerebral palsy (Pfeifer et al., 2014), family and friends were identified as the greatest source of social support for this population.

More recently, social support was investigated among primary caregivers of children and adults with an intellectual disability (ID), and caregivers of children without an ID (Willner et al., 2020). Using a cross-sectional approach via a self-report online survey, Willner et al. (2020) compared participant responses (*n* = 244) between April and June 2020. Questions captured participant demographics, coping strategies, and social supports, among others. Results indicated that caregivers of children with an ID experienced significantly fewer social supports than caregivers of children without an ID. Sources they found most helpful included partners, professionals, and children, while the least helpful supports included neighbours, social/ community groups, and religious organizations.

In light of these findings (Willner et al., 2020), it would seem that a decline in social functioning among participants in the current study is not alarming: especially given the timing of this research. One major factor that could have impacted this variable negatively was the onset of the COVID-19 pandemic which took place during the latter half of the intervention. It is possible that the supports on which these CCWDs relied (e.g., friends, family, neighbours, respite workers) changed drastically and were no longer able to assist with caregiving due to the implementation of public health restrictions. Recent research has highlighted that CCWD have experienced poorer coping abilities overall (Courtenay & Perera, 2020) and feel forgotten, ignored, at their breaking point, and "on the brink of collapse" (Couglan, 2020; Harris, 2020; Hill, 2020, para. 1; Youssef, 2020) due to effects of the COVID-19 pandemic. Further, caregivers sometimes avoid asking for help when they expect others to be unable to relate to them, compounding feelings of isolation further (Brown et al., 2003). And yet, it is interesting that despite this decrease in social functioning, an increase in the mental health subscale was observed.

Indeed, consequences of the COVID-19 pandemic on caregiver social support and mental health have been investigated recently in various populations (e.g., Canadian caregivers to children 1.5-8 years of age [n = 656]; caregivers of people with autism spectrum disorder [n = 70]; and primary caregivers to adults [n = 107] and children with [n = 100] and without a disability [n = 37]) with results indicating some unfavourable outcomes such as severe strain on parenting capacity, increased social isolation/loneliness, decreases in mental health, impaired emotional regulation, loss of established structure, and reduced social support (Roos et al., 2021;

White et al., 2021; Willner et al., 2020). Further, as part of a scoping review examining the effects of COVID-19 on people with ID and their carers (Doody & Keenan, 2021), 16 studies with varying qualitative and quantitative methodologies conducted in 2020 were compared. Results revealed that people with an ID and their carers are particularly vulnerable to the physical, mental, and social effects of the pandemic. According to the authors, when compared to the general population, people with ID and their carers are challenged with: higher rates of mortality; more severe health outcomes; substantial reduction in the availability of and access to face-to-face services; and increased risk of mental illness, such as loneliness, agitation, anxiety, distress, and in some cases increased challenging behaviour. In addition, carers greatest concerns were their family's health, not getting COVID-19 and dealing with their child's behaviour (Doody & Keenan, 2021). Financial worries, managing challenges related to changes in their child's services decreasing or ceasing, and feelings of reduced efficacy to meet their child's needs at home impacted their mental well-being. Based on these studies, Doody and Keenan, (2021) suggested that a loss of routine, educational and therapeutic supports, and the introduction of new stressors (McMahon et al., 2020) are responsible for higher levels of caregiver concern and anxiety (Bailey et al., 2021; Kim et al., 2021; Villani et al., 2020). Caregivers in the present study experienced similar stressors affecting their role and study-experiences associated with the onset of the COVID-19 pandemic (e.g., a change to routine, learning from home, experiencing a loss of services) when everything had "come to a halt."(P3) Studies have also indicated that despite some proactive approaches to use alternative communication means like telehealth medicine to provide support services, caregivers experienced a decreased capacity to cope and increased isolation for the family (Mbazzi et al., 2021, Zaagsma et al., 2020). These findings do, in part, contradict the current study whereby the remotely delivered coaching intervention was identified by some as motivating and supportive. Participants were particularly appreciative of the encouragement provided by coaches with regards to exploring and addressing important personal issues, therefore highlighting the value of this user-tailored and client-centred support model.

As noted previously and in contrast to Doody and Keenan (2021), study participants actually experienced an *increase* in mental health. This might suggest that involvement in the Mi-via-CALC intervention served to boost this construct over time. An article by Fried (2014) discussing MI-via-CALC as a method for stress and anxiety management, commonly measured constructs related to mental health, highlights the utility of coaching for helping clients to feel empowered and capable of making behavioural changes. She noted that stress and anxiety are the result of how an individual reacts to stressors, and that while research supporting MI-via-CALC for management of mental health symptoms is limited, there is some support for this relationship.

Indeed, findings from Newnham-Kanas et al. (2008) attribute a reduction in participants stress levels to their involvement in a coaching intervention. As such, Newnham-Kanas et al. (2008) highlighted MI-via-CALC as a “promising” intervention for stress and anxiety management, involving many components intended to address clients on an individual basis, and that MI-via-CALC should be recommended to individuals experiencing mental-health symptoms (Newnham-Kanas et al., 2008). This individualized aspect of coaching could explain the increase observed in CCWDs mental health scores. While causality and the temporal order of the changes cannot be stated with certainty, it is possible that improvements to parenting satisfaction and efficacy contributed to enhancements in mental health – or vice versa. Additional investigation is needed to examine these changes further in terms of timing, strength, and moderating effects. Moreover, it seems that additional investigation to examine the relationship between social functioning for CCWD and mental health is warranted, during and following the pandemic, given social support seems to be one of the strongest influences on mental-health outcomes (Courtenay & Perera, 2020; Doody & Keenan, 2021; Fried, 2014; Roos et al., 2021; Tull et al., 2020; White et al., 2021; Willner, et a., 2020).

Changes to Health Behaviours

Participants' health behaviours, including physical activity, sleep, smoking, and self-care activities, were examined at pre- and post-intervention. Visual inspection revealed that overall, increases were observed for physical activity, sleep, and self-care activities. These findings align with previous studies which have shown that MI-via-CALC can positively affect HBC as evidenced by improved smoking cessation levels, increased PA and self-care engagement, and improved sleep quality (e.g., Gorczynski et al., 2008; Harvey et al., 2018; Mantler et al., 2014; Newnham-Kanas et al., 2008, 2011a; Pearson et al., 2012). It is also noteworthy that these studies focused on a diverse range of participants (e.g., physically inactive youth aged 12 through 14; undergraduate university students between 19 and 25 years; physically inactive primiparous mothers aged 28-34 whose BMI ≥ 25 kg/m^2; men and women aged 35-55 whose BMI was ≥ 30 kg/m^2; and university students aged 18–24 with a BMI ≥ 30 kg/m^2) which speaks to the universality and utility of MI-via-CALC as a method for evoking HBC. Based on the qualitative findings, it could be the case that the support and accountability provided by the CPCCs contributed to the observed changes among these CCWDs.

From a theoretical perspective, MI-via-CALC has been linked to a number of behaviour change theories and related constructs (Irwin & Morrow, 2005), including Social Cognitive Theory (Bandura, 1977, 1989), Theory of Reasoned Action (Fishbein & Ajzen, 1975), and the Theory of Planned Behaviour (Ajzen, 1988), which could also serve to explain the noted improvements in the current study. For example, core strategies used as part of MI-via-CALC such as providing acknowledgements, championing autonomy, goal setting, and harnessing personal values can be used to enhance self-efficacy – a variable that did show improvement among participants. It may be the case that as participants felt more efficacious in their ability to parent, they were simultaneously able to devote more time to focus on themselves. Future studies should seek to explore the relationships between parental/personal self-efficacy and HBC in this population to understand these connections further.

It is not entirely surprising that positive changes were observed over time to health behaviours with known links to obesity, like physical activity and sleep (Lee et al., 2017). A scoping review conducted by Liu et al. (2015) included 28 articles involving CALC interventions that were designed to improve health behaviours and related outcomes. Seven of the articles directly investigated the impact of CALC as an HBC intervention for those struggling with obesity (Newnham-Kanas et al., 2008, 2011a, 2011b; Pearson et al., 2012, 2013b; van Zandvoort et al., 2008, 2009). These studies commonly assessed anthropometric (e.g., WC, and BMI) and psychosocial measures (e.g., self-efficacy, self-esteem, functional health status, and quality of life), and results generally revealed positive outcomes suggesting that CALC can be used as a viable HBC intervention in this population. Qualitatively, participants in the present study expressed feelings of enhanced well-being and improvements to overall health after the intervention. Quantitively, less pain and heightened physical function were experienced. Taken together, it is possible that these improvements were related to the HBC trends observed.

Further, while the health behaviours assessed did increase overall across the eight-week intervention, it may not have been long enough to see changes in body composition similar to other lengthier MI-via-CALC studies (e.g., Newnham-Kanas et al., 2008, 2011a, 2011b; Pearson et al., 2012; van Zandvoort et al., 2008, 2009). Because full body composition data could not be collected due to the pandemic, it may be valuable for future researchers to examine MI-via-CALC in relation to HBC, mechanisms, contributors, and health outcomes in this population. In addition, given the multiple demands faced by CCWD, it would also be useful to determine the ideal intervention length and intensity for incurring such positive health promoting change.

Study Limitations and Strengths

Limitations

Overall, there are a few limitations that could have affected participant outcomes and experiences across the intervention that are important to note. As the onset of the COVID-19 pandemic could not have been predicted, anthropometric and body composition data were rendered unattainable, and the related effects on these measures are unknown. This was a disappointment given the physical health disparities experienced among CCWD (Lee et al., 2017), including an increased risk of developing weight-related health conditions, and the viability of MI-via-CALC as an effective obesity treatment option (Pearson et al., 2012). As such, further investigation of MI-via-CALC as an HBC intervention among CCWD is warranted, especially in relation to its potential for improving physical risk factors associated with the development of chronic disease (e.g., FM, WC). As noted via other MI-via-CALC studies (e.g., Karmali et al., 2020), the fidelity and content of the coaching sessions is not directly known which can make it challenging to evaluate and replicate the intervention. However, due to the use of trained and certified CPCCs, participants were expected to receive similar coaching tools and techniques which can help to standardize treatment experiences and reduce variability (Co-Active Training Institute [CTI], 2019a, 2019b). A subset of coaching sessions could be analyzed in future interventions aimed at exploring fidelity amongst coaches to confirm similar intervention experiences amongst participants. Additionally, due to the smaller than expected sample size and inherent nature of a pilot study, the results for the quantitative measures should be investigated further with adequately powered samples to complete inferential statistics which would allow for confirmation of study results. Lastly, the generalizability of the findings should be taken with caution. The homogeneity of participants limits the transferability of the findings. Fathers, other caregivers, and same sex couples for example, were not represented within the study participants. Further, CCWD participants volunteered to participate, which may have excluded those who generally shy away from participating in opportunities for self-care activities. Future researchers should aim to achieve a sample representative of CCWD that would allow for greater transferability in this context.

Strengths

This is the first MI-via-CALC study to include CCWD - a unique population known to experience adverse health, be forgotten and neglected often, and rarely thanked for their emotional and physical labour. As indicated by the quantitative data, participants experienced favourable changes in as little as 4-weeks: a shorter timeline in comparison to other MI-via-CALC studies. This may be demonstrative of the client-centred and tailored approaches used as part of the CALC method. It is also noteworthy that this study was delivered during the onset of a worldwide pandemic. Advantageously, the nature of coaching is inherently remote; thus, the rigour of the design and methods could be maintained during lockdown (minus the physical health data) due to the telephone modality. This is an important consideration as the world continues to adapt to the use of telecommunications for health and wellness care provision, which also highlights the novelty and practicality of the intervention. Given CPCCs typically deliver their services using telephone or web-based platforms, it may be valuable to explore these avenues further to identify best practices that can be transferred to other settings and populations. Further, as this study employed a mix of quantitative measures and qualitative exploration, a deeper and more meaningful context could be provided, resulting in an enhanced understanding of CCWD participants and their study-related experiences.

Conclusion

As the first MI-via-CALC intervention to assess the psychosocial, physical, and behavioural health of CCWD, conducted during a global pandemic no less, the results and findings indicate improvements among these CCWD. Several clinically significant results were observed amongst the psychosocial variables examined during this pilot study including dimensions of PSE, FQOL, and POH – important improvements for an ‘at risk’ population that has been identified as a public health priority and recommended for further investigation (National Alliance for Caregiving & American Association of Retired Persons, 2004; Shaji & Reddy, 2012). Additionally, health behaviours including physical activity engagement, sleep quality, and self-care activities increased from pre- to post-intervention for most CCWD participants suggesting that these participants were increasingly able to take time for themselves. Qualitatively, findings complemented and supported the quantitative results. For example, CCWD expressed that their role is unique and unlike that of other caregivers and accounts of study-related experiences suggest that these CCWD started to prioritize themselves more often throughout the intervention. Specifically, they expressed how their CPCCs helped them to help themselves via self-exploration, developing HBC techniques, and providing accountability without judgment and in a supportive way. According to participants, their coaches provided tools and alternative perspectives in service of the caregiver, which in turn led to participants experiencing heightened self-prioritization and self-care.

While these study results should be interpreted with caution, overall, MI-via-CALC appears to be a promising avenue to promote psychosocial health and positive HBC among CCWD. As research is sparse regarding the impact of life coaching on the health and wellbeing of CCWD, especially during the onset and continuation of the COVID-19 pandemic, future researchers should investigate MI-via-CALC across alternative intervention durations, sample sizes, and include a control group when developing and implementing caregiver interventions. This would enhance researchers' ability to compare the effect of the treatment, and thereby allow for inferential statistics and correlations to be explored between variables. Additionally, the CCPC experience should also be examined in parallel as this would provide an additional perspective of study fidelity, methods, and procedures not usually available to researchers due to the confidential nature of coaching sessions between client and coach. In this respect, coaches could provide insights related to MI-via-CALC delivery in this context – especially during a worldwide crisis. Other stakeholders, including spouses and family members, may also experience improved outcomes through participating in life coaching, which could lead to further improvements within the family, and should be included in the research process when implementing interventions inclusive of CCWD.

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Tables

Table 1: Participants' RAW Parental Sense of Competence Scores by Assessment Timepoint

Subscale and Timepoint	Participant						
	1	2	3	4	5	6	M [SD]
Self-Efficacy[*]							
Pre	22	36	23	20	27	33	26.8 [6.4]
Mid	25	33	30	28	35	30	30.2 [3.5]
Post	26	33	33	18	37	32	29.8 [6.8]
Satisfaction[**]							
Pre	30	27	31	25	26	34	28.8 [3.4]
Mid	33	26	41	24	32	33	31.5 [6.0]
Post	30	31	34	32	29	33	31.5 [1.9]
PSOC Composite[***]							
Pre	58	69	60	46	57	72	60.3 [9.3]
Mid	63	63	77	53	72	68	66.0 [8.3]
Post	60	69	73	51	72	70	65.8 [8.6]

Note. PSOC = parental sense of competence.

[*] [Min = 7, Max = 42]. [**] [Min = 9, Max = 54]. [***] [Min = 17, Max = 102].

Table 2: Participants' RAW Family Quality of Life Scores by Assessment Timepoint

Subscale and Timepoint	Participant 1	2	3	4	5	6	M [SD]
Family Interaction*							
Pre	24	23	17	29	26	12	21.8 [6.2]
Mid	25	25	19	27	25	6	21.2 [7.9]
Post	22	24	22	27	28	11	22.3 [6.1]
Parenting**							
Pre	23	24	21	23	26	18	22.5 [2.7]
Mid	22	25	21	20	29	12	21.5 [5.7]
Post	22	23	21	22	28	12	21.3 [5.7]
Emotional Wellbeing***							
Pre	10	14	14	9	13	16	12.7 [2.7]
Mid	14	16	14	12	16	8	13.3 [3.0]
Post	9	15	16	9	15	12	12.7 [3.1]
Physical / Material Wellbeing****							
Pre	17	20	20	18	22	21	19.7 [1.9]
Mid	17	21	22	16	23	20	19.8 [2.8]
Post	18	19	21	16	25	23	20.3 [3.3]
Disability Related Support*****							
Pre	12	15	18	7	16	15	13.8 [3.9]
Mid	11	14	16	10	17	14	13.7 [2.7]
Post	11	16	16	8	17	17	14.2 [3.8]
FQOL Composite******							
Pre	86	96	90	86	103	82	90.5 [7.7]
Mid	89	101	92	85	110	60	89.5 [17.0]
Post	82	97	96	82	113	75	90.8 [13.9]

Note. FQOL = family quality of life.

*[Min = 6, Max = 30]. **[Min = 6, Max = 30]. ***[Min = 4, Max = 20]. ****[Min = 5, Max = 25].

*****[Min = 4, Max = 20]. ******[Min = 25, Max = 125].

Table 3: Participants' RAW Perception of Health Scores by Assessment Timepoint

Subscale and Timepoint	Participant 1	2	3	4	5	6	M [SD]
Physical Functioning*							
Pre	16	18	18	12	18	10	15.3 [3.5]
Mid	14	18	18	14	18	16	16.3 [2.0]
Post	14	18	18	14	18	14	16.0 [2.2]
Pain**							
Pre	2	3	4	4	4	4	3.5 [0.8]
Mid	2	1	4	4	4	4	3.2 [1.3]
Post	2	2	4	4	3	4	3.2 [1.0]
Role Functioning***							
Pre	6	6	6	3	6	6	5.5 [1.2]
Mid	6	6	6	4	6	4	5.3 [1.0]
Post	6	6	6	4	6	6	5.7 [0.8]
Social Functioning****							
Pre	6	5	6	6	6	6	5.8 [0.4]
Mid	6	6	6	5	6	5	5.7 [0.5]
Post	6	6	6	4	6	1	4.83 [2.0]
Mental Health*****							
Pre	17	17	24	14	22	20	19.0 [3.7]
Mid	20	18	22	22	25	16	20.5 [3.2]
Post	21	19	21	23	26	21	21.8 [2.4]
Health Perception******							
Pre	11.99	19.43	13.99	13.43	20.43	15.43	15.8 [3.4]
Mid	15.43	20.43	12.99	15.43	20.43	14.43	16.5 [3.2]
Post	14.43	20.43	14.99	12.99	19.43	10.43	15.5 [3.8]

Note. M = mean; SD = standard deviation.

