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# Exploring the Effects of the Cycling Without Age Program on Older Adults Living in Long-Term Care

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Supervisor: Zecevic, Aleksandra, *The University of Western Ontario* A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences © Victoria Cotnam 2020

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#### Abstract

The Cycling Without Age program, offered in long-term care homes around the world, allows residents to experience the feeling of a bike ride in the trishaw as a volunteer pedals the electrical bike. The purpose of this pragmatic observational study was to measure the effects of an existing program in a Canadian long-term care home on residents' happiness, quality of life, pain and functional status (using Resident-Assessment Instrument Minimum Data Set 2.0). A convenience sample of 39 residents participated in two groups, a biking group (n=23) and a strolls group (n=16) over the period of 12 weeks. Findings show that biking significantly improved participants' happiness, did not cause pain, and was associated with maintenance of quality of life. These findings are encouraging for further implementation of the program and provide guidance for future research.

Keywords: Older adults, long-term care, happiness, pain, quality of life, biking, function.

#### **Summary for Lay Audience**

Cycling Without Age is a biking program offered in long-term care homes around the world. The program allows residents to experience the feeling of a bike ride in the three-wheeled trishaw as a volunteer pedals the electrical bike. The purpose of this study was to investigate the effects of an existing Cycling Without Age program in a Canadian long-term care home on the happiness, quality of life, pain and functional status (using Resident-Assessment Instrument Minimum Data Set 2.0) of residents. A sample of 39 residents participated in two groups, a biking group (n=23) and a strolls group (n=16) over a period of 12 weeks. Findings show that the biking program immediately and temporarily improved the happiness of residents, did not cause more pain, and was associated with maintaining quality of life. This study provides long-term care homes with evidence of the impact of the Cycling Without Age program on residents, which encourages future program implementation.

#### Acknowledgements

One evening in June, as I was writing my thesis on a small desk in a dimly lit room, I came across a quote by Toni Morrison (1981), "if there is a book that you want to read, but it hasn't been written yet, then you must write it." In that moment, it dawned on me; Aleksandra inspired and supported me to the write the book that we both wanted to read, but that had not been written yet.

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#### **1. Introduction and Literature Review**

This study explored the effects of the Cycling Without Age (CWA) biking program on residents of a long-term care (LTC) home who are no longer able to pedal or balance on a bike themselves. CWA bikes are three-wheeled electric bicycles specially designed to fit two people in the front and a bike peddler, called a pilot, in the back. This study focused on various previously reported anecdotal benefits of the CWA program by harvesting existing clinical data, namely Resident Assessment Instrument – Minimum Data Set 2.0 (RAI-MDS 2.0) outcome measures, along with happiness, pain and quality of life (QOL) data that are not routinely recorded in LTC. The anecdotal testimonials from 50 countries on benefits of the CWA program seem to be expansive and have signaled to a potential new way of experiencing old age. They warrant further rigorous investigation.

#### **1.1 Background and Significance**

#### 1.1.1. Demographics

According to the World Health Organization (2018), the global population of older adults (65 years or older) is increasing faster than ever before. In 2015, there were 900 million older adults in the world, and by 2050 this population is expected to more than double, totaling approximately 2 billion older adults worldwide (World Health Organization, 2018). Within Canada a similar trend is observed. From 2014 to 2030, the population of individuals age 65+ is expected to grow from 15% to 23% of the population, along with subsequent increases in life expectancy by two years for women, and three years for men (Government of Canada, 2014). Within the province of Ontario, the number of older adults is expected to nearly double by 2041, with the biggest acceleration of individuals turning 65+ occurring in the next 12 years (Ministry of Finance, 2018).

#### 1.1.2 Health Policy in Canada and Long-Term Care Policy in Ontario

In all provinces and territories across Canada healthcare is administered according to five facets of federal legislation, called the Canada Health Act: pubic administration, comprehensiveness, universality, portability and accessibility (Government of Canada, 2016). Each province and territory must meet the standards delineated in the Canada Health Act to receive Canada Health Transfer funding to pay for health care services. However, the management, organization and delivery of healthcare is decided upon by each province and territory (Government of Canada, 2016)

Within the province of Ontario, 24 ministries exist to manage and administer public services (Government of Ontario, 2020). The Ministry of Health and Long-Term Care oversees the quality of the LTC sector and the safety of residents by developing various legislature such as the Long-Term Care Homes Act (Government of Ontario, 2020). This legislature is intended to, "help ensure that residents of long-term care homes receive safe, consistent, high-quality, resident-centered care" (Government of Ontario, 2011, p. 1). The Long-Term Care Homes Act also describes the regulatory requirements and services to be offered and upheld in all 626 LTC homes across the province (Ontario Long-Term Care Association, 2019).

In response to the growing demographic of older adults, the Governments of Canada and Ontario have developed various policies and incentives to assist and protect older adults both at home and in LTC facilities. For example, "aging in place" incentives were conceived to provide financial assistance for supportive services that would allow older adults to safely remain in their homes as they age (Government of Canada, 2014). In 2017, the province of Ontario created *Ontario's Action Plan for Seniors*, which

focused on the promotion of aging in place due to its affordability over LTC facilities (Government of Ontario, 2017). Improvements to home care combined with an increasing prevalence of dementia (Chambers et al., 2016) have resulted in an altered demographic of individuals utilizing LTC services (Ontario Long-Term Care Association, 2018). These LTC residents are assessed using the mandated RAI-MDS 2.0 system.

#### 1.1.3 RAI-MDS 2.0 Functional Outcome Measures

On the individual level, resident care plans are developed to set individual goals for residents and to provide care-related direction for staff. Part of the care plan includes the regular RAI-MDS 2.0 assessments. In 1991, an international group of researchers and clinicians formed to develop the RAI-MDS instrument and in 1995, the instrument was revised into the RAI-MDS 2.0 (Hutchinson et al., 2010). RAI-MDS 2.0 is a comprehensive, standardized tool that can detect the strengths, needs and potential risks of individuals living in LTC (Hutchinson et al., 2010). The RAI-MDS 2.0 system was developed to provide a standardized assessment system that would evaluate an individuals' clinical status (interRAI, n.d.) using reliable measures (Kim et al., 2015).

The RAI-MDS 2.0 instrument describes important aspects of health and care requirements using the least number of items possible (Poss et al., 2008). The system is consistently used in all LTC homes across Ontario, and various developed countries around the world, which facilitates comparison of data among facilities, regions, or countries (Poss et al., 2008). Data is generated from routine clinical practice and is pertinent to decision-making within LTC (OCED/European Commission, 2013). In a multiple-domain instrument such as RAI-MDS 2.0, data quality is related to the instrument and the assessor (Poss et al., 2008). The use of RAI-MDS 2.0 functional

outcome measures in the present study will allow for comparison of the 13 indicator scales between study participants.

RAI-MDS 2.0 assessment includes 13 outcome measures which are assessed upon admission to generate a personal baseline, and quarterly thereafter to determine change in status. The 13 scales are: The Aggressive Behaviour Scale, Activities of Daily Living Short-Form Scale, Activities of Daily Living Long-Form Scale, Activities of Daily Living Self Scale, Changes in Health and End-Stage Signs and Symptoms Scale, Cognitive Performance Scale, Depression Rating Scale, Pressure Ulcer Risk Scale, Pain Scale, Index of Social Engagement Scale, Communication Scale, Fracture Risk Scale and the Personal Severity Index. Seven of these scales measure anecdotal benefits that have been reported to occur as a result of participation in the CWA program. For example, CWA pilots and LTC staff have noticed that after partaking in a bike ride, residents participate in more activities, experience improved cognition and walking abilities, as well as experience decreased depression and aggression (TedX Talks, 2014). Respectively, the Index of Social Engagement, Cognitive Performance Scale, Activities of Daily Living Short-Form Scale, Activities of Daily Living Long-Form Scale, Activities of Daily Living Self Scale, Depression Rating Scale and Aggressive Behaviour Scale, measures these aspects.

#### 1.1.4 Long-Term Care Demographics

To be admitted into LTC, residents must present "high" or "very high" degrees of physical or cognitive impairments (Alzheimer's Disease International, 2014; Chenoweth et al., 2019; Ontario Long-Term Care Association, 2018). To exemplify, in 2018, 90% of residents in Ontario LTC homes had cognitive impairment and 64% had some form of dementia. Further, in 2018, 85% of residents required extensive care compared to 77% in 2013 (Ontario Long-Term Care Association, 2018). Residents admitted into LTC today require an increasing amount of support with activities of daily living (Ontario Long-Term Care Association, 2018).

With the rapidly changing demographic of residents in LTC, the services and programs offered must be modified to accommodate the increasing needs of residents with dementia. Cognitive impairments as a result of dementia may include deficits in memory, language, executive abilities, visuospatial awareness, and recognition of stimulation (Boustani et al., 2007). Behavioural and psychological impairments may include apathy, depression, anxiety, agitation, aggression, delusions or hallucinations, elation or euphoria, disinhibition, sleep disturbances and appetite changes. Whereas, functional impairments may include the inability to walk, eat or speak (Boustani et al., 2007). With a wide range of challenges faced by individuals living in LTC, planning programming to suit residents' needs can be difficult.

#### 1.1.5 Long-Term Care Recreation

In 2012, the World Health Organization and Alzheimer Disease International recommended LTC facilities adopt person-centered care approaches to improve the wellbeing of residents. Person-centered care is an evidence-based approach that integrates the personal experiences, preferences, needs and interests of the individual to provide a specifically tailored and unique care experience (Fazio et al., 2018; McCormack 2004; Talerico et al., 2003). Person-centered approaches may improve the QOL of LTC residents (Chenoweth et al., 2019; Kim & Park 2017; Tellis-Nayak, 2007). To date, limited attention has been directed towards the relationship between person centered care and meaningful activity (Du Toit et al., 2019), and the role of leisure activities in the lives of older adults with dementia (Genoe & Dupuis, 2014).

According to Mansbach and colleagues (2017), the concept of meaningful activity encompasses three basic features: active and continual engagement, activity content related to ones' interests and past roles, and programs that meet basic needs of identity and belonging. Research has proposed that participating in a meaningful activity has positive psychological benefits among older adults with and without dementia (Mansbach et al., 2017; **Rönnberg**, 1998), such as improvements in life satisfaction and QOL, as well as decreases in depression (Menne et al., 2012). Meaningful activities are active and experiential rather than passive, and provide fulfillment through choice, control and belonging (Eakman et al., 2010). Such activities are unique to the individual as meaningful activity can mean different things to different people. Thus, determining which activities are meaningful to residents may have positive impacts on well-being and QOL on residents (Mansbach et al., 2017). It is probable that the social and participatory nature of a CWA bike ride has made it a meaningful activity for many LTC residents where the program is available.

According to the Long-Term Care Homes Act (Government of Ontario, 2018), LTC homes are required to provide daily recreational activities for residents. It is important that these programs are meaningful and sufficiently engage residents (Cohen-Mansfield et al., 2010). Programs such as watching TV and listening to music are designed to engage a wide range of participants at once, but are often passive (Harmer & Orrell, 2008), and large group activities may only facilitate minimal social engagement for individuals with dementia, whereas staff-facilitated small group programs provides

the highest level of engagement (Casey et al., 2014; Cohen-Mansfield et al., 2010; Wood et al., 2016). Likewise, residents are more actively engaged during structured activity than during unstructured activity (Casey et al., 2014). In large part, residents experience a lack of meaningful social engagement while living in LTC (Meeks & Looney, 2011), and the importance of increasing their engagement after admission has been recognized in the literature (Bliss et al., 2017). The aging processes, combined with the inability to continue participating in activities that were once loved, can contribute to the high rates of depression and lack of engagement of older adults (Conn, 2016; Wood et al., 2016). The CWA program is designed to promote resident engagement as it provides an opportunity for older adults to participate in a natural social interaction with another resident, the bike pilot, and the local community.

#### 1.1.6 Depression in Long-Term Care

Alongside a lack of engagement, high rates of depression and loneliness have plagued LTC homes. Compared to an approximate 5% incidence in the general population (Public Health Agency of Canada, 2016), approximately 30% of individuals living in LTC have depression (Ontario Long Term Care Association, 2018), and loneliness is experienced by 22% to 42% of older adults living in LTC, compared to a 10% of community dwellers (Victor, 2012). Risk factors for depression in older adults include comorbidities, disability and functional decline, and cognitive impairment (Davison et al., 2012; Davison et al., 2018). Depression in older adults is of concern because it leaves individuals more susceptible to poor health outcomes such as insomnia, decreased interest and pleasure in activities, agitation, reduced concentration and morbidity (Elias, 2018; Taylor, 2014). Furthermore, treating depression with medication may cause polypharmacy, which can enhance susceptibility to negative side-effects, such as fatigue,

diarrhea, incontinence, loss of appetite, falls, anxiety and hallucinations (Dagli & Sharma, 2014).

In LTC, depression is primarily treated with antidepressants rather than psychotherapy or nonpharmacological interventions (Taylor, 2014) such as wheelchair biking (Buettner & Fitzsimmons, 2002), acceptance and commitment therapy (Davison et al., 2016), or reminiscence therapy (Meléndez Moral et al., 2015). This may be because staff perceive medication effects as quick and long-lasting, and nonpharmacological interventions as time consuming with short effectiveness, and unfeasible due to low staffto-resident ratios (Janzen et al., 2013). After completing a systematic review of 25 articles, Yoon and colleagues (2018) recommended that minor depression in older adults should first be treated with nonpharmacological interventions, rather than with medications to avoid the risk of polypharmacy. Likewise, Christensen and colleagues (2013) revealed that older adults who participated in outdoor activities 1-2 times per week had significantly lower depression scores. High rates of depression in LTC, along with anecdotally reported improvements in depression as a result of CWA participation provide another reason to further explore this issue.

