MITIGATING APATHY AMONG OLDER ADULTS WITH AND WITHOUT DEMENTIA ACROSS LONG TERM CARE AND COMMUNITY SETTINGS: A MULTIMETHOD STUDY

by

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Abstract

Background: Apathy, characterized by reduced interest in activities and social interaction, is a prevalent yet often underrecognized condition among older adults in long-term care facilities (LTCF) and community settings. It is associated with rapid cognitive decline, functional impairments, and decreased life expectancy. Despite its impact, apathy is frequently misdiagnosed or conflated with other conditions, such as depression and dementia, leading to inadequate intervention strategies. While various non-pharmacological interventions have been proposed, little is known about the effectiveness of eBook clubs as a non-pharmacological option for mitigating apathy. This study seeks to address the overarching research question:

"What are the barriers, facilitators, prevalence, and risk factors of apathy among older adults in LTCF and community settings, and how effective is an eBook club intervention in mitigating apathy in these populations?"

Methods: This multimethod study employed a series of research designs to explore the multidimensional aspects of apathy and its mitigation guided by the Biopsychosocial Model of Health and Illness and Socioemotional Selectivity Theory. The prevalence and predictors of apathy were analyzed cross-sectionally using the InterRAI Minimum Dataset (MDS 2.0) from the Canadian Institute for Health Information, covering LTCF residents admitted between 2015 and 2019. A pre- and post-quasi-experimental multi methods design was used to assess the effectiveness of an eBook club intervention among LTCF residents and community-dwelling older adults in four rural communities in Northern British Columbia. The intervention's impact was measured by comparing apathy levels before and after participation.

Results: Findings highlight key barriers to apathy care, including the lack of a standardized definition, limited awareness, symptom overlap with other disorders, and methodological challenges in clinical trials. Facilitators that promote effective apathy management include caregiver involvement, professional training, and the adoption of innovative screening and intervention methods. Apathy was prevalent in 12.5% of newly admitted LTCF residents (N = 157,596) and 13.1% of those with Alzheimer's disease and related dementias (N = 97,789). Cognitive impairment was identified as the strongest predictor of apathy among the general LTCF population, while depression was the most significant risk factor among residents with dementia. The eBook club intervention demonstrated positive effects, leading to improved social engagement, cognitive stimulation, and emotional well-being among LTCF residents and community-dwelling older adults.

Conclusion: Understanding the barriers, facilitators, prevalence, and risk factors of apathy are essential for developing effective interventions. The findings suggest that structured, accessible, and low-cost programs, such as eBook clubs, have the potential to mitigate apathy in both LTCF and community settings. This study underscores the need for enhanced screening, targeted interventions, and policy-driven efforts to improve apathy care and promote well-being of residents in LTCF and community dwelling older adults.

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Glossary

AD - Alzheimer's disease

ADHD – Attention Deficit Hyperactivity Disorder

ADLs- Activities of Daily Living

ADL-hierarchy - Activity of Daily Living Self-Performance Hierarchy Scale

ADRD- Alzheimer’s disease and related dementias

AES - Apathy Evaluation Scale

CASP - Critical Appraisal Skills Programme

CHESS - Change in Health, End-Stage Disease, and Signs and Symptoms Scale

CNAs – Certified Nursing Assistants

CPS - Cognitive Performance Scale

CTAAN – Center for Technology Adoption for Aging in the North

DAIR - Dementia Apathy Interview Rating

DCA – Diagnostic Criteria for Apathy

DRS- Depression Rating Scale

DSM-IV - Diagnostic and Statistical Manual of Mental Disorders 4th edition

DSM-V - Diagnostic and Statistical Manual of Mental Disorders 5th edition

FTD - Frontotemporal Dementia

GDB - Goal Directed Behaviors

ICD-10 - International Classification of Diseases 10th Revision

IADLs - Instrumental Activities of Daily Living

ICT – Information and Communication Technology

ISE - Index of Social Engagement

LARS – Lillie Apathy Rating Scale

LPNs – Licensed Practical Nurses

LTCF(s) - Long Term Care Facilities

MCI - Mild Cognitive Impairment

MDS 2.0 - InterRAI Minimum Data Set

MMMR- Multimethod research

PRISMA - Preferred Reporting Items for Systematic Reviews and Meta-Analysis

PURS - Pressure Ulcer Risk Scale

QoL - Quality of Life

QUAL – Qualitative-driven study

QUAN – Quantitative-driven study

RCT – Randomized Controlled Trials

RQ – Research sub-Question

SAS – Statistical Analysis System

SSRIs - Selective Serotonin Reuptake Inhibitors

TBI - Traumatic Brain Injury

UNBC - University of Northern British Columbia

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Dedication

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Chapter One: Introduction

Apathy, defined as a reduction in activities of interest and social withdrawal, is a pervasive yet underrecognized condition affecting individuals across the lifespan, including both older and younger adults residing in long-term care facilities (LTCF) and community settings (Marin, 1990; Robert et al., 2018). Traditionally, apathy has been associated with aging and neurodegenerative disorders, such as Alzheimer's disease and related dementias (ADRD) (Levy & Dubois, 2006; Starkstein & Leentjens, 2008). However, research has increasingly demonstrated that apathy is not limited to older populations but can also affect younger individuals with neurological, psychiatric, or chronic medical conditions, as well as those with disabilities or complex care needs in LTCF (Cummings et al., 2015).

Regardless of age, apathy has been linked to rapid cognitive decline, increased care dependency, poorer quality of life, and higher healthcare costs (Brodaty et al., 2010; van Dalen et al., 2018). Studies estimate that apathy affects between 15–30% of community-dwelling individuals, with higher prevalence rates (50–70%) among LTCF residents (van der Linde et al., 2016). Among individuals with neuropsychiatric disorders, such as Alzheimer's, Parkinson's disease, schizophrenia, and traumatic brain injury (TBI), apathy rates can be as high as 80–90% (Lanctôt et al., 2017; Zuidema et al., 2011). Despite its adverse impact on cognitive, emotional, and social well-being, apathy remains poorly understood, misdiagnosed, and often left untreated (Cerejeira et al., 2012).

Apathy in LTCF and community settings remains largely overlooked, leading to delayed diagnosis and ineffective management strategies (Matmati et al., 2022). Several barriers contribute to this challenge. First, the absence of a standardized definition and diagnostic criteria has resulted in inconsistent detection and intervention (Robert et al., 2018). Unlike depression, which is recognized in diagnostic manuals such as the DSM-V (American Psychological Association [APA], 2013) and International Classification of Diseases 10th Revision (ICD-10) (World Health Organization [WHO], 2019), apathy is often classified as a secondary symptom rather than a distinct condition, limiting healthcare providers' ability to diagnose and treat it effectively (Levy & Dubois, 2006). Second, low awareness among caregivers and healthcare providers exacerbates the issue. Many LTCF staff, clinicians, and informal caregivers misinterpret apathy as a lack of effort, defiance, or laziness, particularly among younger residents, leading to stigma and inadequate support (Jao et al., 2019). This lack of training and awareness prevents early identification and appropriate interventions, increasing the risk of long-term disengagement and functional decline (Mele et al., 2020). A third major challenge is the symptom overlap between apathy and other neuropsychiatric conditions, such as depression, schizophrenia, and cognitive impairment (Starkstein & Leentjens, 2008).

While apathy is distinct from depression, it is frequently misdiagnosed, leading to inappropriate pharmacological treatment (e.g., the overprescription of selective serotonin reuptake inhibitors [SSRIs], which have been linked to worsening apathy symptoms) (Padala et al., 2020). Lastly, methodological limitations in clinical trials have hindered the development of effective, scalable interventions for apathy. Many studies face small sample sizes, inconsistent assessment tools, and a lack of long-term follow-up, reducing the generalizability of findings (Cummings et al., 2015). The absence of validated apathy-specific screening tools further complicates efforts to track prevalence, risk factors, and treatment outcomes (Dickson et al., 2022).

Given the high prevalence and negative consequences of apathy among both older and younger LTCF residents, there is an urgent need for effective, evidence-based interventions.

While pharmacological approaches, such as methylphenidate and cholinesterase inhibitors, have shown limited benefits (Theleritis et al., 2017), non-pharmacological interventions offer a safer, more sustainable alternative (Goris et al., 2016). One promising intervention is the use of eBook clubs, which combine cognitive stimulation, social interaction, and structured engagement (Gitlow, 2014). Digital reading platforms (e.g., Kindle, Kobo, tablets, and smartphones) offer a flexible and accessible way for individuals to participate in shared reading activities, regardless of physical or cognitive limitations (Gitlow, 2014). By promoting active participation and social connection, eBook clubs could serve as a low-cost, scalable approach to mitigating apathy in LTCF residents and community-dwelling individuals (Saredakis et al., 2020).

This dissertation employs a multimethod research approach (Morse, 2003; Morse & Niehaus, 2009) rooted in pragmatism, to investigate apathy among older adults residing in LTCF and community settings guided by two theoretical perspectives: the Biopsychosocial Model of health and illness (Engel, 1977) and Socioemotional Selectivity Theory (SST) (Carstensen, 1999). The overarching research question is "What are the barriers, facilitators, prevalence, and risk factors of apathy among residents in LTCF and older adults in community settings, and how effective is an eBook club intervention in mitigating apathy in these populations?". This question was broken down into five sub-questions (RQ) and each sub-question constitute a Chapter as follows:

1) What are the barriers and facilitators to optimal detection and intervention for apathy among older adults? (Chapter Four)
2) What is the prevalence and what are the predictors for apathy among the Canadian LTCF residents? (Chapter Five)

3) What is the prevalence and what are the risk factors for apathy among the Canadian LTCF residents with dementia? (Chapter Six)
4) What impact (s) does eBook club has on apathy among LTCF residents in rural Northern British Columbia? (Chapter Seven)
5) What impact (s) does eBook club has on apathy among community dwellers in rural Northern British Columbia? (Chapter Eight)

To this end, the three main objectives of this study are as follows:

1) To identify barriers and facilitators that influence the recognition and management of apathy in LTCF and community settings (Chapter Four).
2) To determine the prevalence and risk factors of apathy among Canadian LTCF residents with and without dementia (Chapters Five and Six).
3) To evaluate the impact of an eBook club intervention on self-reported apathy levels among LTCF residents and community-dwelling older adults (Chapters Seven and Eight).

Outline of this dissertation

This dissertation is based on a series of manuscripts published or submitted for publication. Each manuscript corresponds to a chapter and addresses an overarching research question or a sub-question. Chapter Two is the background chapter. It provides an overview of the research topic and the researcher's reflection. Chapters Three presents an explanation of the research design, theoretical frameworks, sample/settings, data sources and cleaning. Chapter Four is the literature review chapter and addresses RQ 1 by adopting an integrative review approach to synthesize existing literature on apathy among older adults, focusing on its definitions, dimensions, and distinguishing features compared to other conditions such as depression. Chapter Five and Six focus on RQ 2 and 3, presenting the prevalence and predictors of apathy among newly admitted LTCF residents, with an emphasis on identifying biopsychosocial risk factors. Chapters Seven and Eight address RQ 4 and 5, discussing the impacts of eBook clubs as a non-pharmacological intervention for mitigating apathy among LTCF residents and rural community-dwelling older adults, with attention to outcomes such as emotional engagement, cognitive stimulation, and social connection. Chapter Nine provides a synthesis of findings from all preceding chapters, integrating insights to offer practical recommendations for improving the care of individuals with apathy. This chapter also discusses the theoretical contributions of the dissertation, highlights the strengths and limitations of the studies and identifies directions for future research. Chapter Ten offers key recommendations for nursing practice, nursing education and national policy providing broader insights into the management of apathy among older adults in diverse settings. Lastly, chapter Eleven concludes the dissertation.

Chapter Two: Background

Apathy is a complex construct observable in both people with and without neuropsychiatric, medical, and neurodegenerative disorders (Marin, 1990; Radakovic & Abrahams, 2014). Historically, the term ‘apathy’ is a philosophical concept that has been in existence well before its appearance in the medical literature in the 19th century and its meaning has changed significantly since then (Thant & Yager, 2019). It originally stemmed from the Greek word “apatheia” or “a-pathos,” meaning “without passion” (Prange et al., 2018, p.614) or “without feeling” (Thant & Yager, 2019, p. 709). Prior to 20th century, the concept had a favorable view as it was perceived by the Stoic philosophers as a way of escaping from painful experiences and be in a state of calmness and quietness (Prange et al. 2018). However, during the 20th century, apathy was viewed as a pathology because it was observed primarily among people with psychiatric, neurological, and medical disorders (Marin, 1990). This observation led to the first clinical definition of apathy as loss of motivation characterized by lack of interest or involvement in usual activities (Marin, 1990). As Marin (1990) commented, apathy is “a state of primary motivational impairment” (p.22) implying that it is distinguishable from other clinical disorders. Marin (1990) further states that individuals whose motivational impairment is not attributable to “a diminished level of consciousness, an intellectual deficit, or emotional distress” (p.22) should be regarded as having apathy syndromes whereas individuals whose lack of motivation is secondary to other disorders should be considered as having a feature or symptom of the disorder in question (e.g., depression or dementia). In other words, apathy associated with neuropsychiatric and neurodegenerative disorders are considered as symptoms while apathy associated with non-neuropsychiatric and non-neurodegenerative disorders such as frontal lobe injuries are referred to as syndromes.

As indicated by Marin (1990), both the symptom and syndrome of apathy are of considerable conceptual interest. Specifically, Marin's definition of apathy implies that apathy can be conceptualized as both a syndrome (independent of other disorders) and a symptom (co-occurring with other disorders). Based on this line of thinking, Marin (1990) described two subtypes of apathy: (a) selective or relative apathy (commonly seen in healthy individuals and occurs because the individual has not acquired or maintained interest in a particular activity or interested in a broad range of activities); and (b) pervasive apathy (apathy secondary to other disorders and aging). This conceptualization of apathy also speaks to the multidimensionality of apathy constructs that are currently being advocated in the neuroscience literature (Massimo et al., 2018).

During the 21st century, Stuss et al. (2000) argued that the definition of apathy as a lack of motivation is inadequate because assessing motivation is problematic and usually requires inferences based on observable behavior or affect (Stuss et al., 2000). Instead, Struss defined apathy as a lack of responsiveness to stimuli (internal or external) as evidenced by a "lack of self-initiated action" (Stuss et al., 2000, p.340). The definition proposed by Stuss et al. (2000), has many advantages: (1) it provides more objective measures of behavior; (2) it does not define apathy as a single definable state or syndrome; and (3) it allows apathy to be subdivided into separable types (or domains). Like Marin's conceptualization of apathy, Stuss et al. (2000) categorized apathy according to three domains: (i) emotional apathy (lack of concern and limbic affective input as reward sensitivity); (ii) cognitive apathy, (lack of initiated behavior due to executive dysfunction as planning); and (iii) behavioral apathy, i.e., diminished self-initiated actions (Stuss et al., 2000). This conceptualization of apathy supports the notion that apathy is a multidimensional construct.

Levy and Dubois (2006) reframed the definition of apathy as "the quantitative reduction of self-generated voluntary and goal-directed behaviors" (Levy and Dubois, 2006). Accordingly, Levy and Dubois (2006) argued that: (a) apathy is an observable state that can subsequently be quantified; (b) apathy is a pathology of voluntary action or goal-directed behavior ([GDB]- a series of interrelated processes by which an internal state is translated into the achievement of a goal through action) (Schultz, 1999); and (c) the mechanisms underlying apathy are related to disruptions in the elaboration, execution, or control of GDB (Levy and Dubois, 2006). Contributing to a model of apathy that is partially consistent with previous conceptualizations, Levy and Dubois (2006) emphasized the multifactorial nature of apathy by defining three subtypes based on impairment of different prefrontal cortex-basal ganglia circuits: (1) emotional-affective apathy refers to the inability to associate affective and emotional cues with ongoing and upcoming behaviors and manifests as indifference or flat affect (unconcern); (2) cognitive apathy refers to impaired elaboration of action plans; and (3) auto-activating apathy refers to difficulty initiating the motor program required to perform the behavior (Levy and Dubois, 2006). Taken together, these three subtypes of apathy can be described as cognitive-behavior-emotion framework of apathy. The social domain of apathy is missing within the existing framework of apathy (Ang et al., 2017; Sockeel et al. 2006). In agreement with Marin's conceptualization of apathy, Starkstein and Leentjens (2008) suggest that apathy is a syndrome (independent of other disorders) which overlaps with other neuropsychiatric syndromes, including abulia (loss of will power to carry out day to day activities), akinetic syndromes (deficit in mental processing that can be reversed by external stimulation), despair and demoralization (lack of concern about the future), depression or anhedonia (loss of interest in things one once enjoyed) and the negative syndrome of schizophrenia implying that it is a distinct disorder that warrants investigation (Robert et al., 2009; Starkstein & Leentjens, 2008)

In clinical practice settings, apathy is not explicitly defined in the DSM IV and V instead it is referred to as a type of behavioral symptom of neurocognitive disorders (Agboji et al., 2024a; APA, 2013; Cerejeira et al., 2012). As a result, different criteria by which apathy can be objectively evaluated in clinical practice have been proposed. For example, Marin in his pioneering work established four diagnostic criteria for apathy which are: (1) lack of motivation in comparison to the individual's previous level of functioning or the standards of his or her age and culture as reported by either by self or proxy account (2) presence of at least 1 symptom belonging to each of the following three domains of apathy: goal-directed behavior (lack of effort, dependency on others to structure activity), goal-directed cognition (lack of interest in learning new things, or in new experiences, lack of concern about one's personal problems) and emotion (unchanging affect, lack of emotional responsivity to positive or negative events); (3) the symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning; and (4) the symptoms are not due to diminished level of consciousness or the direct physiological effects of a substance such as drug abuse or negative effects of medication (Marin, 1991). Recently, the criteria for apathy have been revised by an international consensus group focusing on apathy in brain disorders including researchers and healthcare professionals, a representative from a regulatory body, and a representative from the pharmaceutical industry (Robert et al., 2018). A two-step approach was employed to arrive at a consensus: web-surveys followed by a consensus meeting. The new diagnostic criteria provide that: (1) apathy is defined as "a quantitative reduction in goal-directed activity compared with the person's previous level of functioning"; and (2) apathy is a persistent state whose symptoms should be observed in at least two out of the three dimensions of apathy comprising of behavior/cognition; emotion (including spontaneous emotion and emotion in response to the environment/others); and social interaction (including spontaneous social initiative and social interaction stimulated by the environment/others) (Robert et al., 2018). While existing diagnostic criteria for apathy, such as those by Marin (1991) and Robert et al. (2009), provide valuable frameworks, they do not specifically address social withdrawal and reduced social interaction as central aspects of apathy. These behaviors, which are observable and clinically significant, often reflect the emotional and cognitive disengagement seen in apathy (Marin, 1991; Robert et al., 2009).

For this dissertation, apathy is defined as loss of interest characterized by “withdrawal from activities of interest” and/ or “reduction in social interactions” (Volicer et al., 2013, p.418). Adopting this definition offers both conceptual and practical benefits. Conceptually, it provides a more comprehensive understanding of apathy by linking it to observable social behaviors, including withdrawal from activities and reduced social interaction (Volicer et al., 2013). This shift broadens the scope of apathy beyond just motivational or emotional disengagement, incorporating the social aspects that are integral to the well-being of older adults, especially in long term care facilities (LTCF) (Starkstein & Leentjens, 2008). In addition, by recognizing these behaviors as key indicators, the definition aligns more closely with real-world experiences of apathy in populations such as residents of LTCF, where social interaction and engagement are important components of daily life. From a practical perspective, social withdrawal and disengagement are behaviors that caregivers and healthcare providers can observe and document consistently. This makes the definition not only more accessible but also actionable, enabling healthcare professionals to more effectively identify and track apathy in older adults.

Furthermore, this definition can inform intervention strategies by providing clear behavioral targets, helping to improve the management of apathy and, in turn, the quality of care and life for individuals living in LTCF. More importantly, this operational focus facilitates the use of existing tools, such as the MDS 2.0 dataset, making it possible to quantify apathy in a way that is both practical and meaningful in real-world healthcare settings.

Apathy is a transdiagnostic symptom that occurs across a wide range of neurological, psychiatric, and medical conditions, affecting individuals globally (Le Heron et al., 2018; Starkstein & Leentjens, 2008). Research indicates that 10-30% of the global population may experience apathy at some point in their lives, though these estimates vary depending on the population studied and the diagnostic criteria used (Le Heron et al., 2018). Apathy is especially prevalent among individuals with neurodegenerative diseases, such as Alzheimer's disease, where it affects 30-70% of patients, and Parkinson's disease, with prevalence rates ranging from 20-40% (van Reekum et al., 2005). Additionally, apathy is commonly observed in psychiatric disorders, including depression, where it is reported in up to 70% of cases, and in schizophrenia, with prevalence rates of 40-50% (Marin, 1991). Among stroke survivors, apathy occurs in about 20-40% of individuals, while those with traumatic brain injury (TBI) report apathy at rates of 20-30% (Starkstein & Leentjens, 2008). While apathy often overlaps with these disorders, studies have shown that it can occur independently, and therefore it is conceptualized as a syndrome (Ang et al., 2017; Ayers et al., 2017; Brodaty et al., 2010; Marin, 1990)

The prevalence of apathy is influenced by demographic factors, particularly age and the health profile of the population. In high-income countries with aging populations, such as the United States and Japan, apathy is more commonly reported due to the higher prevalence of neurodegenerative diseases, including dementia. For example, in the U.S., 30-50% of older adults with cognitive impairment or dementia exhibit symptoms of apathy (Clarke et al., 2008). Similarly, in Japan, where the aging population is rapidly increasing, apathy is a growing concern in older adult care, with prevalence rates comparable to those seen in Western countries (Takahashi et al., 2017). In contrast, low- and middle-income countries tend to report lower prevalence rates, although this is likely due to underreporting and limited access to mental health services and diagnostic tools (WHO, 2017).

Furthermore, the prevalence of apathy varies by setting. Within community settings, apathy is often linked to depression, chronic illness, and social isolation (Brodaty et al., 2010; Le Heron et al., 2018). Studies estimate that approximately 5-20% of community-dwelling adults experience apathy, with higher rates seen among older adults, particularly due to loneliness, physical decline, and cognitive impairment (Brodaty et al., 2010). Apathy is also present in younger populations, especially those affected by mental health disorders such as depression, anxiety, and chronic stress (Le Heron et al., 2018). By contrast, in LTCF, apathy is one of the most common neuropsychiatric symptoms, particularly in residents with dementia or other chronic conditions. Prevalence rates of apathy in LTCF range from 50-70%, making it a significant concern for caregivers and healthcare providers (Landes et al., 2005).

Despite its prevalence, apathy remains poorly understood, partly due to its multifactorial nature, which spans biological, psychological, and social dimensions (Bolton & Gillett, 2019; Marin, 1990). Research has also shown that apathy is often conflated with other conditions, such as depression, which complicates its accurate detection and diagnosis (Agboji et al., 2024a; Starkstein & Leentjens, 2008; Robert et al., 2018). A significant gap in the literature is the lack of understanding of the contextual factors that influence apathy. In LTCF, systemic challenges such as inadequate caregiver training, the absence of standardized assessment tools, and resource limitations hinder effective management (Lanctôt et al., 2017; Robert et al., 2018). Similarly, older adults in rural communities face unique difficulties, including limited social opportunities, geographic isolation, and restricted access to healthcare, all of which make early detection and treatment of apathy especially challenging (Freeman et al., 2020; Kelly et al., 2017). More importantly, studies examining apathy in the Canadian context is limited.

Several pharmacological and non-pharmacological interventions for apathy have been proposed. Medications such as methylphenidate (a psychostimulant) and acetylcholinesterase inhibitors (colloquially known as anti-dementia) have been shown to be effective against apathy in people with dementia (Drijgers et al., 2009; Theleritis et al., 2017). However, these medications have been observed to have serious adverse effects (Seitz et al., 2012). As a result, non-pharmacological interventions are mostly preferred (Seitz et al., 2012). These include but are not limited to art, music therapy, multisensory stimulation, staff education and cognitive rehabilitation (Goris et al., 2016; Holmes et al., 2006; Theleritis et al., 2018). In addition, technologies such as virtual reality (VR) and repetitive transcranial magnetic stimulation have also been found to mitigate apathy (Leone et al., 2013; Padala et al., 2018b; Saredakis et al., 2020). Despite the growing interest in these non-pharmacological interventions, they can be costly and there is insufficient understanding of their feasibility, scalability, and effectiveness across care settings (Gitlow, 2014). For example, music and pet-assisted therapies can improve mood and reduce apathy but face scalability challenges due to specialized training, logistical requirements, and safety concerns (Tang et al., 2018; Bernabei et al., 2013; Zisselman et al., 1996). Thus, innovative intervention, such as an eBook club is much needed to mitigate apathy among individuals in LTCF and community settings.