*[Min = 6, Max = 18]. **[Min = 1, Max = 6]. ***[Min = 2, Max = 6]. ****[Min = 1, Max = 6].

*****[Min = 5, Max = 30]. ******[Min = 5, Max = 25].

Table 4: Participants' Anthropometric and Body Composition Values

Variable	Participant 1	2	3	4	5	6	Range	M [SD]
Height (cm)	174.0	151.0	163.0	174.0	160.0	152.7	151.0 - 174.0	162.5 [10.0]
Weight (kg)	131.5	71.0	101.0	93.8	95.2	95.2	71.0 - 131.5	98.0 [19.5]
BMI (kg/m^2)	43.4	31.1	38.0	31.0	37.2	40.8	31.0 - 43.4	36.9 [5.1]
WC (cm)	134.5	104.5	120.5	110.5	123.5	126.5	104.5 - 134.5	120.0 [10.9]
FM (%)	51.5	44.5	50.5	45.2	49.6	50.4	44.5 - 51.5	48.6 [3.0]
LDM (%)	13.0	13.5	12.8	14.9	12.9	12.1	12.1 - 14.9	13.2 [0.9]

Note. BMI = body mass index; FM = fat mass; LDM = lean dry mass; WC = waist circumference.

Table 5: Participants' Health Behaviour Values by Assessment Timepoint

Health Behaviour	Participant						
	1	2	3	4	5	6	M [SD]
Physical Activity (minutes per week)							
Pre	90	90	0	400	0	0	96.7 [155.0]
Post	240	750	0	560	480	180	368.3 [276.6]
Diff	+150	+660	0	+160	+480	+180	271.7 [246.4]
+/-	Increase	Increase	-	Increase	Increase	Increase	Increase
Smoking (cigarettes per day)							
Pre	0	0	0	0	0	0	0 [0]
Post	0	0	0	0	0	0	0 [0]
Diff	0	0	0	0	0	0	0 [0]
+/-	-	-	-	-	-	-	-
Sleep (hours per night)							
Pre	5 to 6	6	6	5	8	8	6.6 [1.3]
Post	5 to 6	7	6 to 7	6	7	10 to 11	6.7 [0.6]
Diff	0	+1	+1	+1	-1	+3	0.8 [1.3]
+/-	-	Increase	Increase	Increase	Decrease	Increase	Increase
Self-care Activities (minutes per week)							
Pre	0	60	30	200	30	180	83.3 [85.0]
Post	440	210	0	240	600	240	288.3 [206.9]
Diff	+440	+150	-30	+40	+570	+60	205.0 [242.9]
+/-	Increase	Increase	Decrease	Increase	Increase	Increase	Increase

Table 6: Participants' Health Behaviour Responses by Assessment Timepoint

Health Behaviour Responses
Physical Activity
Pre
P2 - Walking, snowshoeing.
P5 - General walking.
Post
P1 - Spends 30-60 minutes at the gym three to four times a week.
P2 - Walking, yard work (e.g., raking). Spends "at least" 30 minutes everyday being active.
P4 - Spends 80 minutes per day walking, increasing from 1km to 12km per day.
P5 - 3 or 4 walks a day for at least 30 minutes while at camp.
P6 - Walk with a friend twice a week for approximately 90 minutes each time.
Self-care Activities
Pre
P1 - Spent the previous week travelling with her son, but would typically "take a bath, or go for coffee with [her] mom or a friend."
P2 - "I have not done much [self-care] lately".
P3 - Went to the chiropractor and "tries to get a massage every six to seven weeks."
P4 - Long bath, knitting, lay in the sun on her bed, went to dinner with her husband.
P5 - Spent time with family, attended her grandson's hockey game, and went to a shag with friends.
P6 - Acupuncture, massage, spent time with friends, slept in.
Post
P1 - Walking daily, reading before bed, and cross stitch weekly.
P2 - Walking and being active for "at least half an hour every day [is] for [herself]."
P3 - Describes loving her weekly grocery shopping as "the only time I'm really by myself, without having to take care of anybody" but that "you can't enjoy it really right now [because of the pandemic]."
P5 - Spent time with family, played board games, took a bath, sat out on the deck, and relax with her husband.
P6 - Spends time walking with a friend, as well as watching TV after children are in bed.

Appendices

Appendix A: Research Ethics Board Approval Notice

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Research Ethics Board
t: (807) 343-8283
research@lakeheadu.ca

December 06, 2019

Principal Investigator: Dr. Erin Pearson
Student: Jonathan Racine
Faculty of Health and Behavioural Sciences\School of Kinesiology
Lakehead University
955 Oliver Road
Thunder Bay, ON P7B 5E1

Dear Dr. Pearson and Mr. Racine:

Re: Romeo File No: 1467445
Granting Agency: N/A
Agency Reference #: N/A

On behalf of the Research Ethics Board, I am pleased to grant ethical approval to your research project titled, "Caring for Carers: Investigating the Impact of an 8-week MI-via-CALC Intervention on the Psychosocial and Physical Health of Caregivers of Children with a Disability".

Ethics approval is valid until December 6, 2020. Please submit a Request for Renewal to the Office of Research Services via the Romeo Research Portal by November 6, 2020 if your research involving human participants will continue for longer than one year. A Final Report must be submitted promptly upon completion of the project. Access the Romeo Research Portal by logging into myInfo at:

https://erpwp.lakeheadu.ca/

During the course of the study, any modifications to the protocol or forms must not be initiated without prior written approval from the REB. You must promptly notify the REB of any adverse events that may occur.

Best wishes for a successful research project.

Sincerely,

Dr. Kristin Burnett
Chair, Research Ethics Board

/sm

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Appendix B: Participant Recruitment Poster

CAREGIVERS of CHILDREN with a DISABILITY

Researchers from Lakehead University are looking at how a **life coaching program** might **enhance your quality of life**.

Participate in 8 **FREE** weekly **HOMEBASED** phone/skype sessions with a certified life coach to talk about what's important to you.

Attend 3 in-person sessions where you will complete questionnaires about your health and have your body composition measured.

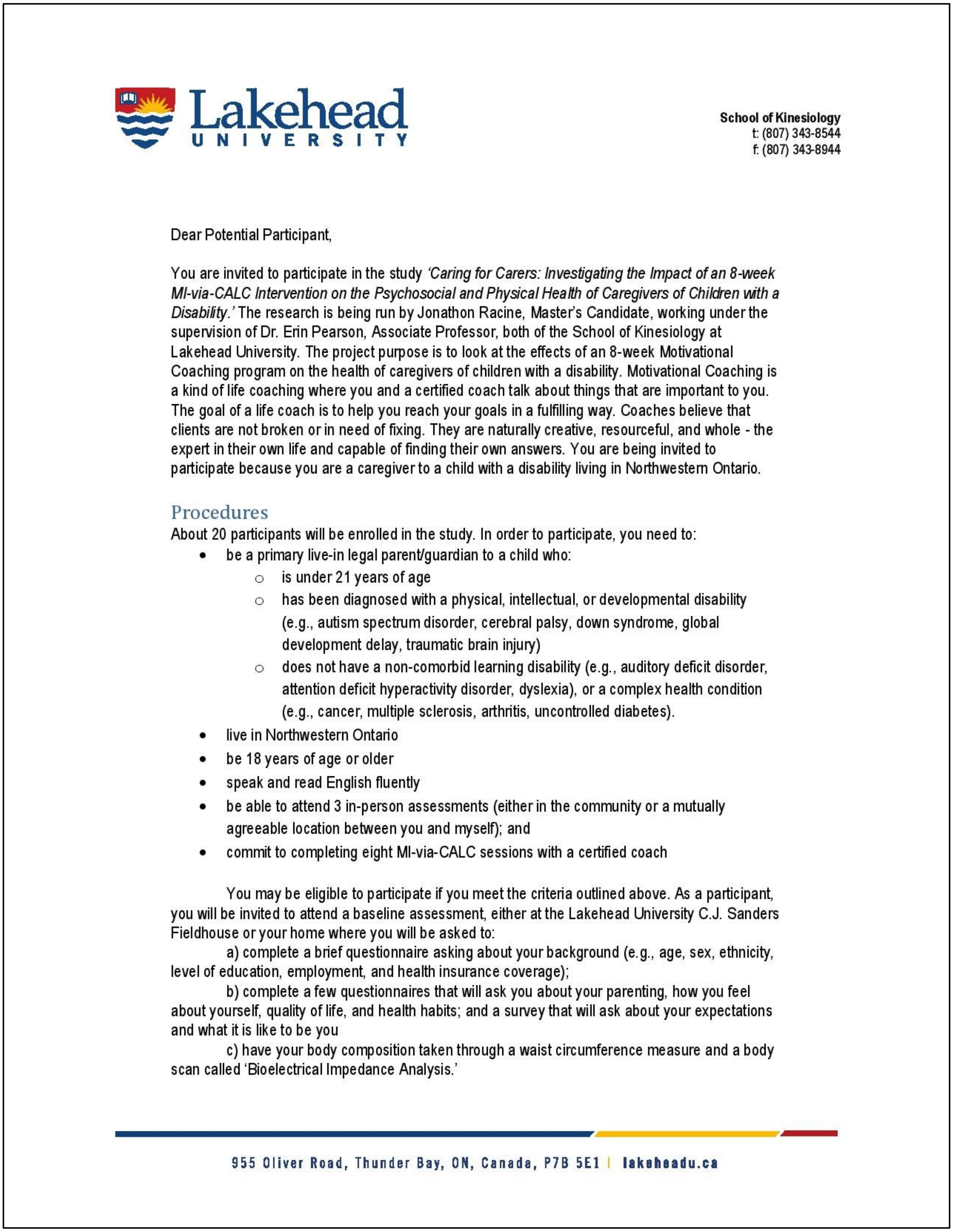
For more details, contact: Jonathon Racine (MSc Candidate)
email: jracine@lakeheadu.ca call/text: 807-472-7655

Supervisor: Dr. Erin Pearson, CPCC

Lakehead UNIVERSITY

This study has been reviewed and approved by the Lakehead University Research Ethics Board. If you have any question regarding participant rights and ethical conduct of research, please contact the Lakehead University Ethics Review Board at 807-343-8283 or research@lakehadu.ca

Appendix C: Caregiver Participant Information Letter



Lakehead UNIVERSITY

School of Kinesiology
t: (807) 343-8544
f: (807) 343-8944

Dear Potential Participant,

You are invited to participate in the study *'Caring for Carers: Investigating the Impact of an 8-week MI-via-CALC Intervention on the Psychosocial and Physical Health of Caregivers of Children with a Disability.'* The research is being run by Jonathon Racine, Master's Candidate, working under the supervision of Dr. Erin Pearson, Associate Professor, both of the School of Kinesiology at Lakehead University. The project purpose is to look at the effects of an 8-week Motivational Coaching program on the health of caregivers of children with a disability. Motivational Coaching is a kind of life coaching where you and a certified coach talk about things that are important to you. The goal of a life coach is to help you reach your goals in a fulfilling way. Coaches believe that clients are not broken or in need of fixing. They are naturally creative, resourceful, and whole - the expert in their own life and capable of finding their own answers. You are being invited to participate because you are a caregiver to a child with a disability living in Northwestern Ontario.

Procedures

About 20 participants will be enrolled in the study. In order to participate, you need to:

- be a primary live-in legal parent/guardian to a child who:
    - is under 21 years of age
    - has been diagnosed with a physical, intellectual, or developmental disability (e.g., autism spectrum disorder, cerebral palsy, down syndrome, global development delay, traumatic brain injury)
    - does not have a non-comorbid learning disability (e.g., auditory deficit disorder, attention deficit hyperactivity disorder, dyslexia), or a complex health condition (e.g., cancer, multiple sclerosis, arthritis, uncontrolled diabetes).
- live in Northwestern Ontario
- be 18 years of age or older
- speak and read English fluently
- be able to attend 3 in-person assessments (either in the community or a mutually agreeable location between you and myself); and
- commit to completing eight MI-via-CALC sessions with a certified coach

You may be eligible to participate if you meet the criteria outlined above. As a participant, you will be invited to attend a baseline assessment, either at the Lakehead University C.J. Sanders Fieldhouse or your home where you will be asked to:

a) complete a brief questionnaire asking about your background (e.g., age, sex, ethnicity, level of education, employment, and health insurance coverage);

b) complete a few questionnaires that will ask you about your parenting, how you feel about yourself, quality of life, and health habits; and a survey that will ask about your expectations and what it is like to be you

c) have your body composition taken through a waist circumference measure and a body scan called 'Bioelectrical Impedance Analysis.'

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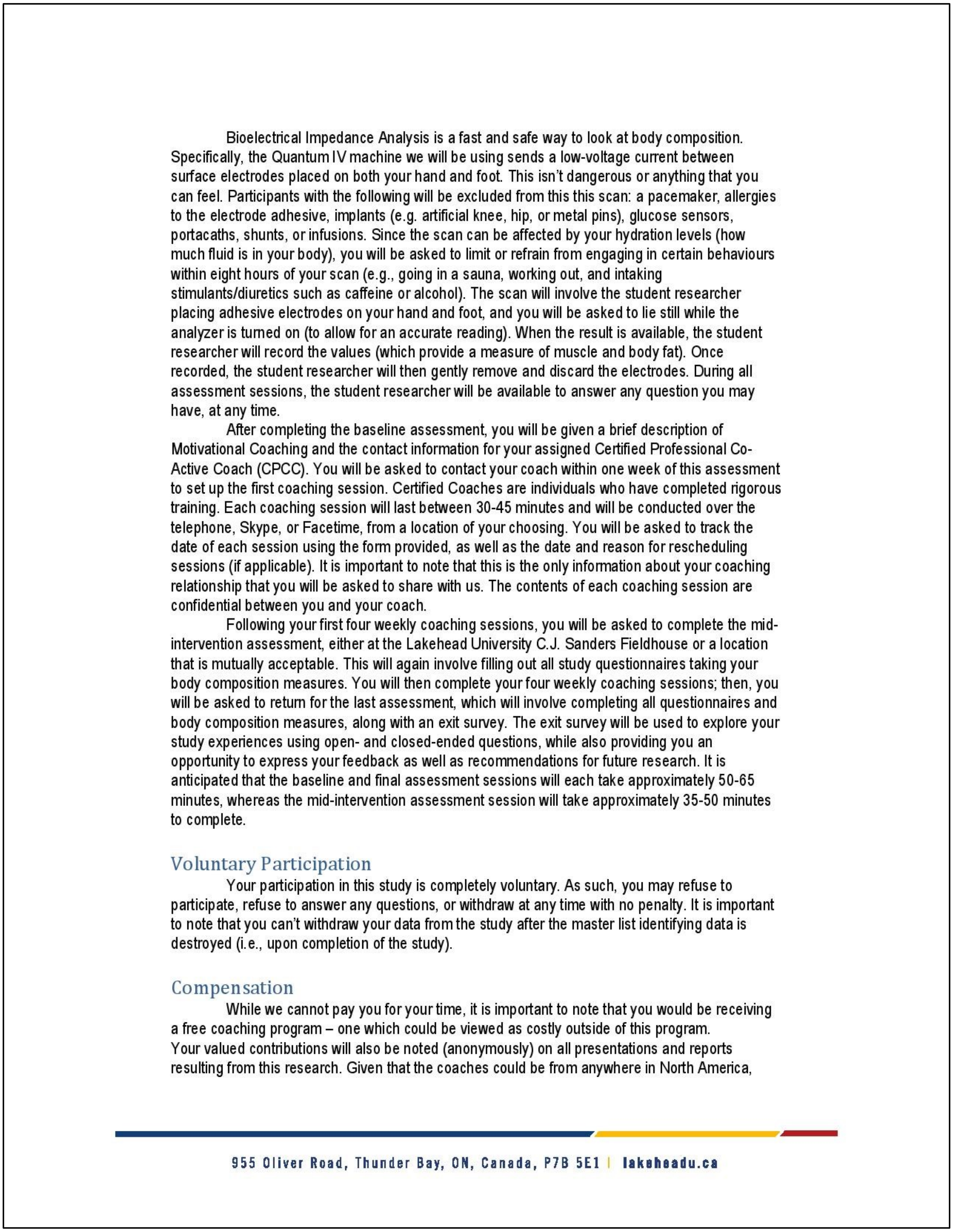


Bioelectrical Impedance Analysis is a fast and safe way to look at body composition. Specifically, the Quantum IV machine we will be using sends a low-voltage current between surface electrodes placed on both your hand and foot. This isn't dangerous or anything that you can feel. Participants with the following will be excluded from this this scan: a pacemaker, allergies to the electrode adhesive, implants (e.g. artificial knee, hip, or metal pins), glucose sensors, portacaths, shunts, or infusions. Since the scan can be affected by your hydration levels (how much fluid is in your body), you will be asked to limit or refrain from engaging in certain behaviours within eight hours of your scan (e.g., going in a sauna, working out, and intaking stimulants/diuretics such as caffeine or alcohol). The scan will involve the student researcher placing adhesive electrodes on your hand and foot, and you will be asked to lie still while the analyzer is turned on (to allow for an accurate reading). When the result is available, the student researcher will record the values (which provide a measure of muscle and body fat). Once recorded, the student researcher will then gently remove and discard the electrodes. During all assessment sessions, the student researcher will be available to answer any question you may have, at any time.

After completing the baseline assessment, you will be given a brief description of Motivational Coaching and the contact information for your assigned Certified Professional Co-Active Coach (CPCC). You will be asked to contact your coach within one week of this assessment to set up the first coaching session. Certified Coaches are individuals who have completed rigorous training. Each coaching session will last between 30-45 minutes and will be conducted over the telephone, Skype, or Facetime, from a location of your choosing. You will be asked to track the date of each session using the form provided, as well as the date and reason for rescheduling sessions (if applicable). It is important to note that this is the only information about your coaching relationship that you will be asked to share with us. The contents of each coaching session are confidential between you and your coach.