#### 1.1.7 Happiness

Happiness may be invoked through recalling a memory, seeing a person, visiting a place, or engaging in an experience. Happiness is a subjective experience (Waterman, 1993), so what makes one person happy may not make everyone happy. Perhaps because of this subjectivity, the definition of happiness varies. In her book, "The How of Happiness," (2007), Sonja Lyubomirsky defines happiness as, "the experience of joy, contentment, or positive well-being, combined with a sense that one's life is good, meaningful and

worthwhile" (p. 32). Merriam-Webster's dictionary defines happiness as, "a state of wellbeing and contentment: joy. A pleasurable or satisfying experience" (n.d.). Furthermore, Veenhoven (2007) defines happiness as, "the overall appreciation one's life-as-a-whole" (p. 450). What happiness truly *is*, remains less clear.

The concept of happiness is generally acknowledged as having two interrelated variables. In his seminal paper, *Two Conceptions of Happiness*, Waterman (1993), explored these two variables, eudaimonia and hedonic enjoyment, and their influence on overall happiness. Eudaimonia is described as a personal expression of the best thing, the best within us, or excellence (Aristotle, 1985). To contrast, hedonic enjoyment is described as a subjective experience that is not linked to specific activities but is the pleasant and enjoyable feeling associated with having physical, intellectual or social needs fulfilled (Ryan & Deci, 2001; Waterman, 1993).The CWA program may influence participants' hedonic happiness by fulfilling social needs and by providing participants with a pleasurable and enjoyable experience.

In his book, The Little Book of Lykke, Meik Wiking (2017), CEO of the

Happiness Research Institute in Copenhagen, Denmark explores factors that may promote the happiness of individuals from a societal level. Written from a Danish perspective, Wiking (2017) discusses six concepts: togetherness, money, health, freedom, trust and kindness. The concept of togetherness related to connection and purpose, such that the happiest countries had the strongest sense of community and deeply rooted belief in the common good, such as paying high taxes or simply taking care of one another. Wiking established the link between money and happiness, but ultimately stated that, "the more of something we have, the less happiness we derive from it" (Wiking, 2017, p. 81), and

that happiness can be generated through purchasing experiences rather than things. Furthermore, the richest countries are not the happiest. Health related to happiness on a societal level may be improved through free healthcare, as people have less to worry about on a regular basis. Building movement into your everyday routine, such as active transportation, along with appealing outdoor spaces may improve health, and ultimately happiness. Freedom related to happiness in connection to time. Freedom with how you spend your time, such as work hours, commute hours, or time spent with family can impact happiness. Maintaining trust and loyalty within one's community may also improve the ability to relax, and ultimately foster happiness. Lastly, kindness with time, money and your behaviour, may promote happiness (Wiking, 2017). The concept of happiness has numerous definitions, along with an ample number of ways to achieve it. In Denmark, it seems that the promotion of happiness coming from both the individual, and societal level, and a general need to care for and protect the community, which includes the oldest of old living in LTC. It is clear why, according to the World Happiness Report 2020, Denmark is named the second happiest country in world, and Copenhagen, Denmark, where the CWA program was founded, is named the 5<sup>th</sup> happiest city in the world (Helliwell et al., 2020).

Happiness has been shown to have positive health benefits such as living longer, greater psychological resilience and better physical health (Tan et al., 2019). Recent literature has revealed that older adults around the world can maintain or improve their happiness as they age. This was consistent across India, China, and Latin America (Cooper et al., 2010), Denmark (Vestergaard et al., 2015), and in Singapore (Tan et al., 2019). Although happiness of older adults with cognitive impairment has been relatively unstudied, they seem to be less likely to report feelings of happiness (Cooper et al., 2010; Tan et al., 2019). However, it is known that LTC residents with dementia express more happiness during planned recreation than at other times of the day (Genoe & Dupuis, 2014). Although many residents are living in LTC primarily to assure their safety and medical care, there is also the need to assure psychological and social well-being to bolster their QOL. Positive human experiences in LTC such as happiness, social interaction, contentedness, time spent outdoors, smiles, laughter, or joy should also be researched (Bieda et al., 2017).

#### 1.1.8 Quality of Life

From a global perspective, the World Health Organization (2020) has defined QOL as,

an individual's perception of their position in life in the context of the culture and the value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of the environment (paragraph 1).

For older adults, Molzahn and colleagues (2010) revealed that particularly important aspects of QOL include high energy levels, freedom from pain, ability to perform activities of daily living, and the freedom to move around. More recently, van Leeuwen and colleagues (2019) performed a thematic synthesis on 48 qualitative studies investigating QOL of older adults. Authors identified nine themes related to QOL: health perception, autonomy, role and activity, relationships, attitude and adaption, emotional

comfort, spirituality, home and neighborhood, and financial security. These are aspects that are important for the maintenance of QOL for older adults.

LTC homes should be able to provide a good QOL for older adults (Pulst et al., 2019). In their systematic review and meta-analysis of 16 studies, Medeiros and colleagues (2020) explored the effects of LTC living on QOL of older adults living in developed countries around the world. Issues that negatively impacted QOL included: lack of socialization, lack of ability to perform personally relevant leisure activities and a high prevalence of depression in LTC. More specifically, their sub-analysis of five studies that assessed QOL using the WHOQOL-BREF questionnaire have show worsened QOL in older adults living in LTC attributed to lack of physical activity, and a lack of engagement in social activities, ultimately aggravated by serious illness. (Medeiros et al., 2020). This study concluded that living in LTC has negative influences on QOL of older adults, but that this issue requires further investigation.

Older adults in the end-stages of life deserve a high QOL, and further research into ways to mediate the negative influence of LTC on QOL is needed. Six of the nine themes noted above, namely, autonomy, role and activity, relationships, attitude and adaption, emotional comfort, and home and neighborhood may be bolstered during the CWA bike ride experience. The CWA may emerge as an activity that can strengthen the QOL of older adults living in LTC.

#### **1.2 Cycling Without Age**

"What fun we had! It turned out to be a 25-minute ride with non-stop laughter. That night she fell asleep with a smile on her face." (Cycling Without Age, 2017, story 20). People of all ages enjoy riding bikes, however for many older adults living in LTC homes, the process of aging has made it unsafe or unfeasible to continue this activity. Since 2012, CWA is a worldwide biking program with origins in Copenhagen, Denmark that supports older adults with limited mobility to participate in trishaw bicycle rides. The loveseat design of the front cushion fits two residents who sit beside one another and enjoy the ride as a volunteer pilot pedals the bike from behind (Figure 1-1). This design provides an opportunity for social interaction among residents and with the pilot. Social interaction with the pilot is often intergenerational and may create a new and unique social opportunity for both the older riders and younger pilots.



*Figure 1-1.* Cycling Without Age participants sitting in front of trishaw bike with pilot sitting behind. Permission to use picture granted by Dundas Manor (Appendix B).

The CWA program operates based on five principles: generosity, slowness, storytelling, relationships and without age (Cycling Without Age, 2020). Generosity links to the community support and volunteerism that is required for a pilot to take elderly out for a bike ride. Slowness means taking the time during the trip; stopping to smell the flowers or chat with a participants' old neighbor. Storytelling is connected to memories of the past that may be recalled by CWA participants and told during bike rides. Developing and maintaining relationships through storytelling between riders is a common experience during bike rides (Cycling Without Age, 2020). Lastly, without age refers to CWA putting aging in a positive context as it facilitates participants to become reintegrated with their community, the city and society without the constricting boundaries of age.

CWA is designed for older adults with medical conditions living in LTC, as it allows for the joyful experience of freedom associated with a bike ride without the physical exertion. Currently, more than 3,000 CWA bicycles, called trishaws, are used in 50 countries around the world, and this number continues to grow (Cycling Without Age, 2020). Approximately 2,200 CWA chapters exist around the world. A chapter refers to a city in which CWA bikes exist. CWA is a not-for-profit company, in which volunteer bike pilots, or staff members at LTC homes with a bike, sign up as often as they would like to pedal the bike. The CWA bike is designed with an electrical motor to support the pedaling which takes the strain off the bike pilot and makes it more inclusive to a variety of volunteers.

Every year, CWA Denmark hosts an event called, "The Longest Ride," where staff, residents and volunteers from various city chapters meet to go on a multi-day bike

trip on CWA bikes. In 2015, this event consisted of 10 CWA bikes, 20 elderly passengers and 15 bike pilots (Figure 1-2). They travelled 300 kilometers from Denmark to Germany on a trip that lasted four days. According to Kassow (TedX Talks, 2014), one participant remarked that she had not been on vacation in 15 years, and it was the best holiday of her entire life. Another longest ride participant remarked that they felt alive again, and many participants did not need to use walking aids at the end of the days. Kassow stated that, "nothing is impossible, and it is all about creating relationships" (TedX Talks, 2014).



*Figure 1-2.* Cycling Without Age pilots pedaling bikes on their way to Germany from Denmark. Permission to use photo received from CWA Global Community Captain (Appendix B).

The CWA program is unique because it deviates from the traditional understanding of cycling, in which a bike ride is a form of physical exercise (Zander et al., 2013) that is done for leisure, recreation or tourism (Lee, 2014). Research on cycling predominantly focuses on the physical benefits of the activity such as its positive effect on cardiorespiratory endurance, blood pressure, diabetes and heart disease (Oja et al., 2011; Bassett et al., 2008). The psychological benefits of cycling have also been explored and reveal positive effects on depression and health related QOL (de Geus et al., 2008). However, these benefits are intrinsically linked to the physical activity of pedaling a bike.

CWA goes further and gets to the essence of bike rides by focusing on the surrounding effects of riding a bike, such as connection with nature, feeling wind in the hair, visiting the community, waving at neighbors and seeing the comings and goings of the town, along with experiencing various scents, sounds, and sights. This program seems to remind older adults of why they loved biking before their physical health prevented them from participating in the activity. It also puts aging in a positive light, such that, even if an older adult can no longer pedal a bike, they may still find pleasure and experience psychological benefits from participating in a bike ride. Since 2012, the CWA program has anecdotally reported that the benefits of a bike ride may be more expansive than the effects experienced from physically pedaling a bike. To the author's knowledge, there is a gap in the literature of understanding this essence.

#### **1.3 Previous Research on CWA**

Until now, the impacts of CWA on participants have been predominantly reported anecdotally, along with four research projects of various methodological rigor. Anecdotal benefits of the CWA program have been reported in TED talks

(https://www.youtube.com/watch?v=O6Ti4qUa-OU&feature=emb\_title), short videos (https://www.youtube.com/watch?v=WCw87Sgrqic,

https://www.youtube.com/watch?v=FAisBQjWoZM&t=1s,

https://www.youtube.com/watch?v=kmrOQLfvp9I&t=1s,

<u>https://www.youtube.com/watch?v=-qzHn9jZNDc</u>), a documentary movie about one Longest Ride event (<u>https://vimeo.com/ondemand/thegreyescape/170594537</u>), a published book titled *Stories From Cycling Without Age* (Cycling Without Age, 2017), and personal testimonials on Facebook

(<u>https://www.facebook.com/groups/cyclingwithoutage/</u>), Instagram (@cyclingwithoutage) and twitter (@cyclingwithoutage).

Through these sources, participants, bike pilots and LTC staff have claimed various positive effects on both the mental and physical health resulting from CWA. Psychological improvements had been witnessed through improved levels of happiness, joyfulness, relaxation and number of smiles in participants. CWA has also been anecdotally reported to have reduced loneliness and isolation, while improving social connectedness of participants. Physical and social changes have been witnessed by bike pilots and LTC staff through improvements in appetite, activity participation, engagement levels, cognitive performance, as well as in decreased depression, medication use, aggressive behaviours and anxiety (TedX Talks, 2014; The Good Life, 2017; Kassow, 2015; Cycling Without Age, 2017).

Although the CWA program has been operating since 2012, as of July 2020, only four research projects have scientifically explored these effects and potential benefits. A non-peer reviewed pilot project from Barcelona, Spain attempted to measure the effects of CWA on QOL (Salas, 2018), a study from Wisconsin qualitatively assessed the effect of the program on participants (McNiel and Westphal, 2019), an impact study from Singapore explored the impact of CWA in relation to the United Nations Sustainable Development Goals (Cycling Without Age Singapore, 2019), and a qualitative study

exploring the impact of day-long CWA bikes on LTC residents in Denmark (Christensen, 2018). Lastly, this CWA literature review will also include one semi-related study that quantitatively measured the effects of a similar program, called wheelchair biking, on depression (Buettner and Fitzsimmons, 2002).