Personal Reflections

Being a nurse with over 20 years of experience working with older adults, my deep passion for improving the quality of care and life for those I care for has always driven me into action. Early in my career, I found myself facing a challenging issue that I didn’t fully understand, that is, apathy. Many of the residents I worked with exhibited signs of withdrawal, disinterest, and emotional flatness. Despite my best efforts to motivate them to participate in activities, nothing seemed to make a difference. At the time, I mistakenly believed that these behaviors were a form of depression. In response, antidepressants were often prescribed to address these symptoms. However, despite the use of these medications, many residents showed little to no improvement. This left me wondering: were we treating the right condition?

This unanswered question pushed me to dive deeper into the literature, where I learned that apathy is distinct from depression, though the two often appear similar. This realization opened my eyes to the complexity of apathy and its potential impact on the lives of older adults. It became clear to me that we had been missing something important in their care. Determined to address this gap, I set out to study apathy in depth and explore ways to better support older adults who struggle with it.

My nursing experience has always been grounded in a commitment to person-centered care. I have seen firsthand that every resident has unique needs, preferences, and ways of engaging with the world around them. When I designed the eBook club intervention, I wanted to make sure it reflected that understanding. I ensured the intervention was flexible and adaptable, allowing residents to engage at their own pace, in a way that felt most comfortable to them. The goal was to make the intervention inclusive, respecting the diverse cognitive abilities and interests of each individual. In addition, my years of work in LTCF and rural communities shaped the selection of the study population. While these groups are essential to understanding apathy, I realize that including a more diverse sample could have given a broader perspective on how apathy affects older adults in different environments and cultural contexts.

That said, I am cognizance of the fact that my nursing background may have introduced certain biases into the study (Polit & Beck, 2017). My experiences with non-pharmacological interventions might have likely led to prioritizing these methods. While the eBook club intervention proved successful, I acknowledge that exploring other treatment options might have further enriched the study. Additionally, my strong belief in the effectiveness of such interventions may have led to confirmation bias (Polit & Beck, 2017), where I unintentionally emphasized positive outcomes and downplayed challenges.

To minimize these biases, I made a conscious effort to engage in reflexivity throughout the research process. Reflexivity, in my view, involves being aware of how my personal experiences, beliefs, and professional background shape my approach to the study (Finlay, 2002). I kept a reflective journal, documenting my thoughts and feelings as I moved through the research. This practice helped me identify any biases early on and adjust my approach as needed. Reflexivity also allowed me to remain open to new perspectives, even when they challenged my initial assumptions, helping me embrace fresh ideas and insights (Finlay, 2002). I also sought feedback from my supervisor, committee members, and experts in different fields to broaden my perspective. Their input helped me maintain objectivity, particularly during data analysis and interpretation (Finlay, 2002).

Chapter Three: Methodology

This chapter outlines the methods employed in this dissertation. It provides an explanation of the research design, research setting/sample, data sources and cleaning.

Research Design

In this study, the multimethod approach was selected. Multimethod research, also referred to as multiple method research, is broadly defined as “the practice of employing two or more different methods or styles of research within the same study or research program, rather than confining the research to the use of a single method” (Anguera et al., 2018, p. 2760). Hesse-Biber & Johnson (2015) described it as studies in which multiple types of qualitative or quantitative data are collected in a single research project. That is, two or more separate research projects are conducted to address different aspects of a research question (each being complete on its own) (Hesse-Biber & Johnson, 2015). Morse & Niehaus (2009) added that a multimethod design is “a scientifically rigorous research program comprised of series of related qualitative and/or quantitative research projects over time, driven by the theoretical thrust of the program” (p.148) implying that a multimethod research program “may include projects using different single methods or include one or more projects using mixed methods designs” (p.149). The multimethod research is rooted in pragmatism, a philosophical belief allowing researcher to use different tools that may be useful in different research contexts (Creswell & Plano Clark, 2018).

In designing multimethod research, there are two key principles that must be followed: primary theoretical drive and the role of the secondary component, both of which define the research framework and the way different methods interact within the study (Morse, 2003). The primary theoretical drive in multimethod research design serves as the foundation for how data is collected, analyzed, and interpreted. In this type of research, two or more distinct research projects are conducted, each designed to address a different aspect of a broader research question (Morse, 2003). For example, if one study within the multimethod research is qualitative, it will follow an inductive methodology, focusing on the exploration of themes, narratives, and subjective experiences. If another study within the same research framework is quantitative, it will follow a deductive methodology, emphasizing statistical analysis and objective measurement. The theoretical drive of each separate study remains distinct, and there is no blending of methodologies within a single research phase (Morse, 2003).

In a multimethod research, Morse (2003) emphasizes that the choice of design should be driven by the specific research questions and objectives at hand. Morse outlines various configurations, such as concurrent and sequential designs, each serving different purposes. For instance, a concurrent design (denoted as [QUAL + QUAN]) involves conducting qualitative and quantitative studies simultaneously, allowing for a comprehensive exploration of a phenomenon from multiple perspectives. In contrast, a sequential design (represented as [QUAL → QUAN] or [QUAN → QUAL]) entails conducting one study after another, where the findings from the initial study inform the subsequent one. The selection between these designs depends on factors such as the nature of the research questions, the desired depth of understanding, and the resources available. Morse (2003) advocates for a thoughtful alignment between the research objectives and the chosen methodological approach to ensure the study's effectiveness and coherence. The uppercase letters: QUAL indicates a qualitative primary drive, and QUAN denotes a quantitative primary drive. The plus sign (+) indicates that methods are applied simultaneously, whereas an arrow (→) represents sequential directionality (Morse, 2003). Further, Morse (2003) states that when the theoretical drive is qualitative (QUAL), the sample is typically small and purposefully selected. If a secondary quantitative component (quan) is included, it is important to have external normative values available for interpreting the quantitative data due to potential sampling limitations. Conversely, when the theoretical drive is quantitative (QUAN), and there's a secondary qualitative component (qual), the sample for the qualitative part should be purposefully selected from the main study to ensure coherence between the components (Morse, 2003).

In alignment with Morse's (2003) framework, each study in this dissertation is independently planned and conducted to answer a particular overarching question (see Figure 1). The first study was an integrative review aimed at identifying barriers and facilitators that influence apathy recognition, assessment, and management in LTCF and community settings. This review systematically synthesized findings from existing literature to establish a strong theoretical and empirical foundation for the subsequent empirical studies (Whittemore & Knafl, 2005). A qualitative-dominant integrative review methodology was employed. Thematic analysis was conducted to identify recurring patterns in apathy care and highlight gaps in research and clinical practice (Braun & Clarke, 2006). This study was essential in informing the research design of the primary data collection studies, ensuring that empirical investigations aligned with existing knowledge and identified areas requiring further exploration

The second study employed a cross-sectional quantitative approach to examine the prevalence of apathy among newly admitted LTCF residents in Canada. Given that apathy is frequently underdiagnosed or misinterpreted in long-term care settings (Lanctôt et al., 2017), the study utilized secondary data from the InterRAI Minimum Dataset (MDS 2.0), a widely recognized tool for assessing health and behavioral needs of residents in LTCF (Hirdes et al., 2008). This dataset was analyzed to estimate the proportion of residents presenting with clinically significant apathy. Descriptive statistical analyses were used to calculate prevalence rates, while logistic regression models were applied to identify potential demographic and clinical predictors of apathy, including cognitive impairment, depressive symptoms, and physical frailty (van der Linde et al., 2016). This study was pivotal in establishing the epidemiologic baseline, providing quantitative evidence on the burden of apathy within LTCF.

Building upon the prevalence findings, the third study examined individual and facility-level predictors of apathy among LTCF residents. Previous research has suggested that both personal and environmental factors contribute to apathy risk (Radakovic & Abrahams, 2018); thus, this study aimed to determine how factors such as facility size, social engagement opportunities, and healthcare access influenced apathy prevalence (Jao et al., 2019). Inferential statistical techniques, including multivariable logistic regression models, were used to determine the strongest predictors of apathy among LTCF residents (Mitchell et al., 2021). This study provided deep insights into modifiable and non-modifiable risk factors, offering valuable information for designing targeted apathy interventions.

The fourth study employed a quasi-experimental mixed methods approach to evaluate the effectiveness of an eBook club intervention in reducing apathy among LTCF residents. Given the growing interest in non-pharmacological interventions for apathy management (Goris et al., 2016), this study sought to assess whether structured reading activities could stimulate engagement and improve social participation. A pre- and post-intervention design was implemented, in which participants engaged in weekly eBook reading sessions using digital reading platforms such as Kindle and Kobo. Quantitative analyses included paired t-tests and McNemar’s test to compare pre- and post-intervention apathy scores (Fagerland et al., 2013).

Further, semi-structured interviews were conducted to explore participants' subjective experiences, with qualitative data analyzed using thematic analysis (Braun & Clarke, 2006).

Apathy was measured using the three-item subset of the Geriatric Depression Scale (GDS-3A), which has been validated for assessing apathy in older adults (Adam, 2001; Bertens et al., 2017; Grool et al., 2014; Ligthart et al., 2012).While more comprehensive apathy scales such as the Apathy Evaluation Scale (AES; Marin et al., 1991) or the Apathy Inventory (Robert et al., 2002) may offer greater sensitivity across cognitive, emotional, and behavioral domains, these tools can be burdensome to administer, particularly for individuals with cognitive impairment, fatigue, or low tolerance for lengthy assessments. Thus, the GDS-3A was selected for the intervention studies because it is brief, easy to administered and suitable for older adults in both long-term care and community settings, some of whom might find longer assessments burdensome. Additionally, the GDS-3A captures core behavioral aspects of apathy relevant to the intervention's focus on engagement, and its results were intended to be interpreted alongside, and enriched by, the extensive qualitative data gathered, providing a more comprehensive understanding of the intervention's impact.

Extending the intervention beyond LTCF, the fifth study examined the impact of the eBook club intervention on community-dwelling older adults. While much research on apathy has focused on institutionalized populations, the experience of older adults living independently remains underexplored (van Dalen et al., 2018). This study followed a similar quasi experimental mixed-methods pre- and post-intervention design as the fourth study but focused on individuals residing in three rural communities in Northern British Columbia. Participants engaged in structured group reading sessions, designed to enhance cognitive and social engagement, and their pre- and post-intervention apathy levels were assessed using the GDS-3A scale ((Adam, 2001; Bertens et al., 2017; Grool et al., 2014; Ligthart et al., 2012). Qualitative interviews provided deeper insights into the feasibility, acceptability, and perceived benefits of the intervention in a community setting (Gitlow, 2014).

Theoretical framework

This study was informed by two complementary theoretical frameworks: the Biopsychosocial Model of Health and Illness (Engel, 1977) and Socioemotional Selectivity Theory (SST) (Carstensen et al., 1999). The Biopsychosocial Model of health and illness (Engel, 1977) was used to guide the quantitative components, examining apathy as a condition shaped by biological, psychological, and social factors. This framework supported the analysis of large-scale data to identify prevalence and key predictors such as cognitive impairment and depression (studies two and three). For the intervention phase (study five), the Socioemotional Selectivity Theory (Carstensen et al., 1999) was drawn upon to understand why the eBook club program which promoted social connection, engagement, and emotionally fulfilling activities was effective in reducing apathy.

The Biopsychosocial Model of health and illness (Engel, 1977) was chosen to guide the quantitative component of this study because it offers a comprehensive and integrated view of health, recognizing that health outcomes such as apathy are not caused by one factor alone, but by the interplay of biological, psychological, and social factors (Marin & Wilkosz, 2005; Massimo et al., 2018). This model is especially relevant in LTCF, where residents often face multiple challenges such as chronic illness, cognitive impairment, and environmental under-stimulation (Jao et al., 2015; Radakovic & Abrahams, 2018; Starkstein & Leentjens, 2008). These overlapping issues contribute to the development and persistence of apathy in ways that are not adequately captured by more traditional models. For example, the Biomedical Model has been valuable in diagnosing medical conditions as it focuses mainly on physical causes of disease (Engel, 1977), but it does not account for the emotional or environmental factors that often underlie apathy in older adults (Jao et al., 2015). Similarly, the Health Belief Model (Rosenstock, 1974) emphasizes personal beliefs and decisions about health risks. This model assumes a level of cognitive awareness and motivation that may not be present in residents with dementia (Horning et al., 2014; Dening et al., 2021).

For the second intervention study (study five), the Socioemotional Selectivity Theory (Carstensen et al., 1999) was used to explain how older adults shift their priorities as they age, especially when they perceive time as limited. The Socioemotional Selectivity Theory suggests that emotional well-being and meaningful social connections become more important than seeking new experiences or information. This made this model a strong fit for understanding how and why participants responded positively to the eBook club intervention. Other theories were considered but did not align as closely with the study aims. For instance, Self-Determination Theory (SDT) (Deci & Ryan, 2000), which focuses on autonomy, competence, and relatedness, is often applied to motivation but assumes that individuals are actively goal setting. This is less applicable to populations with cognitive impairment or diminished motivation, where emotional meaning may drive engagement more than personal achievement. Erikson's psychosocial theory (1959), Activity Theory (Havighurst & Albrecht, 1953) and Continuity Theory (Atchley, 1989) are useful for understanding broad aging patterns but offer less insight into the specific emotional and motivational changes that influence activity engagement among older adults.

By using the Biopsychosocial Model and Socioemotional Selectivity Theory, this study was able to explore both the larger structural factors that shape apathy and the personal experiences and motivations of older adults participating in the eBook club intervention. These frameworks worked in tandem to support a multi-method approach, offering both depth and breadth in understanding the complexity and multidimensionality of apathy among individuals in LTCF and older adults in community settings, and thus contribute to the body of knowledge in both apathy and aging research.

Sample/settings

The sample in studies one to three consisted of all newly admitted LTCF residents assessed between 2014 and 2019 fiscal year (N = 157,596) from across Canada including Yukon, British Columbia, Alberta, Saskatchewan, Ontario, and Newfoundland and partial coverage for Manitoba, New Brunswick, and Nova Scotia. Residents in comatose states or with missing relevant information were excluded. Participants in study four were recruited from four LTCF in rural Northern BC (N=20) while study five was conducted in three rural communities in Northern British Columbia (N=28). Inclusion criteria required participants to (1) have an interest in reading, (2) be able to read and speak English, (3) have the ability or willingness to use digital technology, and (4) provide informed consent. Exclusions are residents who have no capacity to provide informed consents.

Data source

Dataset for studies two and three were obtained from the Continuing Care Reporting System (CCRS) database of the Canadian Institute for Health Information (CIHI) (see details in Chapters Five and Six). The CCRS consists of the InterRAI Minimum Data Set (MDS 2.0). The MDS 2.0 is a mandated standardized assessment instrument for use in most LTCF across Canada and provides comprehensive personal level information about residents that informs decision-making in developing a care plan that reflects their needs, preferences, and strengths (Hirdes et al., 2011). Embedded within the MDS 2.0 are standardized, minimal assessment and screening tools designed to assess residents' sociodemographic, clinical, psychological, and functional characteristics (Morris et al., 2012). Sociodemographic characteristics include but are not limited to sex, age, marital status, language, lived alone, and facility/provincial information. Clinical, psychological, and functional characteristics include disease diagnoses, cognitive status, fluid status, pain, oral problems, skin problems, mobility issues, to mention but a few (Morris et al., 2012). This assessment's output results in clinical algorithms and indicators referred to as the outcome scales and Clinical Assessment Protocols (CAPs), which provide information about a resident's health problems or functional status and guides the care planning process (Morris et al., 2012). For studies four and five, data were gathered through self-report questionnaires (GDS-3A) and semi structured interviews (see Appendices 5 and 6).

Data cleaning

Demographic characteristics were extracted directly from the InterRAI MDS 2.0 dataset and used to describe the study population and explore associations with apathy. Key demographic variables included age, sex, marital status, language, education level, and province of residence. All age groups represented in the dataset were retained. Data cleaning for demographic variables focused on checking for missing, inconsistent, or ambiguous entries. These demographic variables were incorporated into both descriptive statistics and logistic regression models to examine prevalence patterns, group differences, and their potential role as predictors or risk factors of apathy. Retaining the full demographic diversity of the sample ensured that findings were representative of the broader long-term care population in Canada. In addition, several variables from the InterRAI MDS 2.0 dataset were recoded and transformed to facilitate statistical analysis and to align with the theoretical frameworks guiding the study and in alignment with InterRAI guidelines. Apathy was operationalized using behavioral indicators available within the MDS, in a manner consistent with definitions found in the existing literature (Volicer et al., 2013). These indicators reflected observable patterns such as withdrawal from activities and reduced social interaction, which are central to the study's conceptualization of apathy. Cognitive status was measured using the Cognitive Performance Scale (CPS) and was subsequently categorized into clinically meaningful levels to reflect varying degrees of cognitive impairment. This recoding enabled clearer interpretation of cognitive functioning as a predictor of apathy. Similarly, depression was measured using the Depression Rating Scale (DRS), a validated subscale embedded within the InterRAI MDS 2.0 assessment system (Burrows et al., 2000; Hirdes et al., 2003). The DRS scores were recoded into three levels: 0–2 (no or mild symptoms), 3–5 (moderate symptoms), and 6–14 (severe symptoms), following the classification by Burrows et al. (2000). A score of 3 or greater was also used as a cutoff to indicate possible presence of depressive symptoms, as recommended by Hirdes et al. (2008). This classification facilitated the use of depression as an independent variable in regression analyses examining psychological predictors of apathy. Only records of residents who were newly admitted to LTCF during the study period were retained. Cases were excluded if admission data were incomplete or if apathy-related variables were missing, to ensure consistency in baseline assessments across all residents.

Ethical considerations

This study was conducted in accordance with the Tri-Council Policy Statement (TCPS 2, 2018). For the secondary data analysis, fully anonymized data from the InterRAI MDS 2.0 were used under agreement with CIHI. As no identifying information was included, individual consent was not required, and all data access protocols were strictly followed. In the intervention phase, ethical approval was obtained through BC Harmonized Ethics Review process in conjunction with the University of Northern British Columbia (UNBC) Research Ethics Board (REB#H21-02006). Only individuals with the capacity to provide informed consent were eligible to participate. All prospective participants were given a copy of the information letter at least two weeks prior to enrollment, allowing time to review and ask questions. Decision-making capacity was formally assessed using the University of California, San Diego Brief Assessment of Capacity to Consent (UBACC) (Jeste et al., 2007). Only those who demonstrated sufficient understanding and reasoning ability, as indicated by their UBACC assessment, were enrolled in the study. Participants were informed that their participation was voluntary, and they could withdraw at any time without consequence. The eBook club intervention was low-risk, designed to be flexible, inclusive, and respectful of individual preferences. All data collected during the study were de-identified and securely stored on password-protected systems accessible only to the research team. Throughout the research process, the principles of respect for persons, concern for welfare, and justice guided all ethical decisions, ensuring the protection and dignity of all participants.

Brief description of the intervention studies

There were two interventions (chapters seven and eight) developed to mitigate apathy by fostering cognitive, emotional, and social engagement. The first intervention conducted in four LTCF served as the initial pilot, where a thematic analysis was conducted without pre-imposing a theoretical lens (chapter seven). This open approach was chosen to allow participant voices and experiences to guide the understanding of how the eBook club influenced apathy. The second intervention (chapter 8) where early inductive findings from the first intervention study guided the selection of the Socioemotional Selectivity Theory took place in three rural communities in

Northern BC. Materials used in the interventions included Kobo eReaders, participants' personal digital devices, free Kobo accounts, access to the public library via Overdrive app, pre-loaded or downloadable eBooks, reading trackers for independent readers, as well as participant information letters, consent forms, and pre/post-interview protocols.

The procedures followed a three-phase structure: pre-intervention, implementation, and post-intervention (Figure 2). During the pre-intervention phase, participants completed a semi-structured interview that assessed reading preferences and choice of books to read. Kobo accounts were created, and eBooks were either pre-loaded on Kobo devices or made available via the Kobo app on personal devices. Technical support was provided as needed. Weekly eBook club sessions in LTCF were facilitated by the PhD student researcher and facility staff (recreational staff), while trained research assistants and the PhD student researcher facilitated the eBook club program in the community settings. Group reading sessions in both settings involved shared reading and discussion, while independent readers used a reading tracker to reflect on their engagement. Post-intervention interviews included both qualitative feedback and administration of an apathy questionnaire (GDS-3A).

The intervention was delivered in person, both in LTCF and in rural community settings (library) across Northern BC. For those who choose to read after group reading sessions, engagement also occurred digitally via the Kobo app. In terms of duration and intensity, the intervention ran for twelve weeks at each LTCF sites, and eight weeks per rural community site. The frequency was set at once per week in LTCF as it was integrated into the existing weekly activity schedule within the facilities, ensuring it aligned with established routines and could be sustained with support from facility staff, and for the community settings, the group reading sessions occurred once weekly based on participants’ preferences. In addition, the variation in the duration of the intervention between the LTCF and community settings was influenced by a combination of logistical and contextual factors, including staff availability, setting-specific constraints, and participant preferences. In the LTCF, the intervention was delivered consistently over a 12-week period across all sites. This extended duration was feasible due to the structured nature of institutional routines, the availability of staff to co-facilitate sessions, and the ability to incorporate the eBook club into the facilities' regular programming schedules. The longer timeline also allowed for greater continuity and deeper engagement among residents. In contrast, the community-based intervention was limited to eight weeks, primarily due to seasonal timing and participant availability. Many participants had upcoming summer holidays, which constrained the feasible length of their involvement. To respect these preferences and ensure full participation, the program was shortened accordingly.

The intervention was tailored in multiple ways. Book selections were based on participants' stated preferences during the initial interview, and participants had the choice of joining group sessions and supplement with reading independently. Session pacing and structure were adjusted based on individual and group needs. Minor modifications were made during implementation, such as variation in duration between sites and iterative adaptation of reading materials based on group interest. These changes reflected a responsive and person-centered approach. To promote intervention fidelity, structured session plans were developed, and reading trackers were used to monitor individual participation. The PhD student researcher was directly involved in all sites, ensuring consistency in implementation. Fidelity was assessed informally through observation, weekly check-ins, and participant self-report.