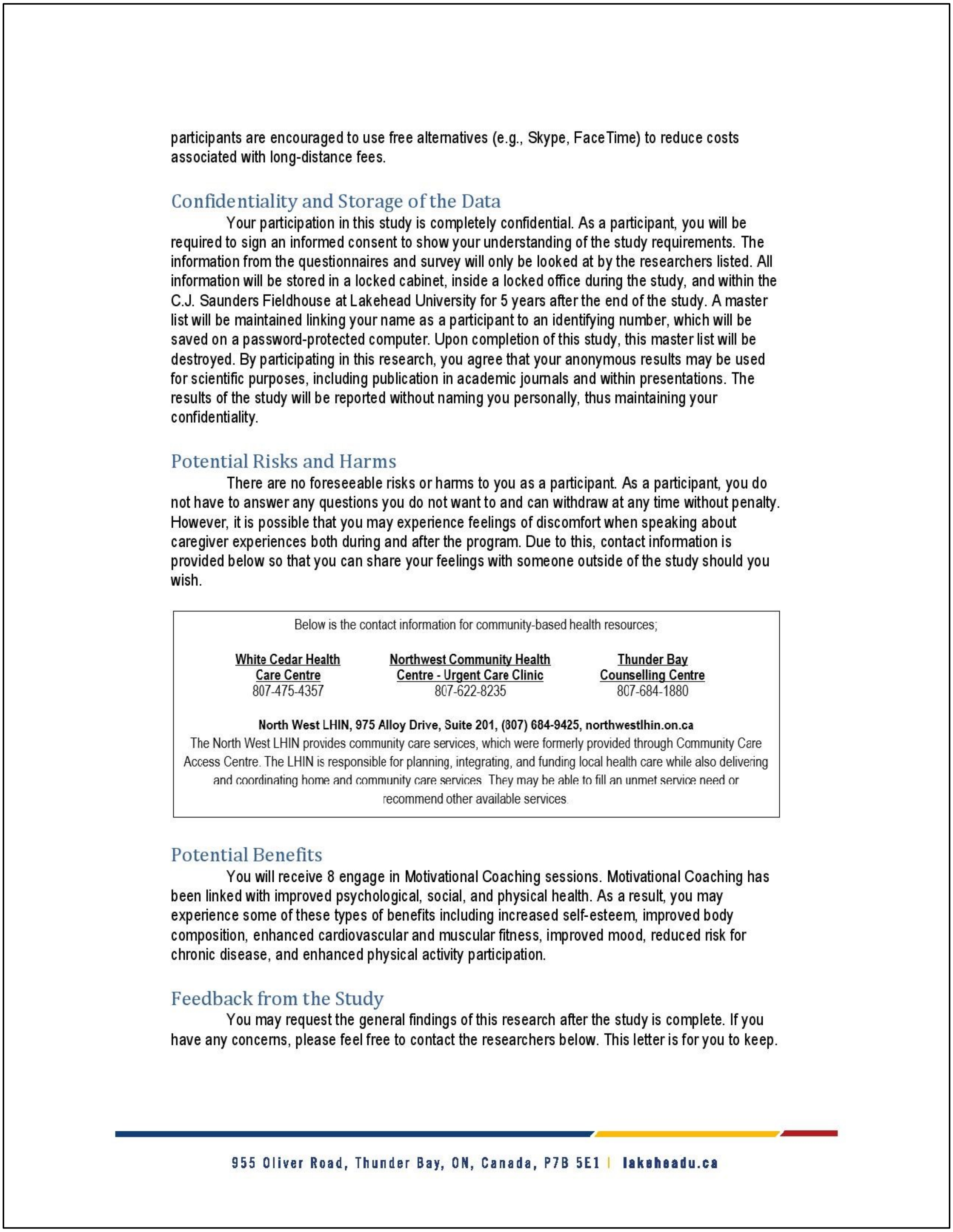
Following your first four weekly coaching sessions, you will be asked to complete the mid-intervention assessment, either at the Lakehead University C.J. Sanders Fieldhouse or a location that is mutually acceptable. This will again involve filling out all study questionnaires taking your body composition measures. You will then complete your four weekly coaching sessions; then, you will be asked to return for the last assessment, which will involve completing all questionnaires and body composition measures, along with an exit survey. The exit survey will be used to explore your study experiences using open- and closed-ended questions, while also providing you an opportunity to express your feedback as well as recommendations for future research. It is anticipated that the baseline and final assessment sessions will each take approximately 50-65 minutes, whereas the mid-intervention assessment session will take approximately 35-50 minutes to complete.

Voluntary Participation

Your participation in this study is completely voluntary. As such, you may refuse to participate, refuse to answer any questions, or withdraw at any time with no penalty. It is important to note that you can't withdraw your data from the study after the master list identifying data is destroyed (i.e., upon completion of the study).

Compensation

While we cannot pay you for your time, it is important to note that you would be receiving a free coaching program – one which could be viewed as costly outside of this program.
Your valued contributions will also be noted (anonymously) on all presentations and reports resulting from this research. Given that the coaches could be from anywhere in North America,



participants are encouraged to use free alternatives (e.g., Skype, FaceTime) to reduce costs associated with long-distance fees.

Confidentiality and Storage of the Data

Your participation in this study is completely confidential. As a participant, you will be required to sign an informed consent to show your understanding of the study requirements. The information from the questionnaires and survey will only be looked at by the researchers listed. All information will be stored in a locked cabinet, inside a locked office during the study, and within the C.J. Saunders Fieldhouse at Lakehead University for 5 years after the end of the study. A master list will be maintained linking your name as a participant to an identifying number, which will be saved on a password-protected computer. Upon completion of this study, this master list will be destroyed. By participating in this research, you agree that your anonymous results may be used for scientific purposes, including publication in academic journals and within presentations. The results of the study will be reported without naming you personally, thus maintaining your confidentiality.

Potential Risks and Harms

There are no foreseeable risks or harms to you as a participant. As a participant, you do not have to answer any questions you do not want to and can withdraw at any time without penalty. However, it is possible that you may experience feelings of discomfort when speaking about caregiver experiences both during and after the program. Due to this, contact information is provided below so that you can share your feelings with someone outside of the study should you wish.

Below is the contact information for community-based health resources;

White Cedar Health Care Centre	Northwest Community Health Centre - Urgent Care Clinic	Thunder Bay Counselling Centre
807-475-4357	807-622-8235	807-684-1880

North West LHIN, 975 Alloy Drive, Suite 201, (807) 684-9425, northwestlhin.on.ca

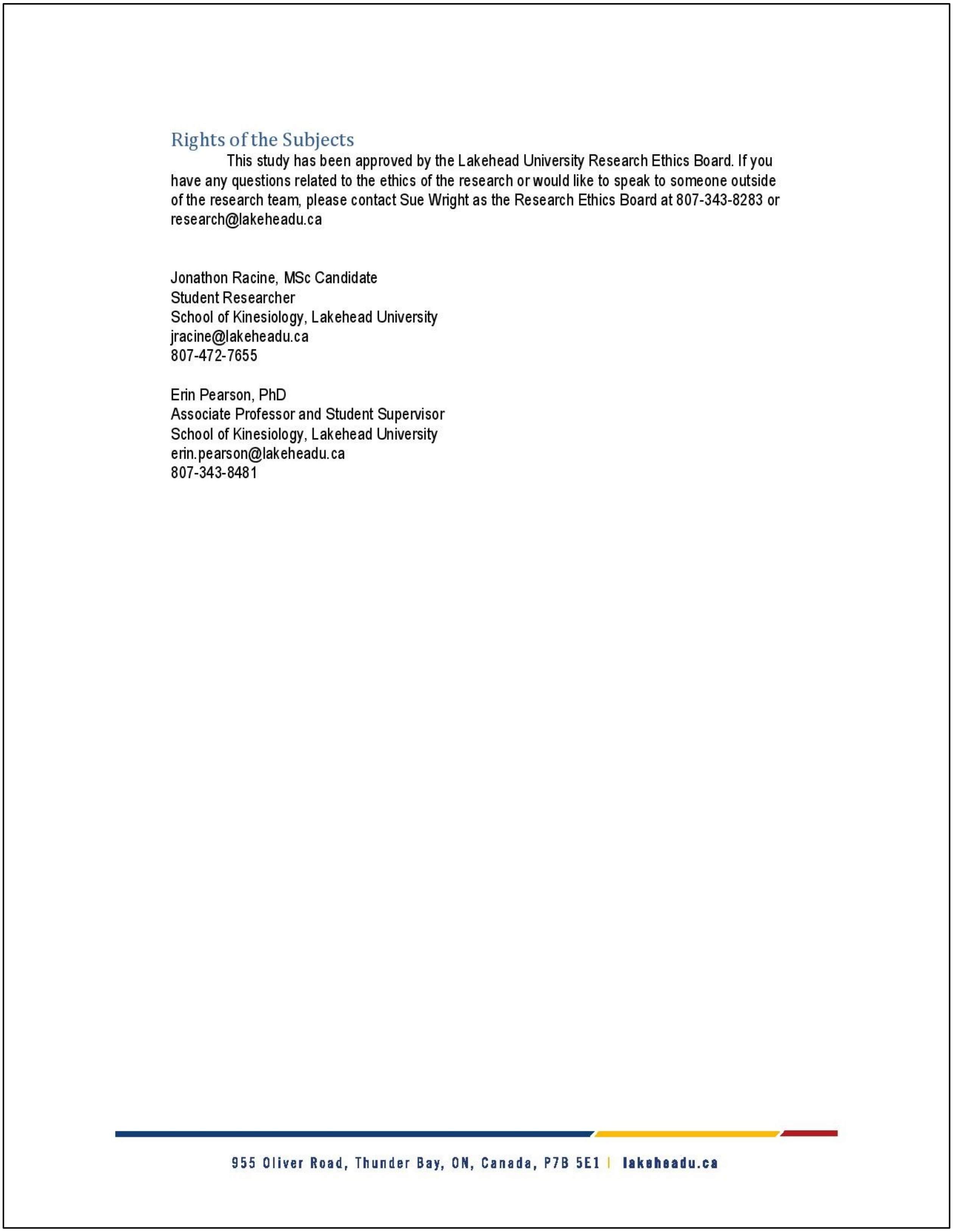
The North West LHIN provides community care services, which were formerly provided through Community Care Access Centre. The LHIN is responsible for planning, integrating, and funding local health care while also delivering and coordinating home and community care services. They may be able to fill an unmet service need or recommend other available services.

Potential Benefits

You will receive 8 engage in Motivational Coaching sessions. Motivational Coaching has been linked with improved psychological, social, and physical health. As a result, you may experience some of these types of benefits including increased self-esteem, improved body composition, enhanced cardiovascular and muscular fitness, improved mood, reduced risk for chronic disease, and enhanced physical activity participation.

Feedback from the Study

You may request the general findings of this research after the study is complete. If you have any concerns, please feel free to contact the researchers below. This letter is for you to keep.



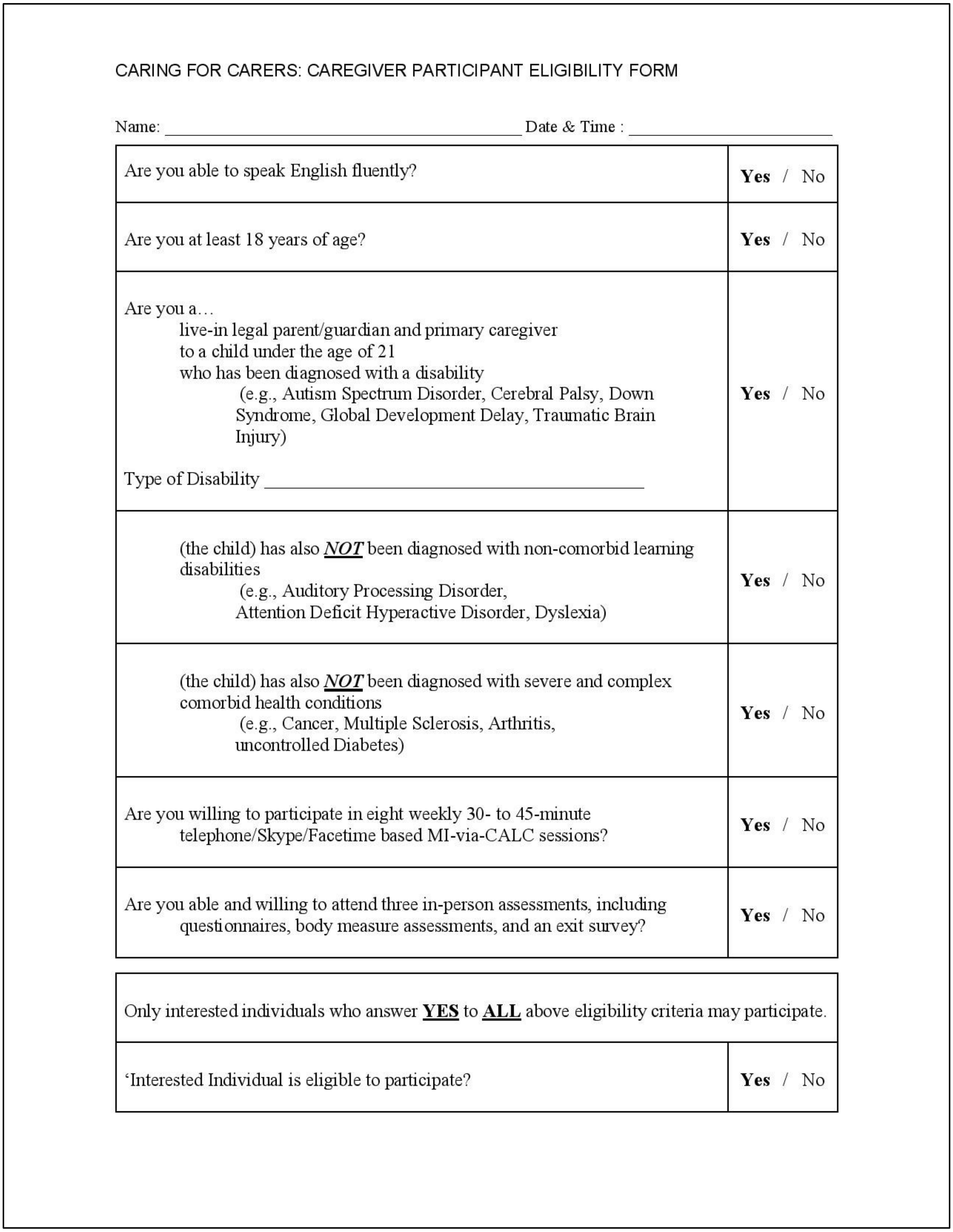
Rights of the Subjects

This study has been approved by the Lakehead University Research Ethics Board. If you have any questions related to the ethics of the research or would like to speak to someone outside of the research team, please contact Sue Wright as the Research Ethics Board at 807-343-8283 or research@lakeheadu.ca

Jonathon Racine, MSc Candidate
Student Researcher
School of Kinesiology, Lakehead University
jracine@lakeheadu.ca
807-472-7655

Erin Pearson, PhD
Associate Professor and Student Supervisor
School of Kinesiology, Lakehead University
erin.pearson@lakeheadu.ca
807-343-8481

Appendix D: Caregiver Participant Eligibility Form



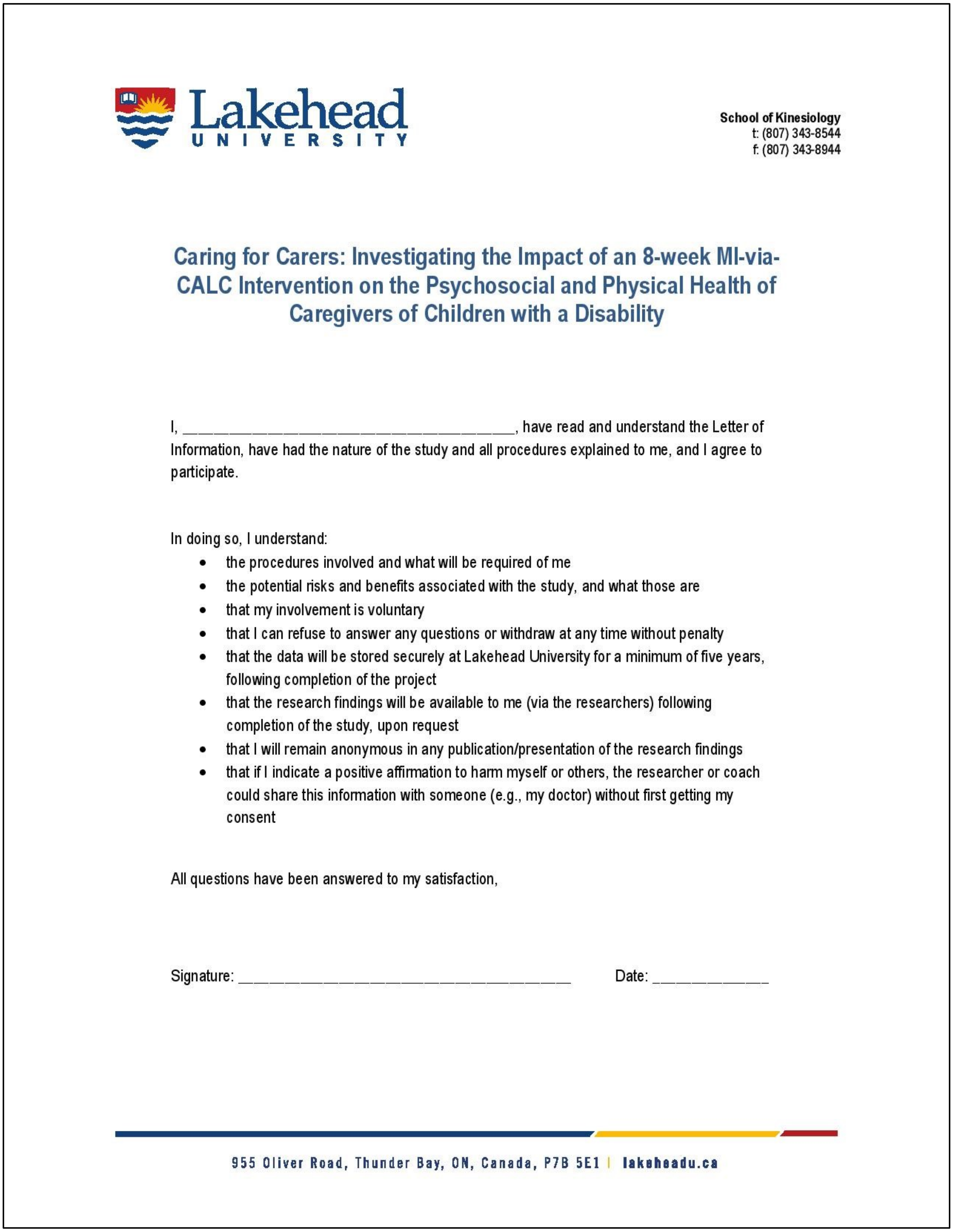
CARING FOR CARERS: CAREGIVER PARTICIPANT ELIGIBILITY FORM

Name: ____ Date & Time : _______________________

Are you able to speak English fluently?	**Yes** / No
Are you at least 18 years of age?	**Yes** / No
Are you a… live-in legal parent/guardian and primary caregiver to a child under the age of 21 who has been diagnosed with a disability (e.g., Autism Spectrum Disorder, Cerebral Palsy, Down Syndrome, Global Development Delay, Traumatic Brain Injury) Type of Disability ____	**Yes** / No
(the child) has also ***NOT*** been diagnosed with non-comorbid learning disabilities (e.g., Auditory Processing Disorder, Attention Deficit Hyperactive Disorder, Dyslexia)	**Yes** / No
(the child) has also ***NOT*** been diagnosed with severe and complex comorbid health conditions (e.g., Cancer, Multiple Sclerosis, Arthritis, uncontrolled Diabetes)	**Yes** / No
Are you willing to participate in eight weekly 30- to 45-minute telephone/Skype/Facetime based MI-via-CALC sessions?	**Yes** / No
Are you able and willing to attend three in-person assessments, including questionnaires, body measure assessments, and an exit survey?	**Yes** / No

Only interested individuals who answer **YES** to **ALL** above eligibility criteria may participate.	
‘Interested Individual is eligible to participate?	**Yes** / No

Appendix E: Caregiver Participant Consent Form



Lakehead
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School of Kinesiology
t: (807) 343-8544
f: (807) 343-8944

Caring for Carers: Investigating the Impact of an 8-week MI-via-CALC Intervention on the Psychosocial and Physical Health of Caregivers of Children with a Disability

I, ______________________________________, have read and understand the Letter of Information, have had the nature of the study and all procedures explained to me, and I agree to participate.