#### 1.3.1 Impact of "Cycling Without Age" on the Health of the Elderly

Located in Barcelona, Spain, Salas (2018) completed the pilot project in conjunction with Hospital Sant Pau to explore the impact of CWA on older adults in the care home. The quasi-experimental pre-test/post-test 12-week intervention project was designed to determine the effects of CWA on health-related QOL, and to assess participants' satisfaction with the program. QOL was assessed using the EuroQol-5 Dimension (EQ-5D) assessment. Participants (N=27) were living in a nursing home in Barcelona and went on weekly bike rides for 12 weeks, lasting 45 minutes ( $\pm 15$  minutes), with the same partner and pilot each time. Participants received a maximum of one ride per week. The majority received a total of 5-8 bike rides. Results of EQ-5D revealed mean health index values improved from 0.53 pre intervention to 0.63 post intervention (score range was 0 to 1) and self-rated health assessed on 100 mm visual analogue scale (VAS) improved from 68.1 to 72.8. One participant experienced improvement in both self-care activities and usual activities, and three participants experienced improvement in mobility. Six participants (22%) experienced worsening pain, and one participant experienced worsened anxiety and depression. Regarding satisfaction, participants (86%) loved the trips, felt safe during trips (79%), and only one person felt unsafe and would not recommend the activity. This study concluded that CWA contributed to an improvement in QOL and that participants experienced a high degree of satisfaction with the program. The authors included recommendations for future research on pain and QOL of CWA

program participants. Limitations of this project include a lack of control group along with lack of information on type of cushion used on the seat, pre-existing pain conditions of participants, and the road conditions (e.g., bumpy vs. smooth biking surfaces). Due to incomplete reporting, and availability of the study findings via slideshow only (http://communitylighteldernetwork.org/wp-content/uploads/Impact-study-on-healthbenefits-and-well-being.pdf), specific methodological details remain unknown. This study concluded that CWA contributed to an improvement in QOL and that participants experienced a high degree of satisfaction with the program.

1.3.2 Cycling Without Age Program: The Impact for Residents in Long-Term Care Located in Wisconsin, McNiel and Westphal (2019) performed a retrospective qualitative study on the effect of the CWA program on QOL of nursing home residents. Participants (N=27) included both residents (n=16) and pilots (n=11) who had partaken in at least one bike ride in the previous year. Participants with cognitive impairment were excluded. Three participants were lost due to death (not associated with the bike ride) or because they moved. Participants were asked, "Tell me about your CWA bike ride experience." Data analysis consisted of inductive and deductive content analysis. Three themes emerged from resident interviews. First theme, "a breath of fresh air," emerged from participants positive experiences getting outside of the facility, experiencing the weather, and becoming engaged with nature. The second theme, "wave, chat and remember," emerged from the social interaction experienced between the pilot and two riders, as well as with people passing by. It also exemplified that the social aspect of the program is a vital aspect of the ride experience. The last theme was, "sit back and relax." This theme highlighted how the ride impacted the demeanor of participants, such that, they enjoyed the ride and felt more relaxed afterwards. Two themes emerged from interviews with pilots. The first theme, a "change in frame of mind," related to the improvement in participants' demeanor that pilots witnessed. They seemed to smile bigger, acted happier, and became more social and interactive. The second theme, "mental and physical rewards" related to the benefits experienced by pilots in their physical and mental health. The study concluded by stating that CWA may be a strategy for person-centered care and made a recommendation for implementation of CWA in LTC homes (McNiel and Westphal, 2018).

#### 1.3.3 CWA Singapore: Our Impact Study

Researchers from CWA chapter in Singapore worked in conjunction with senior care homes and community members across the country to produce a non-peer reviewed mixed method report. This study assessed the connection between the CWA program and the United Nation's Sustainable Development Goals (Figure 1-3) (United Nations, 2015). In 2015, The United Nations developed 17 Sustainable Development Goals as a call to action to end poverty and deprivations around the world (United Nations, 2015). Each goal is referred to by a number and title. Participants in the CWA Singapore study included two groups (N=227): nursing home residents and older adults living in the community. Using Likert rating scales between one and seven, CWA participants were asked two questions before and after biking: how they would rate their mood and outlook on life, and how they would rate their connection to the community. Scores were analyzed using weighted averages. Scores were compared pre and post and change in percents was compared. The report revealed an overlap between the CWA impact on participants and four Sustainable Development Goals. Sustainable Development Goal 3: Good Health and Wellbeing, related to the CWA program as nursing home participants

experienced a 20% increase in QOL when continuously participating in trishaw rides. Further, CWA participants living in the community reported a 19.5% increase in mood and outlook on life, whereas nursing home participants reported up to an 80% increase on the same indicator. Sustainable Development Goal 10: *Reduced Inequalities*, related to the CWA program as older adults were given the opportunity to engage with the community during bike rides. The program developed intergenerational bonds between youth bike pilots and senior riders. Furthermore, up to 59% of nursing home residents experienced an increase in social connectedness. Sustainable Development Goal 11: Sustainable Cities and Communities, was fitting as the electrical bike produces a low carbon footprint and is a sustainable method for various generations to enjoy their community. Lastly, Sustainable Development Goal 17: Partnership for the Goals, related to the teamwork required to complete this project. The report concluded that CWA related to four Sustainable Development Goals and provided enhanced opportunities for older adults living in care homes to enjoy the outdoors, social inclusion and interaction within the community. Furthermore, CWA provided participants with the opportunity to feel happy, feel valued, respected, and to experience positive intergenerational connection. Due to incomplete reporting, and availability of the study findings via slideshow only (https://drive.google.com/file/d/1R0PznT41egIcJqNbB5CDxd7zOii4-<u>Sbz/view</u>), specific methodological details remain unknown regarding sample size, measurement tools and data analysis techniques.



*Figure 1-3.* United Nations 17 Sustainable Development Goals. Retrieved from: <u>https://www.un.org/development/desa/disabilities/about-us/sustainable-development-goals-sdgs-and-disability.html</u> Permission to use photo for educational purposes received from United Nations (Appendix B).

# 1.3.4 Antropologisk Evaluering Af Dag-Og Langture (Anthropological Evaluation of Day and Long Travel [Translated from Danish].

From Denmark, Dr. Suna Christensen developed an anthropological qualitative report to describe the experiences of CWA participants as they engaged in day-long or multi-day bike trips. The report was written in Danish and translated into English using Google Translator for inclusion in this literature review. Christensen's anthropological perspective allowed for viewing the program as a social practice at three different locations across Denmark. Participant observations occurred during 38 km bike rides. Qualitative interviews were performed individually and in focus groups. An analysis of CWA documents was also performed. Themes that emerged included: choreography, mindset, and purpose. Choreography related to the feeling of a well-coordinated movement, resembling a bird migrating during the daytrip. Everybody was happy to go out on the trip, which allowed for humour, equality and togetherness between the biking trio (i.e., two passengers and a pilot). Mindset related to the uniqueness of the idea to go away from the LTC home, on a bicycle for an entire day. Christensen stated that, "CWA adds a twist of adventure to the bike ride. That changes the purpose; it is no longer transport, but relationship, togetherness and joy" (p. 4). This was a drastic change from the rigid LTC structure to embracing uncertainty and taking the day as it came. The final theme, purpose, was derived from the interviews with volunteer bike pilots. Many of them were called "flex workers" within the LTC home, and they worked for only a few hours a day but did odd jobs that they enjoyed, such as piloting the CWA bike. Being a part of the program gave the volunteers a sense of purpose, the feeling that they have positively contributed to the lives of older adults. The report concludes by further highlighting the social nature of the program, the positive effects it had on both staff and participants, and by recommending that daytrips be promoted as positive experiences (Christensen, 2018).

# 1.3.5 AD-Venture Program: Therapeutic Biking for the Treatment of Depression in Long-Term Care Residents with Dementia

"Wheelchair biking" provides a similar experience as the CWA trishaw, as both allow participants to experience the essence of a bike ride without physical exertion. However, a wheelchair bike accommodates only one participant in the front, whereas the CWA bike accommodates two participants in front seat. Due to a lack of research literature on CWA, wheelchair biking was deemed to be similar enough to CWA biking for inclusion in this literature review. Buettner and Fitzsimmons (2002) completed a study measuring the effects of wheelchair biking as a potential treatment for depression in older adults living in LTC. A "wheelchair bike" was utilized in this study rather than a CWA bike.

Intervention consisted of 30 bike rides lasting 15-minutes over 12 weeks as follows: a two-week intensive period with five bike sessions per week, followed by a 10-week maintenance period with two bike sessions per week. A bike session were comprised of four participants sitting together for an hour. Each participant went for a 15-minute bike ride, then returned to the group remaining and discussed the experience. Participants (N=70) were randomly assigned to a treatment or control group. Data collection occurred at three intervals: baseline (week 0), post-intensive period (week 2) and follow-up (week 12). The Geriatric Depression Scale and Cohen-Mansfield Agitation Inventory were administered by nurse practitioners at all three time points throughout the study, and activity participation was recorded over the 12-week period. This study revealed that LTC residents were highly responsive to the program, which was seen by statistically significant changes in Geriatric Depression Scale ratings (p < .000). Participants experienced decreased levels of depression. Results from Cohen-Mansfield Agitation Inventory revealed that the program had no significant effect on agitated behaviour of residents. Activity participation revealed a significant improvement in number of recreational activities participants engaged in (p < .000). The authors concluded that residents became less depressed, were more frequently engaged in other programs, but experienced the same level of agitation. The wheelchair biking allowed residents who were isolated, sad, and lonely the opportunity to get outside and experience freedom and joy (Buettner & Fitzsimmons, 2002).

#### 1.4 Purpose

As this literature review has uncovered, this LTC population experiences less happiness (Tan et al., 2019; Cooper et al., 2010), a lower quality of life (Medeiros et al., 2020), less engagement (Conn, 2016; Meeks & Looney, 2011; Wood et al., 2016), more depression

(Public Health Agency of Canada, 2016), and more loneliness (Victor, 2012) than older adults living in the community. LTC research predominantly focuses on health and social policy issues (Victor, 2012), and the population is hard to get access to for research purposes (Schenk et al., 2013). With a predominant focus on medical care and safety in LTC, these issues demand further inquiry: what needs to be done to make LTC residents happy, what can mediate the prevalent depressive symptoms experienced, and how can social connection be improved for this isolated and socially deprived population? Perhaps the unique and untraditional CWA program of has the power to alter the traditional dialogue surrounding LTC.

As the number of people participating in the CWA program around the world increases and the anecdotal benefits of the program continue to increase, LTC residents everywhere seem to be experiencing the same advantages. There is a lack of rigorous research on the effectiveness of the CWA program, which may provide insights into valuable practice changes for policy makers, caregivers and future researchers, which ultimately benefit the lives of the vulnerable population of LTC residents. The purpose of this study was to explore the effects of an existing CWA program on happiness, pain, QOL and functional status of residents in LTC.

#### 2. Methods

#### 2.1 Study Design

This study utilized a pragmatic observational design (Barnish & Turner, 2017). Together, pragmatic and observational studies can provide insight into the real-world application of research (Barnish & Turner, 2017). The main principle of pragmatism is to understand the multifaceted and authentic human experience by assessing numerous factors involved in an inquisition (Duram, 2010). Pragmatic findings focus on applicability to real life and routine clinical practice (Duram, 2010). This compliments an observational study deign, defined by Rosenbaum (2010) as, "an empiric investigation of treatment effects when random assignment to treatment or control is not feasible" (p.21). Sedgwick (2012) explained that when it is unethical or impractical to impose treatment on a certain population, an observational design is used as it does not intervene with the lives of the participants, but rather observes their choices and treatment decisions. In this study it was not feasible to randomly assign participants to groups as some residents wanted to be in a biking group, while families of other residents did not provide consent for their participation in the biking activity. To tell residents, who may be in last weeks or months of their life, that they cannot participate in a program they like would not be in the participants best interest. An observational study includes a well-defined treatment that begins at a well-defined time and participants can be selected from naturally occurring groups (Sedgwick, 2012). For this project, two naturally occurring groups from the same LTC home were selected: residents who had provided consent to the LTC home prior to this study to participate in the CWA program and residents who did not. The Western
University Health Science Research Ethics Board and the Winchester District Memorial Hospital provided ethics approvals for this study (Appendix A).

#### 2.2 Dual Role of the Researcher

The researcher (VC) had a dual role to both collect data for this project and to work as an activity assistant in the LTC home's recreation department. This dual role allowed her unprecedented familiarity and access into the LTC home's CWA program. As a staff member, the researcher reported to the Activity Coordinator. As a researcher, the researcher reported to the principle investigator and thesis supervisor. During the five month data collection period, the researcher recruited participants, ensured bike questionnaire were completed before and after bike rides, transferred and coded data from the RAI-MDS 2.0 website to password-protected and encrypted excel sheets, and ensured the completion of LTC-QOL questionnaires by staff and residents at specified times. As a staff member in the recreation department, she provided bike rides and strolls for participants in this study, as well as recorded answers to the bike ride and stroll record forms.

#### 2.3 Setting

Data was collected at Dundas Manor LTC home in Ontario, Canada. The home is located in a rural town with 15,000 inhabitants and accommodates 98 residents. Dundas Manor is a not-for-profit LTC home and operates in conjunction with Winchester District Memorial Hospital. The home has been accredited with exemplary standing in 2018, and strictly follows the Ontario Long-Term Care Homes Act (Government of Ontario, 2018). This study was coordinated by the Activity and Recreation Department that has four full time employees, one part time employee and three casual employees. Together, they offer a range of programs such as one-on-one visits, strolls, gardening, Tuesday Tea (tea and cookies with music), entertainment, CWA (called Brad-Lee Rides), pet visits, and a variety of other activities. The CWA program at Dundas Manor has been operating up to three times a week during the Spring, Summer, and Autumn since 2017. The LTC home has designed a pre-determined route for bike rides (Appendix C).

#### 2.4 Sample

A sample of 39 residents from the LTC home were selected using convenience sampling. Inclusion criteria were permanent residence at Dundas Manor, 65 years of age or older, availability RAI-MDS 2.0 assessment data for the study period, and ability to speak English. Exclusion criteria were inability to sit upright, and extreme or unpredictive behaviors. Participants were invited to participate personally or through their substitute decision maker by an Activity Assistant within the residents' circle of care. Each participant, or their legal representative, were required to read the Letter of Information and sign consent (Appendix D). Five participants had the cognitive ability to consent by themselves. Substitute decision makers provided informed consent for the remaining 34 participants. Participants were free to leave the study at any time and for any reason.