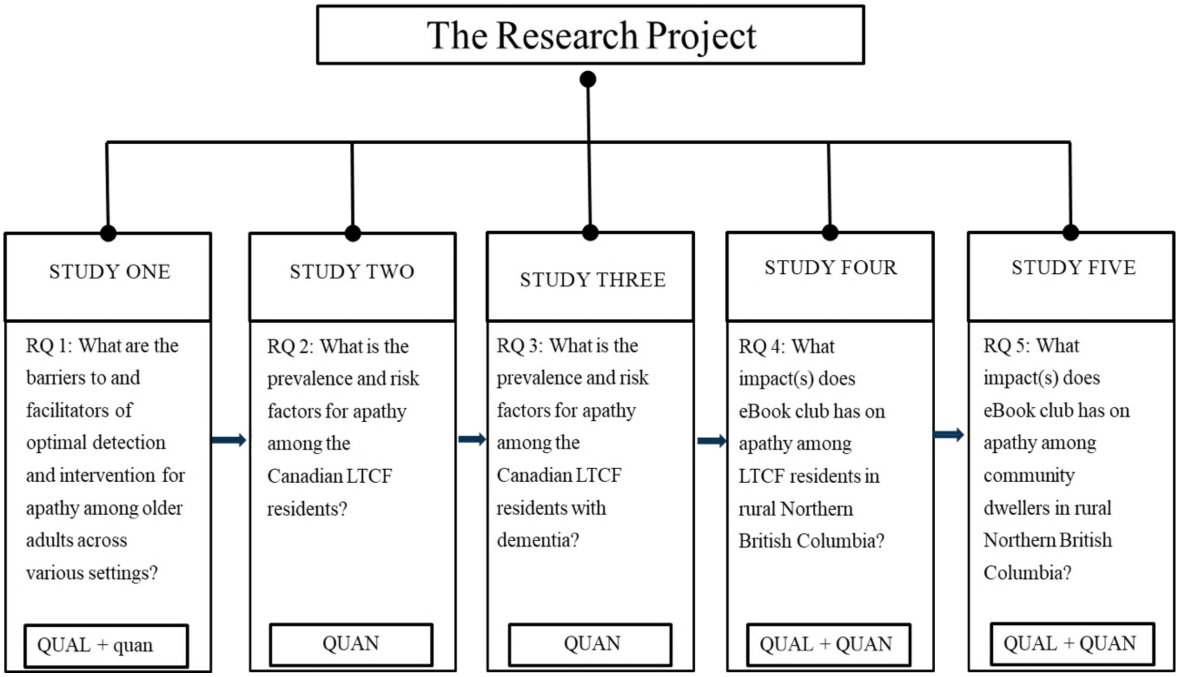


Figure 1: Overview of the research design

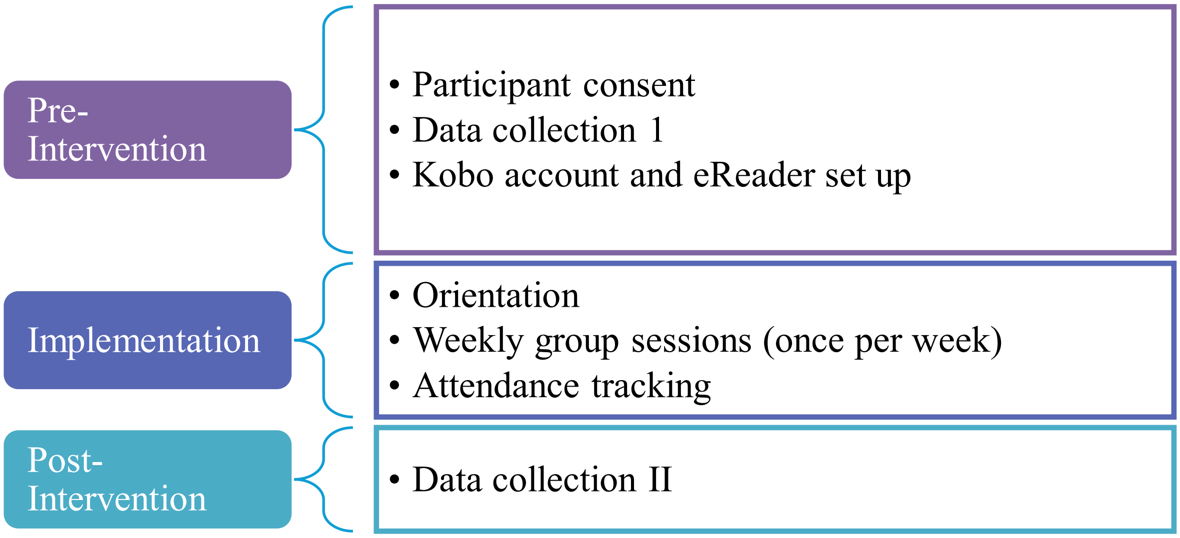


Figure 2: Phases of the intervention studies

Chapter Four: Apathy in Older Adults with and without Dementia: An Integrative Review of Barriers and Facilitators to Care

This chapter addresses RQ 1 “What are the barriers and facilitators to optimal detection and intervention for apathy among older adults?” and has been published in SAGE Open Journal as:

Agboji, A., Freeman, S., Banner, D., Duchesne, A., Armstrong, J., & Martin-Khan, M. (2024). Apathy in Older Adults With and Without Dementia: An Integrative Review of Barriers and Facilitators to Care. *Sage Open*, *14*(2), 1-25. https://doi.org/10.1177/21582440241241882

Abstract

Despite the detrimental impact of apathy on the cognition, functional abilities, and quality of life of older people, it is often under-rated and under-managed. This integrative review provides a comprehensive overview of the barriers as well as potential facilitators to optimal care for older adults with apathy. A systematic search for relevant literature using Whittemore and Knafl’s framework was conducted to identify factors that inhibit or facilitate optimal detection and intervention for apathy in older people with and without dementia. Four key barriers were identified including lack of standardized definition of apathy, lack of awareness, overlap with other disorders, and methodological limitations of clinical trials. Key facilitators included involvement of the dyad (persons with apathy and their families/formal caregivers), education, training and experience, and adoption of new and innovative method of screening and intervention. To provide optimal care for older people with apathy, there is need to adopt a multifaceted approach, including the development of precise definition of apathy, consideration of person-centered approach, caregiver training, and best practice guidelines for management of

apathy. Future research and practice into effective interventions for management of apathy in older adults, and enhanced education and training for healthcare professionals, are needed to ensure quality of care for older adults with apathy.

Introduction

Apathy is a prevalent behavioral and psychological symptom of dementia (BPSD) that is observed across various forms and stages of dementia, including mild cognitive impairment (MCI), Alzheimer's disease (AD), frontotemporal dementia (FTD), and vascular dementia. It is also seen in other neurodegenerative and psychiatric disorders such as Parkinson's disease (PD), schizophrenia, stroke, multiple sclerosis, traumatic brain injury, and major depression (Borjse et al., 2017; Ishii, Weintraub & Mervis, 2016; Selbaek, Engedal & Bergh, 2013). Apathy is defined as a disorder of motivation or lack of interest characterized by diminished goal directed behavior, cognitive activity, emotional display, and social interaction (Marin, Bierdrzycki, & Firinciogullari, 1991; Robert et al., 2018). Thus, individuals with apathy typically have diminished motivation or interest in goal directed behaviors, such as initiating or participating in conversations, performing activities of daily living (ADLs), or seeking social activities (Mizrahi & Starkstein, 2007; Stanton & Carson, 2016). They experience loss of interest in more complex instrumental activities of daily living (IADLs) such as cooking, shopping, financial management, traveling, and medication management, and appear to be emotionally unconcerned about important life affairs (Marin, 1990; Mizrahi & Starkstein, 2007; Stanton & Carson, 2016).

Apathy has been investigated using various criteria and is considered both a symptom and a syndrome (Harrison, Aerts & Brodaty, 2016). Traditionally, apathy is thought to be a symptom of a wide range of disorders including neurocognitive, medical, and psychiatric disorders (Ang, Lockwood, Apps, Muhammed, & Husain, 2017; Robert et al., 2018), but there is evidence to suggest that it affects healthy older adults, and hence it is considered a syndrome (Brodaty, Altendorf, Withall, & Sachdev, 2010; Marin, 1991; Onyike et al., 2007). The prevalence of apathy can vary widely based upon the type of scale and population being studied. In one study, for example, 1.4% of individuals who are cognitively intact, 3.1% of those with a mild cognitive impairment, and 17.3% of those living with dementia were found to experience apathy (Onyike et al., 2007). It has also been reported that the prevalence rate of apathy among people with dementia can be as high as 84% (Zuidema, de Jonghe, Verhey, & Koopmans, 2009), while ranging between 27-36% among those without dementia (Brodaty et al., 2010). Apathy is one of the mood disorders shown to lead to rapid cognitive decline and heightened risk for mortality among older people with dementia (Lavretsky et al., 2015; Nijsten, Leontjevas, Pat-El, Smalbrugge, Koopmans, & Gerritsen, 2017; van Reekum, Stuss, & Ostrander, 2005).

Apathy has been associated with diverse adverse effects in older adults, especially those with dementia or other neurogenerative disorders, including poorer interpersonal relationships, and deteriorating quality of life (Mjorud, Kirkevold, Rosvik, Selbaek, & Engedal, 2014; Palmer et al., 2010; van Almenkerk, Smalbrugge, Depla, Eefsting, & Hertogh, 2015). Apathy can negatively impact caregivers (formal and informal), as people affected might be difficult to engage with and become uncooperative with care and may require more attention and supervision. This can culminate in increased workload, caregiver burden, and increased healthcare costs (Nijsten, Smalbrugge, Depla, Eefsting, & Hertogh, 2019; Stanton & Carson, 2016).

Despite the prevalence and negative impacts of apathy on older people, it is often under-recognized and under-managed (Leone, et al., 2013; Mele, Goodarzi, Hanson, & Holroyd-Leduc, 2019). However, when optimally detected, apathy is treatable pharmacologically (Beasley et al., 1997; Blundo & Grace, 2015; Frakey, Salloway, Buelow, & Malloy, 2012; Masanic, Bayley, van Reekum, & Simard, 2001; Padala et al., 2010; Padala et al., 2020; Rosenberg et al., 2013) and non-pharmacologically (Goris, Ansel, & Schutte, 2016; Holmes, Knights, Dean, Hodkinson, & Hopkins, 2006; Theleritis, Siarkos, Katirtzoglou, & Politis, 2017). The purpose of this review is to describe the various factors that serve as barriers and facilitators to optimal care for people with apathy in terms of its early identification and management in older adults. A comprehensive understanding of these factors is essential to developing effective interventions and enhancing healthcare services for older adults with apathy (Mele, Van, Holroyd-Leduc, Ismail, Pringsheim, & Goodarzi, 2020). Further, this review aimed to inform practice recommendations for improvement in the care of people with apathy.

Methods

This review was guided by Whittemore and Knafl (2005) framework for integrative reviews. An integrated review allows for the integration of various types of methodologies and the synthesis of their findings including qualitative studies, quantitative studies, case reports as well as theoretical literature (Whittemore & Knafl, 2005). The framework consists of five phases, including problem formulation, literature search, data evaluation, data analysis, and data presentation (Whittemore & Knafl, 2005). The review followed PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) (see Figure 3) which provided an overview of the selection process and justified the exclusions made in the review (Moher et al., 2015).

Problem formulation

The overarching questions that guided the search were: a) what are the barriers to optimal detection and intervention for apathy among older adults? and b) what are the facilitators that have been or could be identified for optimal detection and intervention for apathy among older people?

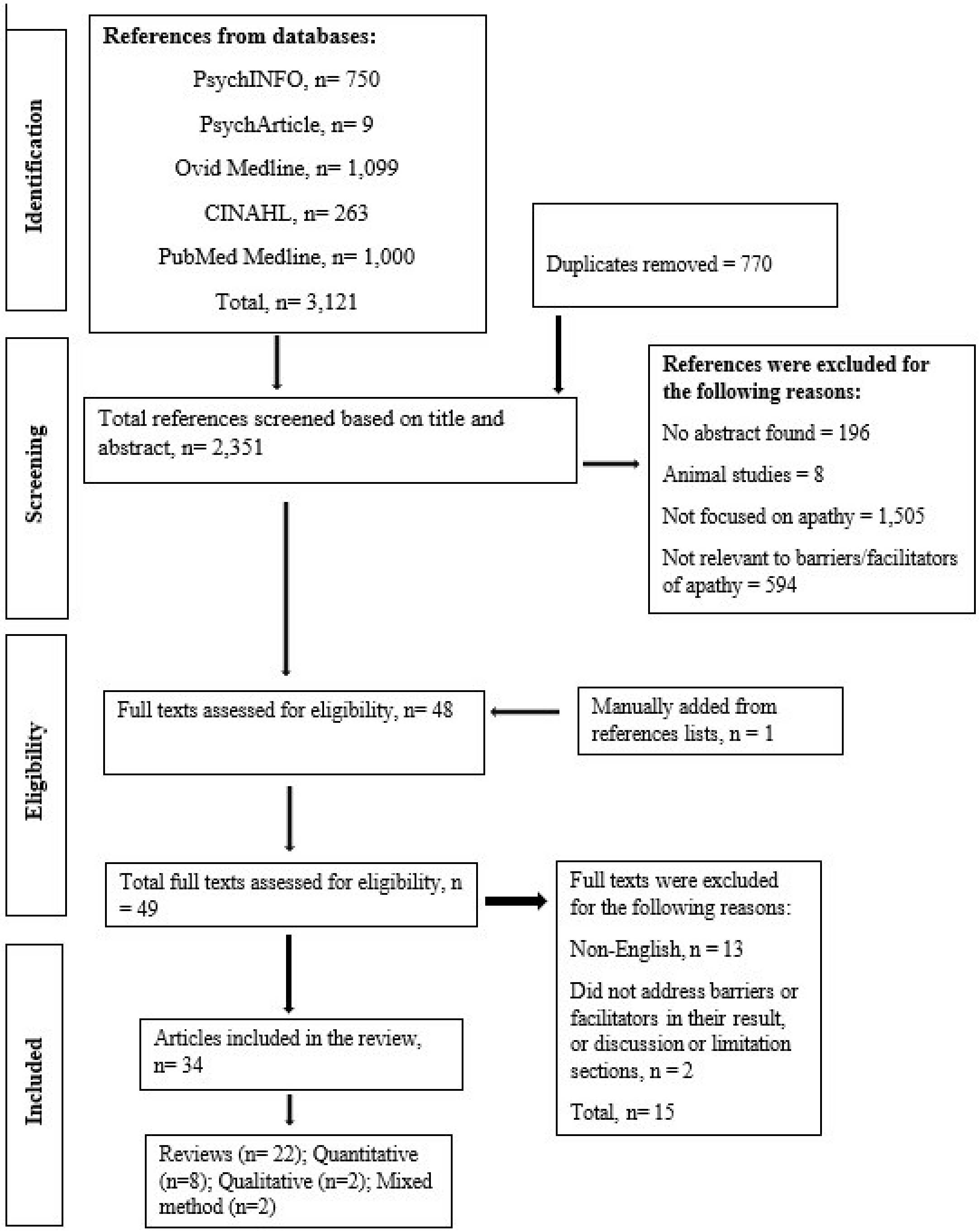


Figure 3: PRISMA flow chart

Literature search

Search Strategy

The search for relevant literature was conducted on March 14th, 2023, by one reviewer (AA) using five databases including PsychINFO, CINAHL, MEDLINE (OVID), PUBMED, and PsychArticles databases. The search terms were developed in consultation with the librarian who has an expertise in systematic searches. Search terms used consist of both keywords and Mesh terms and included "barrier*" OR "challenge*" OR “problem*” OR “hinder*” OR "motivator*" OR "driver*" OR "facilitator*" OR "enabler*" AND "older adult" OR "aged" OR "elderly" OR "geriatric*" OR "senior*” OR "older people" AND "apathy" OR "indifference" OR "lack of motivation" OR "lack of interest". The selection process was recorded in the flow chart (see supplementary file). The inclusion and exclusion criteria were also developed with help of a university health sciences librarian (see Table 1). No additional filters were applied.

Inclusion criteria	1) Addressed apathy in older adults. 2) Focused on assessment, prevention, or interventions for apathy and barriers encountered during research or clinical diagnosis or facilitators to diagnosing or managing apathy effectively. 3) Involved participants aged 60 and above or at least 50% of participants are 60 years and above. 4) Written in English.
Exclusion criteria	1) Solely focused on other behavioral symptoms e.g., depression, aggression, anxiety, or irritability. 2) Aimed at children and adolescents. 3) Unpublished manuscripts. 4) Editorials.

Table 1: Inclusion and Exclusion Criteria

Data evaluation

Study selection

Title and abstract screening were performed by two independent reviewers (AA and SF). A third reviewer (DBL) resolved the conflicts that arose during the screening process. Full text screening was performed by one reviewer (AA). Any papers directly or indirectly discussing barriers and/or facilitators encountered during research or assessment or intervention for apathy in clinical practice were included. Articles were also included if the sample consisted of people who had apathy aged 60 years and above and written in English language. Analysis of retrieved reference lists was also performed manually to find relevant articles that might have been missed during the full text screening. In total, 3,121 citations were retrieved, of which 770 were duplicates and 34 articles met the inclusion criteria (see Figure 3). The search results from all databases were directly imported into Endnote Version 20 (Peters, 2017).

Quality assessment

Given that integrative reviews involve gathering of data from multiple sources, evaluating the overall quality of studies can be complex and papers do not necessarily need to be excluded based on quality criteria and assessment of data quality can be done based on the criteria relevant to the review (Whittemore & Knafl, 2005). As this review included qualitative, quantitative, mixed method and review papers, two quality assessment tools were used including the Critical Appraisal Skills Programme [CASP] (2018) for systematic reviews and the mixed method appraisal tools (MMAT) (Pluye, Bengoechea, Granikov, Kaur, & Tang, 2018). Quality assessment was performed by two reviewers (AA and SF). Overall scores for these tools were interpreted using a 2-point Likert scale (high and low quality) as suggested by Whittemore and Knafl (2005). In this case, articles that scored ≤2 on the MMAT tool were rated as low quality while papers with a score ≥3 were considered high quality. With regards to CASP tool, articles with total score of ≤6 were considered low quality while papers with ≥7 were rated as high quality. Most studies that met the inclusion criteria were rated as high quality (see supplementary table 1). In addition, given the heterogeneity of the selected studies' methodologies, meta-analysis was not conducted.

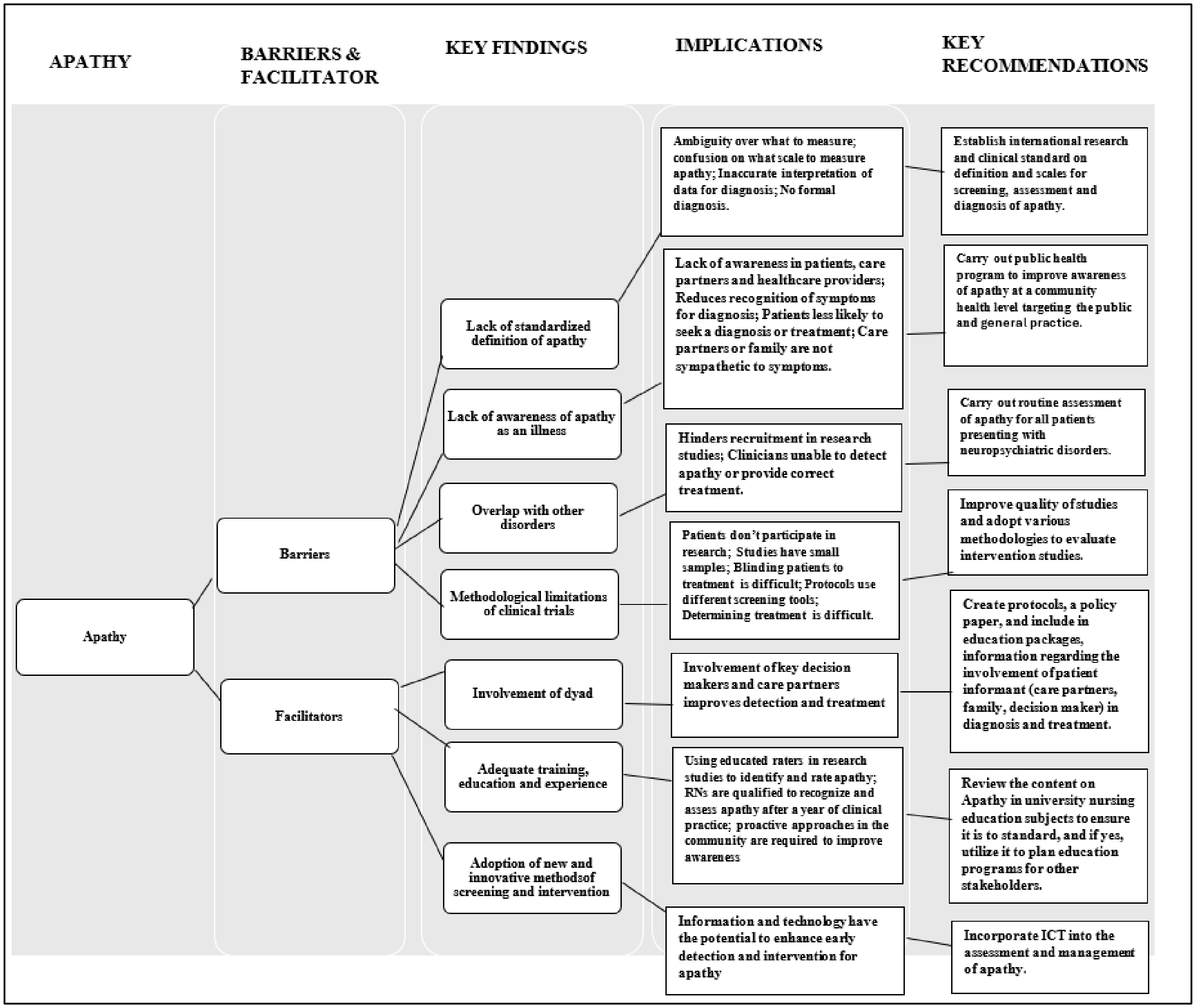
Data analysis

The ordering, coding, categorizing, and summarizing of data was performed using NVivo 12 software (QSR International, 2018) and Microsoft Excel software was used for organization. Identified barriers and facilitators were further reviewed, organized into themes, and conclusion drawn (Braun & Clarke, 2006). In addition, data pertaining to the study location, participants, and research design were extracted where applicable (see Supplementary Table 2).

Data presentation

Study characteristics

Out of 3,121 articles that were retrieved, 34 studies met the inclusion criteria for this review (see Supplementary Table 2). The studies came from three continents including Europe, Australasia, and North America. Most studies were reviews (n=22), eight were quantitative studies, two employed mixed method and the remaining two were qualitative studies. Included studies were published between 2007 and 2023. The focus of most of the studies was on assessment and intervention for apathy. Only one study directly addressed barriers and facilitators to diagnosing and managing apathy. In studies that employed qualitative or quantitative methodologies or both, sample size ranged from 30 to 665 and included people with different types of diseases including dementia of all types, Parkinson's disease, stroke, medical and psychiatric disorders. Some of the studies also include caregivers and healthcare practitioners including doctors, nurses, and allied health professionals such as technical staff, certified nursing assistant and activity staff.



Ambiguity over what to measure; confusion on what scale to measure apathy; Inaccurate interpretation of data for diagnosis; No formal diagnosis.

Lack of awareness in patients, care partners and healthcare providers; Reduces recognition of symptoms for diagnosis; Patients less likely to seek a diagnosis or treatment; Care partners or family are not sympathetic to symptoms.

Hinders recruitment in research studies; Clinicians unable to detect apathy or provide correct treatment.

Patients don't participate in research; Studies have small samples; Blinding patients to treatment is difficult; Protocols use different screening tools; Determining treatment is difficult.

Involvement of key decision makers and care partners improves detection and treatment

Using educated raters in research studies to identify and rate apathy; RNs are qualified to recognize and assess apathy after a year of clinical practice; proactive approaches in the community are required to improve awareness

Information and technology have the potential to enhance early detection and intervention for apathy

Establish international research and clinical standard on definition and scales for screening, assessment and diagnosis of apathy.

Carry out public health program to improve awareness of apathy at a community health level targeting the public and general practice.

Carry out routine assessment of apathy for all patients presenting with neuropsychiatric disorders.

Improve quality of studies and adopt various methodologies to evaluate intervention studies.

Create protocols, a policy paper, and include in education packages, information regarding the involvement of patient informant (care partners, family, decision maker) in diagnosis and treatment.

Review the content on Apathy in university nursing education subjects to ensure it is to standard, and if yes, utilize it to plan education programs for other stakeholders.

Incorporate ICT into the assessment and management of apathy.

Figure 4: Diagrammatic representation of key recommendations for optimal care for older people with apathy

Results

Barriers to Optimal Detection and Interventions for Apathy

The barriers to optimal detection and intervention for apathy were grouped into four main themes: lack of standardized definition of apathy; lack of awareness; overlap with other disorders; and methodological limitations of clinical trials (see Figure 4).

Lack of standardized definition of apathy

Lack of standardized definition of apathy were cited in most studies (Burgon, Goldberg, van der Wardt, Brewin, and Harwood, 2021; Caeiro, Ferro, & Costa, 2013; Chase, 2011; Clarke et al., 2011; Cummings et al., 2015; Drye et al., 2013; Hermann et al., 2008; Leone et al., 2013; Mele, Goodarzi, Hanson, & Holroyd-Leduc, 2019; Matmati et al., 2022; Mele, Van, Holroyd-Leduc, Ismail, Pringsheim, & Goodarzi, 2020; Stanton & Carson, 2016). Despite the increasing effort to establish a commonly accepted diagnostic criteria for apathy (DCA), disagreement continues to exist over its precise definition and description (Drye et al., 2013, Lanctot et al. 2021).

In different fields, the words and meanings associated with apathy can vary and become isolated within specific areas of expertise (Thant & Yager, 2019). There is no category for apathy in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), and the likelihood of its inclusion in the next edition of the DSM is the subject of much debate (Matmati et al., 2022; Miller et al., 2021; Tay et al., 2021). Apathy is not listed in the International Classification of Diseases 10th Revision (ICD-10) (Drye et al., 2013; Stanton & Carson, 2016). The lack of standardized definition and conceptualization of apathy can cause ambiguity over what to measure and the appropriate scale to develop or use when measuring apathy in older adults. Consequently, apathy can easily be overlooked or some of its dimensions being missed during assessment (Clarke et al., 2011; Matmati et al., 2022). For example, participants in a qualitative study investigating the barriers and facilitators to diagnosing and managing apathy in persons living with Parkinson's disease reported that they have never received or offered a formal diagnosis of apathy. In addition, the lack of unified definition of apathy can lead to inaccurate interpretation of data in terms of over-reporting or under-reporting of apathy (Mele, Goodarzi, Hanson, and Holroyd-Leduc, 2019). Caeiro, Ferro, and Costa (2013), for example, noted that the wide range of prevalent rates of apathy (15.2-71.1 %) reported in their study was likely due to the absence of a clear definition and clinical criteria for apathy assessment. Similarly, Flavell & Nestor (2022) found a wide range in the prevalent rate of apathy in their study due to the variability in the assessment tools used to measure apathy. In a recent study by Dickson et al. (2022), it was observed that despite the evidence for the social domain of apathy, most scales that have been used over the past three decades only focus on the cognitive, behavior and emotion domains of apathy implying that the social domain of apathy has been neglected over the years. Lactot et al. (2021) also observed that although there is a strong overlap between the Dementia Apathy Interview Rating (DAIR) scale (a rating scale for assessment of apathy in dementia) and DCA, some participants who scored high in DAIR were not considered apathetic by the DCA. The explanation was that the DCA does not include emotional domain of apathy while the DAIR does. The implication is that apathy in dementia can easily be missed when using the DCA.