In doing so, I understand:

- the procedures involved and what will be required of me
- the potential risks and benefits associated with the study, and what those are
- that my involvement is voluntary
- that I can refuse to answer any questions or withdraw at any time without penalty
- that the data will be stored securely at Lakehead University for a minimum of five years, following completion of the project
- that the research findings will be available to me (via the researchers) following completion of the study, upon request
- that I will remain anonymous in any publication/presentation of the research findings
- that if I indicate a positive affirmation to harm myself or others, the researcher or coach could share this information with someone (e.g., my doctor) without first getting my consent

All questions have been answered to my satisfaction,

Signature: ______________________________________ Date: ______________

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Appendix F: Certified Professional Co-Active Coach Recruitment Poster

Researchers Seeking CPCCs

Lakehead University researchers are seeking volunteer Certified Professional Co-Active Coaches to assist in the delivery of a research study aimed at improving the health of caregivers of children with a disability.

During Fall 2019 & Winter 2020, CPCCs will be matched with study participants.

Each participant will receive 8-weekly 30- to 45-minute telephone/Skype coaching sessions.

For more details, contact: Jonathon Racine (MSc Candidate)
email: jracine@lakeheadu.ca call/text: 807-472-7655

Supervisor: Dr. Erin Pearson, CPCC

Lakehead UNIVERSITY

This study has been reviewed and approved by the Lakehead University Research Ethics Board. If you have any question regarding participant rights and ethical conduct of research, please contact the Lakehead University Ethics Review Board at 807-343-8283 or research@lakehadu.ca

Appendix G: Certified Professional Co-Active Coach Information Letter

Lakehead
UNIVERSITY

School of Kinesiology
t: (807) 343-8544
f: (807) 343-8944

Certified Professional Co-Active Coach Letter of Information

Thank you for considering volunteering your time and expertise to our coaching-based study. You have been invited to participate as one of the study's coaches because you have completed the certification program through the Coaches Training Institute to become a Certified Professional Co-Active Coach, speak English fluently, and are living in North America. Prior to confirming involvement in the study, we would like to provide you with additional details on the research protocols that will be used.

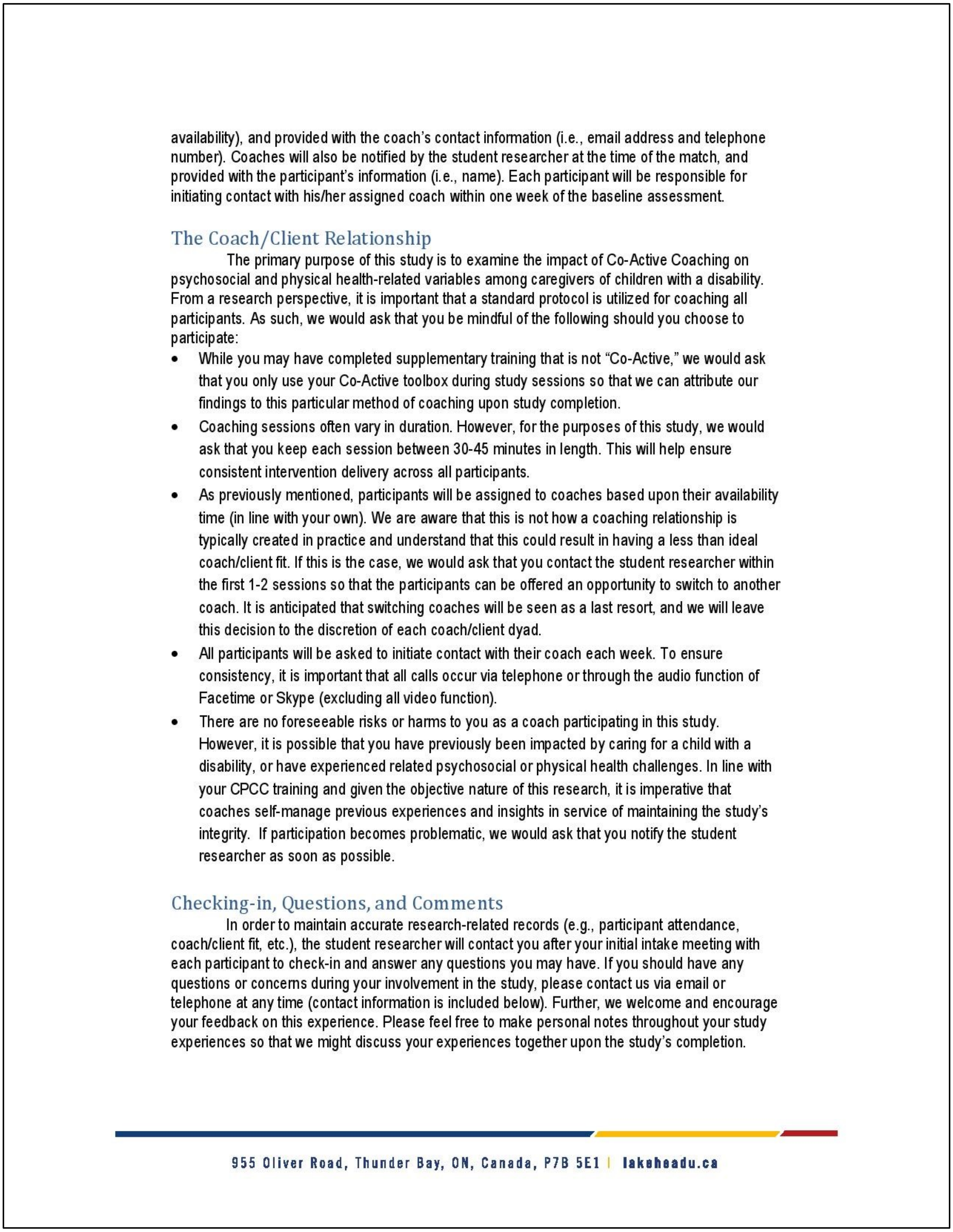
The primary purpose of this project is to examine the impact of an 8-week Co-Active Coaching intervention on psychosocial and physical health and health behaviours of caregivers of children with a disability (CCWD). Caregiver participants will be eligible to participate if they are an English-speaking primary caregiver to a child with a physical, intellectual, or developmental disability living in Northwestern Ontario, Canada.

Recently, research has highlighted CCWD as a unique population which are currently underserved requiring additional supports. It has been suggested that CCWD may find life coaching well suited to elicit positive behaviour change, supporting them in their unique role which has considerable implications for the entire family. More specifically, CCWD have been shown to experience reduced health outcomes when compared to caregivers of typically developing children, including unusual levels of chronic stress. Caregivers of children with a disability are also at an increased risk for early mortality, along with reductions in physical and mental health. These trends are troubling, given that chronic stress along with other related health risks have been linked to preventable health conditions, such as cardiovascular disease, diabetes, and obesity. Due to the inherent nature of the caregiver role, it is essential to optimize the health and well-being in this population.

You may be wondering what is in this for you? Primarily, you would be making a significant contribution toward eliciting positive lifestyle changes in a population faced with unique challenges to experiencing life fulfillment along with increased health disparities. Thus, you would be supporting caregivers to make meaningful lifestyle changes to their current behaviours, while simultaneously providing research evidence for the effectiveness of coaching. Coaching for this study would also allow you the opportunity to expand your coaching repertoire to a demographic that may have been previously unfamiliar to you. For your coaching practice, in particular, it is possible that participants may want to continue on with coaching (on a fee-for-coaching basis) after the study is complete.

Study Timeline and Procedure

It is anticipated that participants will be recruited throughout Fall of 2019. Once individuals are deemed eligible to participate, they will attend a baseline assessment where they will meet with the student researcher to have the study explained to them in detail, provide informed consent, and complete several measures pertaining to psychosocial and physical health. Following this, participants will be matched based upon their availability for coaching sessions (in line with coach



availability), and provided with the coach's contact information (i.e., email address and telephone number). Coaches will also be notified by the student researcher at the time of the match, and provided with the participant's information (i.e., name). Each participant will be responsible for initiating contact with his/her assigned coach within one week of the baseline assessment.

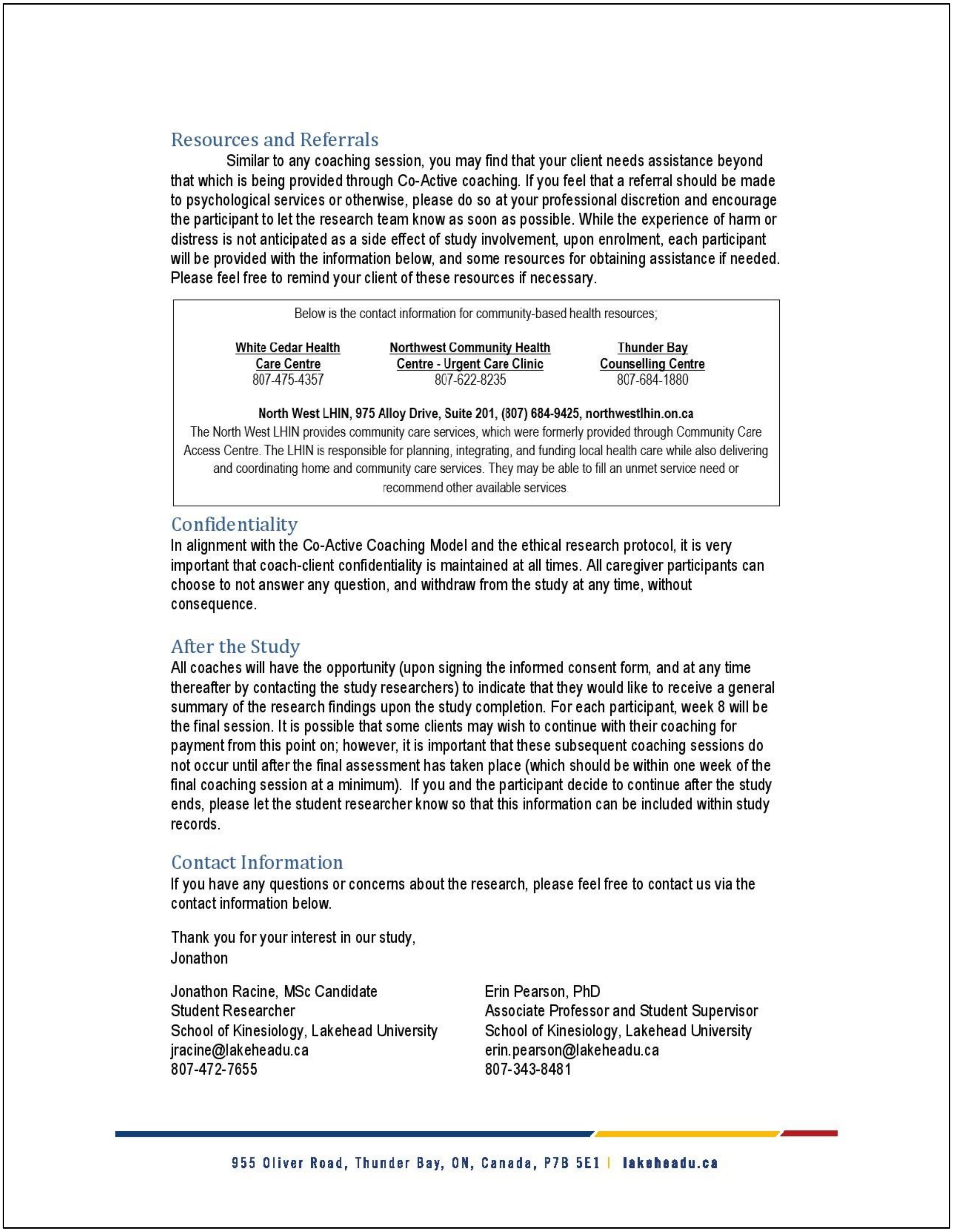
The Coach/Client Relationship

The primary purpose of this study is to examine the impact of Co-Active Coaching on psychosocial and physical health-related variables among caregivers of children with a disability. From a research perspective, it is important that a standard protocol is utilized for coaching all participants. As such, we would ask that you be mindful of the following should you choose to participate:

- While you may have completed supplementary training that is not "Co-Active," we would ask that you only use your Co-Active toolbox during study sessions so that we can attribute our findings to this particular method of coaching upon study completion.
- Coaching sessions often vary in duration. However, for the purposes of this study, we would ask that you keep each session between 30-45 minutes in length. This will help ensure consistent intervention delivery across all participants.
- As previously mentioned, participants will be assigned to coaches based upon their availability time (in line with your own). We are aware that this is not how a coaching relationship is typically created in practice and understand that this could result in having a less than ideal coach/client fit. If this is the case, we would ask that you contact the student researcher within the first 1-2 sessions so that the participants can be offered an opportunity to switch to another coach. It is anticipated that switching coaches will be seen as a last resort, and we will leave this decision to the discretion of each coach/client dyad.
- All participants will be asked to initiate contact with their coach each week. To ensure consistency, it is important that all calls occur via telephone or through the audio function of Facetime or Skype (excluding all video function).
- There are no foreseeable risks or harms to you as a coach participating in this study. However, it is possible that you have previously been impacted by caring for a child with a disability, or have experienced related psychosocial or physical health challenges. In line with your CPCC training and given the objective nature of this research, it is imperative that coaches self-manage previous experiences and insights in service of maintaining the study's integrity. If participation becomes problematic, we would ask that you notify the student researcher as soon as possible.

Checking-in, Questions, and Comments

In order to maintain accurate research-related records (e.g., participant attendance, coach/client fit, etc.), the student researcher will contact you after your initial intake meeting with each participant to check-in and answer any questions you may have. If you should have any questions or concerns during your involvement in the study, please contact us via email or telephone at any time (contact information is included below). Further, we welcome and encourage your feedback on this experience. Please feel free to make personal notes throughout your study experiences so that we might discuss your experiences together upon the study's completion.



Resources and Referrals

Similar to any coaching session, you may find that your client needs assistance beyond that which is being provided through Co-Active coaching. If you feel that a referral should be made to psychological services or otherwise, please do so at your professional discretion and encourage the participant to let the research team know as soon as possible. While the experience of harm or distress is not anticipated as a side effect of study involvement, upon enrolment, each participant will be provided with the information below, and some resources for obtaining assistance if needed. Please feel free to remind your client of these resources if necessary.

Below is the contact information for community-based health resources;

<u>**White Cedar Health Care Centre**</u>	<u>**Northwest Community Health Centre - Urgent Care Clinic**</u>	<u>**Thunder Bay Counselling Centre**</u>
807-475-4357	807-622-8235	807-684-1880

North West LHIN, 975 Alloy Drive, Suite 201, (807) 684-9425, northwestlhin.on.ca

The North West LHIN provides community care services, which were formerly provided through Community Care Access Centre. The LHIN is responsible for planning, integrating, and funding local health care while also delivering and coordinating home and community care services. They may be able to fill an unmet service need or recommend other available services.

Confidentiality

In alignment with the Co-Active Coaching Model and the ethical research protocol, it is very important that coach-client confidentiality is maintained at all times. All caregiver participants can choose to not answer any question, and withdraw from the study at any time, without consequence.

After the Study

All coaches will have the opportunity (upon signing the informed consent form, and at any time thereafter by contacting the study researchers) to indicate that they would like to receive a general summary of the research findings upon the study completion. For each participant, week 8 will be the final session. It is possible that some clients may wish to continue with their coaching for payment from this point on; however, it is important that these subsequent coaching sessions do not occur until after the final assessment has taken place (which should be within one week of the final coaching session at a minimum). If you and the participant decide to continue after the study ends, please let the student researcher know so that this information can be included within study records.