A biking group (n=23) was observed as they participated in bike rides for 12 weeks. A strolls group (n=16) was observed as they participated in strolls for 12 weeks. The strolls group did not participate in CWA bike rides, and the biking group did not participate in strolls. Due to the pragmatic and observational nature of the study, group sizes reflect interest in the programs. Residents who did not want to participate in the biking program was a small sample of the LTC home. Strolls and bike rides occurred as they were scheduled by Recreational Department over the course of the late spring, summer and early fall (May-September). Both activities provided opportunity for social

interaction, as the one-to-one resident to staff ratio of a stroll was similar to the two-toone ratio of bike ride. Both strolls and bike rides were outdoor activities that lasted 35 minutes ( $\pm 15$  min). Bike rides occurred throughout the nearby neighborhood, and strolls occurred along a path around the LTC home or throughout the neighborhood.

## **2.5 Data Collection and Measurement Tools**

Data collection was completed between May and September 2019. Because of a lack of previous research on CWA, a total of 18 measurement tools were selected to garner a deep understanding of the potential effects of the CWA program (Table 2-1). At baseline, the researcher harvested demographic information from participants' electronic medical charts on their name, date of birth, level of education, previous occupation, and marital status. At three regular intervals (baseline, 12 weeks and 24 weeks), 13 routine RAI-MDS 2.0 outcome measures were harvested from electronic medical charts. Daily medication usage was collected from medical charts from week -12 (three months before baseline) to week 24 (six months after baseline) to determine a change before and after being involved in observation. Information on falls and hospital stays were collected from medical charts from baseline to week 24. A VAS scale was used to collect data on happiness and pain before and after each bike ride and stroll. QOL was assessed using the LTC-QOL Assessment scale.

Tool	Indicator	# Times Collected	Time Point	
Demographic Questionnaire	Name Date of Birth Gender		Baseline	
	Highest level of education completed Previous occupation Marital status	1		
Visual Analogue Scale	Happiness	24	Before/after stroll & bike ride	
	Pain	24	Before/after stroll & bike ride	
LTC QoL Scale	Quality of Life	4	Baseline, 4, 8 & 12 weeks	
RAI – MDS Scores	Aggressive Behaviour Scale Activities of Daily Living Hierarchy Scale Activities of Daily Living Long-Form Scale Activities of Daily Living Short-Form Scale Depression Rating Scale Pressure Ulcer Risk Scale		Baseline, 12 weeks, & 24-weeks follow-up	
	Pain Scale Index of Social Engagement Communication Scale Changes in Health and End-Stage Signs and Symptoms Scale Fracture Risk Scale Personal Severity Index Cognitive Performance Scale	3		
Other	Medication Use		12 weeks before	
		Daily	baseline to 24-week follow-up	
	Falls Hospitalization	Daily	Baseline to 24 weeks follow-up	

Table 2-1Summary of Data Collection Tools, Indicators, Frequency and Time of Collection

The starting point for participation in this study coincided with participants regular 12-week RAI-MDS 2.0 assessment period. For example, Mr. Miller (alias) consented to participate in the biking group. His RAI-MDS 2.0 assessment was scheduled for May 06, as a result Mr. Miller began participating in the study on the Saturday after May 06 to ensure his regular baseline assessment was fully completed in the previous work, as they are assessed Monday to Friday. Mr. Miller's RAI-MDS 2.0 data was harvested at three time points: the week before starting the biking program (baseline), the week he finished participation in the biking program (Week 12), and at the 3-month follow-up point (Week 24). Mr. Miller completed VAS before and after every bike ride, and completed the LTC-QoL Assessment at baseline, weeks 4, 8 and 12. Data collection were staggered over the five-month data collection period because the regular 12-week RAI-MDS 2.0 assessment time varied for each participant (Figure 2-1).



Figure 2-1. Data collection timeline

# 2.5.1 Long-Term Care Quality of Life Assessment Scale

QOL was measured using the nine question Long-Term Care Quality of Life (LTC-QoL) Assessment Scale proposed and validated by McDonald in 2013. Assessments were completed by proxy who was the residents full time activity staff member. The scale assesses holistic aspects of QOL by reviewing participants social capacity, self-efficacy, supportive relationships, mood state and the presence or absence of fear or distress. Scale values range from 2 to 10, with 10 being the best QOL. Assessment scale has been validated for both genders and for individuals with and without cognitive deficits living in LTC. McDonald (2013) reported that the tool is validated and has acceptable internal consistency (Cronbach's alpha of 0.88) and test-retest reliability in which 96-100% of answers were within the 95% confidence interval. In this study, LTC QoL assessment was completed four times for each participant to determine if any change occurred during the observation period.

#### 2.5.2 Bike Ride Record Form and Stroll Record Form

The Bike Ride Record form (Appendix E) is a standard form in the LTC home and has been routinely completed by recreational staff before and after residents participate in bike rides. For the purpose of this research, the original Bike Ride Record form was modified to include happiness and pain VAS scales. The form also included a step by step safety guide to ensure the staff member gets the resident properly settled on the bike, as well as a section where pilots can document any changes they witness in participants. A new section was added to document the participants' responses to the statement, "use one word to describe how you are feeling right now." A separate and similar Stroll Record Forms was created to be completed for the strolls group. Stroll record form was the same as bike record form, except for the instructions regarding getting onto the bike.

The main feature of this form were two VAS scales which assessed residents' perception of happiness as being "totally unhappy" to "totally happy," and pain from "no pain" to "the worst pain imaginable" along a 100 millimeter continuum (Figure 2-2). A higher score represents a greater pain or happiness intensity (Hawker et al., 2011). A score of 0 to 4 mm can be considered no pain; 5 to 44 mm indicates mild pain; 45 to 74 mm indicates moderate pain; and 75 to 100 mm indicates severe pain (Jensen et al., 2002). Happiness scale included a green smiley face on the happiest end, and a red sad face on the least happy end. Pain scale included written anchors. The VAS has been used to measure subjective experiences, such as pain and QOL, for the last century (Freyd, 1923; Heller et al., 2016). The VAS scale was chosen because it is ten times more discriminatory than a traditional Likert scale (Studer, 2012). Further, individuals with dementia understand the measure in a similar way as individuals without cognitive impairment (Arons et al., 2013). VAS is seen to be a reliable measure of both happiness (Studer, 2012) and pain (Hawker et al., 2011).

Q3: Ask resident: "This line depicts you being completely happy vs. completely unhappy. Use your finger to show me how you feel right now." Please mark where they point.



Q4: Ask resident: "This line depicts you experiencing no pain vs the worst pain imaginable. Use your finger to show me how much pain you feel right now." Please mark where they point.

Worst Pain	 No Pain
imaginable	• NO Palli

*Figure 2-2.* Visual analogue scales for happiness and pain used on Bike Ride Record and Stroll Record forms, collected before and after biking and strolling activities.

#### 2.5.3 Resident Assessment Instrument – Minimum Data Set 2.0

Thirteen outcome scales are utilized in RAI-MDS 2.0 to understand health status in standardized clinical areas (Canadian Institute for Health Information, 2016). Scores are generated upon admission and are used as a benchmark for quarterly assessments (Canadian Institute for Health Information, 2016). The 13 outcome scales used are the Aggressive Behaviour Scale, Activities of Daily Living (ADL) hierarchy scale, ADL long form scale, ADL short form, Cognitive Performance Scale, Depression Rating Scale, Pressure Ulcer Risk Scale, Pain Scale, Index of Social Engagement Scale, Communication Scale, Fracture Risk Scale, Personal Severity Index and Changes in Health, End-Stage Disease, Signs and Symptoms Scale (CHESS). For the purpose of this study, the researcher accessed the online medical charts and harvested and de-identified scores from all scales to be analyzed.

The RAI-MDS 2.0 outcome scale dataset was chosen because constructs measured by these scales matched the variety of anecdotal evidence regarding the benefits of the CWA program. By harvesting scores on 13 RAI-MDS 2.0 outcome scales, the goal was to record change between groups (biking and strolling), and over time (baseline, 12 weeks, 24-week follow-up). Data was harvested at the 24-week follow-up point to determine if any changes persisted 3-months after the observation period.

#### 2.5.4 Medications

The type and amount of medications taken daily by each participant were harvested from medical records. These medications were coded according to the World Health Organization's Anatomical Therapeutic Chemical classification system. This system is recommended as the international standard for drug research as it facilitates the

presentation and comparison of drug statistics in research (WHO Collaborating Center for Drug Statistics Methodology, 2018-a). The Anatomical Therapeutic Chemical system is comprised of five levels. Level one is most inclusive as it groups active substances according to which organ or system they act on. Level two further groups active ingredients into pharmacological or therapeutic subgroups. Levels three and four group active ingredients based on more specific chemical, pharmacological or therapeutic subgroups. Level five is most specific as it groups active ingredients based on their chemical structure (WHO Collaborating Center for Drug Statistics and Methodology, 2018-b).

Medication usage was first quantified to determine the average number of medications taken by biking and strolls groups. Second, medication usage per participant was aligned by week of study (i.e., week -12 to week 24). Medication were then coded according to Anatomical Therapeutic Chemical classification index (WHO Collaborating Center for Drug Statistics and Methodology, 2019). Particular attention was paid to antidepressants (Anatomical Therapeutic Chemical code N06A), antipsychotics (Anatomical Therapeutic Chemical code N06A), antipsychotics (Anatomical Therapeutic Chemical code N05A) and pain (Anatomical Therapeutic Chemical codes N02 and M01) medications to determine if biking activity influenced medication use in any way. Reduction in medication usage had been anecdotally reported by Kassow (TexX Talks, 2014), as well as through word of mouth in CWA world-wide community.

# 2.6 Analysis

Using descriptive statistics, the average, standard deviation, and range has been calculated for demographic, antidepressant and antipsychotic medication, QOL, happiness, pain, and RAI-MDS 2.0. Further analysis included calculation of the number

of drugs taken by each participant from week -12 to week 24 based on their drug class. Data from QOL, happiness VAS and pain VAS were analyzed using linear mixed effects modelling to determine if CWA influenced these in participants. Mixed effects modelling for QOL used group (biking and strolling) and time (1, 2, 3, 4) as fixed effects, and subject as random effect. Mixed effects modelling for happiness VAS and pain VAS grouped scores by participant and averaged pre and post scores. Fixed effects included group (biking and strolling) and time (pre vs. post). Subject was entered as random effect. Because this analysis included both happiness and pain as dependent variables, percomparison alpha was adjusted from 0.05 to 0.025 to control for Type 1 error.

All statistical analyses were performed using R version 3.6.1 (R Core Team, 2019), with linear mixed effects analyses conducted using the lme4 (Bates et al. 2015) and lmerTest (Kuznetsova et al. 2017) packages. All possible comparisons amongst the time periods were assessed using the emmeans package (Lenth, 2019). As an extension of the classic linear regression models, linear mixed effect modelling can accommodate both fixed effect and random effects (Fitzmaurice & Laird, 2015). Fixed effects are defined as the usual regression parameters, whereas a random effect occurs whenever there is correlation between repeated measures taken from a single individual (Fitzmaurice & Laird, 2015). This allows for greater flexibility in modelling the correlation of unbalanced designs, such as this one where bike rides and strolls occurred at irregularly spaced intervals (Fitzmaurice & Laird, 2015). This approach was appropriate for the analysis because it reduces concerns regarding missing data on the dependent variables. As such, the analysis includes all available data without the need for interpolation. A significance level of p < .05 was used to determine significance for QOL data.

#### 3. Results

Results section begins with an overview of participant characteristics. Next, descriptive statistics for happiness, pain, QOL, depression medication use, antipsychotic medication usage, and all 13 RAI-MDS 2.0 outcome scales are provided. Further, the findings from a mixed effects modelling analysis are reported for happiness, pain and QOL data.

#### 3.1 Sample

Participant characteristics at baseline are summarized in Table 3-1. Mean age was 86, with a range of 65 to 100; 72% of participants were female. Biking group consisted of 23 participants who received an average of 16 bike rides over the 12-week observation period. Comparatively, strolls group consisted of 16 participants who received an average of two strolls over the 12-week observation period. Of participants in the biking group, 70% (n=16) were ambulatory, compared to 38% (n=6) in the strolls group. Over the 12week observation period, 57% of participants (n=13) in the biking group experienced at least one fall, 13% of participants (n=3) spent time in the hospital, and 13% (n=3) were on isolation precautions due to illness. Comparatively, 25% of participants (n=4) in the strolls group experienced at least one fall, and no participants had a hospital stay or experienced isolation precautions. Inclement weather included rain or low temperatures which the participant found too cold to go out (Appendix F). Often, when participants experienced a fall event, they did not resume biking or strolling activities for a week to allow them to recuperate. The groups were different in percent of females, marital status, falls, ability to ambulate independently, and the average number of activities participants engaged in during the 12-week observation period.