Lack of Awareness

Lack of awareness of apathy as an independent disorder or a symptom that manifests in other brain disorders is a major barrier to the optimal detection and intervention for apathy (Drye et al., 2013; Jao, Liu, Williams, Chaudhury, & Parajuli, 2019; Leone et al., 2013; Mele et al., 2019). The lack of awareness is not limited to informal caregiver, but also healthcare practitioners and persons with apathy themselves (Jao et al., 2019). For example, Mele et al. (2019) identified that healthcare practitioners seldom offer a diagnosis of apathy because they do not recognize it as a distinct disorder and likewise, participants with apathy did not seek for a formal diagnosis of apathy or seek for treatment because they lacked insight and often perceive their symptoms of apathy as part of the natural ageing process. Lack of awareness by informal caregivers can lead to apathy being misinterpreted as laziness or oppositional behavior (persistent patterns of hostility, and negativity) or part of aging process or response to other illnesses (Drye et al., 2013; Stanton & Carson, 2016), and consequently, they might find it difficult to detect or seek for interventions for their relatives with apathy.

Overlap with Other Disorders

The presence of neurodegenerative disorders (e.g., dementia and Parkinson's disease) and psychiatric symptoms such as depression or anhedonia or cognitive impairment can serve as an impediment to the optimal detection and provision of appropriate treatment for apathy as these symptoms mimics the symptoms of apathy (Cummings et al., 2015; Drye et al., 2013; Jao et al., 2019; Mele et al., 2019). This was expressed by Cummings et al. (2015) who commented that the overlap of apathy with other neuropsychiatric disorders such as Alzheimer's dementia and Parkinson's disease was a significant confounder in their study and had limited the clinical benefits of the result of their findings. Drye et al. (2013) discovered that due to overlap of apathy with depression, excluding participants who are on antidepressants hindered recruitment and limited the generalizability of their results. This barrier was also highlighted in Mele et al. (2019) study where healthcare practitioners stated that due to the overlap of apathy with Parkinson's disease, they were unable to detect or provide appropriate treatment for their patients who presented with apathy symptoms. In addition, overlap of apathy with depression in neurodegenerative disorders such as dementia, Huntington's disease (HD), and Parkinson’s disease can lead to apathy being misconstrued as depression and subsequently, anti-depressant being used to treat apathy. However, research has shown that anti-depressants lead to worsening of apathy (i.e., selective serotonin reuptake inhibitors [SSRI]-induced apathy syndrome) (Padala et al., 2020).

Methodological limitations of clinical trials

Methodological problems were reported frequently, with some authors noting lower than expected recruitment rate in randomized controlled studies (Cummings et al., 2015; Drye et al., 2013; Goris, Ansel & Schutte, 2016; Harrison, Aerts & Brodarty, 2016; Manera et al., 2020; Starkstein et al., 2016; Tay, Morris & Marcus, 2021; Theletiris et al., 2018). Low response rates resulted from participants’ refusal to participate in research and unavailability of suitable informants (Drye et al., 2013; Jao et al., 2019; Padala et al., 2010; Padala et al., 2018; Starkstein et al., 2016); difficulty in randomizing or determining the suitable method to blinding participants to treatments (Drye et al., 2013; Clarke et al., 2007; Leone et al., 2013); use of variable scales to and difficulty in determining appropriate test treatment (Drye et al., 2013; Saredakis et al., 2020; Roth et al., 2007). For example, in a recent randomized controlled trial conducted by Padala et al. (2018) which included a sample size of 60 male participants (treatment group=30; placebo group = 30) to compare the effects of Methylphenidate (a drug commonly used in the treatment for apathy) with placebo, it was concluded that although, the treatment effect of Methylphenidate on apathy was statistically significant ($p < 0.001$), the small sample limited the clinical relevance and generalizability of the findings. Burgon et al. (2021) concluded that the lack of systematic approach and transparency when developing apathy scales made it difficult to draw valid conclusions about the content validity, reliability, and internal consistency of most of the scales used to measure apathy during clinical trials. Some authors have also alluded to the fact that methodological limitations of clinical trials have hampered the approval of licensed medications for the treatment of apathy in clinical settings (Chase, 2011; Steffen et al., 2022).

Facilitators for Optimal Detection and Interventions for Apathy

The facilitators for optimal detection and intervention for apathy were grouped into three themes: involvement of the dyad; education, training, and experience; and adoption of new/innovative method of screening and intervention (see Figure 2).

Involvement of the dyad

Involving the persons who have apathy and informal/formal caregivers (dyad) in the assessment of apathy both clinically and in research is key to optimal detection and intervention for apathy (Clarke et al., 2007; Drye et al., 2013; Jao et al., 2019; Mele et al., 2019; Mele et al., 2020) because of the discrepancies that may occur between raters. For example, physicians' ratings of the clinician version of the AES were found to be less accurate when compared to the informant version (AES-I) (Clarke et al., 2007). In that study, it was noted that physicians' training and experiences with the use of apathy scale may have affected the reliability of apathy measurement, and it was recommended that raters of apathy should know the person well or spend sufficient time to observe the person's behaviors prior to assessment. Similarly, Jao et al. (2019) examined the relationships among AES ratings for three raters including families, certified nursing assistants (CNAs) or activity staff, and licensed practical nurses (LPNs). They found that families performed better at apathy ratings than LPNs and CNAs or activity staff. They also noted that family members are knowledgeable about the individual's past behaviors and as a result, were able to accurately detect deviation in behavior. Jao et al. (2019) further recommended that family's input should be sought during assessment of apathy as those affected may not be able to understand or answer some of the questions asked.

Education, training, and experience

Accurate assessment of apathy in clinical settings is dependent on the level of education, training, and experience of the raters (Carrozzino, 2019; Clarke et al., 2007; Drye et al., 2013; Jao et al., 2019). Clarke et al. (2007) alluded to the fact that raters of apathy should obtain a minimum bachelor's degree in health-related field to accurately assess apathy. Jao et al. (2019) argued that registered nurses (RN) are better positioned to assess apathy in long term care facilities than other healthcare staff, including LPNs, CNAs or activity staff, because of their educational attainment (typically four years of formal education) and experiences with clinical assessments. Admittedly, Carrozzino (2019) stated that some researchers who don't have clinical experience tried to increase the value of the alpha coefficient of rating scales by adding as many questions as possible to their rating scales. Unfortunately, this resulted in rating scales with similar or unnecessary questions that do not provide any new clinical information (Carrozzino, 2019). Carrozzino (2019) recommended that clinicians with experience are needed to establish the clinical validity of apathy assessment tools. Furthermore, Clarke et al. (2007) recommended that for healthcare practitioners to accurately assess apathy, they need to have at least a year of experience working with people who have apathy and a minimum of six hours of experience in apathy assessment.

The need to increase awareness through education to overcome the barrier to the optimal intervention for apathy was highlighted by a few studies (Drye et al., 2013; Mele et al., 2019; Leone et al., 2013). As reported by Drye et al. (2013), educating the local community about apathy helped to overcome the barrier to participant's recruitment for their study. Likewise, the focus group study by Mele et al. (2019) corroborated these findings, noting that educating healthcare practitioners about apathy as a symptom distinct from other neurodegenerative disorder, such as Parkinson's disease, may help to increase awareness. Leone et al. (2013) observed that educating long term care staff was effective at raising awareness about apathy and led to a change in staffs' perception that apathy is the least behavioral problem among the other neuropsychiatric symptoms resulting in implementation of evidence-based strategies to mitigate apathy.

Adoption of new and innovative method of screening and intervention

Over the past few years, researchers have come up with different ways to measure apathy. However, these methods are not very useful at detecting apathy optimally because they rely on human observation (Konig et al., 2014). To facilitate more objective measures of apathy, the use of information and communication technologies (ICT) was alluded to by some authors (Konig et al. 2014; Lanctot et al., 2017; Manera et al. 2021). For example, in a narrative review of ICT tools for apathy assessment, Konig et al. (2014) commented that those technologies such as ambulatory actigraphy (a small device containing a piezoelectric accelerometer which tracks motor activity), automatic facial emotion recognition or electrodermal conduction could be better at detecting apathy than the conventional apathy scales including the AES and NPI. In terms of intervention for apathy, technology such as repetitive transcranial magnetic stimulation (rTMS) has been proposed (Lanctot et al., 2017; Tay et al., 2021).

Discussion

Provision of appropriate care in terms of assessment and management of apathy in older people, especially people with comorbidities, such as dementia, stroke, schizophrenia, and Parkinson's disease, can be challenging (Clarke et al., 2007). A clear understanding of the factors that inhibit or facilitate the optimal detection and intervention for apathy is necessary to prevent its negative consequences. As noted by many authors in this review, apathy has only been listed as a symptom in various disorders, including neurological, psychiatric, and medical disorders. The fourth and fifth Diagnostic and Statistical Manual of Mental Disorders (DSM-IV and DSM-V) have not provided a formal definition nor a universally agreed diagnostic criteria for detection and management of apathy in clinical settings (Clarke et al., 2011; Thant & Yager, 2019). It is also not listed as a disease in The International Classification of Diseases 10th Revision (ICD-10) (Drye et al., 2013; Stanton & Carson, 2016). The fact that apathy has not been widely accepted as a clinical condition that requires treatment has likely played a role in why there are varying terms and concepts used to describe it across different fields of study. For instance, in psychiatry, the terms “apathy” and “abulia" are commonly used to describe apathy (Thant & Yager, 2019, p.707). Meanwhile, in psychotic disorders, the terms "negative symptoms" and "avolition" are preferred (Thant & Yager, 2019, p.707). In cannabis and other substance use, personality, depressive, and psychotic disorders, the term "amotivation" is often used (Thant & Yager, 2019, p.707).

In ADHD and some learning disorders, the term "boredom" is more commonly used (Teixeira et al., 2021; Thant & Yager, 2019, p. 707). In the absence of formalized definition and conceptual operationalization of apathy, there continues to be lack of consensus on essential items to include in apathy scales for clinical diagnosis and research studies. Healthcare professionals may continue to face uncertainty over the right type of diagnostic tool to use when measuring apathy (Clarke et al., 2011). Inappropriate selection of apathy measurement scales can lead to inaccurate interpretation of research findings and clinical data and subsequently, flawed conclusions. To mitigate this inaccuracy, Harrison, Aerts and Brodarty, (2016) suggested that a more rigorous approach is needed in evaluating apathy treatments. This includes better documentation of the study population, baseline apathy diagnosis and severity, and the consideration of confounding factors. Additionally, there should be a focus on both clinically and statistically significant effect sizes, utilization of apathy-specific measurement scales, caregiver input, and an adequate study duration to assess the sustainability of treatment effects and detect meaningful improvements (Harrison, Aerts & Brodarty, 2016).

Furthermore, uncertainty over the best tool to select can lead to the abandonment of the existing apathy assessment scales by healthcare practitioners and increase their reliance on self-report or proxy account of apathy (Mele, Goodarzi, Hanson, & Holroyd-Leduc, 2019). Relying solely on family or proxy accounts or self-report of apathy may lead to inconsistent information and impose limits on the treatment provided to people who have apathy (Cummings et al., 2015; Jao, Liu, Williams, Chaudhury & Parajuli, 2019; Mele, Goodarzi, Hanson, & Holroyd-Leduc, 2019). This reinforces the need to develop international consensus on the definition and conceptual operationalization of apathy.

It is well established that apathy plays a critical role in the aspect of maintenance of ADLs, IADL, and quality of life (QoL) (Tierney, Woods, Weinborn, & Bucks, 2018) as older adults with apathy are more likely to have difficulties in carrying out ADL and experience lower QoL than those without even in the absence of mild cognitive impairment or dementia (Tierney et al., 2018). The relationship between apathy and ADLs and QoL was independent of depression. This highlights the need for inclusion of cognitively well older people without depression in research investigating apathy and provision of apathy assessment among older adults experiencing ADL decline.

Although this review identified education and training of healthcare staff as important elements in the optimal detection and intervention for apathy, chances are that apathy will be overlooked by healthcare staff after being trained. This may be due to what Villar, Chacur, Celdrán, and Serrat (2021) referred to as "common practices" (p. 614). Common practices are how staff are managing apathy in their day-to-day practices as opposed to best practices (how they think apathy should be managed) (Villar et al., 2021). Common practices are behavior-focused or no intervention strategies where care staff provide any kind of activity to stimulate people with apathy without considering their needs and personal preferences or ignore the situation and do nothing while best practices are person centered strategies. In their cross-sectional study involving technical staff (nurses, physiotherapists, psychologists, and occupational therapists) and care assistants, Villar et al. (2021) found that even though most health care workers recognize that person-centered care strategies are the best ways to manage apathy, they continue to implement common practices for addressing apathy. This will highlight the importance of considering the staff's previous experiences and common practices when designing training programs (Villar et al., 2021). In other words, reflection-based training should be implemented.

Given the overlap of apathy with other neuropsychiatric and neurodegenerative disorders, the differentiation of apathy from these disorders is essential for a comprehensive and accurate evaluation of apathy. To achieve this, a multidimensional assessment approach has been proposed (Konig et al., 2014). This approach involves utilization of a combination of traditional applied neuropsychological assessment, extensive interviews with family or caregivers, clinical observations, and detailed medical history analysis (Konig et al., 2014). This approach should be complemented using ICT to identify apathy components and relevant associations (Konig et al., 2014, Manera et al., 2021).

Limitations of the study

A limitation of the current literature review is that included studies tended to use focused homogenous samples that consisted of participants who had experienced with a specific health condition such dementia, stroke, and Parkinson's disease. Therefore, the results described in this review may not be generalizable to the healthy older adult, underscoring the importance of including larger and more diverse sample populations. A further limitation includes the gap of in-depth understanding garnered from use of qualitative methodology. Of note, only one qualitative study directly addressed this topic. Some of the findings reported were extracted from either the discussion or limitation sections of the included studies. As a result, the barriers, and facilitators discussed may not be exhaustive.

Clinical Implications

From a clinical perspective, the findings of this study highlight the absence of a unified definition and conceptual operationalization of apathy, both of which should be incorporated into subsequent updates to the Diagnostic and Statistical Manual of Mental Disorders. Specific training/education on apathy assessment should be provided for healthcare staff working with older people including LPNs, CNAs and activity staff on how to accurately detect and manage apathy. For the training to be effective, resources should be standardized and accessible by adopting online format or a blend of online and offline method (Saredakis et al., 2020). Education should also be made freely available for informal caregivers and older adults on how to recognize symptoms of apathy. Since apathy is often associated with depression and dementia, older adults presenting these symptoms should be routinely assessed for apathy. In addition, older adults with decline in functional abilities should be offered assessment for apathy. When assessing apathy in older adults and people with dementia, apathy specific scales such as the AES and LARS, should be considered given that these scales have sufficient reliability, content validity and internal consistency (Burgon et al., 2021). It is worthy of note that medication interventions for apathy should be tailored to the type of disorders associated with apathy as treatment options which are effective in one disorder may not be effective in another disorder (Azhar et al., 2022).

Implications for research

Future research exploring apathy should focus on the efficacy of both pharmacological and non-pharmacological interventions for apathy using a rigorous clinical trial approach (Ferrero-Arias et al., 2011). More qualitative research is needed to increase understanding about individuals' lived experiences of apathy. This may broaden understanding of apathy and help inform consensus on how apathy should be conceptualized and defined (Mele et al., 2019). In addition, longitudinal studies should be considered by future researchers to better understand the pattern of changes in individuals with apathy. This might help in drawing valid conclusions about effective care, preventative interventions, and treatment approaches for those experiencing apathy. In addition, the efficacy of ICT for apathy assessment needs to be further investigated and validated with larger population sizes and stronger methodologies (Konig et al., 2014). An automatized fusion of sensor measurements should be developed to capture all sub symptoms of apathy and provide immediate visual feedback to clinicians, caregivers, and patients (Konig et al., 2014). The integration of early intervention strategies, such as serious games or robotics, with ICT detection of apathy symptoms could further advance the field (Konig et al., 2014).

Recommendations

Based on the findings of this review, the following key recommendations are made to improve the optimal care provision for people with apathy:

- Establish international research and clinical standard on definition and scales for screening, assessment, and diagnosis of apathy.
- Develop a guideline on the prevention, assessment, and treatment of apathy among older adults.
- Carry out a public health program to improve awareness of apathy at a community health level targeting the public and general practice.
- Adopt multidisciplinary approach in the assessment and management of apathy.
- Improve quality of studies, and the range of study methodologies which are accepted as clinically valid (RCTs are not the only reliable option).
- Review the content on apathy in universities offering nursing and medical education subjects to ensure it is up to standard, and if up to standard, utilise it to plan education programs for other stakeholders.

Conclusion

Without a gold standard and universally accepted definition of apathy, its assessment and management remain complex and challenging. The findings of this review suggest that optimal detection and treatment can occur with increased effort at arriving at a consensus in the conceptualization of apathy and recognizing it as both a symptom and a syndrome. Interventions aimed at mitigating apathy for older people should specifically consider addressing these barriers by increasing awareness of the signs and symptoms of apathy as well as enhancing availability and accessibility to educational resources and technologies to support more accurate detection of apathy by healthcare providers.

Chapter Five: Investigating the prevalence and predictors of apathy among the Canadian long-term care residents: A secondary data analysis

This chapter addressed RQ 2 “What is the prevalence and predictors for apathy among the Canadian LTCF residents?” and has been published in the Canadian Journal of Nursing as: Agboji, A., Freeman, S., Banner, D., Armstrong, J., & Martin-Khan, M. (2024). Investigating the Prevalence and Predictors of Apathy among the Canadian Long-Term Care Residents: A Secondary Data Analysis. *The Canadian Journal of Nursing Research = Revue Canadienne De Recherche en Sciences Infirmieres*, *56*(4), 468–482. https://doi.org/10.1177/08445621241276613

Abstract

Background: In LTCF, apathy is a prevalent issue, leading to cognitive decline, functional impairment, and increased mortality risk. Despite its significance, apathy often remains underrecognized and undermanaged in these settings. Recognizing and addressing the predictors of apathy is critical for early intervention and improved care outcomes.

Purpose: This study aims to assess the prevalence of apathy and identify its associated risk factors among newly admitted residents in the Canadian LTCF, using the InterRAI Minimum Data Set (MDS 2.0).

Methods: We conducted a cross-sectional analysis of MDS 2.0 admission assessment data between 2015 and 2019, covering 157,596 residents across six Canadian provinces and one territory. Apathy was measured using the Apathy Index of the MDS 2.0, with the biopsychosocial model guiding the analysis.

Results: The prevalence of apathy was 12.5% (19,758 individuals). The most significant predictors include cognitive impairments, specific age groups, hearing impairments, vision impairments, facility size and location.

Conclusions: The findings of this study underscore the need for tailored strategies in LTCF to address apathy, considering individual, institutional, and regional variations. Emphasis on environmental and personal factors is crucial in the management and prevention of apathy in these settings.

Background & Purpose

In Canada, as in many developed countries, LTCF are vital for supporting individuals with complex health needs that exceed the scope of community-based care (Freeman et al., 2017). LTCF, also known as nursing homes or personal care homes, cater to those who require specialized care due to chronic physical, mental, or other disabilities, which is not typically available through home care or retirement services (Canadian Institute for Health Information [CIHI], 2013). The significance of LTCF in the healthcare system has been growing; in 2013, there were 2,036 LTCF across Canada, with a projection that by 2041, the number of residents requiring these facilities will increase to 320,000. However, by 2020, the number of residents in these facilities had reached 474,000, surpassing the forecasted needs (Statistics Canada, 2022).

Apathy is a complex and multidimensional construct (Marin, 1990; Marin & Wilkosz, 2005; Robert et al., 2018), that is increasingly observed among those in LTCF (Gerritsen et al., 2005; Jao et al., 2018; Roth et al., 2007; Tang et al., 2018). Cognitively, it manifests as diminished intellectual engagement such as a lack of curiosity or motivation to pursue knowledge or engage in problem-solving activities (Le Heron et al., 2018, Robert et al., 2002). Behaviorally, it is characterized by a reduction in goal-directed actions including a decrease in initiated activities, a decline in participation in previously enjoyed activities, or a lack of response to motivational cues (Marin, 1991). Emotionally, apathy leads to a blunted affective response or emotional indifference (Starkstein & Leentjens 2008). Socially, it precipitates a withdrawal from social interactions and activities (Sockeel et al., 2006). Thus, individuals with apathy may manifest one or more symptoms depending on the domains implicated (Marin 1990; Levy & Dubois, 2006; Robert et al., 2018). It is noteworthy that various terms are used to describe apathy in clinical settings, including abulia, negative symptoms, avolition, amotivation, anhedonia and boredom (Thant & Yager, 2019). However, these terms are distinguishable from apathy (Barch et al., 2016). For example, anhedonia is characterized by a diminished capacity to enjoy activities that are usually pleasurable, often appearing as a symptom of depression (Ang et al., 2018; Serreti, 2023). Apathy, in contrast, is marked by a broad disinterest or lack of motivation, without necessarily affecting emotional responses related to pleasure (Fahed & Steffens, 2021).

The prevalence of apathy among LTCF populations has been variably reported in literature, with estimates ranging significantly due to differences in assessment methods and population. For instance, using the Neuropsychiatric Inventory-Nursing Home Version (NPI-NH) to measure apathy, a study involving LTCF residents with Alzheimer's disease (AD) and other dementias observed that 84.1% of residents had apathy (Wood et al., 2000). An observational study which utilized the NH-version of the Apathy Evaluation Scale (AES10) to assess apathy in a sample of LTCF residents with stroke demonstrated that apathy was found in 28% of the individual within this population (van Almenkerk et al., 2015). A comprehensive review found that the frequency of apathy was 69% among 162 residents admitted to LTCF

(Starkstein et al. 2006). In other systematic reviews and meta-analytic studies, it has been reported that 50% of the residents in LTCF have apathy (Leung et al., 2021; Zhao et al., 2017).

Research has consistently shown that apathy contributes to a range of adverse outcomes among LTCF residents, including accelerated cognitive decline, increased dependency in daily activities, and a higher risk of mortality (Aguera-Ortiz et al., 2015; Ayers et al., 2017; Lavretsky et al., 2010; Nijsten et al., 2017; van Reekum et al., 2005). These outcomes not only affect the individuals but also pose challenges for caregivers (formal and informal) and the healthcare system (Jao et al., 2019; Wong et al. 2020). The burden of apathy on caregivers is particularly noteworthy, as it often leads to increased caregiver stress and burnout (Wong et al. 2020). The Canadian healthcare system, with its diverse population and unique healthcare policies (Martin et al., 2018), provides a distinct context for examining apathy.

Despite the significance of apathy among LTCF residents, it is rarely diagnosed or specifically addressed (Nijsten et al., 2023). This oversight can be attributed to several factors. Firstly, there is a lack of standardized, validated tools for apathy assessment and diagnosis among the LTCF population (Agboji et al., 2024; Clarke et al., 2011; Volicer et al., 2013; Miller et al., 2021; Tay et al., 2021). Secondly, symptoms of apathy are often mistakenly attributed to other neuropsychiatric conditions like depression, leading to misdiagnosis and inappropriate management (Jao et al., 2019; Leone et al., 2013). Thirdly, prior research has primarily focused on apathy as a secondary symptom of neurodegenerative diseases including Alzheimer's and Parkinson's (Manera et al., 2020; Roberts et al., 2009; Robert et al., 2018; Jao et al., 2019). However, recent studies suggest that apathy can exist independently (Khan & Watson, 2018; Lopez et al., 2022).

Existing literature suggests that predictors of apathy in the LTCF included a range of demographic, psychological, and social factors (Ang et al., 2018; Cummings et al., 2015; Drye et al., 2013; Robert et al., 2018; Yuen et al., 2014). Variables such as age, cognitive impairment, depression, and physical health status have been implicated, but findings are not consistent across studies (Roberts & Reed, 2019; Singh et al., 2021). For example, in a study by Starkstein et al. (2009), it was found that older age was a risk factor for apathy, whereas, in other studies, it was reported that younger age (age below 65 years) was a predictor of apathy (Appenholf et al., 2019; Jao et al., 2018). By contrast, Holtta et al. (2012) found no differences in age among those who have apathy. With regards to sex, some studies showed that being male was a risk factor (Jao et al., 2020; Vilalta-Franch et al., 2013), while other studies found no relationship between sex and apathy (Clarke et al., 2008; Proitsi et al., 2011; Starkstein et al.,2006). These inconsistencies underscore the need for more targeted research using standardized measures.