Contact Information

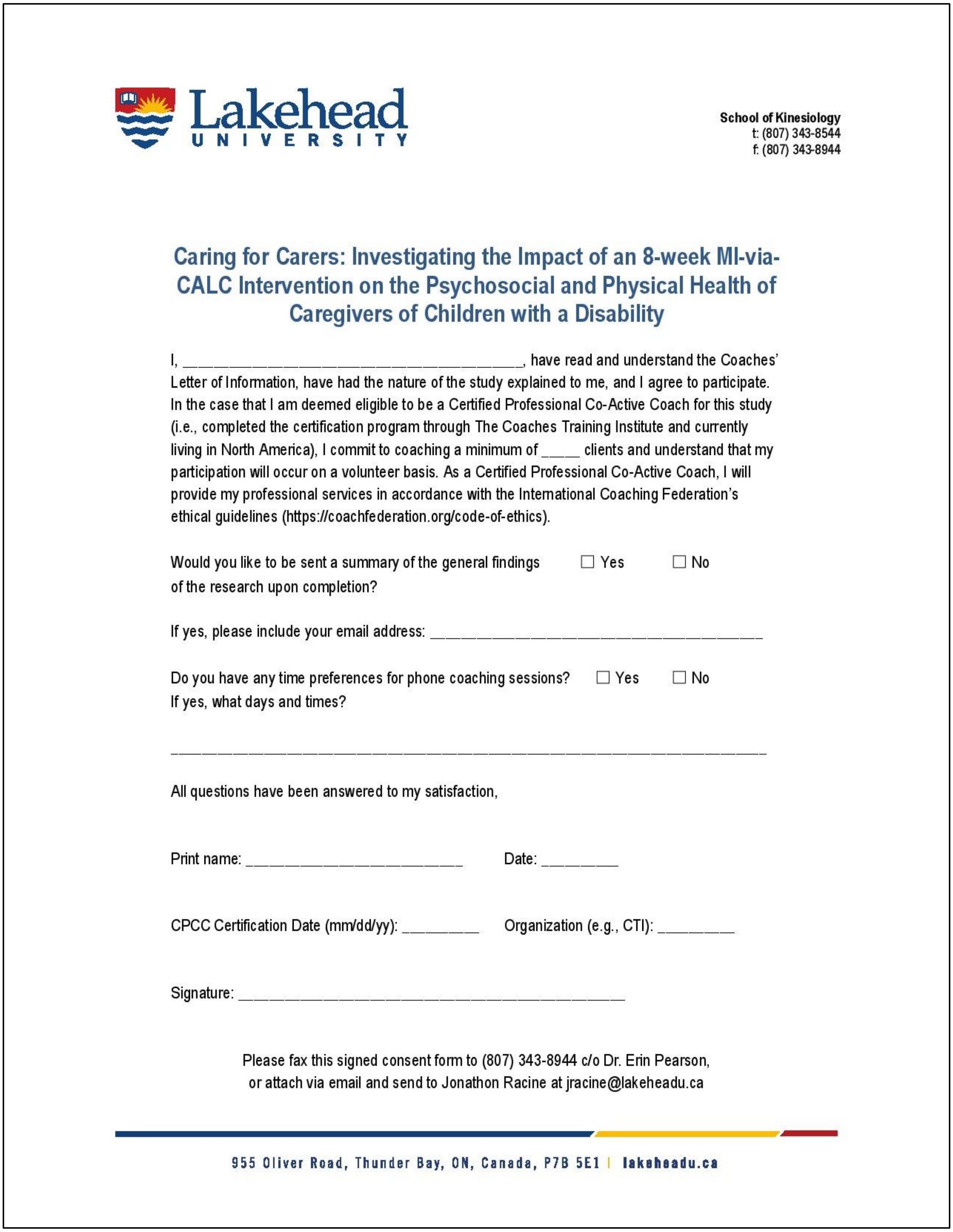
If you have any questions or concerns about the research, please feel free to contact us via the contact information below.

Thank you for your interest in our study,
Jonathon

Jonathon Racine, MSc Candidate
Student Researcher
School of Kinesiology, Lakehead University
jracine@lakeheadu.ca
807-472-7655

Erin Pearson, PhD
Associate Professor and Student Supervisor
School of Kinesiology, Lakehead University
erin.pearson@lakeheadu.ca
807-343-8481

Appendix H: Certified Professional Co-Active Consent Form



Lakehead
UNIVERSITY

School of Kinesiology
t: (807) 343-8544
f: (807) 343-8944

Caring for Carers: Investigating the Impact of an 8-week MI-via-CALC Intervention on the Psychosocial and Physical Health of Caregivers of Children with a Disability

I, ____, have read and understand the Coaches' Letter of Information, have had the nature of the study explained to me, and I agree to participate. In the case that I am deemed eligible to be a Certified Professional Co-Active Coach for this study (i.e., completed the certification program through The Coaches Training Institute and currently living in North America), I commit to coaching a minimum of _____ clients and understand that my participation will occur on a volunteer basis. As a Certified Professional Co-Active Coach, I will provide my professional services in accordance with the International Coaching Federation's ethical guidelines (https://coachfederation.org/code-of-ethics).

Would you like to be sent a summary of the general findings of the research upon completion? ☐ Yes ☐ No

If yes, please include your email address: ____

Do you have any time preferences for phone coaching sessions? ☐ Yes ☐ No
If yes, what days and times?

____

All questions have been answered to my satisfaction,

Print name: ___________________________ Date: _________

CPCC Certification Date (mm/dd/yy): _________ Organization (e.g., CTI): _________

Signature: ____

Please fax this signed consent form to (807) 343-8944 c/o Dr. Erin Pearson,
or attach via email and send to Jonathon Racine at jracine@lakeheadu.ca

955 Oliver Road, Thunder Bay, ON, Canada, P7B 5E1 | lakeheadu.ca

Appendix I: Coach Contact Information for Caregivers Letter

Lakehead
UNIVERSITY

School of Kinesiology
t: (807) 343-8544
f: (807) 343-8944

Dear ______________________________________,

Attached: Caregiver Information Letter

Welcome to the study! Now that you have completed your baseline assessment (i.e., questionnaires and body composition analysis), you are ready to begin your motivational coaching sessions.

You have been assigned to work with ______________________________. Please call or email this individual before ______________________________ to arrange your first session. Once you have arranged this appointment, please notify Jonathon with the start date via email or telephone.

Coach's Name: ______________________________

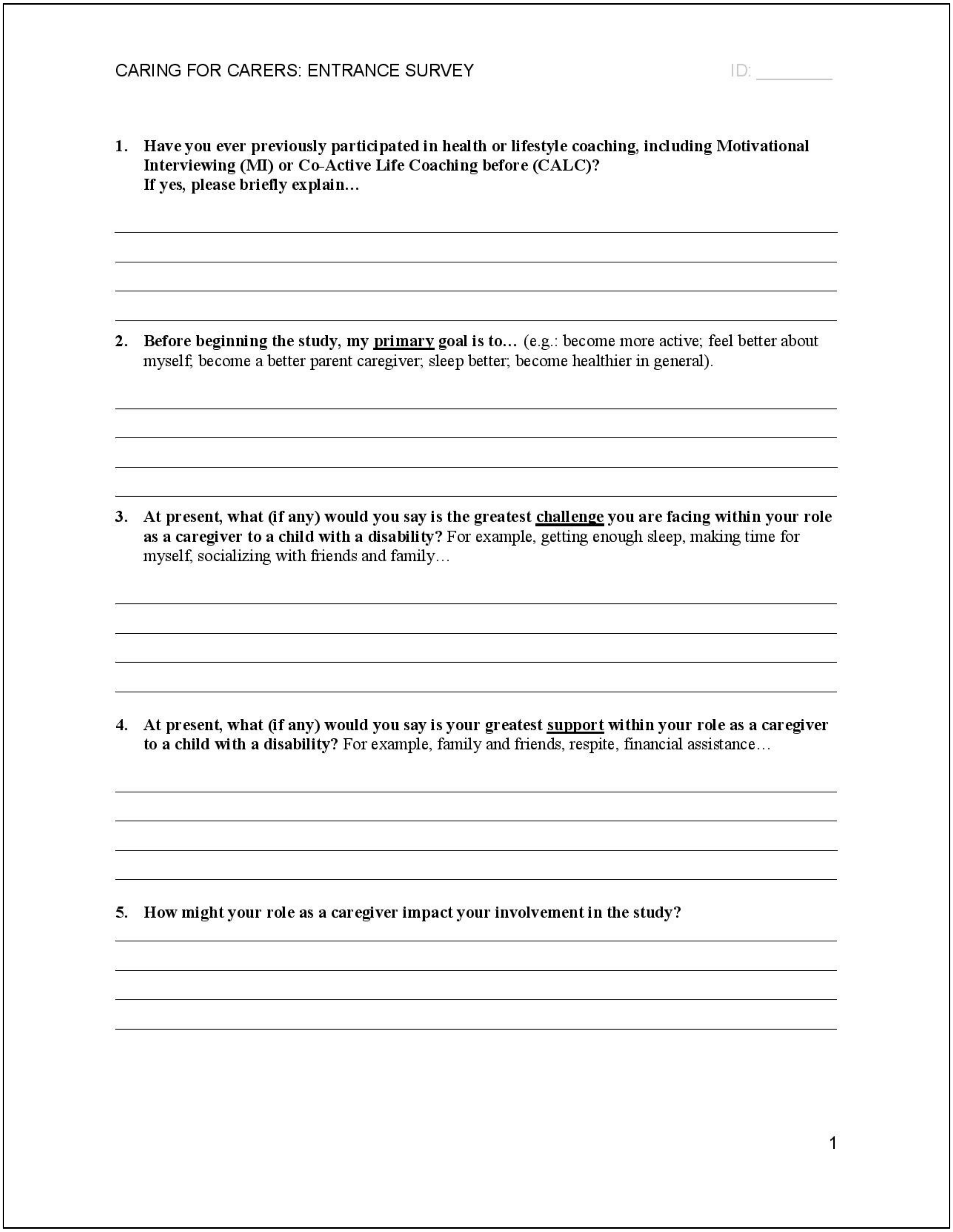
Email: ______________________________

Telephone: ______________________________

Jonathon Racine, MSc Candidate
Student Researcher
School of Kinesiology, Lakehead University
jracine@lakeheadu.ca
807-472-7655

955 Oliver Road, Thunder Bay, ON, Canada, P7B 5E1 | lakeheadu.ca

Appendix J: Entrance Survey



CARING FOR CARERS: ENTRANCE SURVEY

ID: ________

1. **Have you ever previously participated in health or lifestyle coaching, including Motivational Interviewing (MI) or Co-Active Life Coaching before (CALC)?**
   If yes, please briefly explain…

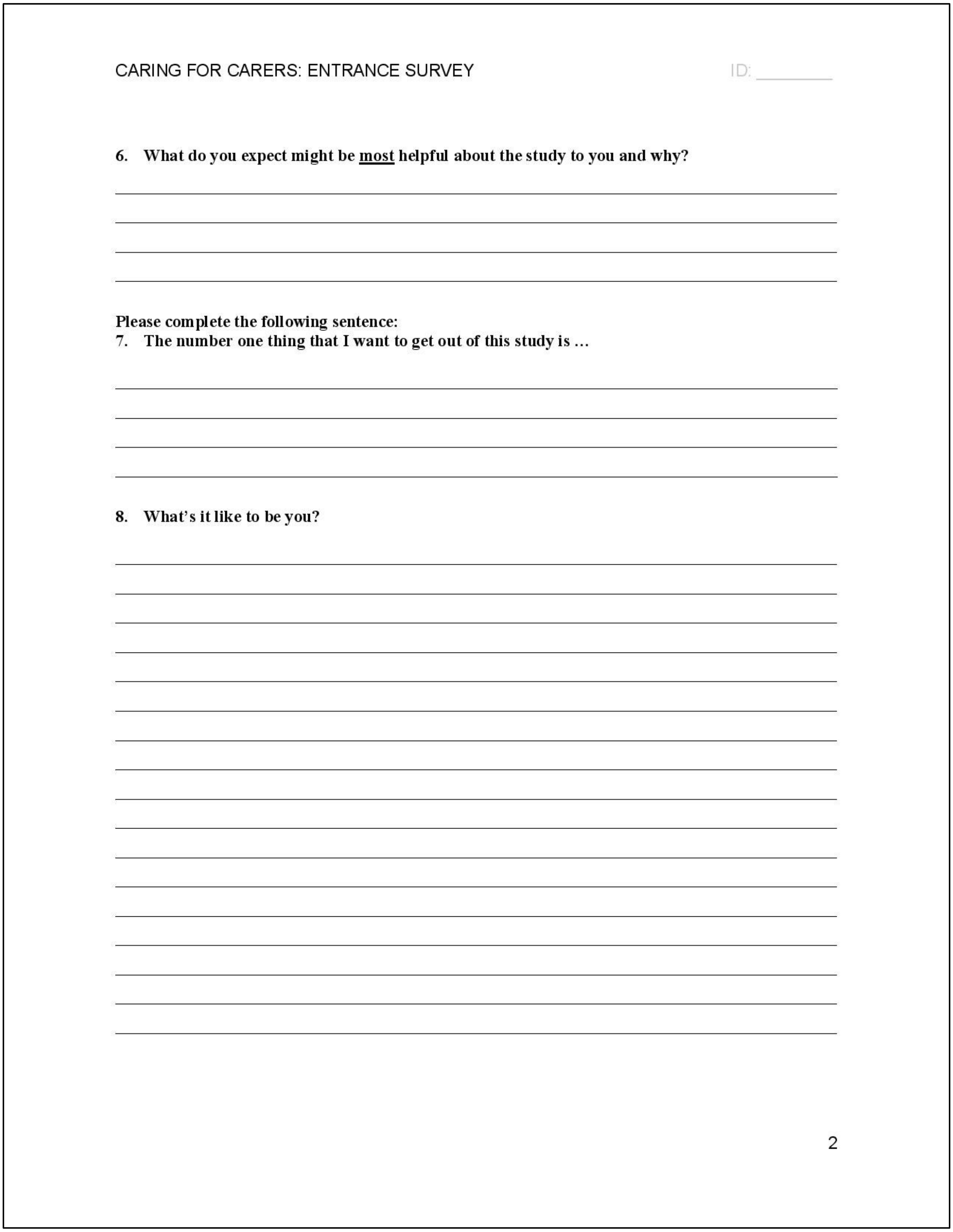
2. **Before beginning the study, my <u>primary</u> goal is to…** (e.g.: become more active; feel better about myself; become a better parent caregiver; sleep better; become healthier in general).

3. **At present, what (if any) would you say is the greatest <u>challenge</u> you are facing within your role as a caregiver to a child with a disability?** For example, getting enough sleep, making time for myself, socializing with friends and family…

4. **At present, what (if any) would you say is your greatest <u>support</u> within your role as a caregiver to a child with a disability?** For example, family and friends, respite, financial assistance…

5. **How might your role as a caregiver impact your involvement in the study?**

1



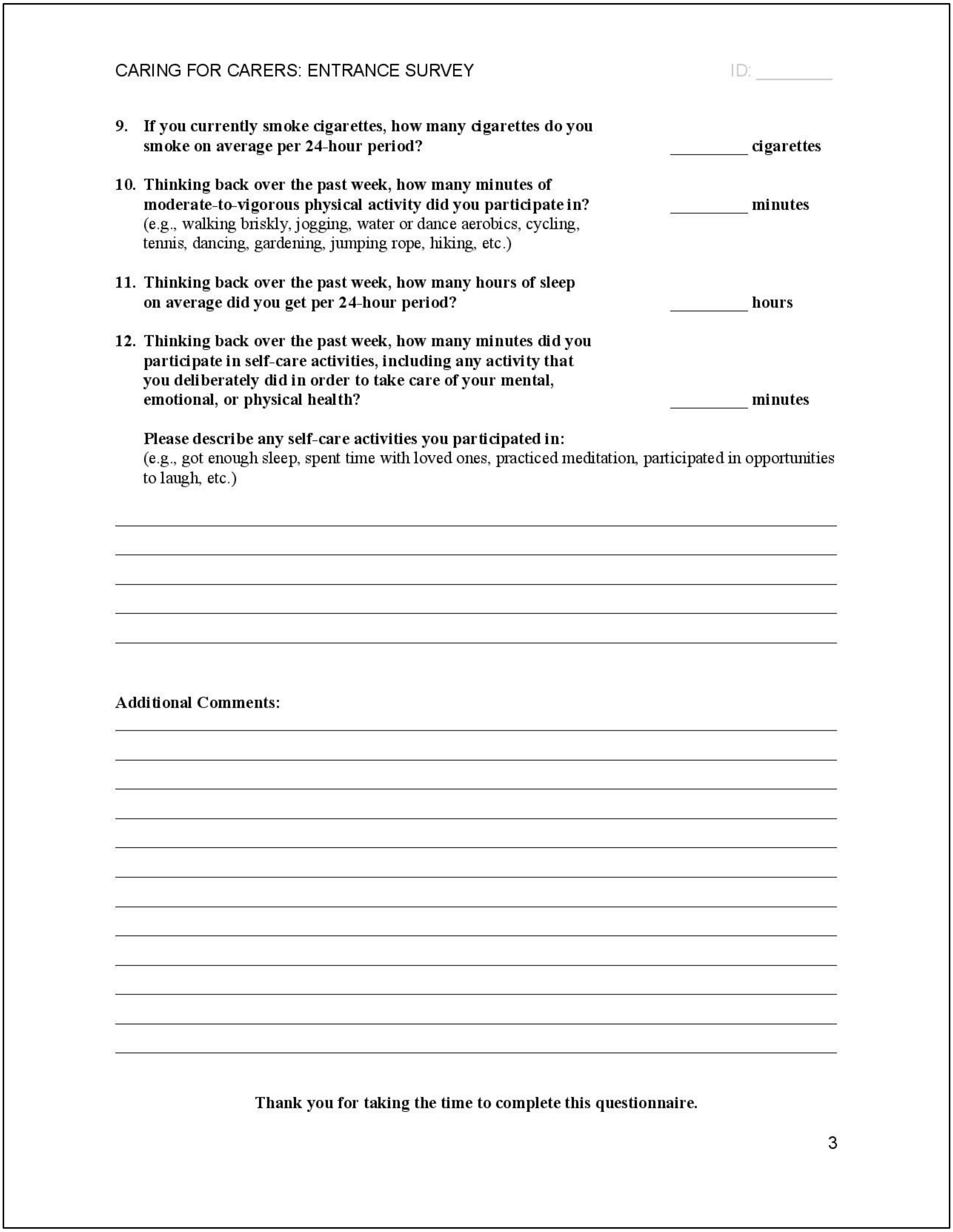
CARING FOR CARERS: ENTRANCE SURVEY ID: ________

6. What do you expect might be <u>most</u> helpful about the study to you and why?

Please complete the following sentence:
7. The number one thing that I want to get out of this study is …

8. What's it like to be you?

2



CARING FOR CARERS: ENTRANCE SURVEY ID: ________

9. If you currently smoke cigarettes, how many cigarettes do you smoke on average per 24-hour period? _________ **cigarettes**

10. Thinking back over the past week, how many minutes of moderate-to-vigorous physical activity did you participate in? _________ **minutes**
(e.g., walking briskly, jogging, water or dance aerobics, cycling, tennis, dancing, gardening, jumping rope, hiking, etc.)