	Overall	Biking Group	Strolls Group
	N=39	n=23	n=16
	n (%)	n (%)	n (%)
Average Age (years)	86 (65-100)	86 (71-100)	87 (65-99)
Women	28 (72)	15 (65)	13 (81)
Marital Status (%)			
Married	9 (23)	7 (30)	2 (13)
Widowed	26 (67)	13 (57)	13 (81)
Single	2 (5)	1 (4)	1 (6)
Divorced	2 (5)	2 (9)	0 (0)
Education (%)			
Grade School	5 (13)	4 (17)	6 (38)
Grade 10	8 (21)	6 (26)	2 (13)
Grade 12	17 (43)	8 (35)	7 (43)
Apprenticeship	2 (5)	2 (9)	0 (0)
College	5 (1)	2 (9)	2 (13)
University	2 (5.0)	1 (4)	1 (6.0)
Experienced a Fall	17 (44)	13 (57)	4 (25)
Ambulatory*	22 (56)	16 (70)	6 (38)
Average # of Daily Medications (n)	10	10	9
Average # Activities in 12-weeks		16 (4-24)	2 (0-4)
# of Bike Rides			
24		5 (21)	
18-23		5 (21)	
12-17		7 (29)	
< 12		7 (29)	

Table 3-1Baseline Characteristics of Study Participants by Group

\* Ambulatory residents include those who can walk on their own with or without a walker.

# **3.2 Happiness**

Descriptive statistics of happiness VAS data, including mean, standard deviation and score range are presented in Table 3-2. Mixed effects modelling analysis revealed a statistically significant main effects for group [F (1,36) = 13.55, p< 0.001] and time [F (1,36) = 45.4213, p < 0.001]. As a result, participants in the biking group were significantly happier after biking than participants in the strolls group were after strolling, and biking immediately improved participants happiness from before to after the activity.

There was no significant interaction between the two effects [F (1,36) = 0.0057, p =

0.94].

Table 3-2

Descriptive Statistics of Happiness Visual Analogue Scores Pre and Post Bike Rides and Strolls

Group		Pre	Pos	t
	Mean (SD)	Range	Mean (SD)	Range
Biking	76.3 (21.5)	0 - 100	88.2 (15.9)	10 - 100
Strolls	52.3 (19.0)	15 - 86	67.3 (27.6)	3 - 100

Note: The score range was 0 mm to 100 mm.

# 3.3 Pain

In this study, data on pain was collected from three different sources: pain VAS, RAI-MDS 2.0 Pain Scale, and daily pain medication intake. Descriptive statistics of pain VAS data are presented in Table 3-3. Mixed-effects modelling analysis revealed that the selfreported pain VAS data, collected before and after bike rides and strolls, was not statistically significant for the main effect of group [F (1, 36) = 3.7346, p=0.06], nor time [F (1,36) = 0.0696, p = 0.79]. Similarly, the interaction between group and time did not demonstrate statistical significance [F (1,36) = 0.0916, p = 0.76)]. This indicates that participants did not experience significantly more pain after biking and strolling than before participating in these activities, and that participants in both groups did not experience significantly different levels of pain. Importantly, no participant left the study early due to pain.

Group	Pre		Post	
	Mean (SD)	Range	Mean (SD)	Range
Biking	6.4 (18.4)	0 - 90	5.9 (18.7)	0 - 97
Strolls	20.0 (24.4)	0 - 72	19.2 (24.4)	0 - 72

Table 3-3Descriptive Statistics of Pain Visual Analogue Scale Pre and Post Bike Rides and Strolls

Note: The score range was 0 mm to 100 mm.

Pain among biking group has been further analyzed. Analysis of average pain VAS scores, pre and post biking, per participant, indicated that 70% of participants (n=16) experienced no pain (0-4mm), 22% (n=5) experience mild pain (5-44mm), 9% (n=2) experienced moderate pain (45-74mm) and no participants experienced severe pain (75-100mm). Only 9% of participants (n=2) experienced an increase in pain after biking. The remaining 22% of participants (n=5) experienced a decrease in pain after biking (Figure 3-1).



*Figure 3-1.* Visual analogue scale self-reported pain scores of biking group participants before and after bike rides during 12-week intervention period.

The two participants that experienced an increase in pain after biking underwent significant events that may have added to their pain level. Participant 19 received only four bike rides due to a critical incident that resulted in an extended period-of-time spent

in the hospital. When Participant 19 returned to the LTC home, they required extensive rehabilitation to regain their mobility. Their pain management protocol was not changed, and they did not use opioids to manage pain. After this incident, this participant resumed participation in the biking program. Similarly, Participant 22 experienced two falls during the 12-week observation period that may have contributed to aggravation of pain after biking. Participant 22 also experienced a serious illness in which continuing with biking was unfavorable until rehabilitated. This participant was using opioids to manage pain. This incident occurred at the end of the observation period and the participant was unable to continue participation.

There may be a relationship between self-reported pain and opioid use for pain management. Of the participants that reported mild (n=5) and moderate (n=2) pain on the VAS, four participants used opioids daily for pain relief. This may to indicate that, irrespective of biking, these participants regularly experience a high level of pain. Of the remaining three participants who indicated pain on VAS but do not use opioids to manage it, two experienced a decrease in pain after biking.

Only one participant that reported pain on VAS experienced an increased in pain on RAI-MDS 2.0 pain scale. According to RAI-MDS 2.0 pain scale ratings completed by nursing staff, from baseline to week 12, 30% of participants (n=7) experienced an increase in pain score. For 22% of participants (n=5), pain score increased from 0 to 1, ("no pain" to "less than daily pain."), for 4% of participants (n=1) scores changed from 0 to 2 ("no pain" to "daily pain but not severe"), and for 4% of participants (n=1), scores changed from 1 to 3 ("less than daily pain" to "daily severe pain"). RAI-MDS 2.0 pain scale scores also indicated that two participants experienced a decrease in pain from 2-0

("daily pain but not severe to "no pain") and 2-1 ("daily pain but not severe" to "less than daily pain"). Neither participant had their analgesic medications altered during the 24-week observation period. Figure 3-2 shows comparatively the change in VAS scores for happiness and pain by participant. The feeling of happiness does not seem to be impacted in the participants that experienced pain.



Figure 3-2. Happiness and Pain VAS score averages per participant of biking group. Scores range from 0 to 100.

#### 3.4 Quality of Life

On the LTC-QOL assessment scale, higher scores indicated a better QOL. Over the observation period, average QOL scores remained stable for the biking group. They remained the same from baseline to week four of observation, they increased slightly at week 8, and then decreased back to baseline by week 12 (Table 3-4). On contrary, QOL scores of the strolls group decreased steadily over the 12-week observation period. A linear mixed effects modelling analysis revealed no significant effects for the main effect of group [F (1, 37) = 0.0043, p = 0.98], time, [F (3, 110) = 0.3741, p = 0.77], nor the interaction between group and time [F (3, 110) = 0.9277, p = 0.43].

 Table 3-4

 Descriptive Statistics of LTC-QOL Assessment Scale

	Base	eline	We	ek 4	We	ek 8	Wee	ek 12
Group	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range
Biking	6.3 (1.4)	3.2 - 8.9	6.3 (1.1)	4.4 - 8.9	6.4 (1.4)	4.1 - 9.1	6.3 (1.2)	4.2 - 9.5
Strolls	6.5 (1.6)	4.0 - 9.3	6.3 (1.6)	4.1 - 8.9	6.2 (1.2)	4.4 - 8.3	6.1 (1.3)	4.0 - 8.3

#### 3.5 Antidepressant and Antipsychotic Medication Usage

Analysis of means for biking group antidepressant medication usage revealed no meaningful change between or within groups over observation and follow-up periods. These findings are consistent with the RAI-MDS 2.0 Depression Rating Scale scores, which remained stable at all three timepoints. Daily antidepressant prescriptions were taken by 83% of participants (n=19) in the biking group, and 56% of participants (n=9) in the strolls group. Antidepressants were prescribed PRN (as needed) to 26% of participants (n=6) in the biking group and 13% of participants (n=2) in the strolls group. In the biking group, antidepressant usage remained the same for 14 participants from baseline to week 24, dose increased for two participants during the observation period (weeks 0-12) and for two participants during the follow up period (weeks 13 - 24). Subsequently, dose decreased for one participant in the biking group during the follow-up period (weeks 13-24). In the strolls group, during the observation period (weeks 1-12) dose remained the same for six participants. During the follow-up period (weeks 13 - 24), dose decreased for one participant and increased for two participants.

Analysis of means for biking group's antipsychotic medication usage also revealed no meaningful change between or within groups over observation and follow-up periods. A single antipsychotic prescription was taken daily for 35% of participants (n=8) in the biking group, and 25% of participants (n=4) in the strolls group (Table 3-5). Two participants in the biking group, and no participants in the strolls group were using antipsychotics medications PRN. For seven out of eight participants in the biking group, and all participants in the stroll group, their antipsychotic medication usage remained the same from baseline to 24 weeks. The remaining participant experienced a decrease by half in their antipsychotic medication in week 16.

Participant's Antipsychotic and Antidepressant Use						
	Overall	Biking	Strolls			
	N = 39 (%)	n = 23 (%)	n = 16 (%)			
Antipsychotics						
Overall use	12 (31)	8 (35)	4 (25)			
Antidepressants						
Overall use	29 (74)	19 (83)	9 (56)			
1 daily	13 (33)	9 (39)	5 (31)			
2 daily	10 (26)	8 (35)	3 (19)			
3 daily	4 (10)	2 (9)	1 (6)			

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# 3.6 RAI-MDS 2.0 Functional Outcome Measures

Descriptive statistics of 13 RAI-MDS 2.0 outcome scales are presented in Table 3-6 and Figures in Appendix G. Scores show no meaningful change over time (baseline, week 12, week 24), or between groups (biking and strolling). Due to constraints of small sample size and insufficient power, significance was not tested for the 13 RAI-MDS 2.0 outcome scales.

Outcome Scale	Scale Range	Group	Time					
			Pre		Post		Follow-	up
			Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range
Aggressive Robevieur Scele	0.12	Biking	0.6 (1.2)	0-5	0.4 (0.6)	0-2	0.7 (1.4)	0-6
Aggressive Benaviour Scale	0-12	Strolls	0.4 (0.6)	0-2	0.4 (0.5)	0-1	0.2 (0.4)	0-1
Activities of Daily Living Short	0.16	Biking	6.0 (3.0)	0-12	6.3 (3.6)	0-12	7.1 (3.7)	0-12
Form	0-10	Strolls	7.3 (3.7)	0-12	6.9 (3.7)	0-12	7.3 (3.4)	0-13
Activities of Daily Living Long-	0.28	Biking	11.6 (5.9)	0-21	11.8 (6.8)	0-21	13.4 (6.9)	0-21
Form	0-28	Strolls	14.0 (6.9)	0-21	13.3 (7.4)	0-21	13.6 (6.7)	0-22
Activities of Daily Living Self	0.6	Biking	2.7 (1.1)	0-4	2.7 (1.4)	0-5	3.1 (1.3)	0-5
Activities of Daily Living Sen	0-0	Strolls	3.1 (1.4)	0-5	3.1 (1.5)	0-5	3.3 (1.2)	0-5
Cognitive Performance Scale	0.6	Biking	2.8 (0.9)	0-4	2.9 (0.6)	2-4	2.7 (0.8)	0-4
Cognitive renormance Searc	0-0	Strolls	2.0 (1.2)	0-3	2.1 (1.2)	0-3	2.0 (1.2)	0-3
Depression Rating Scale	0.14	Biking	1.0 (1.1)	0-3	1.0 (1.3)	0-5	1.0 (1.0)	0-3
Depression Rating Scale	0-14	Strolls	1.1 (1.1)	0-3	0.8 (1.0)	0-3	0.8 (1.1)	0-4
Pressure Illeer Risk Scale	0.8	Biking	1.7 (1.3)	0-4	1.7 (1.2)	0-4	2.0 (1.4)	0-5
Tressure Oreer Kisk Searc	0-8	Strolls	2.1 (1.5)	0-5	2.1 (1.6)	0-5	1.9 (1.3)	0-4
Pain Scale	0-3	Biking	0.5 (0.7)	0-2	0.7 (0.8)	0-3	0.8 (0.6)	0-2
T am Seale	0-3	Strolls	1.0 (0.6)	0-2	0.6 (0.9)	0-2	0.9 (0.8)	0-2
Index of Social Engagement*	0.6	Biking	4.0 (1.1)	2-6	3.7 (1.0)	2-6	3.8 (1.2)	1-6
index of Social Engagement	0-0	Strolls	4.3 (1.1)	2-6	3.9 (0.9)	2-5	4.4 (0.6)	3-5
Communication Scale	0.6	Biking	1.3 (1.3)	0-4	1.4 (1.3)	0-4	1.3 (1.2)	0-4
Communication Scale	0-0	Strolls	0.8 (0.8)	0-2	0.9 (0.9)	0-2	0.9 (0.9)	0-2
Fracture Dick Scale	18	Biking	4.3 (1.7)	2-7	4.1 (1.7)	2-7	4.2 (1.5)	3-7
Tacture Kisk Scale	1-0	Strolls	3.1 (0.9)	2-5	3.0 (1.3)	2-7	3.2 (1.4)	2-7
Dersonal Severity Index	0.18	Biking	1.8 (1.5)	0-6	1.8 (1.9)	0-6	2.5 (2.2)	0-8
Fersonal Seventy Index	0-18	Strolls	2.6 (1.5)	0-6	2.3 (1.5)	0-5	2.1 (1.4)	0-4
Changes in Health and End-	0-5	Biking	0.7 (0.9)	0-3	0.7 (0.9)	0-3	0.9 (0.9)	0-3
Stage Signs and Symptoms		Strolls	1.1 (1.0)	0-3	1.1 (0.8)	0-2	0.6 (0.6)	0-2

# Table 3-6Descriptive Statistics of RAI-MDS 2.0 Assessment Scale

\* Higher score on this scale indicates the positive direction; for all other scales higher score indicates more severe impairment

#### 4. Discussion

This study was conducted to evaluate the impact of the CWA program on older adults living in LTC. Discussion chapter will provide an overview of key findings in context of previous studies, concepts, and policies. This chapter will begin with happiness and expand on why happiness improved in program participants. It will then discuss pain findings and why they may differ from a previous study. QOL findings will then be investigated in relation to recent QOL literature in LTC, and RAI-MDS 2.0 functional outcome measures results will be examined. Strengths and limitations of the study will be summarized, followed by potential application of this research in practice. Discussion will conclude with directions for future research.