To date, a comprehensive study examining the factors that may increase the risks of apathy in the LTCF context is sparse. The purpose of this current study was to examine the prevalence and predictors of apathy among persons living in the Canadian LTCF using the Apathy Index of the MDS 2.0, a standardized tool approved for use in LTCF across Canada.

Methods and Procedures

Study Design

This retrospective cross-sectional study analyzed de-identified data from residents in LTCF, using the MDS 2.0 from the Continuing Care Reporting System (CCRS) database of the Canadian Institute for Health Information (CIHI).

Setting and Sample

We included residents from the Canadian LTCF across six provinces (Alberta, British Columbia, Manitoba, Newfoundland and Labrador, Ontario, and Saskatchewan) and one territory (Yukon) who participated in the admission assessments between 2015 and 2019. Exclusions were residents in comatose states or with missing relevant information.

Data collection

As aforementioned, the MDS 2.0 is a mandated assessment tool used in most Canadian LTCF. It provides comprehensive personal-level information about residents that clinicians may use to inform their decision-making when developing a care plan that reflects the individual's needs, preferences, and strengths (Hirdes et al., 2008). The assessments were completed by trained healthcare staff within 14 days of admission (admission assessment) and quarterly thereafter, involving multiple information sources, including observations and consultations with various healthcare professionals (Hirdes et al., 2008). Built into the MDS 2.0 are the clinical assessment protocols (CAPs), also referred to as outcome scales. The CAPs are used to identify residents who can improve with appropriate care or are at risk of adverse outcomes (Hirdes et al., 2008).

This study incorporated several key scales including Cognitive Performance Scale (CPS), which monitors changes in cognitive status (Hirdes et al., 2008); Activity of Daily Living Self-Performance Hierarchy Scale (ADL-hierarchy), offering insight into the progression of residents' disabilities through ADL performance analysis (Hirdes et al., 2008); the Pressure Ulcer Risk Scale (PURS), aimed at identifying the risk of developing pressure ulcers (Poss et al., 2008); Change in Health, End-Stage Disease, and Signs and Symptoms Scale (CHESS), which evaluates the resident's health instability and aids in predicting mortality (Morris et al., 2012);

the Index of Social Engagement (ISE) measures residents' sense of initiatives and social involvement, and consists of six items, including at ease interacting with others, doing planned or structured activities, doing self-initiated activities; establishes own goals; pursues involvement in the facility's life, and accepting invitations into most groups' activities (Morris et al., 1999); and the Depression Rating Scale (DRS) measuring mood and behavior (Burrows et al., 2005).

Apathy measures

Apathy was measured using two items, termed the Apathy Index of the MDS 2.0, assessing withdrawal from activities and reduced social interactions in line with the framework for apathy assessment proposed by Volicer et al. (2013). These two items were rated on a 3-point Likert scale by the CCRS as follows: 0 = Indicator not exhibited in last 30 days; 1 = Indicator of this type exhibited up to 5 days a week; 2 = Indicator of this type exhibited daily or almost daily (6, 7 days a week). We converted these two items into a dichotomous variable. Thus, a score of 0 indicates non-apathetic and 1 is apathetic. Studies have reported a Cronbach's Alpha coefficient of 0.75-0.89 for this measure indicating a high level of internal consistency (Gerritsen et al., 2008; Stone et al., 2006; Volicer et al., 2013). Additionally, these two items are core symptoms of apathy included in the screening questions of the Neuropsychiatric Inventory (NPI) and have demonstrated a high degree of internal consistency (Cummings et al., 1994). High internal consistency indicates that the items on the apathy index are measuring the same underlying concept of apathy consistently across different assessments.

Data analysis

Data analysis was conducted using SAS version 9.4. (SAS Institute, Cary, NC, USA, 2013). Descriptive statistics described participant characteristics, and simple logistic regression identified apathy predictors. Prevalence was defined as the percentage of LTCF residents with an apathy score of 1. Statistical significance was set at an alpha level of $p < .05$.

Theoretical Framework

Considering the interplay of biological, psychological, and social influences on apathy, the biopsychosocial model served as the theoretical foundation for this study (Bolton & Gillett, 2019; Ghaemi, 2009). Variables were classified accordingly: biological (age, sex, weight, and sensory impairment), psychological (cognitive performance scores), and social (marital status, language, facility size, and facility province) factors.

Results

Sample characteristics

Table 2 presents the sociodemographic characteristics of the study participants. Of the 157,596 residents included in the sample, over half of the population were female (63.5%), 51.1% were aged 85 years or older, 66.6% did not have a partner or spouse (never married, widowed, divorced, or separated), 16% lived alone before admission, 84.9% were English speakers, over two-thirds lived in large LTCF (over 100 beds-Morris et al., 2012) (69.9%), and approximately one quarter entered the facilities from inpatient acute care services (27.9%). Figure 1 shows the diagnosis of the disease in the study population. Over half of the population (62.1%) was diagnosed with dementia. Hypertension was also prevalent, affecting 61% of the population. A small percentage of residents were diagnosed with amyotrophic lateral sclerosis (0.2%), multiple sclerosis (1.1%), Parkinson’s disease (6.6%), manic depressive disorder (1.8%), schizophrenia (2.2%), and traumatic brain injury (1.3%). Additionally, less than a quarter of the population had anxiety disorder (11.5%) and depression (24.1%).

Variables	**Total Population** 100% (N=157,596)	**Apathetic** 12.5% (n=19,758)	**Non-apathetic** 87.6% (n=137,838)
Age at admission (years)			
Less than 65	6.04 (9,519)	14.22 (1,354)	85.78 (8,165)
65-74	11.95 (18,840)	13.90 (2,619)	86.10 (16,221)
75-84	30.95 (48,782)	12.73 (6,209)	87.27 (42,573)
85 and above	51.05 (80,455)	11.90 (9,576)	88.10 (70,879)
Sex			
Female	63.46 (100, 009)	12.05 (12,052)	87.95 (87,957)
Male	36.46 (57,452)	13.39 (7,690)	86.61 (49,762)
Other	0.09 (135)	11.85 (16)	88.15 (119)
Marital status			
Married	29.87 (40,598)	11.87 (4,818)	88.13 (35,780)
Never married/widowed/ separated/divorced	66.61 (90,530)	11.70 (10,590)	88.30 (79,940)
Not specified	3.51 (4,774)	13.57 (648)	86.43 (4,126)
Lived alone before entry to LTCF			
No	84 (124,118)	12.34 (15,322)	87.66 (108,796)
Yes	16 (23,648)	12.50 (2,957)	87.50 (20,691)
Language			
English	84.85 (133,718)	13.06 (17,462)	86.94 (116,256)
French	2.23 (3,509)	11.97 (420)	88.03 (3,089)
Other	12.92 (20,369)	9.21 (1,876)	90.79 (18,493)
Facility size			
Large (100+ beds)	69.78 (109,965)	11.38 (12,513)	88.62 (97,452)
Medium (30-99 beds)	28.00 (44,134)	14.87 (6,561)	85.13 (37,573)
Small (1-29 beds)	2.22 (3,497)	19.56 (684)	80.44 (2,813)
Entry Service Type			
Ambulatory health Service	0.63 (991)	13.22 (131)	86.78 (860)
Inpatient Acute Care Service	27.94 (44,031)	14.96 (6,586)	85.04 (37,445)
Inpatient Rehabilitation Service	1.55 (2,450)	11.67 (286)	88.33 (2,164)
Inpatient Continuing Care Service	6.19 (9,758)	13.12 (1,280)	86.88 (8,478)
Residential Care Service	15.11 (23,808)	14.54 (3,461)	85.46 (20,346)
Inpatient Psychiatric Service	1.15 (1,818)	20.96 (381)	79.04 (1,437)
Other/Unclassified service	0.84 (1,323)	13.38 (177)	86.62 (1,146)
Inpatient Rehabilitation Service-Specialized	0.37 (589)	12.05 (71)	87.95 (518)
Home Care Service	9.78 (15,415)	11.14 (1,717)	88.86 (13,698)

Residential Care Service-board and care	15.35 (24,192)	10.25 (2,479)	89.75 (21,713)
Private Home-no home care	21.08 (33,221)	9.60 (3,189)	90.40 (30,032)
Cognitive Performance Scale (CPS)			
Intact (score = 0)	9.39 (14,796)	7.98 (1,181)	92.02 (13,615)
Borderline Intact (score = 1)	12.30 (19,839)	11.59 (2,247)	88.41 (17,142)
Mild impairment (score = 2)	22.11 (34,837)	10.80 (3,762)	89.20 (31,075)
Moderate impairment (score = 3)	36.88 (58,120)	13.01 (7,560)	86.99 (50,560)
Moderate severe impairment (score = 4)	7.98 (12,583)	14.11 (1,775)	85.89 (10,808)
Severe impairment (score = 5)	8.84 (13,935)	18.43 (2,568)	81.57 (11,367)
Very severe impairment (score = 6)	2.50 (3,936)	16.90 (665)	83.10 (3,271)
Activity of daily living self performance hierarchy scale (ADL-hierarchy)			
Low levels of decline (score = 0-1)	11.80 (18,601)	11.84 (2,202)	88.16 (16,399)
Moderate levels of decline (score = 2-3)	48.41 (76,298)	12.12 (9,248)	87.88 (67,050)
High levels of decline (score = 4-6)	39.78 (62,697)	13.25 (8,308)	86.75 (54,389)
Pressure ulcer risk (PURS)			
Low risk (score = 0-2)	71.99 (113,447)	12 (13,616)	88 (99,831)
Moderate risk (score = 3-5)	27.45 (43,264)	13.82 (5,979)	86.16 (37,285)
High risk (score = 6-8)	0.56 (885)	18.42 (163)	81.58 (722)
Change in Health, End Stage Disease and Signs and Symptoms (CHESS)			
Low levels of medical complexity (score = 0-1)	84.47 (133,115)	11.26 (14,987)	88.74 (118,128)
Moderate levels of medical complexity (score = 2-3)	14.79 (23,303)	18.77 (4,374)	81.23 (18,929)
High levels of medical complexity (score = 4-5)	0.75 (1,178)	33.70 (397)	66.30 (781)
Index of Social engagement (ISE)			

Low levels of engagement (score = 0-1)	20.79 (32,771)	23.33 (7,644)	76.67(25,127)
Moderate levels of engagement (score = 2-3)	40.66 (64,084)	12.20 (7,817)	87.80 (56,267)
High levels of engagement (score = 4-6)	38.54 (60,741)	7.07 (4,297)	92.93 (56,444)
Depression Rating Scale (DRS)			
Low levels of depressive symptoms (score = 0-2)	79.64 (125,509)	9.58 (12,020)	90.42 (113,489)
Moderate levels of depressive symptoms (score = 3-5)	15.61 (24,597)	21.29 (5,237)	78.71 (19,360)
High levels of depressive symptoms (score = 6-14)	4.75 (7,490)	33.39 (2,501)	66.61 (4,989)
Antidepressant use			
No	54.66 (86, 136)	11.30 (9,732)	88.70 (76,404)
Yes	45.34 (71,460)	14.03 (10,026)	85.97 (61,434)

Table 2: Sociodemographic characteristics by status of apathy of residents newly admitted to the Canadian LTCF between 2015 and 2019 (N=157,596).

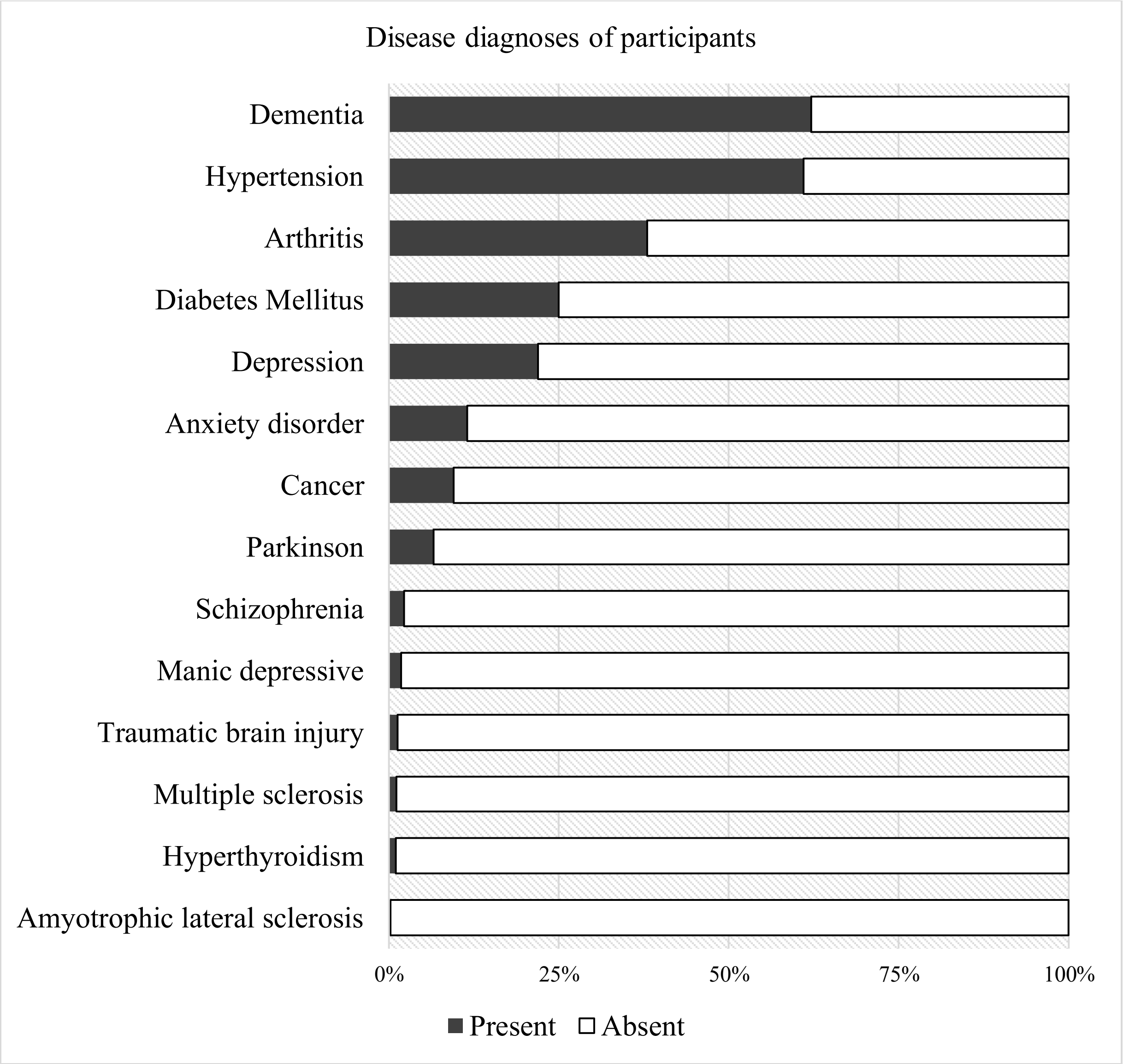


Figure 5: Disease diagnoses of residents newly admitted to the Canadian LTCF between 2015 and 2019 (N=157,596).

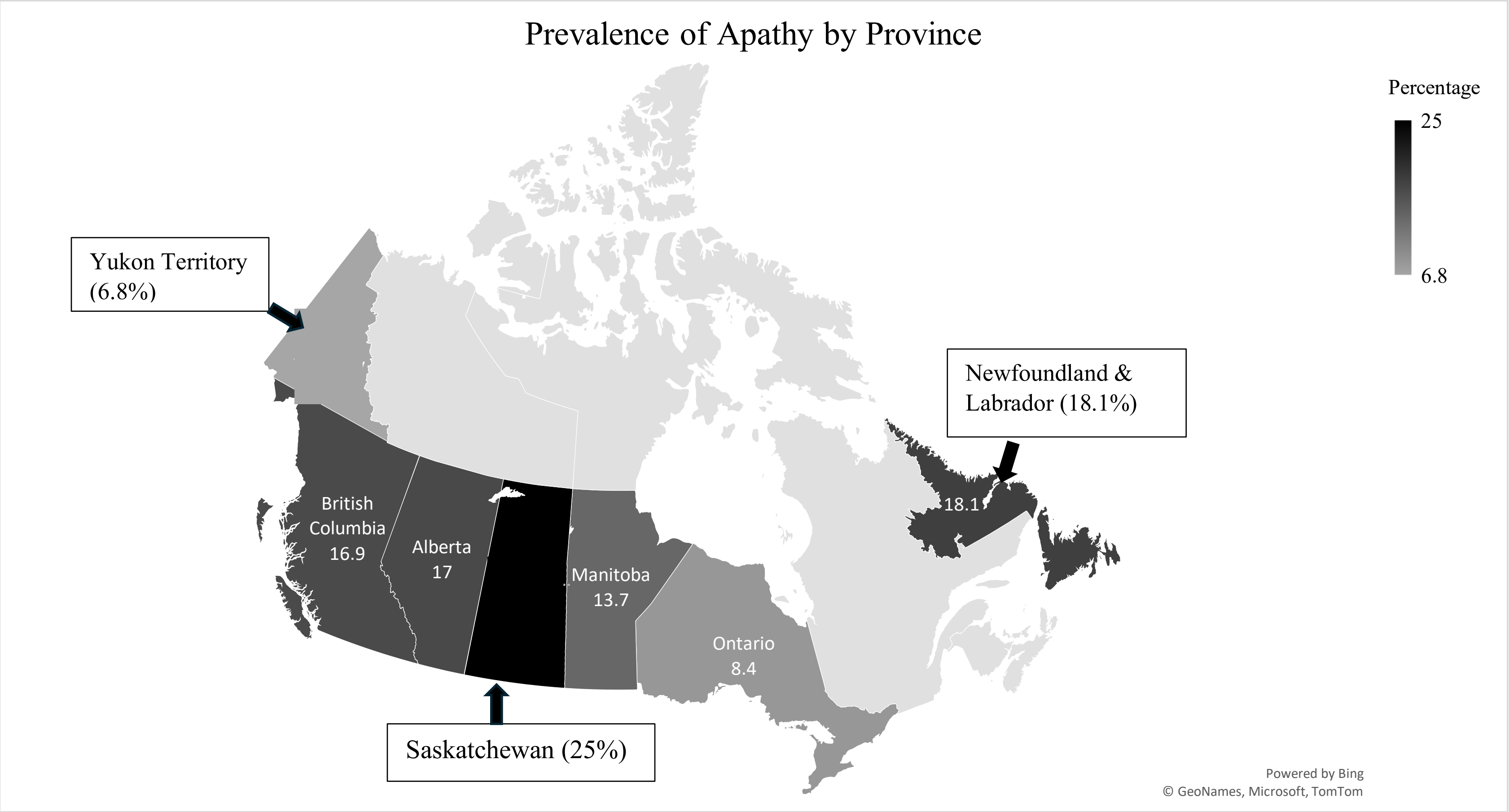


Figure 6: Prevalence of apathy among the newly admitted Canadian LTCF residents by province

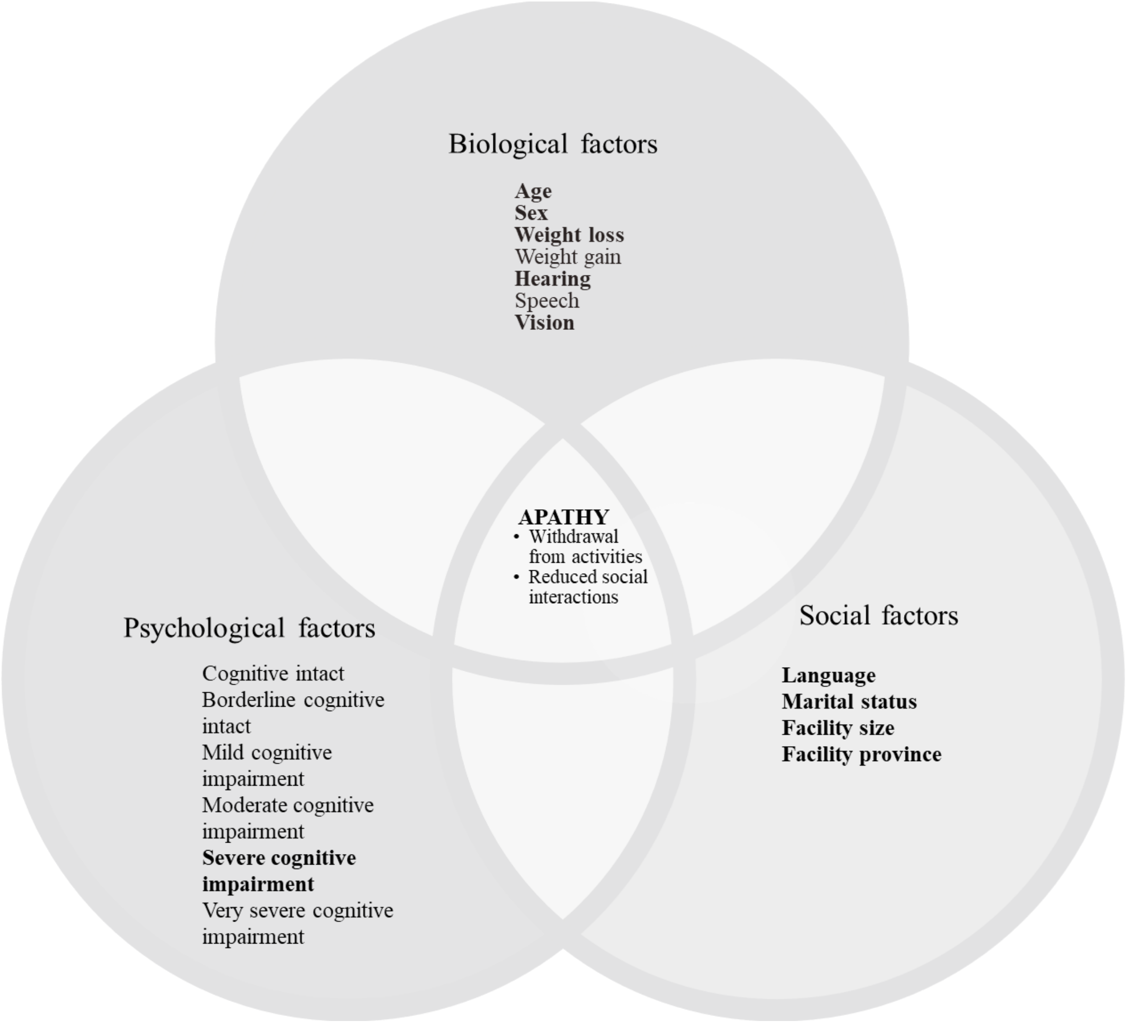


Figure 7: The Biopsychosocial Model of Apathy in LTCF

Prevalence of apathy

The prevalence of apathy among Canadian LTCF residents, as measured by the Apathy Index of the MDS 2.0 was 12.5% (Table 3). The prevalence of apathy was higher among residents who were under 65 years of age (14.2%) than among those aged 85 years and above (11.9%). Apathy was nearly twice as prevalent among residents of small LTCF compared to those residing in large LTCF (19.6% vs. 11.3%). Additionally, geographical region influenced the prevalence of apathy; it ranged from 6.8% in Yukon to 25.6% in Saskatchewan (Figure 6). Apathy was reported by the highest proportion of individuals (21%) entering LTCF via inpatient psychiatric services, as opposed to individuals who entered the facilities via private homes and were not receiving home care (9.6%). Apathy was more frequent among English speakers (13.1%) compared to French speakers (11.8%) and speakers of other languages (9.2%). No significant differences were found between those who lived alone before admission to LTCF and those who did not.

Furthermore, apathy was more prevalent among residents who had a high score (4+, severe impairment) on various outcome scales than among those who had a low score (0-2, low impairment) (Table 2), including the ADLS-hierarchy (13.3% vs. 11.4%), PURS (18.4% vs 12%), CPS (16.9 % vs 10%), DRS (33.4% vs. 9.6%) and CHESS scales (37.7% vs. 11.3%). In addition, the proportion of residents who had a low score on the ISE (0-1, low engagement) and exhibited apathy was higher in comparison with those who had a high score (4+, high engagement) on this item (23.3% vs. 7.1%). Apathy was more prevalent among residents who were using anti-depressants compared to those who did not (14% vs. 11.3%).