11. Thinking back over the past week, how many hours of sleep on average did you get per 24-hour period? _________ **hours**

12. Thinking back over the past week, how many minutes did you participate in self-care activities, including any activity that you deliberately did in order to take care of your mental, emotional, or physical health? _________ **minutes**

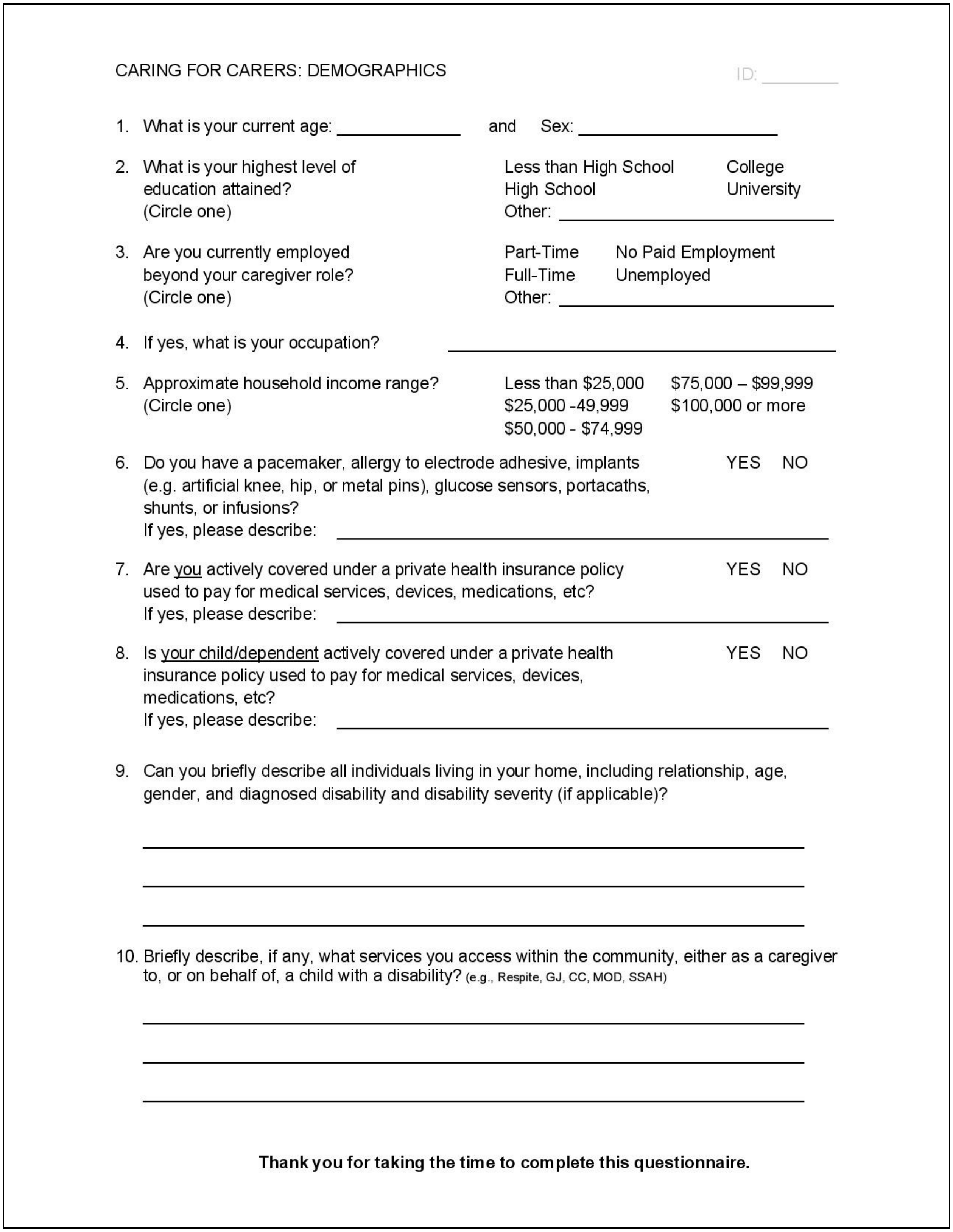
Please describe any self-care activities you participated in:
(e.g., got enough sleep, spent time with loved ones, practiced meditation, participated in opportunities to laugh, etc.)

Additional Comments:

Thank you for taking the time to complete this questionnaire.

3

Appendix K: Demographic Questionnaire



CARING FOR CARERS: DEMOGRAPHICS

ID: ________

1. What is your current age: ____________ and Sex: ____________________

2. What is your highest level of education attained? (Circle one)
   Less than High School College
   High School University
   Other: ____________________

3. Are you currently employed beyond your caregiver role? (Circle one)
   Part-Time No Paid Employment
   Full-Time Unemployed
   Other: ____________________

4. If yes, what is your occupation? ______________________________

5. Approximate household income range? (Circle one)
   Less than $25,000 $75,000 – $99,999
   $25,000 -49,999 $100,000 or more
   $50,000 - $74,999

6. Do you have a pacemaker, allergy to electrode adhesive, implants (e.g. artificial knee, hip, or metal pins), glucose sensors, portacaths, shunts, or infusions? YES NO
   If yes, please describe: ______________________________

7. Are <u>you</u> actively covered under a private health insurance policy used to pay for medical services, devices, medications, etc? YES NO
   If yes, please describe: ______________________________

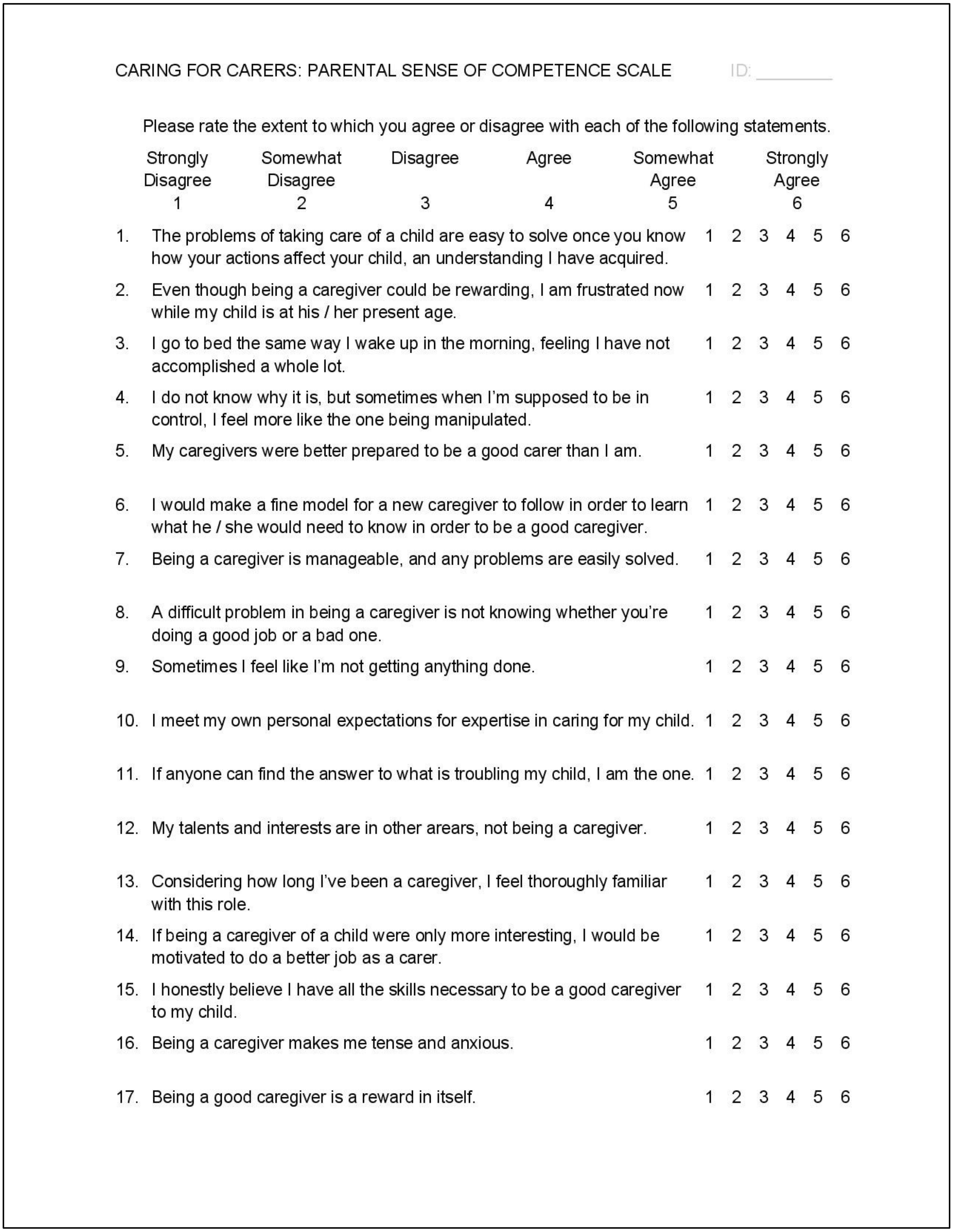
8. Is <u>your child/dependent</u> actively covered under a private health insurance policy used to pay for medical services, devices, medications, etc? YES NO
   If yes, please describe: ______________________________

9. Can you briefly describe all individuals living in your home, including relationship, age, gender, and diagnosed disability and disability severity (if applicable)?
   ____
   ____
   ____

10. Briefly describe, if any, what services you access within the community, either as a caregiver to, or on behalf of, a child with a disability? (e.g., Respite, GJ, CC, MOD, SSAH)
    ____
    ____
    ____

Thank you for taking the time to complete this questionnaire.

Appendix L: Parental Sense of Competence



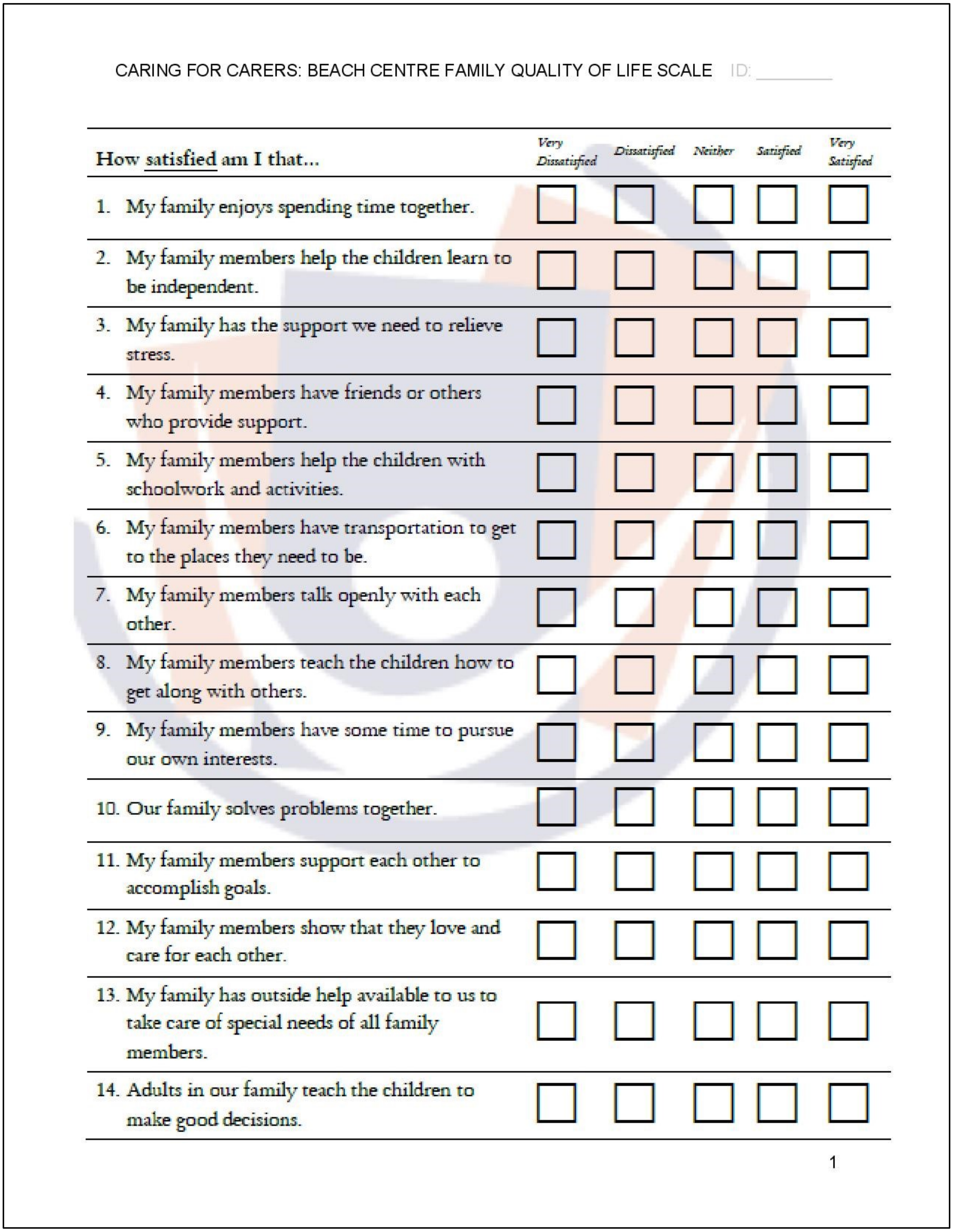
CARING FOR CARERS: PARENTAL SENSE OF COMPETENCE SCALE ID: ________

Please rate the extent to which you agree or disagree with each of the following statements.

Strongly Disagree	Somewhat Disagree	Disagree	Agree	Somewhat Agree	Strongly Agree
1	2	3	4	5	6

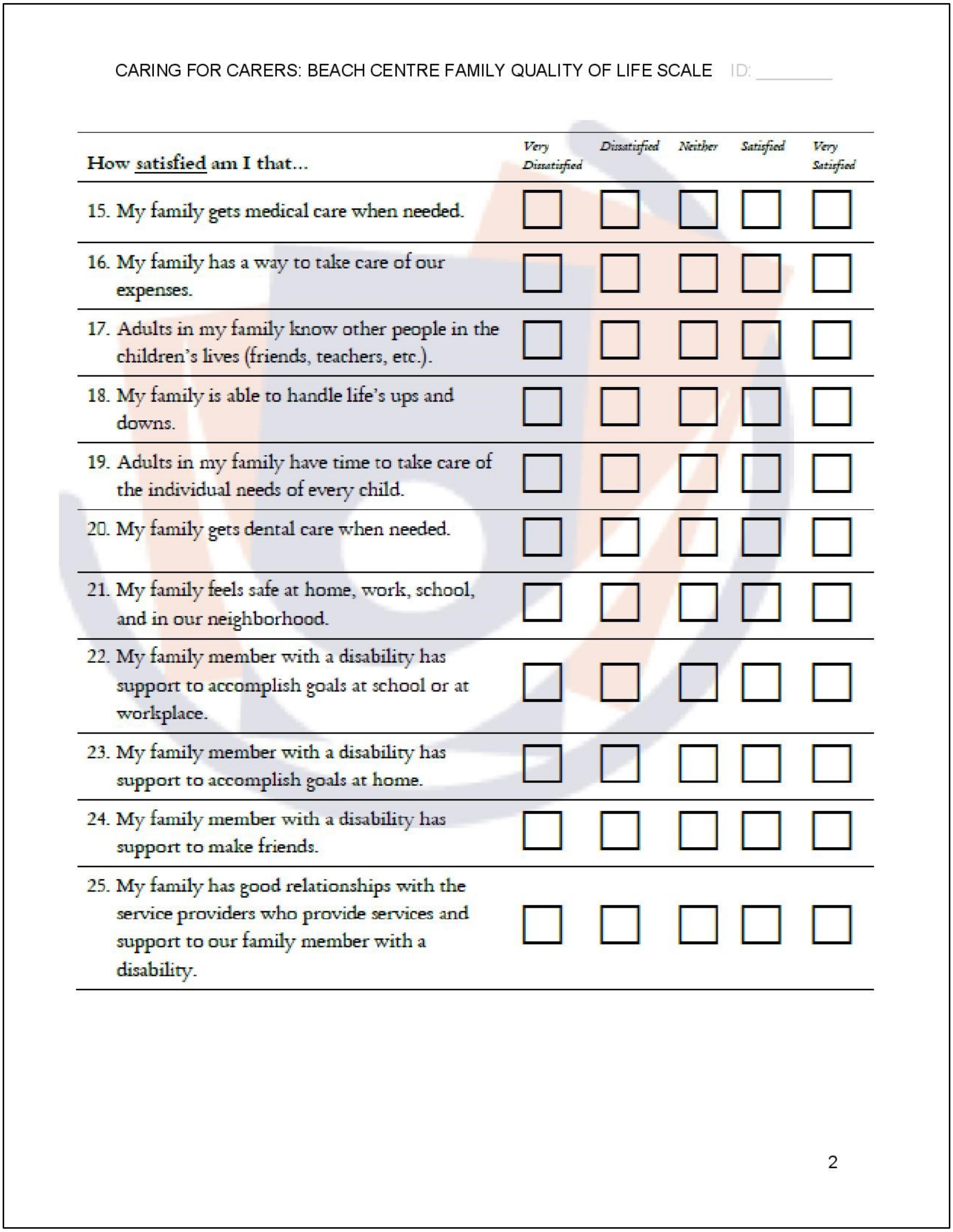
1. The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired. 1 2 3 4 5 6
2. Even though being a caregiver could be rewarding, I am frustrated now while my child is at his / her present age. 1 2 3 4 5 6
3. I go to bed the same way I wake up in the morning, feeling I have not accomplished a whole lot. 1 2 3 4 5 6
4. I do not know why it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated. 1 2 3 4 5 6
5. My caregivers were better prepared to be a good carer than I am. 1 2 3 4 5 6
6. I would make a fine model for a new caregiver to follow in order to learn what he / she would need to know in order to be a good caregiver. 1 2 3 4 5 6
7. Being a caregiver is manageable, and any problems are easily solved. 1 2 3 4 5 6
8. A difficult problem in being a caregiver is not knowing whether you're doing a good job or a bad one. 1 2 3 4 5 6
9. Sometimes I feel like I'm not getting anything done. 1 2 3 4 5 6
10. I meet my own personal expectations for expertise in caring for my child. 1 2 3 4 5 6
11. If anyone can find the answer to what is troubling my child, I am the one. 1 2 3 4 5 6
12. My talents and interests are in other arears, not being a caregiver. 1 2 3 4 5 6
13. Considering how long I've been a caregiver, I feel thoroughly familiar with this role. 1 2 3 4 5 6
14. If being a caregiver of a child were only more interesting, I would be motivated to do a better job as a carer. 1 2 3 4 5 6
15. I honestly believe I have all the skills necessary to be a good caregiver to my child. 1 2 3 4 5 6
16. Being a caregiver makes me tense and anxious. 1 2 3 4 5 6
17. Being a good caregiver is a reward in itself. 1 2 3 4 5 6