This study demonstrated that participating in the CWA program had an immediate and temporary effect on improved happiness and no significant changes in pain of LTC residents after bike rides. The CWA program also had an effect in maintaining but not improving QOL of biking group participants when compared to participants in the strolls group. Further, this study revealed no change in RAI-MDS 2.0 functional outcome measures, antidepressant and antipsychotic medication use over 12-week observation period or the 12-week follow-up period. These findings are both in agreement and contention with other CWA studies, as discussed below.

Some methodological decisions require justification. As presented in introduction, comparable research regarding the effects of CWA programming for the older adult population living in LTC is limited to only four studies. This has influenced the choice of research methods, and the number of relatable studies for the discussion. Determining

which indicators to collect and analyze was challenging because previous studies did not offer much and the various anecdotal effects pertaining to the CWA program were puzzling. As a result, the intention in this research project was to use readily available measures of function (RAI-MDS), routinely collected within the medical model of LTC driven by its funding structure, to explore various indicators anecdotally reported to improve in participants of the CWA program. Indicators were collected over an intensive 24-week data collection period by harvesting routinely completed clinical functional outcome measures and by selecting standardized happiness, pain and QOL measures, that may have been impacted by the CWA program but were not assessed routinely in LTC.

# 4.1 Happiness

Findings from the VAS happiness scale reveal that participants in the biking group were significantly happier after biking than participants in the strolls group after strolling. It was also found that biking immediately improved participants happiness from before to after the activity. Albeit important to the lives of older adults living in LTC, this finding is not surprising as improvements in happiness were seen in the project done by the Singapore CWA chapter (2019), and mentioned anecdotally various times by program founder, Ole Kassow (TedX Talks, 2014; Kassow 2015). Both CWA participants and pilots around the world have experienced and witnessed this happiness effect. The CWA program allowed for older adults living in LTC to engage in a unique outdoor cycling activity that immediately promoted happiness.

Previous research indicated that residents are happier when they are engaged in activities compared to when they are not, but because happiness is a subjective experience (Waterman, 1993), different activities may evoke happiness more strongly in some than others (Watkins et al., 2017; Moore et al., 2007). Providing residents with the opportunity to participate in activities that are of specific interest to them may make them happier (Watkins et al., 2017; Dixon et al, 2010). In accordance, participants in this study were selected based on their prior interest or disinterest in the biking program. Differences in happiness levels between groups may be explained by time spent in nature, social interaction, and through acquiring experiences.

Dose, or the time spent outdoors during a bike ride, may have impacted happiness results as the CWA group showed immediate and significant improvements in happiness compared to the strolls group. In the present study, participants in the biking group experienced approximately seven hours more outside in nature when compared to participants in the strolls group. In their qualitative study in Wisconsin about the effects of CWA, McNiel and Westphal (2019) uncovered the theme "breath of fresh air," which related to participants' positive experiences and feelings from being outdoors. Similarly, the CWA report done in Singapore related time spent outdoors to SDG number 10: *Reduced Inequality*, as participants were able to get outside and reengage in their community (Cycling Without Age Singapore, 2019). MacKerron and Mourato (2013) found that participants were happier in natural environments, while Capaldi and colleagues (2014) found a positive relationship between happiness and connection to nature. To further emphasize the outside effect, positive moods may be produced from walking outdoors compared to walking indoors (Nisbet & Zelenski, 2011). However, happiness associated with time spent outdoors is also in relation to what is experienced outdoors.

Bhattacharjee and Mogilner (2014), revealed that acquiring happiness requires acquiring experiences, but the type of experience changes with age. For older adults, ordinary experiences, those that are common, frequent and within the realms of everyday life, are most important for generating happiness. Opposed to extraordinary experiences, defined as uncommon, infrequent and that go beyond the realm of everyday life, which are vital for the generation of happiness in younger people (Bhattacharjee & Mogilner, 2014). The CWA program studied here has been offered at the LTC home for two years prior to this project, and participating residents had engaged in the activity multiple times a year. It is conceivable that participants perceived biking as an ordinary experience. Similar to the theme of, "wave, chat and remember," from McNiel and Westphal (2019), this ordinary experience may have provoked memories of the past while participants were engaged in quality time with friends or loved ones, which may have led to improved happiness.

Older adults living in LTC may be more susceptible to social exclusion due to their lack of routine social engagement from tasks such as shopping (Dennis et al., 2016). Feelings of happiness (Lakey, 2013) and well-being (Custers et al., 2010) can be improved through high quality social relationships. The CWA program promotes connection of LTC residents among one another and with staff members or volunteer pilots through storytelling and community integration. Furthermore, the program promotes an intergenerational relationship between the younger pilot and older adult. This is mutually beneficial and facilitates higher levels of engagement, enhanced wellbeing and improved communication in older adults (Blais et al., 2017). The loveseat design in front of the CWA bike fosters a unique connection between two riders and the

pilot. The recollection of memories often sparked conversation among riders, promoted closeness and positive social relationships, which might have contributed to improved happiness scores from study participants.

# 4.2 Pain

In this study, substantial time and effort was dedicated to examining the effect of CWA on pain. Previous research by Salas (2018) indicated that 22% of participants (n= 6) reported an increase in pain after biking. The current study assessed pain in three ways: VAS pain scale self-ratings before and after every biking and strolling event; RAI-MDS 2.0 Pain Scale scores collected at baseline, 12 and 24 weeks; and the analysis of participants' daily pain medication intake over the period of 24 weeks. The overall results of this study reveal a negligible effect of pain on CWA participants.

Self-reported pain, such as from the VAS pain scale, has been found to be the most accurate and reliable measure of pain (Herr, 2011; Herr & Gerand, 2001). This study revealed a non-significant change in self-reported VAS pain scores, which indicated that CWA biking did not cause pain in participants. On RAI-MDS 2.0 Pain Scale, where the pain is assessed by nursing staff, 30% of participants (n=7) had an increase in pain scores during the study period. However, only one of them reported any pain on VAS, and pain for this individual decreased after biking. This may indicate that for those seven participants who did experience pain regularly, the CWA program took the person's mind off the pain and provided temporary relief.

# 4.3 Quality of Life

For many people, moving into LTC is a necessary, rather than desirable, end-of-life transition to receive the required level of care. The goal of LTC is to create an

environment where, "... residents feel at home, are treated with respect, and have the supports and services they need for health and well-being" (Government of Ontario, 2011, p. 1). Using the LTC QOL Assessment Tool, this study revealed a non-significant change in QOL between the biking and strolls group over the 12-week period. However, analysis of mean scores at the four timepoints identified differences in groups. The biking group experienced a maintenance of QOL scores, whereas the strolls group experienced a steady decline in QOL over the 12-week observational period.

In their systematic review of 34 studies on interventions designed to enhance the QOL of LTC residents, Van Malderen and colleagues (2013) revealed an overall lack of effect on QOL. The authors explain that QOL is a large concept and the included interventions were impacting only one dimension of QOL, such as a behavioural or a psychological aspect (Van Malderen et al., 2013). Using the LTC-QOL assessment scale, this study similarly revealed a non-significant effect of CWA on QOL. However, maintenance in QOL scores in the biking group may still be impactful for the lives of study participants and older adults around the world who participate in CWA.

Recently, van Leeuwen and colleagues (2019) completed a thematic synthesis review of 48 qualitative studies to understand what QOL means to older adults. Nine themes emerged: feeling healthy and not limited by one's physical condition, maintaining autonomy and dignity as to not feel like a burden, spending time participating in activities that brought a sense of value, joy and involvement, maintaining close supportive relationships, maintaining a positive attitude, feeling at peace, experiencing faith, feeling secure at home, and having financial security (van Leeuwen et al., 2019). The themes of joy and involvement, and maintaining close supportive relationships have been similarly

uncovered by Christensen (2018) in relation to the CWA program. Such that, the CWA program promotes relationships, togetherness and joy, and has the influence to positively change the mindset of participants.

Close and supportive social relationships are vital for the maintenance of QOL for older adults as they help avoid loneliness (van Leeuwen et al., 2019; Stadnyk et al., 2017). In the present study, during bike rides many residents developed new friendships with staff members, pilot volunteers and other residents that they did not know before. Bike rides also provided the opportunity for residents to spend quality time with family members invited to participate in this unique and stimulating activity. The magnitude of relationship development during a bike ride needs to be explored further.

Autonomy and a sense of control were common themes that emerged when promoting QOL in older adults (van Leeuwen et al., 2019; Stadnyk et al., 2017). During bike rides, residents were given the autonomy to determine certain aspects of the route (i.e., left or right turns, detours through the park or a different sub-division). This autonomy may have aided in the maintenance of QOL in the biking group. In contrast, a stroll often occurred along the same path around the LTC home, which did not afford the same level of choice regarding direction, vastness of space to travel around, nor the speed to feel the wind in the hair. These factors, mainly attributed to the biking program, may account for the maintenance of QOL in the biking group compared to the decrease in QOL seen in the strolls group.

Results regarding QOL of participants from the current study contrast findings from Salas (2018), in which, having used a different QOL instrument, overall QOL increased for participants. Comparatively, the present study revealed a non-significant

change in QOL, but a potential maintenance of QOL over the observation period. These findings need to be assessed with caution. Although EQ-5D, used by Salas (2018) and LTC-QOL assessment scale, used in this study, both assess QOL of older adults, comparison of findings between tools is not possible as they do not evaluate comparable aspects of QOL. The EQ-5D assessment tool is defined as generating, "a generic measure of health status .... for clinical and economic appraisal" (EuroQOL Research Foundation, 2018, p.5). In her project report, Salas (2018) used this measure as one of QOL, but it seems that it is a measure of health status based on five key areas: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. To compare, the LTC QOL Assessment Tool used in this project evaluates the following domains: self-efficacy, supportive relationships and outlook on life (McDonald & Shaw, 2018). Future research should assess various aspects of QOL individually in order to precisely determine the effect of the CWA program on different domains of QOL.

#### 4.4 RAI-MDS 2.0 Functional Outcome Measures

This study revealed no change in any of the 13 RAI-MDS 2.0 outcome measures. Because the RAI-MDS 2.0 dataset is widely used across the province and world, and because it is routinely collected within the LTC home, the authors anticipated it might provide insight into the effects of the CWA program. Further, a variety of these measures overlapped with the anecdotal benefits reported about the CWA program, such as decreased depression and aggressive behaviours (TedX Talks, 2014), which were to be explored using the RAI-MDS 2.0 Depression Rating Scale and Aggressive Behaviour Scale. The 13 RAI-MDS 2.0 functional outcome measures assess a range of important aspects of clinical care. This research revealed no change in participants scores over time or between biking and strolling groups, which provides indication that these measures

may not assess aspects of LTC living that are impacted from CWA. Future research could instead focus on effects of other anecdotally mentioned variables, such as improvements in sleep and eating.

#### 4.5 Strengths of the Study

The first strength of the current study is its pragmatic and observational nature. Biking and strolling activities explored in this study were based on the monthly activity schedule created by the activity coordinator and were embedded into the routine practice within the LTC home. Due to the observational and pragmatic nature of this study, biking and strolling groups were naturally occurring based on resident's prior interest in those programs, and program offerings were similar to previous years. Likewise, as 90% of older adults living in LTC experience cognitive impairment (Ontario Long-Term Care Association, 2018), the inclusion of participants with and without cognitive impairment allowed for an unrestricted sample of the LTC home. Thus, as the researchers did not alter the natural flow of the LTC home, results truly reflect the effects of these activities.

The chosen LTC-QOL assessment scale, pain VAS, and happiness VAS had been previously validated against age, gender, and level of cognitive impairment. As a result, these scales were directly applicable to the older adult population in the present study. Because recruited participants exhibited a range of cognitive impairment – from intact cognition to moderate and severe impairment, it was important to select standardized measuring tools that were appropriate for participants with different levels of cognition. This allowed for a broader range of study participants, and a more accurate depiction of residents, further enhancing the true depiction of the LTC home.

This study would not have been possible without the student researcher performing bike rides as a staff member. This dual role allowed for unique and unprecedented access into the LTC home, which had been difficult to achieve for other researchers (Schenk et al., 2013). Because the student researcher has worked in the LTC home for five years prior to this study, she has integrated meaningful clinical practicebased perspectives and insights. Two years prior, she helped develop the CWA program in the LTC home and experienced first-hand the positive effect it had on participants. The local CWA chapter was booming and LTC homes across the province of Ontario, Canada were purchasing CWA bikes. She then had the opportunity to go to Denmark, meet the founder of the CWA program, and witness LTC residents from Copenhagen participate in CWA. Surprisingly, the biking experience seemed to be much the same. Residents were smiling, they looked happy, at peace, and content. It was becoming clear that some universal attributes make this program loved around the world. However, why exactly, remained relatively unknown. This mix of context, knowledge, understanding and passion from the student researcher have benefitted this project immensely.