Predictors of apathy

Figure 7 shows the theoretical framework for the regression results modelling the predictors of apathy among Canadian LTCF newly admitted residents. With regards to biological variables (Table 2), the predictors of apathy were age groups- less than 65 years of age (OR 1.26 (95% CI 1.16, 1.37), between 65 and 74 years of age (OR 1.30 (95% 1.22, 1.39) and between 75 and 84 years of age (OR 1.11 (95% CI 1.06, 1.16); weight loss (OR 1.49 (95% CI 1.38, 1.2); hearing- minimal difficulty (OR 1.13 (95% CI 1.08, 1.19), hears in special situations (OR 1.19 (95% CI 1.11, 1.26), and highly impaired (OR 1.62 (95% CI 1.41, 1.85); vision- minimal impaired (OR 1.17 (95% CI 1.12, 1.23), moderately impaired (OR 1.39 (95% CI 1.29, 1.50), and severely impaired (OR 1.14 (95% CI 1.11, 1.17). Concerning psychological variables (Table 2), severe cognitive impairment (OR 2.60 (95% CI 2.42,2.28) was the strongest predictor of apathy. With respect to social variables (Table 2), the predictors were French language (OR 1.27 (95% CI 1.15,1.42); unspecified marital status (OR 1.14 (95% CI 1.04, 1.24); medium sized facility (OR 1.18 (95% CI 1.14,1.22), and facility province (Saskatchewan) (OR 1.58 (95% CI 1.49-1.68).

Biological Variables	**Adjusted Odds Ratio** (95% Confidence limits)	**p value**
Sex	Reference = Female	
Male	1.09 (1.04-1.13)	<0.0001
Other (e.g. Hermaphrodite)	1.28 (0.60-2.72)	0.52
Age group	Reference = 85+ years	
Less than 65	1.26 (1.16-1.37)	<0.0001
65-74	1.30 (1.22-1.39)	<0.0001
75-84	1.11 (1.06-1.16)	<0.0001
Weight gain (Reference = No)	1.13 (0.97-1.32)	0.13
Weight loss (Reference = No)	1.49 (1.38-1.62)	<0.0001
Hearing	Reference = Adequate	
Minimal difficulty	1.13 (1.08-1.19)	<0.0001
Hears in special situations	1.19 (1.11-1.26)	<0.0001
Highly impaired	1.62 (1.41-1.85)	<0.0001
Uses speech to communicate (Reference = No)	0.93 (0.83-1.04)	0.20
Vision	Reference = Adequate	
Minimal impaired	1.17 (1.12-1.23)	<0.0001
Moderately impaired	1.39 (1.29-1.50)	<0.0001
Highly impaired	1.04 (0.94-1.15)	0.51
Severely impaired	1.37 (1.18-1.59)	<0.0001
Psychological variables	Reference = Intact	
Borderline intact	1.51 (1.40-1.63)	<0.0001
Mild impairment	1.40 (1.30-1.49)	<0.0001
Moderate impairment	1.72 (1.62-1.84)	<0.0001
Moderate severe impairment	1.89 (1.75-2.05)	<0.0001
Severe impairment	2.60 (2.42-2.80)	<0.0001
Very severe impairment	2.34 (2.12-2.60)	<0.0001
Social Variables		
Primary language	Reference = Eng	
French	1.27 (1.15-1.42)	<0.0001
Other	0.78 (0.74-0.82)	<0.0001
Marital status	Reference = Married	
Never married/widowed/ separated/divorced	0.88 (0.81-0.96)	0.11
Unspecified	1.14 (1.04-1.24)	0.01
Facility size	Reference = Large	
Medium	1.18 (1.14-1.22)	<0.0001
Small	1.11 (0.10-1.23)	0.57
Facility Province	Reference = British Columbia	
Manitoba	0.80 (0.74-0.93)	<0.0001
Newfoundland & Labrador	1.06 (0.98-1.16)	0.24

Ontario	0.46 (0.44-0.48)	<0.0001
Saskatchewan	1.58 (1.49-1.68)	<0.0001
Yukon	0.33 (0.21-0.53)	<0.0001

Table 3: The biopsychosocial predictors of apathy among Canadian LTCFs residents, 2015-2019 fiscal year

Discussion

This study aimed to investigate the prevalence and predictors of apathy among residents of Canadian LTCF. Apathy was present in all age groups and various disorders. The prevalence of apathy as measured by the Apathy Index of the MDS 2.0 was 12.5% among a large sample of the Canadian LTCF residents. This corroborates with previous studies, including a Dutch study involving 199 residents that reported a prevalent rate of 12% (Aalten et al., 2005), a UK study involving 1,419 participants utilizing the Neuropsychiatric Inventory to rate apathy that reported the prevalence of clinically significant apathy to be 21.4% (Sommerlad et al., 2022), and another Dutch study comprising of 290 LTCF residents from nine LTCF which found that the prevalence of apathy was 19% (Wetzels et al., 2010). However, the prevalence rate in the current study was substantially lower than the range of 19-88% as reported in a systematic review and meta-analysis of 25 studies (Zhu et al. 2019) and a study in the Netherlands which found a 28% prevalence of apathy among LTCF residents with stroke (van Almenkerk et al., 2015). The discrepancies in the prevalence rates across studies could be attributed to various factors, including differences in the demographic characteristics of the participants, settings of the studies, and methodologies employed in assessing apathy.

In the current study, the measurement tool used to assess apathy focused only on two items: “withdrawal from activities of interest (e.g., no interest in long-standing activities or being with family, friends)” and “reduced social interaction” (e.g. less talkative, more isolated) (Morris et al. 2012, p.2) suggesting that the behavioral and social domains of apathy were captured while the emotional and cognitive domains of apathy were not accounted for. Nonetheless, in the absence of a comprehensive tool to measure apathy, the Apathy Index of the MDS 2.0 provides an important starting point to increasing awareness about apathy in the Canadian LTCF.

In relation to the prevalence of apathy among different age groups, the current study revealed that apathy was more frequent among residents who were younger than 65 years compared to those in the older age group (85 years and over). This is consistent with previous studies investigating the prevalence of neuropsychiatric symptoms in young-onset dementia (Bauhuis et al., 2020; Mulder et al., 2014; 2016), but in contrast to studies involving persons with advanced dementia (Selbaek et al., 2014; van Reekum et al., 2005; van Vliet et al., 2012; Zuidema et al., 2009). It has been suggested that apathy is one of the primary reasons for institutionalization in individuals with young-onset dementia (Bakker et al., 2013). Early identification of apathy in this age group may be valuable for testing experimental medicines aimed at this syndrome or its associated symptoms (Dujardin et al., 2014).

Furthermore, apathy and depression frequently co-occur, as observed in over half (21.3% with moderate and 33.4% with high scores on DRS) of our sample. While some symptoms overlap between apathy and depression, each condition has distinct characteristics (Levy et al., 1998; Lueken et al., 2007; Starkstein et al., 2005): apathy is marked by blunted emotional response, indifference, low social engagement, diminished initiation, and poor persistence (Ishizaki & Mimura 2011); depression, on the other hand, includes dysphoria, suicidal ideation, self-criticism, guilt feelings, pessimism, and hopelessness (Levy et al., 1998). Furthermore, apathy and depression differ in the brain regions implicated and have different progression patterns (Fahed & Steffens, 2021). This has implication for the use of anti-depressants in this population because treatment with selective serotonin reuptake inhibitor (SSRI) antidepressants may worsen apathy (Masdrakis et al., 2023). In our study, 14% of residents who exhibited apathy were treated with antidepressants.

Regarding the biological predictors of apathy, age emerged as a predictor, demonstrating that younger residents (<65 years) are more likely to be apathetic compared to older age groups. This finding aligns with the results of previous cross-sectional studies (Appenholf et al. 2019; Jao et al. 2018) and appears to be somewhat counterintuitive given that one might expect higher frequencies of apathy in the oldest age group, suggesting that younger residents in LTCF might experience factors that predispose them to apathy, such as early onset dementia or other comorbidities that necessitate long-term care at a younger age or it might be that younger individuals in LTCF might experience greater challenges in adjusting to the institutional environment, leading to higher levels of apathy (Van Malderen et al., 2013). The relatively high prevalence of apathy in the 65-74 and 75-84 age groups emphasizes the need for targeted interventions across different age categories.

In congruence with previous research, male sex was a predictor of apathy (Jao et al., 2020; Vilalta-Franch et al., 2013). This highlights the importance of personalized and sex/gender-sensitive approaches to enhancing the well-being of LTCF residents with apathy. In addition, weight emerged as an important variable, with weight loss associated a higher likelihood of apathy compared to those without. Volicer et al. (2013) noted a similar result, however, due to the cross-sectional nature of this study, it is unclear which came first, the weight change or the apathy and to which direction the temporal sequence may occur. Nonetheless, weight loss management through avoidance of certain medications that increases the risk of anorexia such as psychoactive medications and adequate treatment of medical disorders associated with anorexia including vit B12 deficiency and gastrointestinal disorders, may play a crucial role in mitigating the development of apathy among newly admitted residents in LTCF (Volicer et al., 2013).

Sensory impairments in hearing and vision also emerged as significant predictors. Various levels of hearing impairments (minimal, moderate, and high) were associated with a higher likelihood of apathy than adequate hearing. Similarly, various levels of visual impairment were associated with apathy, with moderately impaired vision showing the highest likelihood (adjusted odds ratio: 1.39; $p<0.0001$). Speech impairment, indicated by an adjusted odds ratio of 1.14 ($p<0.0001$), suggests that residents with speech impairment are more likely to exhibit apathy than those without. This could be attributed to the potential isolation, communication barriers, and resultant reduced social engagement experienced by individuals with speech impairment. Konig et al. (2019) highlighted the efficacy of using speech characteristics, including acoustic, semantic, and prosodic features, as reliable indicators of apathy among individuals with speech impairments. Notable changes in speech, such as flatter intonation and decreased volume, alongside reduced vocabulary, and varied content, mirror the emotional and motivational deficits typical of apathy. Prosodic features such as extended pauses and speech disruptions also indicate apathy-related cognitive and emotional disturbances (Konig et al., 2019). In LTCF, early identification of apathy among residents with speech impairments by integrating automatic speech analysis into routine assessments can enhance care and enable timely intervention. These findings suggest that interventions aimed at improving sensory function might mitigate apathy in this population.

In terms of psychological factors, this current study showed that cognitive performance, as measured by CPS, has a significant association with apathy among newly admitted Canadian LTCF residents. This association was stronger for all levels of cognitive impairment. The early recognition of high cognitive performance scores could be instrumental in implementing early interventions and tailoring care plans for residents in LTCF. More importantly, interventions aimed at stimulating and supporting executive functions may be beneficial in mitigating the progression of apathy (Drijgers et al., 2011). Additionally, considering that apathy is associated with poor initiation, structured, and guided activities that encourage participation and engagement without relying heavily on self-initiation might be effective in promoting social interaction and mental stimulation among LTCF residents (Drijgers et al., 2011). Evidence also suggests that the presence of apathy is a potential risk factor for conversion to dementia in people with mild cognitive impairment (Lanctôt et al., 2017; Robert et al. 2006; van Dalen et al., 2018). The progression from mild to severe cognitive impairment showing a graded increase in the odds of apathy underscores the importance of early cognitive interventions and continuous monitoring to manage apathy effectively.

Social factors play an important role in predicting apathy. In this study, language, particularly French, shows a statistically significant association with apathy, with adjusted odds ratio 1.27 ($p<0.0001$), indicating that residents who speak this language are more likely to exhibit apathy compared to those speaking English language. This suggests that linguistic and possibly cultural factors may play a role in the display or recognition of apathy among LTCF residents. Further, our findings suggests that those who speak other languages are at lower odds of exhibiting apathy (adjusted odds ratio: 0.78; $p<0.0001$). This underscores the importance of language concordance (Hsueh et al., 2021) in the recognition of apathy among speakers of other languages in LTCF. It would be insightful to explore whether these associations are influenced by factors such as communication barriers, social integration, cultural perceptions of mental health, and emotional expression. Additionally, marital status impacts apathy, with those of unspecified marital status showing higher odds compared to residents who were married. This may point to the complexities of social support systems and their influence on residents' health outcomes.

Facility size also emerged as a crucial predictor, with medium sized facility associated with a higher likelihood of apathy (adjusted odds ratio 1.18, $p<0.0001$) compared to large sized facility, which might be due to differences in the availability of resources and activities (Zimmerman et al., 2005). The relationship between institutional environment and apathy is well documented (Chaudhury et al., 2017; Jao et al. 2015; 2019). This finding also aligns with the broader literature highlighting the protective effects of personalized care on apathy (Zuidema et al., 2010). Smaller facilities may facilitate more personalized care due to a lower staff-to-resident ratio (Zuidema et al., 2010). This personalized attention can be pivotal in recognizing and addressing early signs of apathy. In contrast, medium and larger facilities, despite having more resources, might struggle with providing individualized care to the same extent.

Furthermore, the province of the facilities emerged as a notable predictor of apathy, with residents in Manitoba, Ontario, and Yukon showing statistically significant lower likelihood of apathy while those in Saskatchewan demonstrating a higher likelihood of apathy compared to residents in British Columbia. This finding highlights the importance of considering geographical differences when developing interventions for apathy rather than just focusing on individual and institutional factors because geographical variation could be influenced by various factors, such as differences in healthcare policies, and socio-cultural contexts across provinces. This finding warrants further exploration to better understand the underlying mechanisms.

Implication for practice/policy

In this study, apathy was examined from a biopsychosocial perspective, and the results of our findings showed that various biological, psychological, and social factors are associated with apathy among residents in LTCF. To this end, health care professionals and policymakers should consider the following:

- Create an awareness campaign about apathy at the institutional, provincial, and national levels.
- Develop a standard assessment tool for evaluating apathy in LTCF that considers the needs and preferences of younger people.
- Screen for apathy in all residents presenting with high cognitive performance scores using both systematic speech analysis and apathy screening tools to enhance early detection of apathy.
- Incorporate technology-based meaningful activities into existing programs to keep residents engaged during the day while simultaneously preventing additional workloads for care staff.

Strengths and limitations of the study

This study has several strengths, including the use of a large population sample, which is representative of the LTCF population. This enhances the generalizability of the findings across Canadian populations and provides a solid cross-section of apathy within the LTCF. Additionally, the results indicated that the prevalence of apathy among Canadian LTCF residents is comparable to existing studies, signifying the utility of the apathy index in the early detection of apathy among this population. This study also provides a thorough and multifaceted exploration of predictors of apathy, encompassing biological, psychological, and social factors, and offers a holistic view of the factors influencing apathy among LTCF residents.

While this study was the first to investigate the prevalence of apathy among a very large sample of residents across Canadian LTCF, using data from the MDS 2.0, a validated tool approved for use in all healthcare settings across Canada, not all provinces and territories are included. This suggests that caution should be exercised when generalizing the results to all the provinces and territories in Canada. Furthermore, the use of this data, which is not primarily for clinical diagnosis or research purposes, might have made it difficult to examine more nuanced relationships between apathy and the various variables included in this study. Future studies should adopt a more rigorous methodology to examine these relationships.

Conclusion

This study examined the prevalence and predictors of apathy among residents of Canadian LTCF. The study found a complex interaction between apathy and various biological, psychological, and social factors. Apathy was found to be associated with biological indicators such as age, weight loss, and sensory deficits, highlighting the complicated relationship between apathy and physical health of LTCF residents. Psychological factors, particularly cognitive impairment, have a complex relationship with apathy. Severe cognitive impairment was associated with the highest risk for apathy than very severe impairment. This indicates that cognitive function and apathy are not linearly related. The study also found that marital status, facility size, and facility province were significantly associated with apathy. This highlights the impact of social settings and relationships on LTCF residents' well-being. Apathy was also predicted by language underscoring the importance of efficient communication and meaningful social interactions for preventing apathy.

Given these findings, a comprehensive and individual-focused approach to address and reduce apathy LTCF is essential. Interventions must address the physical, social, and psychological wellbeing of residents with apathy. Future research should examine the qualitative aspects of social connections and activity engagement, as well as their interactions with biological and psychological parameters, to better understand how they affect apathy in LTCF residents. This may help to develop approaches and interventions to improve the quality of life and well-being of LTCF residents. It is important to note that facility province was a strong predictor of apathy, and to the best of the author’s knowledge, no research has explored this factor. Future studies should expand this factor and explore more effective interventions to mitigate apathy at the provincial level.

Chapter Six: The Prevalence and Risk Factors of Apathy among the Canadian Long-Term Care Residents with Alzheimer’s Disease and Related Dementias

This chapter addressed RQ 3 “What is the prevalence and risk factors for apathy among the Canadian LTCF residents with dementia?” and has been published in the Journal of Alzheimer’s Disease as:

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Abstract

Background: Apathy is a prevalent and debilitating neuropsychiatric symptom among persons living with Alzheimer's disease and related dementias, particularly those residing in LTCF. Despite its profound effects on the quality of life for both residents and their caregivers, apathy remains underrecognized and poorly understood in the context of dementia care.

Objective: To investigate the prevalence and biopsychosocial characteristics of apathy among newly admitted residents with dementia in Canadian LTCF using an Apathy Index derived from the interRAI Minimum Data Set (MDS) 2.0.

Methods: This cross-sectional study analyzed data from newly admitted residents with dementia from various LTCF (N=97,789) across seven Canadian provinces between 2015 and 2019. Logistic regression analysis was performed to determine the relationship between apathy and multiple variables including sociodemographic and clinical variables. The biopsychosocial model of health was used to guide analysis.

Results: The prevalence rate of apathy among the Canadian long-term care residents with Alzheimer’s disease and related dementias was 13.1%. Apathy was associated with various variables including male sex, pain, use of psychotropics, high ADL-hierarchy scores, depression, aggression, severe cognitive impairment, and insomnia. Preferences for certain activities such as card games, art and craft, reading, music and exercise were inversely related to apathy while gardening was not.

Conclusions: By shedding light on this complex phenomenon within a Canadian context, we recommend that targeted interventions and improved care strategies to enhance the well-being of persons living with dementia should be prioritized in LTCF.

Introduction

Dementia, a chronic and progressive syndrome characterized by cognitive impairment and functional decline, poses a significant public health challenge in the twenty-first century. It affects over 47 million people worldwide and as the global population ages, it is anticipated that the prevalence of dementia will triple by 2050 (World Health Organization [WHO], 2019). which will have significant implications for healthcare systems worldwide. A report by the Alzheimer Society of Canada (2020) estimated that 564,000 Canadians were living with dementia in 2020. This number is expected to increase to 937,000 by 2031. This escalating trend highlights the need for extensive research into the various facets of dementia, including its lesser known but equally debilitating symptom, apathy.

Apathy, marked by reduction in motivation or interest, goal-directed actions, affect and/o social interactions, is one of the most prevalent and clinically significant behavioral symptoms observed in people living with dementia, especially those in LTCF (Robert et al., 2009; Brodaty & Burns, 2012; Ginsberg et al., 2017; Robert et al., 2006; Robert et al., 2012; Massimo et al., 2018; van Reekum et al., 2005). The prevalent rates of apathy among people living with dementia vary ranging between 12% and 100% depending on a few factors including methodologies for apathy assessment, severity of dementia and co-morbidities (Aarsland et al., 2009; Diehl-Schmid et al., 2006; Leung et al., 2021; Peavy et al., 2013). In a US study, for instance, it was observed that 84.1% of LTCFs' residents with dementia had apathy (Wood et al., 2000). A comprehensive review found that the frequency of apathy was 27% among community dwelling population of 329 individuals without dementia and 69% among 162 residents with dementia admitted to a specialized dementia unit (Starkstein et al., 2006). A German study also showed that 7% of cognitively intact residents, 8% of those with mild cognitive impairment, and 85% of residents with dementia exhibited apathetic behaviors (Leuken et al., 2007). In a cross-sectional, observational study carried out in the Netherland which involved a sample of LTCF residents with stroke, the result demonstrated that apathy was prevalent in 28% of this population (van Almenkerk et al., 2015). Tagariello (2009) also reviewed the literature on apathy (but didn't include the previous studies) in dementia and noted that it is the most common neuropsychiatric syndrome in Alzheimer's disease, affecting 19-76% of residents, and difficult to distinguish from depression.

Studies have investigated the association between apathy and various neuropsychiatric symptoms such as depression (Ang et al., 2018; Batail et al., 2018; van Almenkerk et al., 2015), anhedonia (Ang et al., 2018), fatigue (Daumas et al., 2022; Kuppuswamy, 2017), and agitation (Mouriz-Corbelle et al., 2021) among LTCF residents with dementia but the results are mixed. For example, a study involving people with Alzheimer's dementia found that apathy is strongly associated with depression (Starkstein et al., 2006). In contrast, another study reported that apathy is not clinically significantly associated with depression (van Almenkerk et al., 2015). Additionally, a study by Jao et al. (2019) examining the relationship among apathy, depression and agitation, no relationship was found between apathy and these disorders. Furthermore, certain contextual factors have been linked with apathy among LTCF residents with dementia. For example, Jao et al. (2015) found that care environments with clear and sufficient stimulation were significantly associated with lower resident apathy levels. Engagement in activities has also been inversely associated with apathy in dementia, indicating that increased activity participation among residents leads to reduced symptoms of apathy (Ellis et al., 2016). Vilalta-Franch (2012) identified the use of antipsychotic medication as the sole risk factor for apathy in dementia. Moreover, persons living with dementia who resided with someone other than their spouses were found to be more susceptible to apathy compared to those living with their spouses (Clarke et al., 2008).

Despite the significance of apathy among residents living with dementia, its associative characteristics are still not entirely understood (Massimo et al., 2018). More importantly, research on apathy among the Canadian LTCF residents with dementia is limited. Further, while existing studies have primarily focused on the neurobiological underpinnings of apathy in dementia, including changes in specific brain regions and neurotransmitter systems (Mortby et al., 2018; Steffens et al., 2022), a comprehensive study linking resident-related biological, psychological, and social characteristics that increase the risk of apathy is lacking. Additionally, most studies did not prioritize apathy as the focus, and research examining factors associated with apathy in dementia, distinct from depression or other behavioural issues, remains scarce (Lanctot et al., 2023; Parrotta et al., 2023). These gaps underscore the need for a more holistic investigation into apathy in dementia among LTCF residents, particularly in the Canadian context given its diverse population and unique healthcare policies (Martin et al., 2018). The purpose of this study was to examine through the lens of the biopsychosocial model of care (Engel, 1977), the prevalence and the associative biopsychosocial characteristics of apathy among the Canadian LTCF residents with dementia (Alzheimer and non-Alzheimer), drawing from the MDS 2.0 dataset. Such research is instrumental to inform design of targeted interventions and clinical practice guidelines to best identify, manage, and possibly prevent apathy in this population.

Materials and Methods

Settings and Participants

This cross-sectional study used secondary data derived from MDS 2.0 dataset collected through the Continuing Care Reporting System (CCRS) at the Canadian Institute of Health Information (CIHI) across six provinces (Alberta, British Columbia, Manitoba, Nova Scotia, Saskatchewan, and Ontario) and one Territory (Yukon) in Canada (N=97,786). The MDS 2.0 is a mandated standardized assessment instrument for use in most LTCF across Canada and provides comprehensive personal-level information about residents that informs decision-making in developing a care plan that reflects their needs, preferences, and strengths (Hirdes et al., 2011). The assessment is completed by trained healthcare staff (usually staff nurses) using information from multiple sources including observation, resident interview, medical records, and consultation with team members and other healthcare professionals, including attending physicians, social workers, physical, occupational, speech, or recreation therapists, dieticians, and pharmacists (Freeman et al., 2017; Hirdes et al., 2011).

Embedded in the MDS 2.0 are the outcome scales, also known as clinical assessment protocols (CAPs). Included in this study are the Cognitive Performance Scale (CPS) which monitors changes in cognitive status (Hirdes et al., 2008), and consisted of five items including comatose, short-term memory, cognitive skills for daily decision making, express communication and eating (CIHI, 2013). The score ranges from 0-6. This score was recoded into three groupings: 0-1 (no/mild impairment), 2-3 (moderate impairment) and 4-6 (severe impairment) (Carpenter, 2006; Fredericksen et al., 1996; Hartmaier et al., 1995; McConnell et al., 2002; Morris et al., 2012), the Depression Rating Scale (DRS) assesses mood and behavior (Perlman & Hirdes, 2008). The DRS comprises of seven items including negative statements, persistent anger, expression of unrealistic fears, repetitive health complaints, repetitive anxious complaints, sad, pained, worried facial expression; and crying and tearfulness. The score on this scale ranges from 0-14. This was recoded into 3 levels: 0-2 (no/mild), 3-5 (moderate), and 6-14 (severe) (Burrows et al., 2000). A score of 3 or more on the DRS may indicate a potential or actual depression symptoms (Hirdes et al., 2008); the Activity of Daily Living Self-Performance Hierarchy Scale (ADL-hierarchy) reflects the process of resident's disability by grouping ADL performance into different stages: early loss (personal hygiene), middle loss (toileting and locomotion), and late loss (eating) (Morris et al., 2013). The score ranges from 0 (independent) to 6 (total dependence). The score was recoded as 0-1 (no loss), 2-3 (moderate loss) and 4-6 (severe loss); the Aggressive Behavior Scale (ABS) measures aggression, and includes four items-verbally abusive, physically abusive, socially inappropriate/disruptive behavior and resists care (Hirdes et al., 2008). The score ranges from 0-12 (Freeman et al., 2017). This score was recoded into three categories: 0-2 (no/mild), 3-5 (moderate) and 6-12 (severe), and the pain scale which measures the frequency and intensity of pain among the residents. The scores range from 0 to 3 with higher values indicating severe pain (Fries et al., 2001; Zyczkowska et al., 2007).