Appendix M: Beach Center Family Quality of Life Scale



CARING FOR CARERS: BEACH CENTRE FAMILY QUALITY OF LIFE SCALE ID: ________

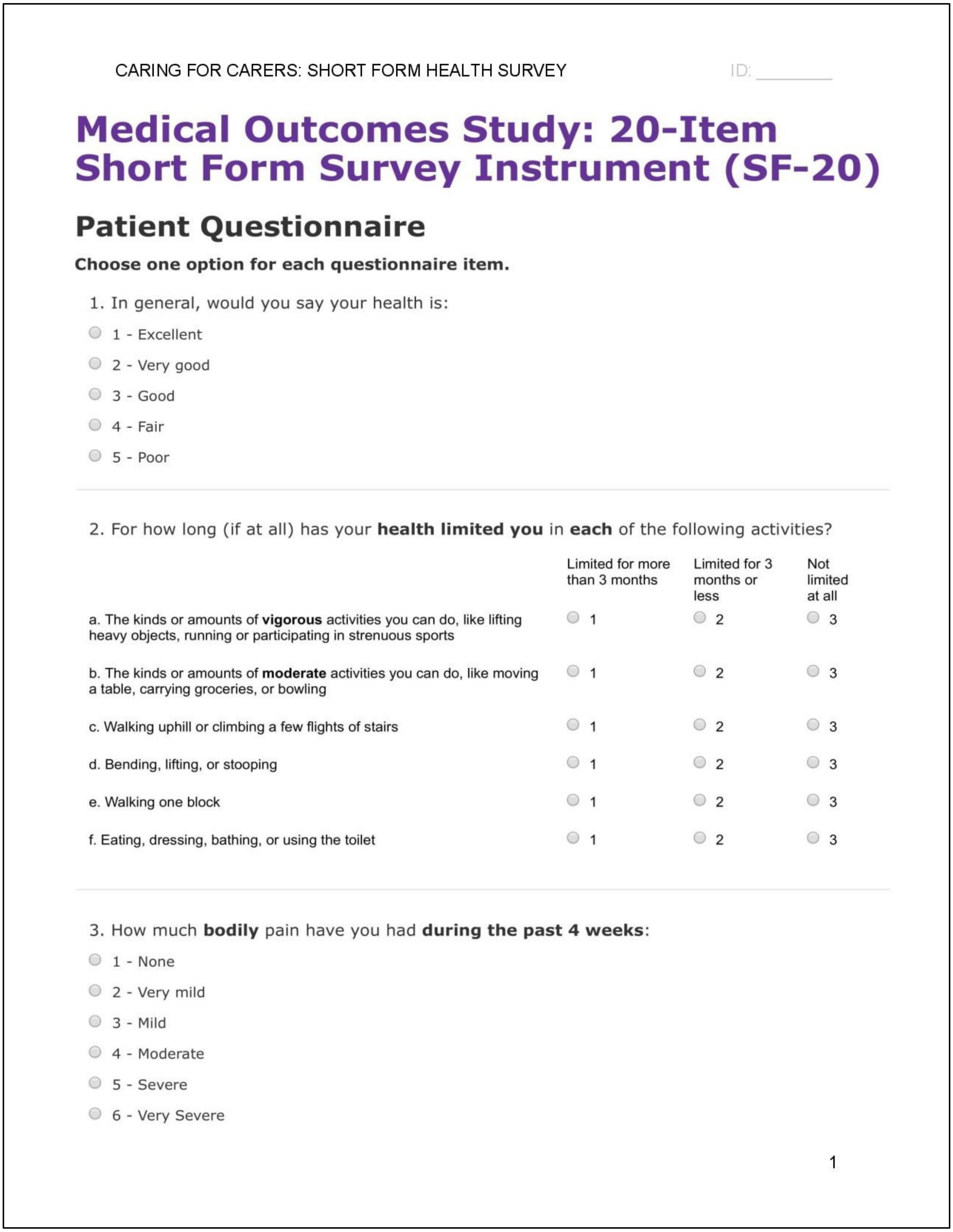
How satisfied am I that...	*Very Dissatisfied*	*Dissatisfied*	*Neither*	*Satisfied*	*Very Satisfied*
1. My family enjoys spending time together.	☐	☐	☐	☐	☐
2. My family members help the children learn to be independent.	☐	☐	☐	☐	☐
3. My family has the support we need to relieve stress.	☐	☐	☐	☐	☐
4. My family members have friends or others who provide support.	☐	☐	☐	☐	☐
5. My family members help the children with schoolwork and activities.	☐	☐	☐	☐	☐
6. My family members have transportation to get to the places they need to be.	☐	☐	☐	☐	☐
7. My family members talk openly with each other.	☐	☐	☐	☐	☐
8. My family members teach the children how to get along with others.	☐	☐	☐	☐	☐
9. My family members have some time to pursue our own interests.	☐	☐	☐	☐	☐
10. Our family solves problems together.	☐	☐	☐	☐	☐
11. My family members support each other to accomplish goals.	☐	☐	☐	☐	☐
12. My family members show that they love and care for each other.	☐	☐	☐	☐	☐
13. My family has outside help available to us to take care of special needs of all family members.	☐	☐	☐	☐	☐
14. Adults in our family teach the children to make good decisions.	☐	☐	☐	☐	☐



CARING FOR CARERS: BEACH CENTRE FAMILY QUALITY OF LIFE SCALE ID: ________

How satisfied am I that...	*Very Dissatisfied*	*Dissatisfied*	*Neither*	*Satisfied*	*Very Satisfied*
15. My family gets medical care when needed.	☐	☐	☐	☐	☐
16. My family has a way to take care of our expenses.	☐	☐	☐	☐	☐
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).	☐	☐	☐	☐	☐
18. My family is able to handle life's ups and downs.	☐	☐	☐	☐	☐
19. Adults in my family have time to take care of the individual needs of every child.	☐	☐	☐	☐	☐
20. My family gets dental care when needed.	☐	☐	☐	☐	☐
21. My family feels safe at home, work, school, and in our neighborhood.	☐	☐	☐	☐	☐
22. My family member with a disability has support to accomplish goals at school or at workplace.	☐	☐	☐	☐	☐
23. My family member with a disability has support to accomplish goals at home.	☐	☐	☐	☐	☐
24. My family member with a disability has support to make friends.	☐	☐	☐	☐	☐
25. My family has good relationships with the service providers who provide services and support to our family member with a disability.	☐	☐	☐	☐	☐

Appendix N: 20-Item Short-Form Health Survey



CARING FOR CARERS: SHORT FORM HEALTH SURVEY ID: ________

Medical Outcomes Study: 20-Item Short Form Survey Instrument (SF-20)

Patient Questionnaire

Choose one option for each questionnaire item.

1. In general, would you say your health is:

○ 1 - Excellent
○ 2 - Very good
○ 3 - Good
○ 4 - Fair
○ 5 - Poor

---

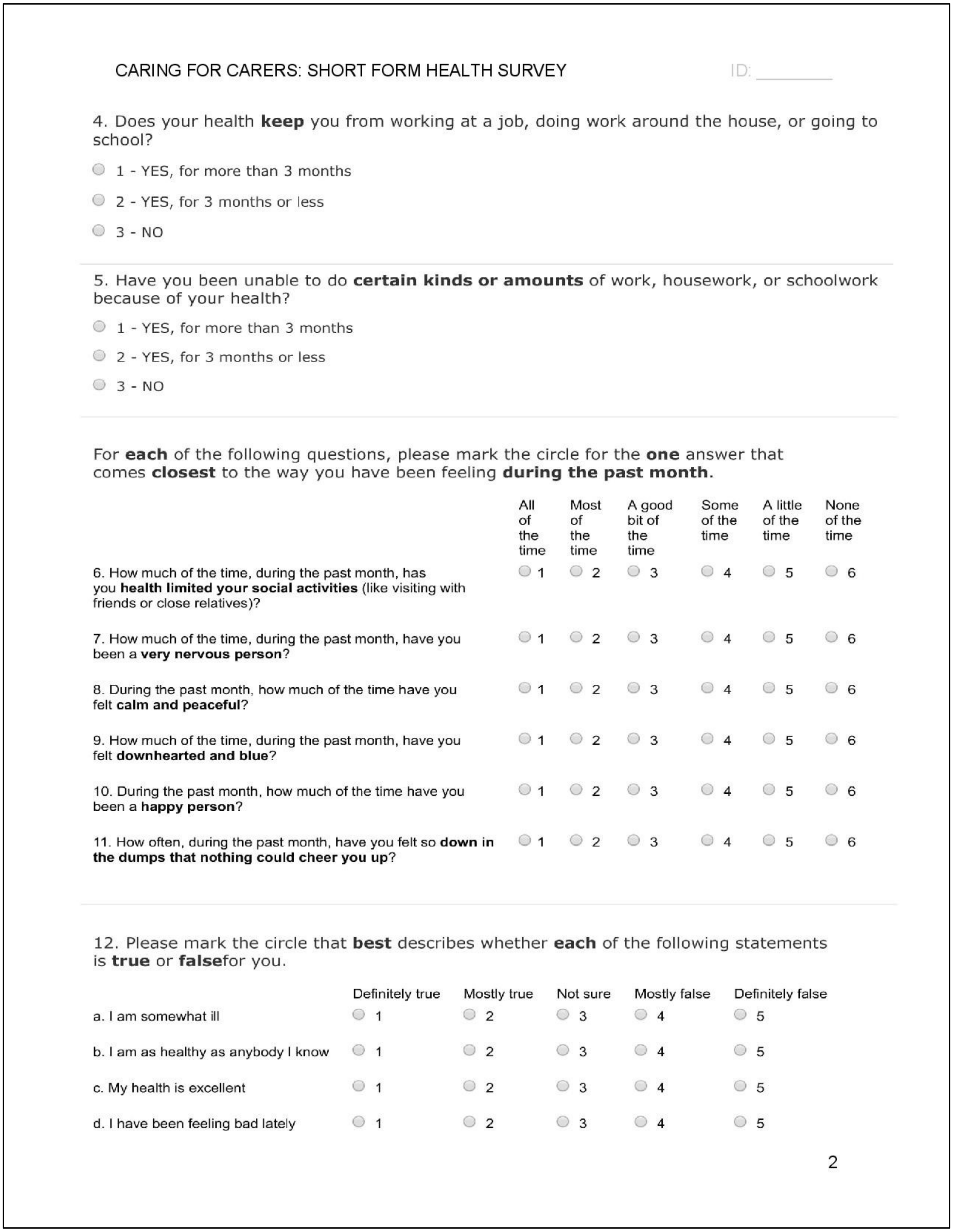
2. For how long (if at all) has your **health limited you** in **each** of the following activities?

	Limited for more than 3 months	Limited for 3 months or less	Not limited at all
a. The kinds or amounts of **vigorous** activities you can do, like lifting heavy objects, running or participating in strenuous sports	○ 1	○ 2	○ 3
b. The kinds or amounts of **moderate** activities you can do, like moving a table, carrying groceries, or bowling	○ 1	○ 2	○ 3
c. Walking uphill or climbing a few flights of stairs	○ 1	○ 2	○ 3
d. Bending, lifting, or stooping	○ 1	○ 2	○ 3
e. Walking one block	○ 1	○ 2	○ 3
f. Eating, dressing, bathing, or using the toilet	○ 1	○ 2	○ 3

---

3. How much **bodily** pain have you had **during the past 4 weeks**:

○ 1 - None
○ 2 - Very mild
○ 3 - Mild
○ 4 - Moderate
○ 5 - Severe
○ 6 - Very Severe



CARING FOR CARERS: SHORT FORM HEALTH SURVEY ID: ________

4. Does your health **keep** you from working at a job, doing work around the house, or going to school?

○ 1 - YES, for more than 3 months

○ 2 - YES, for 3 months or less

○ 3 - NO

5. Have you been unable to do **certain kinds or amounts** of work, housework, or schoolwork because of your health?

○ 1 - YES, for more than 3 months

○ 2 - YES, for 3 months or less

○ 3 - NO

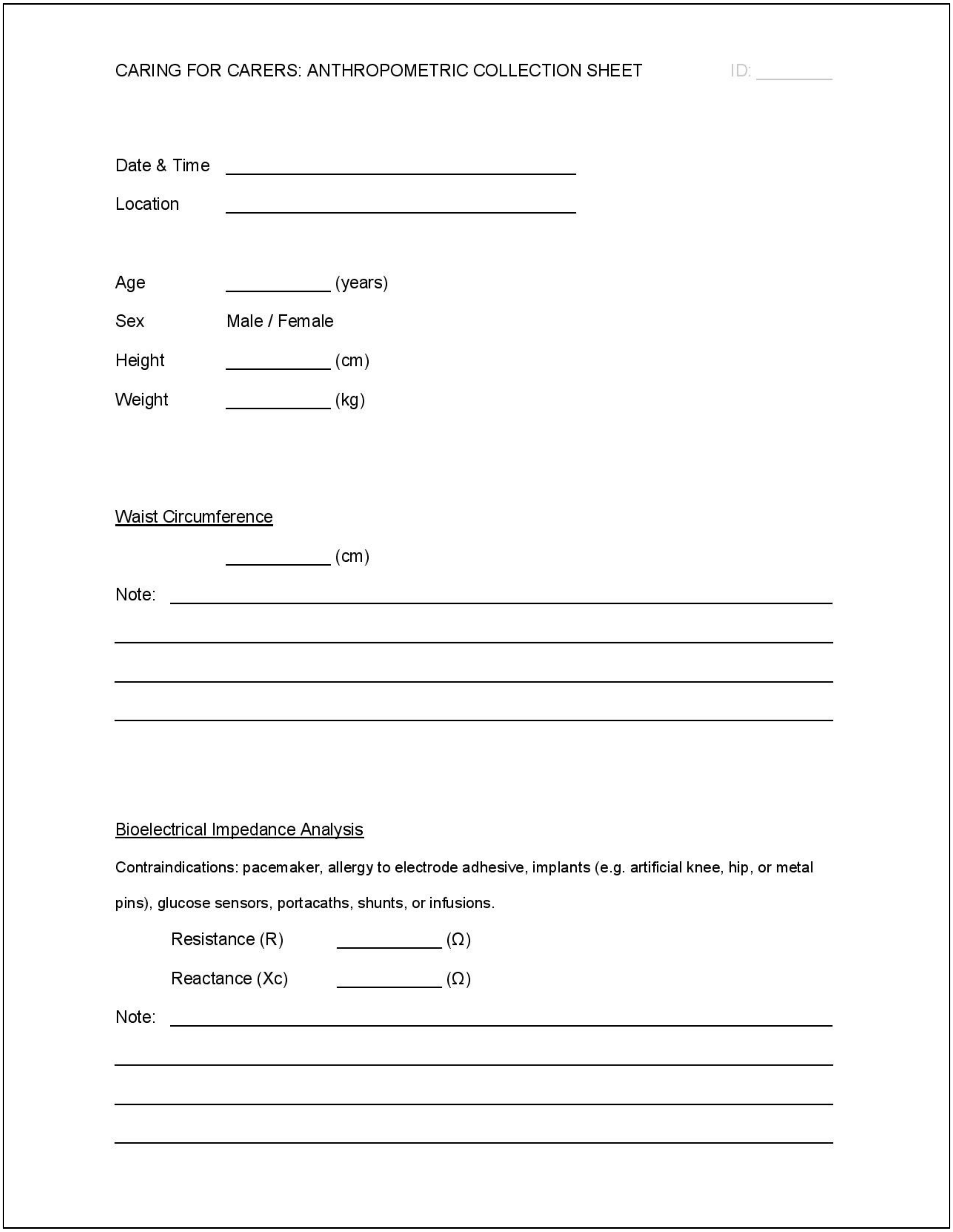
For **each** of the following questions, please mark the circle for the **one** answer that comes **closest** to the way you have been feeling **during the past month**.

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
6. How much of the time, during the past month, has you **health limited your social activities** (like visiting with friends or close relatives)?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
7. How much of the time, during the past month, have you been a **very nervous person**?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
8. During the past month, how much of the time have you felt **calm and peaceful**?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
9. How much of the time, during the past month, have you felt **downhearted and blue**?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
10. During the past month, how much of the time have you been a **happy person**?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
11. How often, during the past month, have you felt so **down in the dumps that nothing could cheer you up**?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6

12. Please mark the circle that **best** describes whether **each** of the following statements is **true** or **false**for you.

	Definitely true	Mostly true	Not sure	Mostly false	Definitely false
a. I am somewhat ill	○ 1	○ 2	○ 3	○ 4	○ 5
b. I am as healthy as anybody I know	○ 1	○ 2	○ 3	○ 4	○ 5
c. My health is excellent	○ 1	○ 2	○ 3	○ 4	○ 5
d. I have been feeling bad lately	○ 1	○ 2	○ 3	○ 4	○ 5

Appendix O: Anthropometric Collection Sheet



CARING FOR CARERS: ANTHROPOMETRIC COLLECTION SHEET ID: ________

Date & Time ______________________________

Location ______________________________

Age ________ (years)

Sex Male / Female

Height ________ (cm)

Weight ________ (kg)

Waist Circumference

________ (cm)

Note: ____

____

____

____

Bioelectrical Impedance Analysis

Contraindications: pacemaker, allergy to electrode adhesive, implants (e.g. artificial knee, hip, or metal pins), glucose sensors, portacaths, shunts, or infusions.