The student researcher's dual role requires deeper reflection. She was able to view CWA from two perspectives: a LTC programming perspective, and a research perspective. She brought with her the knowledge of how the CWA program operates in various LTC homes across Ontario and in Denmark and integrated that knowledge into methodological decisions. Such as the decision to make this study design observational and pragmatic. She decided to assess how the program operates *in situ*, with residents that already participated in the program, rather than how it may operate under optimal, controlled and unrealistic conditions. Next, she brought with her a working knowledge of

LTC policy, funding schemes, and assessment tools. She knew about the importance of the RAI-MDS assessments in funding of LTC homes, and how using this readily available data may assist in knowledge transfer to policy makers. She also knew how polypharmacy, prevalent in residents of long-term care homes, could impact the results. For example, if a participant began using antidepressants halfway through the observation period, this may have had an impact on their happiness and pain scores. As a result, data on medication use was harvested and analyzed to mitigate some of the confounding variables. Overall, the dual role of the researcher has been of benefit to this project.

#### 4.6 Limitations of the Study

Various limitations of this study need to be acknowledged. The LTC home where this research took place is a relatively small facility with 98 residents and is located in a small rural town. A modest size of available sample (n=39), resulted in a lack of power for further data analysis. Participants for the strolls group (n=16) were selected because the LTC home did not have signed consent for their participation in the biking program. This lack of consent for bike rides was a result of residents' own interests, or their power of attorney's choice. Often, the family of residents are highly protective over their wellbeing and interests, and tend to decline participation on residents' behalf, which might not have been the residents' choice. As a result, uneven group sizes and difference in total number of activities completed per group made comparison between groups less than optimal.

Due to the complexity of the LTC- QOL assessment scale and participants' strain in recollecting the number of activities in the previous week, QOL was assessed by proxy for 82% of participants. The main proxy was the participant's full-time recreational staff

member who was most knowledgeable about the nine questions presented. It is generally acknowledged in the literature that proxy ratings are not as accurate as self-ratings as they are often lower when reporting for participants with cognitive impairment (Römhild et al., 2018; Sheehan et al., 2012). Additionally, according to Shippee and colleagues (2015), QOL is better predicted when assessed by separate domains. An in-depth analysis would be required to determine the effect of CWA on the different domains assessed by the LTC-QOL assessment scale, such as self-efficacy, supportive relationships and outlook on life (McDonald and Shaw, 2018). Due to lack of power, this analysis was not possible in the current study.

Performing a sample size calculation for the present study was not feasible. According to Bhalerao and Kadam (2010), sample size calculations require the acceptable level of significance, power of the study, expected effect size, underlying event rate in the population and the standard deviation in the population. A significance level of p<0.05 is generally acceptable and was used in this study, however, the effect size, underlying event rate (prevalence rate) in the population and standard deviation in the population are estimated based on previous studies (Bhalerao & Kadam, 2010). As limits in previous research have been exhibited, sample size calculation could not be calculated effectively.

The student researcher performed a dual role in this research project. While the student researcher collected study consent from participants and families, harvested data from electronic medical records, and organized the completion of LTC-QOL assessments, she also worked in the Activity Department at the LTC home, where she prepared and implemented scheduled programming. The CWA program was a regularly

scheduled program, and due to the auxiliary nature of the student's job, she had been the main bike pilot over the course of the summer. This had potential to introduce systematic error and bias into the study, as she collected data on bike ride and stroll record forms from participants. Bias occurs in research when a systematic error exists in the design of the study, which occurs consistently and causes an incorrect interpretation of results (Camerini & Schulz, 2018; Pandis, 2014). The potential of reporting bias, where participants may skew their answers in hopes of providing an ideal answer to the student researcher exists here. However, according to Delgado-Rodríguez and Llorca (2004), reporting bias is often unavoidable in observational studies. Although some participants were aware that the researcher had a dual role, they were not coerced into participation.

Further, confirmation and desirability bias may have impacted this study. Confirmation bias refers to the tendency to interpret evidence in a way that agrees with prior beliefs and expectations (Metzgar, 2013; Nickerson, 1998). Having witnessed the benefits of the CWA program locally and internationally, the researcher may have interpreted findings in a positive manner. Desirability bias refers to the tendency of respondents to skew answers in order to put themselves in a positive light (Camerini & Schulz, 2018; Ford 1970). This may have occurred during the completion of the bike ride record and LTC-QOL assessment. Some participants did know they were in a research study and may have given answers according to what they believed the researcher wanted to hear. Researchers should be mindful of these biases when designing future studies.

## 4.7 Recommendations for Future LTC Practice

To maximize positive effects of the CWA program, future practitioners should routinely use happiness and pain VAS scales before and after bike rides. These scales are quick to

administer and easy for residents to understand. This data will allow staff to determine which residents experience the biggest improvements in happiness while participating in the program, which may assist in determining who the program should focus on. Furthermore, the self-reported pain information can bring to light any pain before the bike ride or potentially aggravated by the CWA program. This information can be communicated to nursing staff to quickly mediate negative changes and capitalize on program benefits.

During a bike ride, happiness of participants can be maximized using a personcentered approach by providing the autonomy to choose certain aspects of the route, and by tailoring the discussion to participants' interests, previous experiences, passions and lives. This may spark unique conversation and reinforce positive memories. Furthermore, the pilot should remain engaged with the surroundings to encourage engagement and spark attention of participants by pointing out the trees, flowers, pets, cars, animals or kids.

The pilot must pay the utmost attention to avoiding unnecessary pain from the moment a resident decides to participate in the program in order to capitalize on benefits of CWA. The CWA concept of slowness applies to getting residents into and out of the bike, as well as to pedaling the bike. Ensure that staff take their time assisting participants into the bike to avoid jolting, twisting or falling as any of these events may ultimately cause pain for participants. Before the pilot begins the ride, they should ask residents if they are comfortable. During the bike ride, pilots should keep focused on the road approximately 3 meters ahead of the bike. This allows time to slow down for a bump or swerve around a pothole to avoid any pain aggravation.
#### **4.8 Recommendations for Future Research**

Although some research questions have been addressed in this study, further questions persist. Because this study revealed statistical significance in feelings of happiness in biking participants, further exploration into feelings of calmness, joy or excitedness may provide additional insights into the potential benefits of the CWA program. Although not measured in the current study, previous research has suggested sustained levels of happiness after LTC residents engaged in activities of interest to them (Dixon et al., 2010; Moore et al., 2007). Future research on persistence of happiness after engaging in the CWA program may provide further insight onto how long the effects of the CWA program lasts. The effect of dose, or the number of bike rides per week, is also of interest for further exploration. Previous studies utilized a 12-week timeframe and two bike rides per week (Salas, 2018; Buettner and Fitzsimmons, 2002), however, a shorter timeframe along with more or longer rides could be explored.

#### 5. Conclusions

The CWA program is offered in an increasing number of LTC homes around the world with an intention to allow residents to become reintegrated with the community, to chat and get to know one another, to wave at neighbors passing by, to laugh, sing and smile with friends, and to feel happy. The guiding principles of the CWA program encourage participants and pilots to embrace slowness, to engage in storytelling, to foster relationships, and to be generous and kind all while feeling the wind in their hair. By observing an existing CWA program in one LTC home in rural Ontario, Canada and letting it run naturally, the effects of the program on older adults have been uncovered. The CWA program has an immediate and temporary positive effect on happiness of participants, it is not causing additional pain, it has a preserving effect on QOL, and had produced no change in the 13 RAI-MDS outcome measures. Although some benefits of this program have been uncarthed, there is still a great deal to uncover and further research exploring the effects of the CWA program on older adults living in LTC is needed.

The author's dual role of the staff member and researcher benefited the project though her familiarity with the residents, prior two years of experience of how the CWA program operates, decision to make the study design observational and pragmatic, and the opportunity to evaluate the program *in situ*. All of this made findings more applicable to the reality of the long-term care program delivery and knowledge transfer to policy makers. This project also has brought to light the challenges of conducting research with older adults with cognitive impairment living in long-term care. Although trying, it is important that researchers continue this work in order to find ways to improve residents'

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happiness and QOL. In order to study this population, the research process should be flexible and adaptable to the needs and abilities of the participants.

As Thomas Wolfe (1929) expressed, "we are the sum of all the moments in our lives – all that is ours is in them." Perhaps CWA could allow for a moment of time in which older adults who are confined to living in LTC facilities can get outside, sit beside a friend, and feel a greater sense of happiness without pain. For that opportunity may truly be the greatest of all.

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#### Appendices

Appendix A: Proof of Approval for Images Used in Thesis

## **Re: Photo Use in Thesis**

Yes approved to use. Having good time off ~ hope all is well with you & work See you soon!

Susan Sent from my iPhone

On Aug 21	, 2020, at 6:50 PM, Victoria	Cotnam
<	> wrote:	

Hi Susan!!

I hope you are having a good vacation – sorry to be emailing you on a Friday evening. Can I have your permission to use this photo in my thesis? It was posted on facebook in 2018.

<4477018641214A45949FE167DECA4778.jpg>

Thanks, Victoria Re: Use of CWA Photo in Thesis



I'm answering on behalf of Ole, I hope that's OK.. Just to say that yes please use that photo, and break a leg! I can't wait to read it!! Best regards Pernille



On Thu, Aug 20, 2020 at 9:40 PM Victoria	Cotnam	wrote:
Hello Olel		

1 hope you are doing well. I want to thank you for your support of my research project so far, I am nearing the finish line and should be submitting it within the next week or so. Woohoo! :)

I came across this photo from the Longest Ride 2014 and was looking for your permission to use it in my thesis. (https://cyclingwithoutage.org/odense-hamburg-14/)

Please let me know. Thanks so much!

Victoria



To:

Greetings from the Public Inquiries Team,

Thank you for your inquiry. SDG branding may be used without permission for informational purposes only subject to <u>Sustainable</u> <u>Development Goals Guidelines</u>. For commercial and fundraising use as described in the guidelines, please request permission to as outlined below.

For requests pertaining to the use of the **Sustainable Development Goals branding for commercial or fundraising purposes**, please resend your request, and use the following in all caps in the subject line: **SDG LOGO/ICON REQUEST**. You do not need to resend your request if it already contained SDG LOGO/ICON REQUEST in the subject line.

Only questions pertaining to use of the SDG branding for commercial and fundraising purposes will be answered. Please note that due to the very high volume of requests we receive, our response time may be delayed.

Note that only the United Nations can use the UN Emblem.

Best regards,

#### Appendix B: Ethics Approval Forms



Date: 2 April 2019

To: Dr. Aleksandra Zecevic

Project ID: 113229

Study Title: Measuring the Effect of Bike Rides on Quality of Life of Residents in Long Term Care

Application Type: HSREB Initial Application

Review Type: Delegated

Full Board Reporting Date: 09April2019

Date Approval Issued: 02/Apr/2019 08:58

REB Approval Expiry Date: 02/Apr/2020

#### Dear Dr. Aleksandra Zecevic

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

#### **Documents Approved:**

Document Name	Document Type	Document Date	Document Version
Demographic Data Extraction Form Mar 21 2019	Other Data Collection Instruments	21/Mar/2019	
End of Study Letter	End of Study Letter	18/Mar/2019	
interRAI_LTCF_OS_RefGuide_EN	Other Data Collection Instruments		
LOIC Biking Group Final Mar 26	Written Consent/Assent	26/Mar/2019	
LOIC CG Final Mar 26	Written Consent/Assent	26/Mar/2019	
LTC QOL Assessment V2	Paper Survey	18/Mar/2019	1
RAI MDS Data Collection	Other Data Collection Instruments	21/Mar/2019	
RAI Outcome Scales	Other Data Collection Instruments	11/Feb/2019	
Stroll and Bike Ride Record Data Collection Tool	Other Data Collection Instruments	21/Mar/2019	
VC Project Proposal Mar 21, 2019	Protocol	21/Mar/2019	

#### **Documents Acknowledged:**

Document Name	Document Type	Document Date	Document Version
Letter of Support - Final	Letter Document	11/Feb/2019	1

No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Westem HSREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical

Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).



Date: 30 March 2020

To: Dr. Aleksandra Zecevic

Project ID: 113229

Study Title: Measuring the Effect of Bike Rides on Quality of Life of Residents in Long Term Care

Application Type: Continuing Ethics Review (CER) Form

Review Type: Delegated

REB Meeting Date: 07/Apr/2020

Date Approval Issued: 30/Mar/2020

REB Approval Expiry Date: 02/Apr/2021

#### Dear Dr. Aleksandra Zecevic,

The Western University Research Ethics Board has reviewed the application. This study, including all currently approved documents, has been re-approved until the expiry date noted above.

REB members involved in the research project do not participate in the review, discussion or decision.

Western University REB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The REB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).



#### WDMH Ethics Approval

April 16th, 2019

Attn. Victoria Cotnam University of Western Ontario Health and Rehabilitation Sciences

#### Study Title: Measuring the effects of a cycling program on older adults living in long-term care

I am writing to acknowledge receipt of your recent ethics submission. We have examined the protocol details submitted April 2019 for your project and consider it to be ethically acceptable. This approval is valid for one year from the date of the Ethics Committee Chairperson's signature below. This approval will be reported to the Research Ethics Board. Please attend carefully to the following listing of the ethics requirement you must fulfill over the course of your study.

**Reporting of Amendments**: If there are any changes to the study (i.e. consent, protocol, study procedures, etc.) you must submit an amendment to our Research Ethics Board for approval.

**Reporting of Serious Adverse Events:** Any unexpected serious adverse event occurring locally must be reported within two working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information.

**Reporting of Complaints:** Any complaints made by participants or persons acting on behalf of participants must be reported to the Research Ethics Board within 7 days of becoming aware of the complaint. Note: All documents supplied to participants must have the contact information of our research office.

Sincerely,

#### Appendix C: Bike Route Used

#### BradLee Ride Route 1

After reviewing and completing the Cycling Without Age checklist, proceed with the following route:

Turn right on Clarence Street.