The sample for this study included residents diagnosed with dementia who participated in the admission assessments of the MDS 2.0 between April 2015 and March 2019. Excluded from the study were residents with missing data, those in a comatose state, or those without dementia diagnosis. Selection of variables was based primarily on the definition of each component of the biopsychosocial model of care as proposed by Engel (1977), availability of variables, gaps identified in extant literature and co-morbidities of dementia such as depression, anxiety, and cognition (Johansson et al., 2020; Levy et al., 1998; Starkstein et al., 2006). In the MDS 2.0 assessment, the diagnosis of dementia and comorbidities is based on the International Statistical Classification of Diseases and Related Health Problems (ICD-10) as published by the World Health Organization (WHO) (CIHI, 2018).

Apathy measures

We used two items from the MDS 2.0, heretofore referred to as the Apathy Index to measure apathy. Each of these two items were originally scored by CCRS as follows: 0 = Indicator not exhibited in last 30 days; 1 = Indicator of this type exhibited up to 5 days a week; 2 = Indicator of this type exhibited daily or almost daily (6, 7 days a week). We converted these two items into a dichotomous variable. Thus, a score of 0 indicates non-apathetic and 1 is apathetic. This classification is based on the framework for apathy assessment proposed by Volicer et al. (2013) which they referred to as the 'Apathy Scale'. According to Volicer et al. (2013), the Apathy Scale measures apathy by focusing on two specific items from the MDS 2.0 including withdrawal from activities of interest and reduced social interaction. In this study, apathy was conceptualized as the presence of one or both two items suggesting that a score of 0 is non-apathetic and 1 is apathetic. The study further cited the reliability of the apathy scale as alpha values of 0.88 to 0.89. These values suggest a high level of internal consistency for the items measuring apathy within the MDS 2.0 meaning that it measures the same underlying concept of apathy consistently across different assessments. Additionally, these two items are core symptoms of apathy included in the screening questions of the Neuropsychiatric Inventory and have also demonstrated a high degree of internal consistency (Cummings et al., 1994).

Utilizing instruments that assess one or more domains of apathy can potentially enhance targeted treatment of apathy in dementia residents (Massimo et al., 2018).

Theoretical framework

Taking into account the combined effects of biological, psychological, and social factors on apathy, this study was grounded in the biopsychosocial model as its theoretical basis (Engel, 1977; Bolton & Gillett, 2019; Ghaemi, 2009; Tripathi et al., 2019). As highlighted by Engel (1977), biological factors encompass genetic influences, neurochemical processes, and other physiological aspects that contribute to the development and maintenance of health and disease; psychological factors relate to an individual's mental processes and behavior that influence health and disease, and social factors refer to the broad range of influences stemming from the societal and environmental context in which individuals live. Accordingly, variables were categorized as follows: biological (age, sex, pain, use of psychotropic medications and ADL-hierarchy), psychological (DRS, CPS, ABS, insomnia, and wandering), and social (language, marital status, and activity preferences) variables.

Statistical analyses

Analysis of data involved the use of SAS software version 9.4. (SAS Institute, 2013). Descriptive statistics were conducted to describe the characteristics of the study sample. Bivariate analyses used chi-square to determine the significance of the relationship of apathy with various variables based on findings from existing literature or gaps identified in the literature. Logistic regression was conducted to determine the association between apathy and various variables that are associated with apathy in dementia. The prevalence of apathy was defined as the percentage of LTCF residents with dementia with an apathy score of 1. An alpha level of $p < 0.05$ was considered statistically significant.

Results

Table 4 shows the socio-demographics of the study sample. Out of the total sample of 97,786, most were residents with non-Alzheimer's dementia (82%, n=80,170). More than half of the sample were female (64%) and 53% were aged 85 years and older, 64% were never married/widowed/divorced/separated, 14% lived alone before admission, 84% were English speakers, 70% lived in a large LTCF (over 100 beds), and the majority lived in Ontario (57%). Over two-thirds participated in the assessment (79%), 66% were prescribed psychotropic (anti-depressants, hypnotics, anti-anxiety, and anti-psychotic) medications and 24% experienced mild pain. Residents have various comorbidities of neuropsychiatric disorders including depression (24%), anxiety disorders (11.5%), Parkinson's disease (5.8%), multiple sclerosis (0.3%), Huntington's chorea (0.1%), amyotrophic lateral sclerosis (0.1%), manic depressive (1.4%), schizophrenia (1.3%) and traumatic brain injury (0.9%).

Figure 8 shows the activity preferences of the study sample. Majority of the residents preferred listening to music (79%) to other types of activities including talking (78%), watching TV (65%), exercise (43%), card games (36%), spiritual activities (36%), reading (31%), art and craft (23%), trips (15%), gardening (14%), helping others (13%), and walking (4%).

Prevalence of apathy

The prevalence of apathy among LTCF residents with dementia was 13.1% (n=12,818). Apathy was more prevalent among residents who were younger than 65 years of age compared to those who were 85 years and over (17% vs 12%, p = <0.0001). English speakers exhibited a higher prevalence of apathy compared to residents speaking other languages (14% vs 10%, p = <0.0001). The prevalence rate of apathy was higher among residents living in small LTCF compared to those in large LTCF (20% vs 12%, p = <0.0001). No significant difference was found in the prevalence of apathy between residents who lived alone before admission and those who lived with a spouse or family (13% vs 13%, p = 0.40). Apathy was slightly more frequent among residents who exhibited wandering behaviors compared to those who did not (14% vs 13%, p = 0.03). The prevalence of apathy was higher among residents who experienced severe pain compared to those with no pain symptoms (25% vs 12%), and residents who exhibited insomnia daily showed a higher prevalence of apathy compared to those who did not (30% vs 12%).

Those who indicated preferences for various types of activities have a lower frequency of apathy than those who did not (Figure 8). These activities included card games (10% vs 15%, p = <0.0001), helping others (8% vs 14%, p = <0.0001), exercise (9% vs 14%, p = <0.0001), trips (9% vs 14 %, p = <0.0001), art and craft (9% vs 14%, p = <0.0001), spiritual activities (10% vs 15%, p = <0.0001), gardening (10% vs 13%), reading (10% vs 14%, p = <0.0001) , walking (10% vs 15%, p = <0.0001), talking (11% vs 19%, p = <0.0001), music (11% vs 20%, p = <0.0001), and watching TV (12% vs 17%, p = <0.0001). When stratified by cognitive performance (supplementary table), apathy prevalence across different activities increases with the severity of cognitive impairment.

Residents who were diagnosed with co-morbid neuropsychiatric disorders showed a higher prevalence of apathy than those without these disorders including depression (15 % vs 13%, p = <0.0001), anxiety (15% vs 13%, p = <0.0001), manic depressive (15% vs 13%, p = 0.08), schizophrenia (16% vs 13%, p = 0.0009), and traumatic brain injury (17% vs 13%, p = 0.02) and Huntington's chorea (19.3% vs 14.8%, p=0.10). However, apathy was slightly less frequent among those with co-morbid certain types of neurodegenerative diseases than those without, but the results were statistically insignificant. These included multiple sclerosis (13% vs

13.1%, p = 0.87), Parkinson's disease (12% vs 13%, 0.08), and amyotrophic lateral sclerosis (12% vs 13%, p = 0.85).

Biopsychosocial characteristics of apathy in dementia

Table 5 displays the variables that were associated with apathy. Following the biopsychosocial model of care as a theoretical framework to guide analysis, biologically, the characteristics associated with apathy were male sex (odds ratio [OR] = 1.13, 95% confidence interval [CI]:1.09-1.18, p<0.0001), pain (OR = 1.16, 95% CI: 1.11-1.21, p < 0.0001 for mild; OR = 1.72, 95% CI: 1.66-1.88, p < 0.0001 for moderate; OR = 2.44, 95% CI: 2.07-2.87, p<0.0001 for severe), use of psychotropics (OR = 1.39, 95% CI: 1.00-1.14, p<0.0001) and high ADL-hierarchy score (OR = 1.07, 95% C1: 1.00-1.114, p = 0.439) . Among the psychological variables, depression (OR = 2.05, 95% CI: 1.95-2.14, p<0.0001 for moderate; OR = 3.24, 95% CI: 3.03-3.46, p<0.0001 for severe), aggression (OR = 1.37, 95% CI: 1.30-1.44, p < 0.0001 for moderate; OR = 1.51, 95% CI: 1.41-1.62, p<0.0001 for severe), severe cognitive impairment (OR = 1.15, 95% CI: 1.06-1.24, p = 0.0009) and insomnia (OR = 1.14, 95% CI: 1.34-1.48 for exhibited up to 5 days; OR = 2.0, 95% CI: 1.80-2.23 for exhibited daily, p<0.0001). In relation to social variables, the analysis demonstrated that preferences for certain activities except gardening were inversely associated with apathy (all p<0.0001).

	Total Population 100% (N=97,786)	**Apathetic** 13.1% (n=12,818)	**Non-Apathetic** 86.9% (n=84,968)	**p value**
Dementia types				
Alzheimer	18 (17,616)	12.3 (2,173)	87.7 (15,443)	0.01
Non-Alzheimer	82 (80,170)	13.3 (10,645)	86.7 (69,525)	
Age at admission				
Less than 65 years	2.7 (2,652)	16.8 (445)	83.2 (2,207)	<0.0001
65-74 years	10.1 (9,859)	15.5 (1,527)	84.5 (8,332)	
75-84 years	33.9 (33,119)	13.2 (4,374)	86.8 (28,745)	
85 years and over	53.3 (52,156)	12.4 (6,472)	87.6 (45,684)	
Sex				
Female	64.3 (62,861)	12.6 (7,925)	87.4 (54,936)	<0.0001
Male	35.6 (34,838)	14 (4,885)	86 (29,953)	
Other	0.1 (87)	9.2 (8)	90.8 (79)	
Marital status				
Married	32.8 (27,913)	12.3 (3,441)	87.7 (24,472)	<0.0001
Never married/widowed/ separated/divorced	63.9 (54,458)	12 (6,555)	88 (47,903)	
Not specified	3.4 (2,851)	13.5 (385)	86.5 (385)	
Lived alone before entry to LTCF				
No	86.2 (79,231)	12.9 (10,238)	86.3 (68,993)	0.40
Yes	13.8 (12,675)	13.2 (1,672)	86.8 (11,003)	
Province of LTCF				
Alberta	12.1 (11,861)	19.5 (2,309)	80.5 (9,552)	
British Columbia	19.2 (18,896)	17.6 (3,319)	82.4 (15,677)	<0.0001
Manitoba	4.6 (4,479)	14.5 (651)	85.5 (3,828)	
Newfoundland and Labrador	2 (1,988)	19.7 (391)	80.3 (1,597)	
Ontario	57.2 (55,969)	8.9 (4,977)	91.1 (50,992)	
Saskatchewan	4.6 (4,464)	26 (1,160)	74 (3,304)	
Yukon	0.1 (129)	8.5 (11)	91.5 (118)	
Language				
English	84.4 (82,549)	13.7 (11,271)	86.4 (82,549)	<0.0001
French	2.4 (2,345)	12.1 (284)	87.9 (2,061)	
Other	13.2 (12,892)	9.8 (1,263)	90.2 (11,629)	

Facility size				
Large (100+ beds)	70.8 (69,244)	12.2 (8,321)	88 (60,923)	<0.0001
Medium (30-99 beds)	27.2 (26,625)	15.5 (4,115)	84.5 (22,510)	
Small (1-29 beds)	2 (1,917)	19.9 (382)	80.1 (1,535)	
Insomnia				
Not exhibited in the last 30days	83.9 (81,962)	11.5 (9,429)	88.5 (72,533)	<0.0001
Exhibited up to 5 days per week	14.3 (13,983)	20.3 (2,833)	79.7 (11,150)	
Exhibited daily or almost daily	1.9 (1,841)	30.2 (556)	69.8 (1,285)	
Wandering				
No	86.1 (84,168)	13 (10,958))	87 (73,214)	0.031
Yes	13.9 (13,618)	13.7 (1,864)	86.3 (11,754)	
PAIN				
No pain (0)	67.9 (66,421)	12 (7,989)	88 (58,432)	<0.0001
Mild (1)	23.7 (23,156)	13.7 (3,179)	86.3 (19,977)	
Moderate (2)	7.6 (7,427)	19.5 (1,451)	80.5 (5,976)	
Severe (3)	0.8 (782)	25.4 (199)	74.6 (583)	
Use psychotropic medications				
No	33.9 (33,163)	10.5 (3,486)	89.5 (29,677)	<0.0001
Yes	66.1 (64,623)	14.4 (9,332)	85.6 (55,291)	
Resident’s participation in assessment				
No	22 (21,493)	18.5 (3,977)	81.5 (17,516)	<0.0001
Yes	78 (76,293)	11.6 (8,841)	86.4 (67,452)	
Comorbidities				
Depression				
No	75.8 (74,119)	12.5 (9,234)	87.5 (64,885)	<0.0001
Yes	24.2 (23,667)	15.1 (3,584)	84.9 (20,083)	
Anxiety disorders				
No	88.5 (86,497)	12.9 (11,126)	87.1 (75,371)	<0.0001
Yes	11.5 (11,289)	15 (1,692)	85 (9,597)	
Parkinson’s disease				
No	94.2 (92,099)	13.2 (12,116)	86.8 (79,983)	0.08
Yes	5.8 (5,687)	12.3 (702)	87.7 (4,985)	
Multiple sclerosis				
No	99.7 (97,481)	13.1 (12,779)	86.9 (84,702)	0.87
Yes	0.3 (305)	12.8 (39)	87.2 (266)	

Amyotrophic lateral sclerosis				
No	99.9 (97,721)	13.1 (12,810)	86.9 (84,911)	0.85
Yes	0.1 (65)	12.3 (8)	87.7 (57)	
Huntington’s chorea				
No	99.9 (97,696)	13.1 (12,801)	86.9 (84,895)	0.10
Yes	0.1 (90)	18.9 (17)	81.1 (73)	
Manic depressive				
No	98.6 (96,461)	13.1 (12,623)	86.9 (83,838)	0.08
Yes	1.4 (1,325)	14.7 (195)	85.3 (1,130)	
Schizophrenia				
No	98.7 (96,525)	13.1 (12,613)	86.9 (83,912)	0.01
Yes	1.3 (1,261)	16.3 (205)	83.7 (1,056)	
Traumatic brain injury				
No	99.1 (96,885)	13.1 (12,669)	86.9 (12,669)	0.02
Yes	0.9 (901)	16.5 (149)	83.5 (752)	

Table 4: Socio-demographics of newly admitted residents with dementia assessed between 2015 and 2019 by status of apathy.

Variables	**Odds Ratio**	**(95% CI)**	**p value**
Biological factors			
Age group (years)			
Under 65	Reference		
65-74	0.92	0.82-1.03	0.14
75-84	0.78	0.70-0.86	<0.0001
85+	0.75	0.68-0.84	<0.0001
Sex			
Female	Reference		
Male	1.13	1.09-1.18	<0.0001
Other	0.71	0.34-1.47	0.36
Pain			
No pain	Reference		
Mild	1.16	1.11-1.21	<0.0001
Moderate	1.72	1.66-1.88	<0.0001
Severe	2.44	2.07-2.87	<0.0001
Use of psychotropics			
No	Reference		
Yes	1.39	1.33-1.45	<0.0001
ADL hierarchy			
Low (0-1)	Reference		
Medium (2-3)	0.98	0.92-1.04	0.54
High (4-6)	1.07	1.00-1.14	0.04

Psychological factors			
DRS (Depression)			
No/Mild (0-2)	Reference		
Moderate (3-5)	2.05	1.95-2.14	<0.0001
Severe (6-14)	3.24	3.03-3.46	<0.0001
CPS (Cognitive impairment)			
No/Mild (0 -1)	Reference		
Moderate (2-3)	0.93	0.86-1.00	0.06
Severe (4-6)	1.15	1.06-1.24	0.01
ABS (Aggression)			
No/Mild (0-2)	Reference		
Moderate (3-5)	1.37	1.30-1.44	<0.0001
Severe (6-12)	1.51	1.41-1.62	<0.0001
Insomnia			
Not exhibited	Reference		
Exhibited up to 5 days	1.41	1.34-1.48	<0.0001
Exhibited daily or almost daily	2.0	1.80-2.23	<0.0001
Wandering (Reference = No)	0.99	0.94-1.05	0.75
Social factors			
Language			
English	Reference		
French	0.97	0.85-1.10	0.59
Other	0.63	0.59-0.68	<0.0001
Marital status			
Married	Reference		
Never married/widowed/separated/divorced	1.01	0.97-1.06	0.62
Unspecified	1.08	0.98-1.21	0.19
Activity preferences	Reference = Yes		
Card games/other games	1.16	1.12-1.22	<0.0001
Art and Craft	1.11	1.04-1.15	0.01
Exercise/sports	1.39	1.32-1.46	<0.0001
Music	1.43	1.36-1.50	<0.0001
Reading	1.08	1.03-1.13	0.01
Spiritual activities	1.21	1.15-1.27	<0.0001
Trips	1.16	1.08-1.25	0.01
Walking	1.08	1.03-1.13	0.02
Watching TV	1.22	1.16-1.27	<0.0001
Gardening	0.88	0.82-0.96	0.01
Talking	1.50	1.43-1.57	<0.0001
Helping others	1.17	1.08-1.26	<0.0001

Table 5: Logistic regression modelling the biopsychosocial characteristics of apathy among the newly admitted Canadian LTCF residents with dementia (N=97,786) assessed between 2015 and 2019.

Discussion

The prevalence of apathy among newly admitted residents with dementia in Canadian LTCF was 13.1%. This prevalence is consistent with existing literature, which reports apathy prevalence rates ranging from 11% to 40% in dementia populations (Makimoto et al., 2019; Starkstein et al, 2006) but is lower than the frequencies (23.1% and 56%) observed in two Dutch studies (Holtta et al., 2012; Mulders et al., 2016), and a systematic review of 28 studies which demonstrated the prevalence rate of 36% (Selbaek et al., 2014). These discrepancies could be due to differences in the stages of dementia of the participants, or the methodologies used to assess symptoms. The variation in prevalence rates across studies highlights the importance of standardized assessment tools and diagnostic criteria for apathy. Moreover, it could have been that apathy was perceived as a symptom of dementia, and therefore, under or overrated.

Consistent with studies examining apathy in young onset dementia (Bauhuis et al., 2020; Mulders et al., 2016) but in contrast to previous studies investigating apathy in late onset dementia (Starkstein et al., 2006; Lanctot et al., 2017), a small percentage of our sample falls into the age group of less than 65 years (2.7%), however, they comprise a sizeable proportion exhibiting apathy in comparison with those who are 85 years and over (17% vs 12%). In addition, our analysis found that apathy prevalence was slightly higher in non-Alzheimer dementia in comparison with Alzheimer dementia (13% vs 12%). This may suggest the difference in neuroanatomical changes between these types of dementias and reflect the type of dementia common in this population (Devanand et al., 2022). These findings underscore the importance of age and disease specific interventions in mitigating apathy in this population.

Although females constitute most of the population, the proportion of individuals with apathy in this sex category is slightly lower than males. This is congruent with the findings reported by Holtta et al. (2012) where apathy was observed to be more prevalent in males than females. Previous research has indicated that when compared to females, males with dementia often exhibit more severe neuropsychiatric symptoms, including apathy, potentially due to differences in disease progression (Mouriz-Corbelle et al., 2021; Mortby et al., 2022). In addition, we found that marital status does not have a significant impact on the likelihood of apathy among newly admitted Canadian LTCF residents with dementia. One possible explanation is that while marital status might traditionally be seen as a proxy for social support, residents in LTCF may receive various forms of social interaction and support from staff, other residents, and structured activities that mitigate the lack of a spouse or partner or it could be that residents may adapt to the structured environment, where regular interaction with care staff and communal activities provide substantial social support, potentially reducing differences between married and unmarried residents.

In congruence with previous research, our analysis showed that apathy was more prevalent among residents with co-morbid neuropsychiatric disorders, including depression, anxiety disorder, traumatic brain injury (TBI), and schizophrenia (Grossman et al., 2013; Holtta et al., 2012; Starkstein et al., 2009; van Almerk et al., 2015; Zuiderma et al., 2007). This highlights the complex interplay between apathy and other neuropsychiatric conditions in residents with dementia and underscores the need for a multidisciplinary approach to dementia care. This may include the involvement of psychiatrists, psychologists, neurologists, and other healthcare professionals in developing and implementing care plans. It is also important to note that although depression often co-occurs with apathy in dementia, these two constructs can be differentiated (Ang et al., 2018; Levy et al., 1998; Marin et al., 1994; Tagariello et al. 2009, Zhou et al., 2022). Apathy is marked by a noticeable lack of effort and a dependency on others to organize activities. Individuals with apathy show little interest in learning new things or engaging in new experiences. They exhibit a marked indifference toward their personal problems and maintain an unchanging emotional affect (Ishizaki & Mimura, 2011). In contrast, depression is characterized by persistent tearfulness, sadness, feelings of worthlessness and hopelessness (Fahed & Steffens, 2021; Ishizaki & Mimura, 2011). Additionally, apathy is often related to neurodegenerative changes, particularly in areas of the brain associated with motivation and executive function, whereas depression involves a broader range of emotional and psychological symptoms that can sometimes be alleviated with antidepressants (Lanctot et al., 2023).

With regards to biological characteristics of apathy, our findings revealed that males have significantly higher odds of experiencing apathy compared to females (OR = 1.42, 95% CI = 1.25 - 1.62, $p < 0.0001$). Previous research has indicated that males with dementia often exhibit more severe neuropsychiatric symptoms, including apathy, potentially due to differences in disease progression (Mouriz-Corbelle et al., 2021; Vilalta-Franch et al., 2013). In addition, the significant association between severe pain ad increased odds of apathy is consistent with existing literature (Starkstein et al., 2006). Effective pain management is crucial in dementia care to improve resident's outcome. The strong association between use of psychotropic medications and apathy highlights the importance of regular medication reviews to minimize adverse effects while managing neuropsychiatric symptoms (Ruthirakuhan et al., 2018). Evidence has shown that the use of psychotropics in dementia is complicated by increased risks of mortality, falls, and cardiovascular events (Magierski et al., 2020). Therefore, careful assessment and monitoring are needed to balance the potential benefits with these risks.

Among the psychological variables, our study demonstrates that moderate to severe depression, severe aggression and severe cognitive impairment significantly increased the odds of apathy. This aligns well with previous studies (Leontjevas et al., 2018; Robert et al., 2009; Starkstein et al., 2006), highlighting the influence of cognitive and behavioural health on the overall well-being of residents with dementia (Tang et al., 2018). This finding further validates our current understanding of apathy as a distinct symptom requiring proper investigation and intervention (Steffens et al., 2022; Yan et al., 2023). Furthermore, the association between insomnia and increased apathy is consistent with previous research emphasizing the need for addressing sleep issues through careful monitoring using technologies such as ambulatory actigraphy (Mulin et al., 2011). Social factors, particularly activity preferences, play a notable role in the health outcomes of residents with dementia. Our study found that a lack of preference for activities significantly increases the odds of apathy among these residents. This finding supports existing literature which emphasizes the importance of social engagement and personalized activities in mitigating apathy (Ellis et al., 2016; Theleritis et al., 2018). Guidance and better activities of interest can lead to enhanced engagement time among residents with dementia (Leone et al., 2013). Ensuring that residents have access to meaningful and engaging activities tailored to their interests can help mitigate apathy and improve their overall quality of life. The role of care staff in motivating residents experiencing apathy to participate in activities cannot be over-emphasized (Leone et al., 2013).