Resistance (R) ________ (Ω)

Reactance (Xc) ________ (Ω)

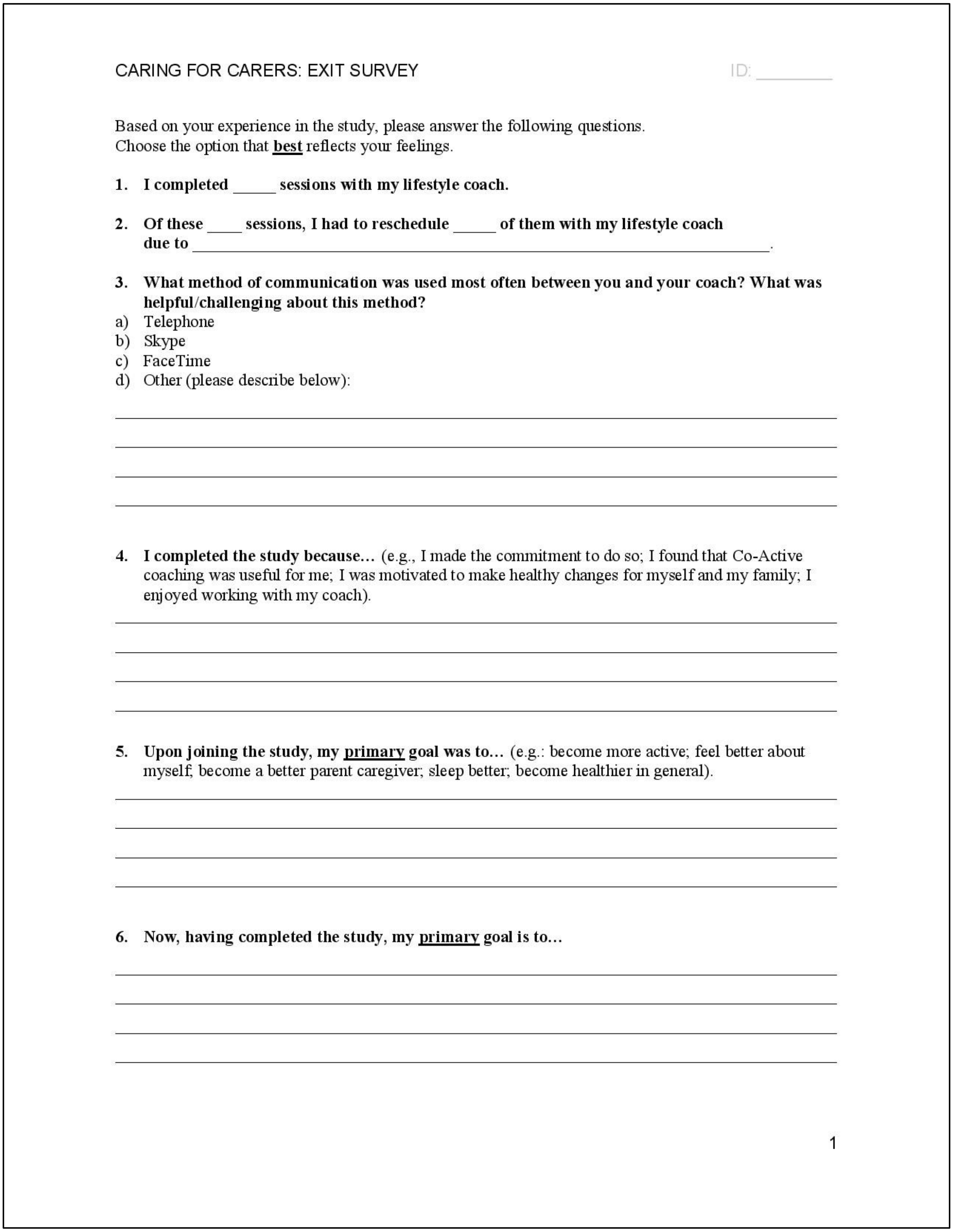
Note: ____

____

____

____

Appendix P: Exit Survey



CARING FOR CARERS: EXIT SURVEY ID: ________

Based on your experience in the study, please answer the following questions.
Choose the option that **best** reflects your feelings.

1. **I completed _____ sessions with my lifestyle coach.**

2. **Of these ____ sessions, I had to reschedule _____ of them with my lifestyle coach due to** ____.

3. **What method of communication was used most often between you and your coach? What was helpful/challenging about this method?**

a) Telephone
b) Skype
c) FaceTime
d) Other (please describe below):

____
____
____
____

4. **I completed the study because…** (e.g., I made the commitment to do so; I found that Co-Active coaching was useful for me; I was motivated to make healthy changes for myself and my family; I enjoyed working with my coach).

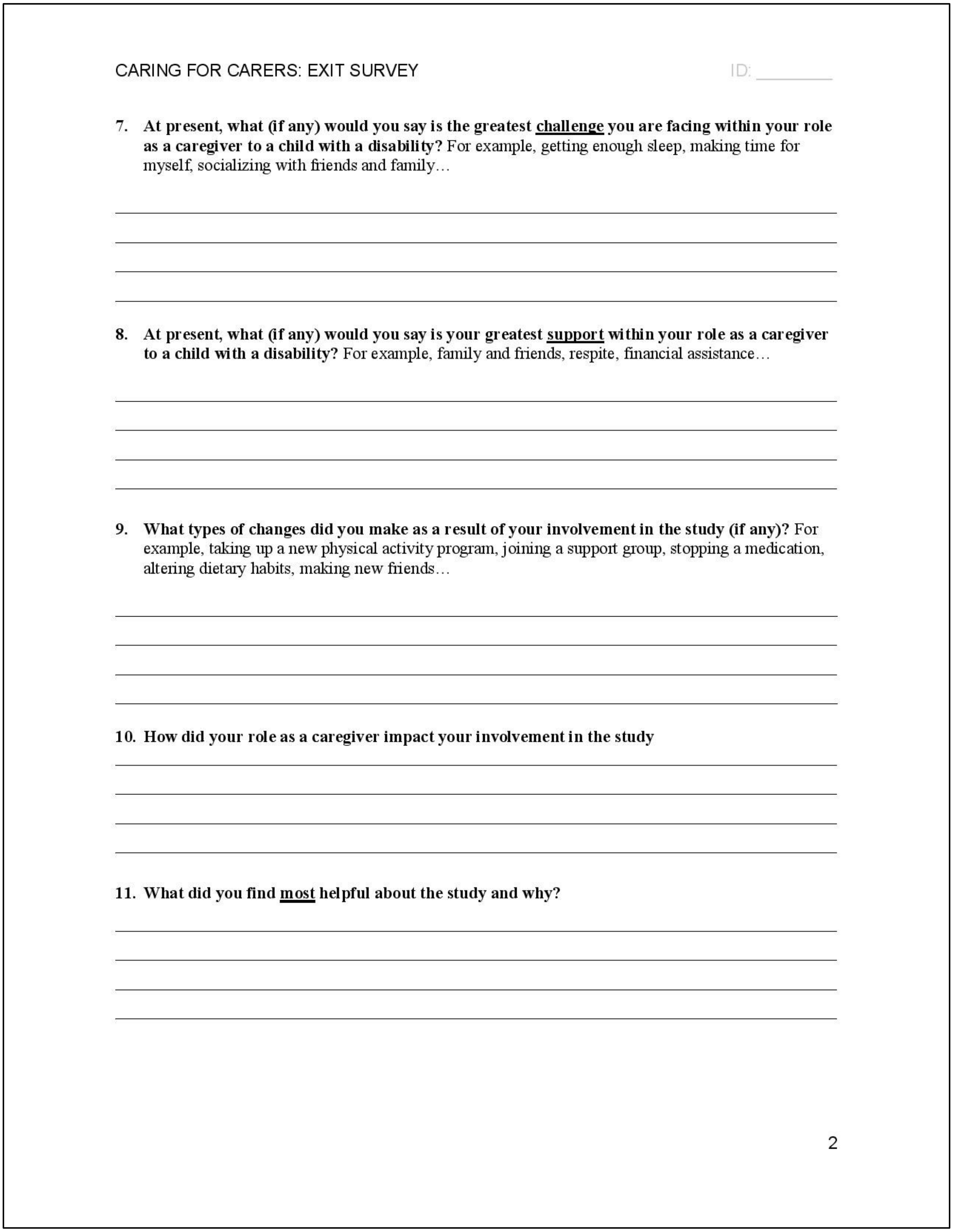
____
____
____
____

5. **Upon joining the study, my primary goal was to…** (e.g.: become more active; feel better about myself; become a better parent caregiver; sleep better; become healthier in general).

____
____
____
____

6. **Now, having completed the study, my primary goal is to…**

____
____
____
____



CARING FOR CARERS: EXIT SURVEY ID: ________

7. **At present, what (if any) would you say is the greatest <u>challenge</u> you are facing within your role as a caregiver to a child with a disability?** For example, getting enough sleep, making time for myself, socializing with friends and family…

____

____

____

____

8. **At present, what (if any) would you say is your greatest <u>support</u> within your role as a caregiver to a child with a disability?** For example, family and friends, respite, financial assistance…

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9. **What types of changes did you make as a result of your involvement in the study (if any)?** For example, taking up a new physical activity program, joining a support group, stopping a medication, altering dietary habits, making new friends…

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10. **How did your role as a caregiver impact your involvement in the study**

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11. **What did you find <u>most</u> helpful about the study and why?**

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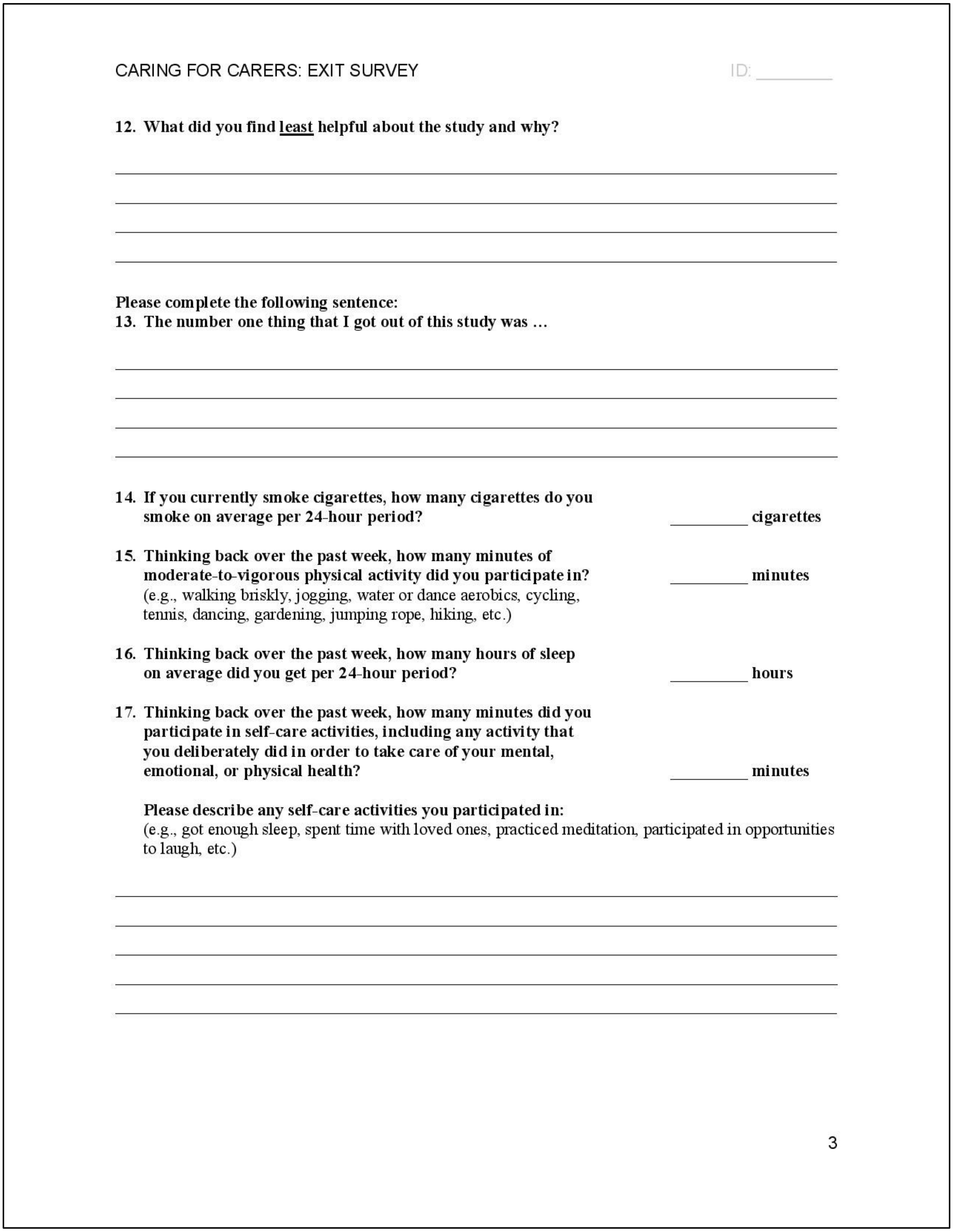

CARING FOR CARERS: EXIT SURVEY ID: ________

12. What did you find least helpful about the study and why?

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Please complete the following sentence:
13. The number one thing that I got out of this study was …

____

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____

14. If you currently smoke cigarettes, how many cigarettes do you smoke on average per 24-hour period? _________ **cigarettes**

15. Thinking back over the past week, how many minutes of moderate-to-vigorous physical activity did you participate in? _________ **minutes**
(e.g., walking briskly, jogging, water or dance aerobics, cycling, tennis, dancing, gardening, jumping rope, hiking, etc.)

16. Thinking back over the past week, how many hours of sleep on average did you get per 24-hour period? _________ **hours**

17. Thinking back over the past week, how many minutes did you participate in self-care activities, including any activity that you deliberately did in order to take care of your mental, emotional, or physical health? _________ **minutes**

Please describe any self-care activities you participated in:
(e.g., got enough sleep, spent time with loved ones, practiced meditation, participated in opportunities to laugh, etc.)

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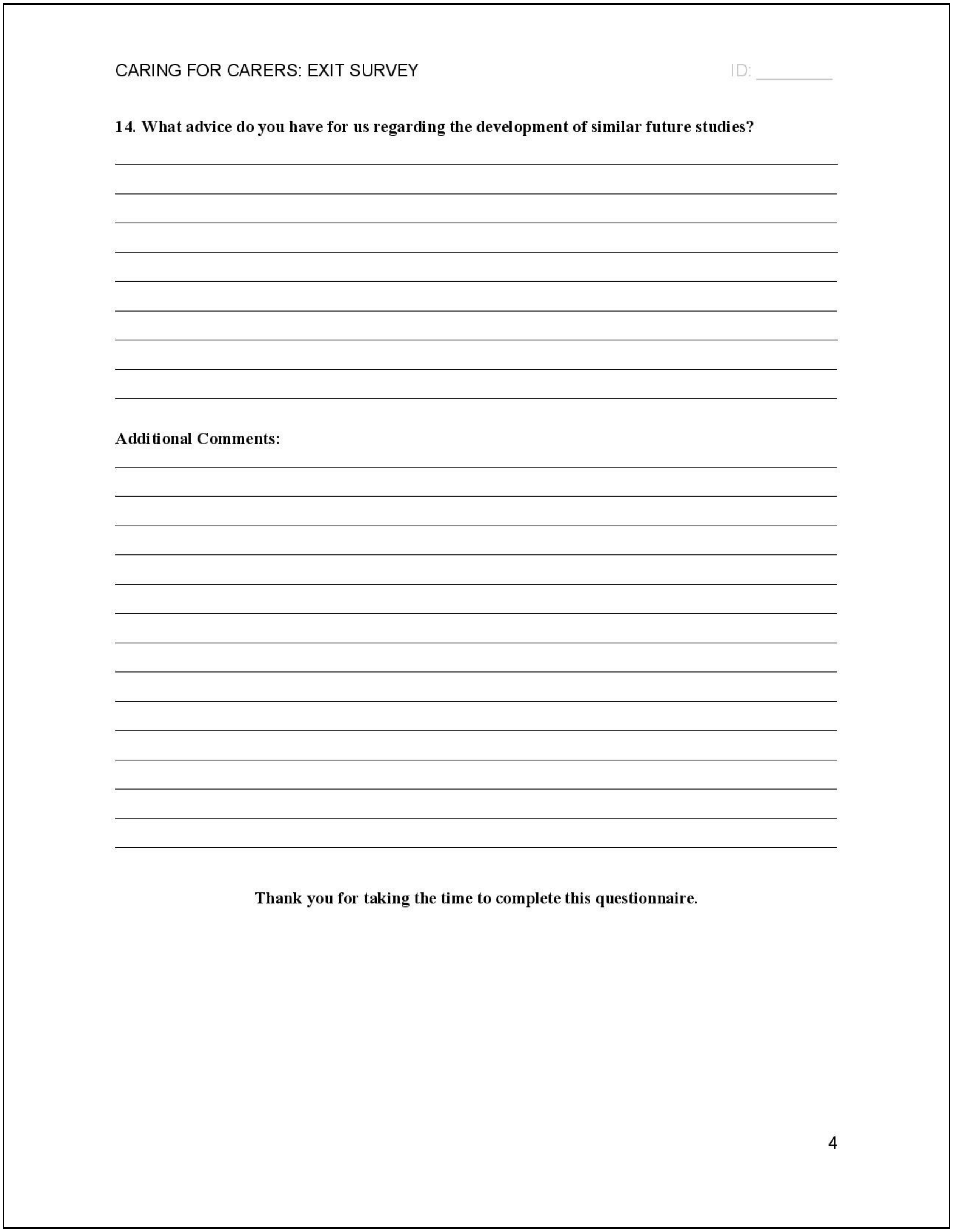

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14. What advice do you have for us regarding the development of similar future studies?

Additional Comments:

Thank you for taking the time to complete this questionnaire.

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