Stop at intersection and turn <u>right</u> on Louise Street South.

Stop at intersection beside hospital.

Pass hospital entrance, watch for slight bump before stop sign.

Stop at intersection of Fred Street and Louise Street South.

Turn <u>right</u> on Henderson Crescent, watch for slight bump.

Circle around Henderson Crescent and watch for a minor bump before turning <u>left</u> and emerging back onto Louise Street South.

Stop at intersection of Fred Street and Louise Street South.

At this point, you can proceed back to Clarence Street by heading north on Louise Street and turning <u>left</u> onto Clarence Street.

For an extended drive, turn <u>left</u> onto Fred Street East, caution for slight bumps after the intersection.

At this point, you will be passing the Community Care Building.

Proceed around the Christie Lane subdivision.

At this point, there is an option to shorten the ride and head back home. For this option, turn right on Victoria Street, followed by right on Cass Crescent and right on Clarence Street.

For an extended ride, proceed on Christie Lane around loop.

Stop at Christie Lane intersection.

Proceed and turn right on Cass Crescent.

Stop at Victoria Street and Cass Crescent intersection.

Turn <u>right</u> onto Clarence Street and drive back to the home.



Appendix D: Letter of Information and Consent for Biking Group Participants



# Letter of Information and Consent

# Measuring the Effects of Bike Rides on Quality of Life of Residents in Long-Term Care

Letter of information – Biking Group

**Principal Investigator** 

**Student Researcher** 

# 1. Invitation to Participate

You are being invited to participate in a research study examining the effects of the Cycling Without Age (CWA) program (Brad-Lee Rides) on happiness and quality of life. Because you have gone for bike rides in the past or will be going for bike rides this summer, you are an eligible participant.

In this Letter of Information and Consent Form, "you" always refers to the study participant, the resident of the long-term care home. If you are a substitute decision maker (i.e., someone who makes the decision for participation on behalf of a participant), please remember that "you" refers to the study participant. If required, a substitute decision maker will be asked to review and sign this consent form on behalf of the participant.

# 2. Why is this study being done?

The purpose of this study is to observe the current Brad-Lee Rides program, and its' effects on residents like you who are living at Dundas Manor. Previous research has shown that people living in long-term care homes can have low levels of engagement and can sometimes feel depressed or sad. Participating in an activity that relates to your interests and past roles can improve your feelings of belonging and have positive effects on you. The research team is going to explore the effects of a regularly scheduled activity Brad-Lee Rides. To do this, we will compare information from a group of residents that frequently go on bike rides with a group of residents who are not participating in this program. Up to 50 residents of Dundas Manor will be invited to participate in this study.

# 3. How long will you be in this study?

You will be enrolled in the study for 12 consecutive weeks (three months) sometime between May 1<sup>st</sup>, 2019 and September 30, 2019. The exact time will depend on your Resident Assessment Instrument – Minimum Data Set (RAI MDS) assessment dates. During this time, you will participate in Brad-Lee Rides as normal.

# 4. What are the study procedures?

If you agree to participate, you will also be asked to answer a short nine-question questionnaire looking at your quality of life. This will happen four times over the 12-weeks. Each questionnaire will take less than 15 minutes to complete. Lastly, you give your permission to the research team to obtain information from your routine 12-week RAI-MDS assessments. All information you provide or allow access to is for research purposes only.

# 5. What are the risks and harms of participating in this study?

The only risk in participating in this study is that of a potential privacy breach.

# 6. What are the benefits of participating in this study?

You will not receive any direct benefits from participating in this study.

# 7. Can participants choose to leave the study?

If you decide to withdraw from the study, you have the right to request (e.g., written, calling, in person) removal of information collected about you. If you wish to have your information removed please let the researcher know and all traces of your information will be destroyed from our records.

# 8. What personal information will be collected and who will have access to it?

For the purpose of this research, we will collect your name to access your RAI-MDS data records and harvest information routinely collected by Dundas Manor about your RAI-MDS scores. This information will be retrieved three times over six months. Other information that we will collect is your date of birth, gender, education level, marital status, previous occupation and your length of stay at Dundas Manor. All collected information will be de-identified and your name will be replaced by a code. Finally, we will use routinely collected information on Bike Records and data from the quality of life questionnaires.

Representatives of Western University's Health Sciences Research Ethics Board may require access to your study-related records to monitor the conduct of the research. However, no one else outside of the principle investigator and research assistant will have access to your personal information.

The results of this study will not contain personal identifiers and will be reported as a group. For example: "study participants were 26 men and 34 women over the age of 65". The use of your full name, full date of birth, and sex/gender may allow someone to link the data and identify you. The research team will all identifiable information about you in a secure and confidential location for seven years as per Western's Faculty Collective Agreement data retention policy. A list linking your study code with your name will be kept by the researcher in a different place, separate from your study file. If the results of this study are published, your name and personal information will not be used. Any data that is stored electronically will be kept as safe as possible by using passwords. Quotes that cannot be attributed to you may be used.

# 9. Will you be paid for your participation in this study?

You will not be paid for your participation in this research. Your participation in this study is voluntary. You may decide not to take part in this study. Even if you consent to participate, you have the right to not answer individual questions or to withdraw from the study at any time. If you choose not to participate or to leave the study at any time it will have no effect on your care. You may refuse to answer any question you do not want to answer.

# 10. Conflict of Interest Declaration

The research assistant for this project Victoria Cotnam is also working an Activity Aide during the summer at Dundas Manor. Because of this, a conflict of interest exists as she will performing a dual role. Her roles as a researcher and as an Activity Aide will be handled separately and she will report to Jennifer Hill as an activity aide, and to the principle investigator Dr. Aleksandra Zecevic for research purposes. She will be involved with activity programming as an activity staff and collect questionnaires and data as the research requires.

# 11. What are the rights of participants?

You do not waive any legal rights by signing this consent form.

## 12. Whom do participants contact for questions?

If you have any questions about this research study, please contact Dr. Aleksandra Zecevic at

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics email The REB is a group of people who oversee the ethical conduct of research studies. The HSREB is not part of the study team. Everything that you discuss will be kept confidential.

Thank you for considering participation in this project.

# This letter is yours to keep for future reference

Measuring the Effects of Bike Rides on Quality of Life of Residents in Long-Term Care

Consent Form –Biking Group

**Principal Investigator** Dr. Aleksandra Zecevic, PhD Western University Student Researcher Victoria Cotnam, BHSc, Health Science

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction. I know I may leave the study at any time.

Print Name of Participant	Signature	Date (DD-MMM-YYYY)

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person	
Obtaining Consent	

Signature

Date (DD-MMM-YYYY)

Your signature on this form indicates that you are acting as a substitute decision maker(s) for the participant and the study has been explained to you and all your questions have been answered to your satisfaction. You agree to allow the person you represent to take part in the study. You know that the person you represent can leave the study any time.

Print Name of Substitute Decision Maker Signature

Date (DD-MMM-YYYY)

Relationship to Participant

### Appendix E: Bike Ride Record and Stroll Record Forms Bike Ride Record

#### To be completed by the pilot before the ride

Resident Name:	Pilot Initials:
Date:	Time Leaving:
<ol> <li>Consent: Ye</li> <li>Have you ha</li> <li>Helmets on</li> <li>Sunscreen _</li> <li>Shades (if re</li> <li>Basket in fro</li> <li>Cell Phone _</li> <li>Footplate is</li> <li>As staff assi</li> <li>Ensure resid</li> <li>Is an extra of</li> <li>No rides if t</li> <li>Dundas Mai</li> </ol>	If No then no ride d safety training Yes No If no, then no ride. both rider and resident quired) out with: Emergency numbers, Sunscreen, First Aid, Maps, Purell out out st resident on the bike, the brake is applied ent is comfortable and ready ushion being used on the bike seat? Yes No here is a weather advisory for heat or thunderstorms. hor staff will safely transfer residents into the bike. No volunteer is to dents in or out

Q1: Please ask resident: "Use one word to describe how you are feeling right now." Please write response verbatim.

Q2: Is there anything notable about residents' behavior/demeanor now? (i.e., agitation, wandering, sadness, happiness, boredom). Describe the residents' demeanor in detail.

Q3: Ask resident: "This line depicts you being completely happy vs. completely unhappy. Use your finger to show me how you feel right now." Please mark where they point.





Q4: Ask resident: "This line depicts you experiencing no pain vs the worst pain imaginable. Use your finger to show me how much pain you feel right now." Please mark where they point.

Worst Pain		No Dain
imaginable	-	

### Pilot completes after the ride

Time Returned: \_\_\_\_\_

14. Notify staff to assist resident out of the bike

15. Wipe down helmets after use

16. Report any concerns to staff (if any)

Q5: Please ask resident: "Use one word to describe how you are feeling right now." Please write response verbatim.

Q6: Was there anything notable about residents' behavior/demeanor now or during the ride? (i.e., agitation, sadness, happiness, boredom). Describe the residents' demeanor in detail.

Q7: Please ask resident: "This line depicts you being completely happy vs. completely unhappy. Use your finger to show me how you feel right now." Please mark where they point.





Q8: Ask resident: "This line depicts you experiencing no pain vs the worst pain imaginable. Use your finger to show me how much pain you feel right now." Please mark where they point.

Worst Pain		No Dain
imaginable	-	

**Q9:** Notes from bike pilot: Did anything out of the ordinary happen during the ride? For example: meeting familiar people, observing animals, weather conditions, temperature, rain, cold, road conditions, topics discussed, laughter, change in residents' usual behavior, change in communication or emotions etc.
## **Stroll Record:**

## Staff member to complete before going for stroll

Resident Name: \_\_\_\_\_

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

Date: \_\_\_\_\_

Time Leaving: \_\_\_\_\_\_

Q1: Please ask resident: "Use one word to describe how you are feeling right now." Please write response verbatim.

Q2: Is there anything notable about residents' behavior/demeanor now? (i.e., agitation, wandering, sadness, happiness, boredom). Describe the residents' demeanor in detail.

Q3: Please ask resident: "This line depicts you being completely happy vs. completely unhappy. Use your finger to show me how you feel right now." Please mark where they point.



Q4: Ask resident: "This line depicts you experiencing no pain vs the worst pain imaginable. Use your finger to show me how much pain you feel right now." Please mark where they point.

Worst Pain		No Doin
imaginable	12	

## Staff member to complete after stroll:

Time Returned: \_\_\_\_\_

Q5: Please ask resident: "Use one word to describe how you are feeling right now." Please write response verbatim.

Q6: Is there anything notable about residents' behavior/demeanor now? (i.e., agitation, wandering, sadness, happiness, boredom). Describe the residents' demeanor in detail.

Q7: Please ask resident: "This line depicts you being completely happy vs. completely unhappy. Use your finger to show me how you feel right now." Please mark where they point.



Q8: Ask resident: "This line depicts you experiencing no pain vs the worst pain imaginable. Use your finger to show me how much pain you feel right now." Please mark where they point.

Worst Pain		No Dain
imaginable	-	

**Q9: Notes from staff member:** Did anything out of the ordinary happen during the stroll? Meeting familiar people, observing animals, weather conditions, temperature, rain, cold, road conditions, topics discussed, laughter, change in residents' usual behavior, change in communication etc.



Appendix F: Occurrence of Bike Rides, Falls, Time Spent in Isolation, Hospital Stays and Inclement Weather Over Participants' 12-week Observation Period.







Appendix G: Graphs of 13 RAI-MDS 2.0 Outcome Measure Scores





*Figure G-2* Mean scores of Activities of Daily Living Short Form Scale. \*Possible score range of 0-16



*Figure G-3* Mean scores of Activities of Daily Living Long Form scale \*Possible score range of 0-28



*Figure G-4* Mean scores of Activities of Daily Living Self scale \*Possible score range of 0-6







*Figure G-6* Mean scores of Cognitive Performance Scale \*Possible Score Range of 0-6



*Figure G-7* Mean scores of Depression Rating Scale. \*Possible score range of 0-14



*Figure G-8* Mean scores of Pressure Ulcer Risk Scale. \*Possible score range of 0-8







Figure G-10 Mean scores of Index of Social Engagement Scale \*Possible Score Range of 0-6, higher scores indicate better social engagement



*Figure G-11* Mean scores of Communication Scale \*Possible score range of 0-6



Figure G-12 Mean scores of Fracture Risk Scale \*Possible score range of 1-8



Figure G-13 Mean scores of Personal Severity Index

## **Curriculum Vitae**

Name:	Victoria A. Cotnam
Post-Secondary Education and Degrees:	Western University London, Ontario, Canada 2014 – 2018 B.H.Sc.
	Western University London, Ontario, Canada 2018 – 2020 M.Sc.
Honours and Awards:	Mitacs Accelerate Internship Grant, 2019 (\$15,000)
Related Work Experience:	Teaching Assistant Western University 2018 – 2019 HS 3091 Aging Globally Lessons from Scandinavia
	Teaching Assistant Western University 2019 – 2020 HS 3071 Determinants of Health and Disease
Presentations:	Cotnam, V., & Zecevic, A. (2019). Measuring the effects of a biking program on quality of life of older adults living in long-term care: a preliminary analysis. Gerontological Society of America's Annual Scientific Conference, Austin Texas, November 8-12, 2019. Poster Presentation.
	Cotnam, V., Zecevic, A., Mantler, T., Johnson, A., & Silva, C. (2020). Measuring the effects of a biking program on quality of life of older adults living in long-term care. Health and Rehabilitation Science Graduate Research Conference. Western University, Feb 4, 2020. Oral Presentation.