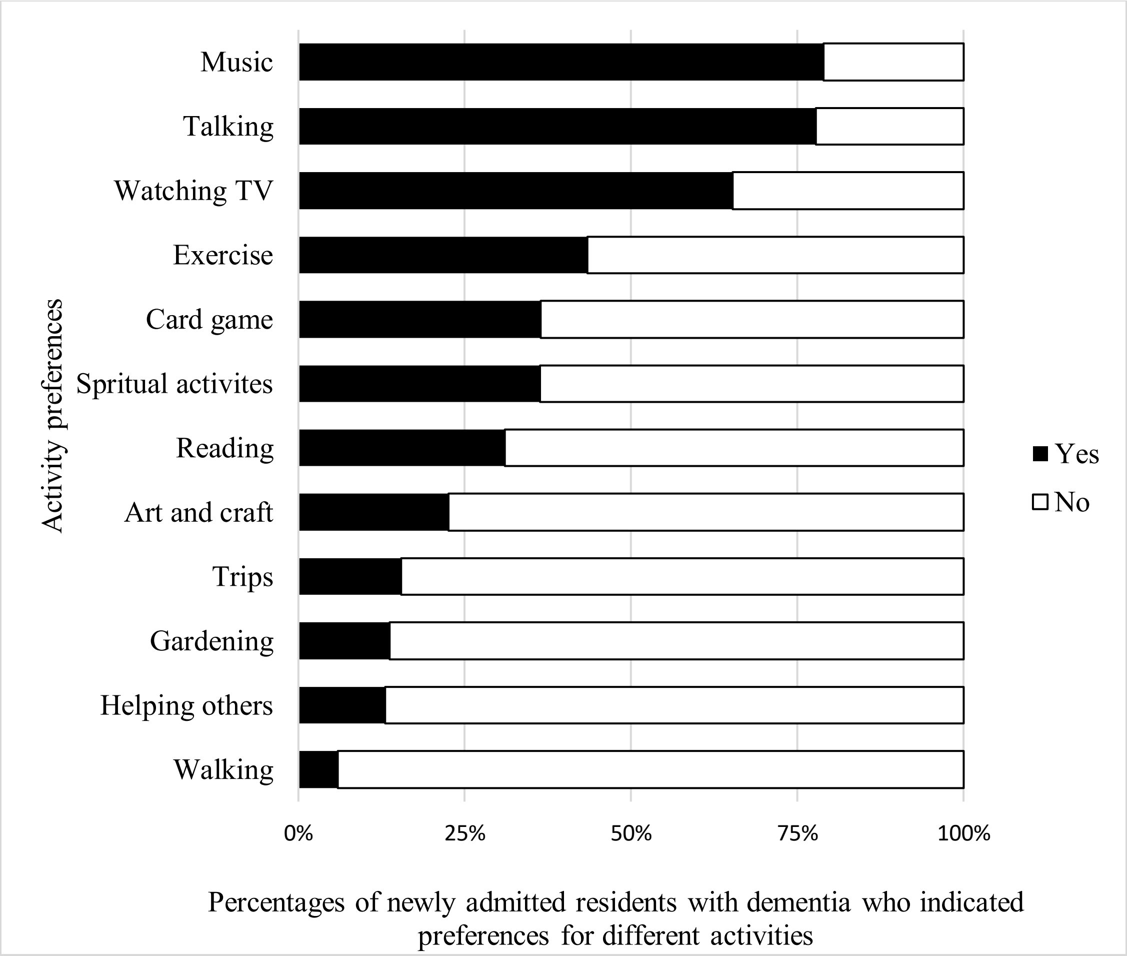


Figure 8: Activity preferences of the Canadian LTCF newly admitted residents with dementia (N=97,786) assessed between 2015 and 2019.

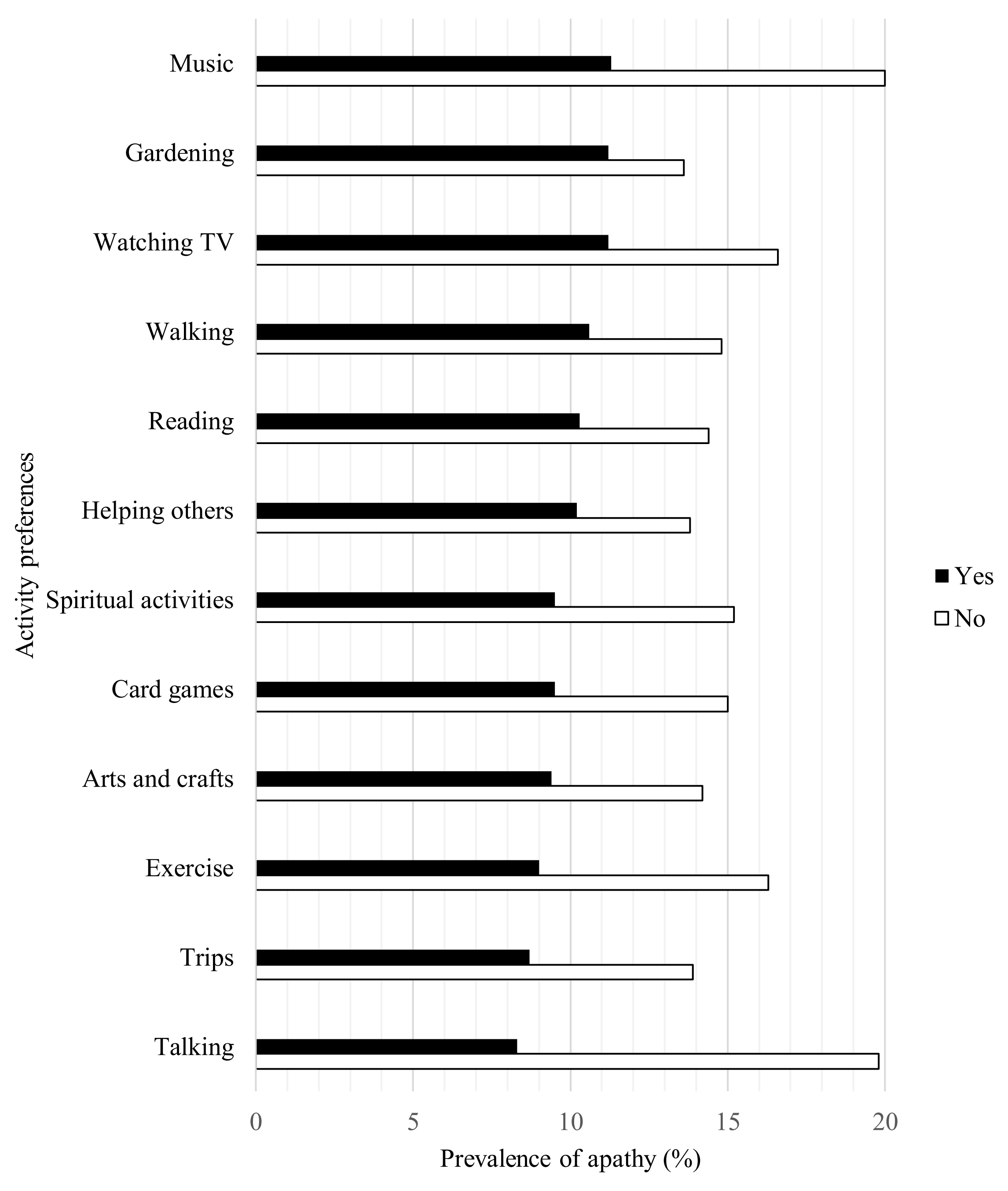


Figure 9: Prevalence of apathy among newly admitted Canadian LTCF residents with dementia who indicated preferences for different activities compared to those who did not (N=97,786).

Strengths and limitations

To the best of the authors' knowledge, this is the first Canadian study that used an apathy scale derived from the MDS 2.0 dataset to measure apathy and its associated biopsychosocial characteristics in a large sample within LTCF setting. The inclusion of several variables from the MDS 2.0 provides a robust and multidimensional understanding of the symptoms of apathy in the context of dementia and enhances the generalizability of the findings to this context. However, while this cross-sectional study provides valuable insights, it also has limitations, particularly the inability to establish causality due to the simultaneous measurement of exposures and outcomes. Longitudinal studies are necessary to confirm the temporal relationships and causative factors for apathy in dementia. Furthermore, future research should explore the effectiveness of specific interventions in reducing apathy and improving the quality of life of people living with dementia in LTCF. It is also of note that given the limitations of the MDS 2.0 dataset, some pertinent biological variables associated with apathy in dementia such as apolipoprotein epsilon 4 allele (APOE ε4) and PRND 3'UTR polymorphism (D'Onofrio et al., 2011; Flirski et al., 2012) were not considered in this current study.

Furthermore, the measurement instrument employed in this research solely assessed two dimensions of apathy: "reduced social interaction" and "withdrawal from activities of interest (e.g., lack of interest in long-standing activities or socializing with family and friends)" (Morris et al. 2012, p.2) implying that the behavioral and social domains were adequately assessed while the emotional and cognitive domains of apathy were not accounted for. However, given the lack of a comprehensive apathy measurement instrument, the Apathy Index of the MDS 2.0 serves as a significant initial starting point towards enhancing the recognition of apathy within the Canadian LTCF.

Implications for practice

The findings of this study have several practical implications for improving dementia care in LTCF. First, routine screening for apathy should be integrated into the care plans for newly admitted residents, especially those with identified correlates such as young age, male sex, insomnia, functional decline and severe pain. Second, tailored interventions addressing co-morbidities of apathy in dementia could significantly reduce apathy symptoms. Third, enhancing meaningful engagement through personalized activity programs might serve as a crucial strategy in mitigating apathy and improving overall well-being. Finally, policymakers should consider these findings when developing healthcare policies and allocating resources for dementia care. This may involve funding for the development of more engaging care environments, support for technology-based interventions, and training programs for care staff in early recognition of apathy.

Conclusion

This study provides valuable insights into the prevalence and biopsychosocial characteristics of apathy among newly admitted residents with dementia in Canadian LTCF. The findings emphasize that apathy is more prevalent in younger residents and males, indicating the need for age-specific and sex-sensitive approaches. Biological characteristics such as severe pain and the use of psychotropic medications are strongly associated with apathy, suggesting that effective pain management and careful medication review are crucial. Psychological factors, particularly depression, can also play a significant role in the development of apathy as previously understood, underscoring the importance of addressing depressive symptoms to mitigate apathy. Preferences for social and recreational activities, such as music and exercise, is inversely associated with apathy, highlighting the value of providing meaningful activities for residents. The size and regional location of LTCF also influence apathy prevalence, indicating that facility resources and practices impact resident outcomes.

Taken together, our study calls for routine screening for apathy, effective pain and depression management, enhanced activity engagement, and careful medication management to improve quality of life for residents with dementia. Future longitudinal research is needed to better understand the causative factors of apathy and evaluate the effectiveness of targeted interventions. Ultimately, this current study underscores the need for a holistic and person-centered approach to dementia care that incorporates both pharmacological and non-pharmacological interventions. By recognizing the diverse factors influencing apathy, care staff can better support residents with dementia, enhancing their engagement, well-being, and overall quality of life.

Chapter Seven: The Impact of eBook Clubs on Apathy among Long Term Care Residents: A Pilot Study

This chapter addressed RQ 4 “What impact does eBook club has on apathy among LTCF residents in rural Northern British Columbia?” and has been submitted for publication in two formats: a research letter and a full manuscript. The research letter, submitted to the Journal of the American Medical Directors Association has been published and cited as:

Agboji, A., Freeman, S., Banner, D., Armstrong, J., & Martin-Khan, M. (2024). Value of eReaders to Mitigate Apathy and Reduce the Digital Divide in Long-Term Care Settings. *Journal of the American Medical Directors Association*, *26*(1), 105362. Advance online publication. https://doi.org/10.1016/j.jamda.2024.105362

The full manuscript is under review by Sage Open Aging is included in this chapter to ensure an in-depth exploration of the findings and their relevance to the overarching research objectives of this dissertation.

Abstract

Apathy, prevalent among long-term care facilities (LTCF) residents, diminishes motivation, social interaction, and quality of life. This study explored the impact of eBook clubs as a non-pharmacological intervention to reduce apathy. A convergent parallel mixed-methods design was employed with 20 residents from four LTCF participating in a 3-month program. Apathy was assessed using the Geriatric Depression Scale (GDS-3A) before and after the intervention, with paired t-tests and Cohen’s d measuring changes. Qualitative insights were derived from semi-structured interviews and thematic analysis. Apathy prevalence dropped from 55% to 35%, and mean scores decreased significantly (1.6 to 0.9; Cohen’s d = 0.85). Participants highlighted cognitive, emotional, and social benefits, valuing program flexibility and eReaders but noting some preference for physical books. These findings suggest eBook clubs as a scalable, cost-effective strategy for LTCF. Future studies should evaluate its broader applicability and explore culturally tailored implementations.

What This Paper Adds:

- Demonstrates the effectiveness of eBook clubs as a non-pharmacological intervention for reducing apathy among LTCF residents.
- Highlights the multidimensional benefits of eBook clubs, including cognitive stimulation, emotional upliftment, and enhanced social interaction, as key mechanisms for improving well-being in older adults.
- Provides evidence of the feasibility and acceptability of eReaders in LTCF, showcasing their adaptability for residents with diverse needs and preferences.

Applications of Study Findings:

- **Gerontological Practice**: eBook clubs offer LTCF a scalable and cost-effective group activity to promote social connection, reduce isolation, and enhance cognitive engagement among residents.
- **Policy**: Findings support investments in digital literacy programs and infrastructure in LTCF, including eReaders and staff training, to expand access to stimulating activities.
- **Research**: Establishes a foundation for future studies on the long-term effects of digital group interventions and comparisons with other non-pharmacological therapies to reduce apathy in aging populations.

Keywords: Nursing home, eReaders, Technology, Mixed methods, Intervention.

Background

Apathy, characterized by a lack of motivation and diminished interest in daily activities, is a significant health concern in long-term care facilities (LTCF) residents (Jao et al., 2015, 2019; Volicer, 2013, 2016). It affects the cognitive, behavioral, emotional, or social domains (Robert et al., 2018), leading to reduced problem-solving interest, withdrawal from activities, lack of response to motivational cues, or social disengagement (Le Heron et al., 2018; Marin, 1991; Sockeel et al., 2006). Unlike depression, which involves sadness and emotional distress, apathy is marked by emotional flatness and dependence on others for activity initiation, posing unique challenges (Marin et al., 1994). Apathy adversely affects residents by reducing health-related quality of life, accelerating cognitive decline, and increasing mortality risk, while also burdening caregivers due to uncooperative behavior (Nijsten et al., 2017, 2019; Jao et al., 2019).

Pharmacological and non-pharmacological interventions aim to address apathy by encouraging activity participation. Due to trial limitations and side effects of pharmacological treatments (Agboji et al., 2024; Sepehry et al., 2017; Ruthirakuhan et al., 2018), non-pharmacological approaches are preferred (Zuidema et al., 2009). Music therapy, multisensory stimulation, pet therapy, and cognitive stimulation effectively reduce apathy in LTCF residents by providing engaging experiences (Cai et al., 2020; Tan et al., 2022). However, these interventions require significant resources and training, posing challenges for implementation in LTCF (Md Hussin et al., 2023). Additionally, therapeutic and leisure activities reduce apathy by fostering social engagement and reducing loneliness through group interactions (Ellis et al., 2016; Altintas et al., 2017). Personalizing interventions, such as hobbies or familiar activities, enhances engagement, while tailored social activities with appropriate materials support participation despite impairments. Emerging technologies including virtual reality (VR) and companion robots such as PARO offer promising solutions for reducing apathy but face challenges with complexity, side effects, and usability, particularly for residents with cognitive or physical impairments (Saredakis et al., 2021; Moyle et al., 2013). Adapting these technologies is essential to meet LTCF needs.

Reading is a cognitively stimulating activity that can mitigate apathy by promoting mental engagement and emotional well-being. However, challenges such as vision impairment, frailty, and limited access to books often hinder continued reading in later life. Technology-based solutions, specifically, eReaders, have made literature more accessible, encouraging frequent reading and reducing social isolation among older adults (Gitlow, 2014; De Oliveira et al., 2017). Despite these benefits, limited research has explored the impact of group reading sessions facilitated through digital means (eBook clubs) on self-report apathy among LTCF residents. This study addresses this gap by pilot testing the effect of eBook clubs on reducing apathy and integrating quantitative and qualitative findings to better understand the contributing factors.

Research Design and Methods

Study Design

This study used a convergent parallel mixed-methods design (Creswell & Plano Clark, 2018). Quantitative and qualitative data were collected simultaneously to provide a comprehensive understanding of the impact of eBook clubs on apathy among LTCF residents. This design enabled the integration of both objective measures of apathy and subjective experiences of participants, ensuring complementary insights. Following the principles of convergent parallel design, the quantitative and qualitative findings were integrated at the interpretation stage. The quantitative reduction in apathy scores was cross-referenced with themes from the qualitative data to provide a deeper understanding of key factors contributed to the observed improvements. A joint display table was used to present the integration of both data strands (Fetters, 2020).

Setting and Participants

Participants were recruited from four LTCF located in rural areas. Inclusion criteria required participants to (1) have an interest in reading, (2) be able to read and speak English, (3) have the ability or willingness to use digital technology, and (4) provide informed consent. Residents with severe cognitive or physical impairments that precluded group participation were excluded. A purposive sampling strategy was used to recruit participants. Recruitment efforts included information sessions at each LTCF, posters displayed in common areas, and support from staff (e.g., recreation therapists) in identifying interested residents. Participants were provided with a copy of the information letter two weeks prior to enrollment and were assessed for decision-making capacity using the University of California, San Diego Brief Assessment of Capacity to Consent (UBACC) (Jeste et al., 2007).

Study procedure

The eBook club program was implemented over 12 weeks in each site. Each participant received access to eReaders (KobolibraH20) with a minimum of 20 pre-selected books tailored to their interests, based on preferences identified during the first interview. Books were freely accessible through the Rakuten Kobo platform (www.kobo.com), and participants were encouraged to request additional books throughout the program, with a waiting period of 1 to 2 weeks for new titles. The intervention consisted of weekly group reading sessions facilitated by trained staff and involved 4–8 participants per group. Each session lasted 45–75 minutes, depending on participant preferences, and included reading aloud and group discussions about preselected books. This design aimed to foster social engagement, cognitive stimulation, and emotional connection among participants. Independent reading was included as a supplementary activity, providing participants with eReaders and access to a curated library of books. While participants were encouraged to explore the eReaders between sessions, the primary focus remained on group interactions during the weekly meetings. For participants unfamiliar with digital devices, a hands-on tutorial was provided during the orientation session.

Quantitative Data Collection and Analysis

Quantitative data were collected using the Geriatric Depression Scale (GDS-3A), which includes three apathy-related items. The GDS-3A has been employed in multiple studies (Adam, 2001; Bertens et al., 2017; Grool et al., 2014; Ligthart et al., 2012). The items included the following questions: (1) "Have you dropped many of your activities and interests?" (2) "Do you prefer to stay in your room rather than going out and doing new things?" and (3) "Do you feel full of energy?" For questions 1 and 2, a score of 1 was assigned for a "Yes" response, while for question 3, a score of 0 was assigned for a "Yes" response. The validity of the GDS-3A (Geriatric Depression Scale-3) as a measure of apathy has been explored in two populations of older adults including those with and without depression.

According to Bertens et al. (2017), the GDS-3A shows varying sensitivity and specificity depending on depression status. Among older adults with depression, it had 32.8% sensitivity and 92.6% specificity, indicating high accuracy in ruling out apathy. For those without depression, sensitivity was 29.3%, with specificity at 88.5%. These results suggest the GDS-3 is more effective at confirming the absence of apathy than detecting it, particularly in individuals with co-existing depression. Despite its limitations, the GDS-3A remains a valuable tool for initial screening purposes. The GDS-3A includes key components relevant to apathy detection, making it useful for prompting further clinical investigation (Szymkowicz et al., 2022). Its three-item structure offers psychometric and evaluative advantages over single-item approaches (Szymkowicz et al., 2022). The selection of the GDS-3A was guided by pragmatic and contextual considerations specific to the study setting. Firstly, our research was conducted in long-term care environments where participants exhibited varying degrees of cognitive functioning and fluctuating levels of engagement. In these real-world contexts, the GDS-3A provided a brief, easy-to-administer, and low-burden screening tool suitable for use by researchers without requiring extensive training or certification. Secondly, while we acknowledge that the GDS-3A is not a diagnostic instrument for apathy, it was not used for diagnostic purposes in our study. Instead, it functioned as a proxy measure for observable behavioral disengagement, consistent with its use in prior studies (Adam, 2001; Bertens et al., 2017; Grool et al., 2014; Ligthart et al., 2012; Maruta et al., 2021). Lastly, we were mindful of the GDS-3A's psychometric limitations and addressed this by incorporating a mixed-methods approach. The qualitative component of the study provided a richer, context-sensitive understanding of participant engagement, emotional responsiveness, and perceived changes related to apathy. This methodological complementarity helped to enhance the depth and interpretive validity of our findings and provided a more nuanced picture than quantitative screening alone could achieve.

In this study, a cut-off score of ≥2 indicated apathy (Bertens et al., 2017). To maintain consistency across sites, the first author administered the GDS-3A pre- and post-intervention, measuring apathy at baseline and after the program. Descriptive and inferential statistics were used to evaluate the eBook club's impact on self-reported apathy. Demographic data, such as age and gender, were analyzed using Excel for descriptive statistics, providing an overview of the participant sample. Paired t-tests were conducted in SPSS (IBM Corp., 2023) to assess the program's impact. The analysis emphasized Cohen's d as a measure of effect size over p-values, offering a clearer interpretation of the intervention's impact, with Cohen's d values indicating the strength of the observed changes (Cohen, 1988). For analysis, apathy scores were categorized into a binary variable: scores of 2 or higher indicated "apathy," while scores below 2 were classified as "no apathy."

Qualitative Data Collection and Analysis

Qualitative data were collected through semi-structured interviews conducted at enrollment and after the program. The first interview focused on reading habits and expectations, while the second explored participants' experiences with the eBook club and eReaders. Interviews were audio-recorded, transcribed verbatim, and analyzed using NVivo 12 software (QSR, 2020). Thematic analysis with open coding identified key themes and patterns, ensuring accurate representation of participants' experiences (Braun & Clarke, 2006; Bazeley & Jackson, 2013). Ethical approval was obtained via the Harmonized Ethics Review and Institutional Research Ethics Board. Informed consent was secured at enrollment and reconfirmed before each session.

Reflexivity

Reflexivity is vital in mixed-methods research to recognize how researchers' backgrounds and assumptions can influence the study process (Finlay, 2002). In this study, the first author's involvement in recruitment, data collection, and analysis posed a potential for bias in data interpretation. To address this, the research team engaged in ongoing self-reflection, remaining open to unexpected findings, whether positive or negative, and critically examining their expectations about the intervention's effectiveness. Additionally, the team acknowledged that pre-existing relationships between staff and residents might affect participants' responses. To mitigate this, interviews were conducted in neutral settings by the first and second authors, who were not involved in the residents’ care.

Credibility and Reliability

To ensure credibility and reliability, we employed triangulation by using multiple data sources including pre- and post-apathy scores and semi-structured interviews to cross-validate findings, enhancing trustworthiness (Creswell & Plano Clark, 2018). Transcripts were independently coded by the first and second authors using NVivo 12, with discrepancies resolved through discussion and consensus with the third author. Regular peer debriefing sessions were conducted throughout the coding process, allowing the research team to challenge assumptions and explore alternative interpretations, reducing the risk of confirmation bias (Creswell & Poth, 2018).

Results

Sample characteristics

Table 6 shows the characteristics of the study participants. A total of 20 residents participated fully in the program. The mean age of participants was 76.4 years (SD = 7.2) with a range between 51 and 98 years. The majority identified as woman (75%), half of the participants (50%) completed high school, College or University degree, and over half were widowed (60%). Less than half (40%) reported that they had never used technology before but were excited to try out a technology for reading. Many participants described themselves as avid readers, engaging with a variety of texts for a considerable portion of each day and had experienced a change in their reading habits since admission into LTCF (25% read less and 30% read more). Fictional books were of interest to most of the participants (80%) and none of the participants had a dementia diagnosis.

Impact of participation in eBook clubs on self reported apathy

Participants reported significant social and emotional benefits from group reading sessions. Quantitative analysis revealed a significant reduction in apathy scores from baseline to post-intervention. Pre-intervention mean score: 1.6 (SD = 0.99); post-intervention mean score: 0.9 (SD = 0.71), mean difference: 0.7 (95% CI, 0.23–1.17). A paired t-test indicated that the reduction in apathy scores was statistically significant ($t(19) = 3.42$, $p < 0.01$). The effect size, measured using Cohen's d, was 0.85, indicating a large effect. Additionally, apathy prevalence decreased from 55% at baseline to 35% post-intervention (Figure 10). All participants attended at least 80% of the scheduled sessions, with an average attendance rate of 87% across the study sites.

Key Factors Contributing to the Reduction in Apathy

Table 7 shows the joint display table of key factors contributing to the observed reduction in apathy among participants. Four major themes emerged from the qualitative data: cognitive stimulation, emotional well-being, social interaction, and program flexibility. These themes provide insight into the mechanisms underlying the reduction in apathy observed in the quantitative data.

Cognitive Stimulation

Participants described the eBook club as mentally engaging, with some noting that reading kept their minds active and provided something to look forward to. This cognitive engagement aligns with the reduction in apathy scores, as it helped participants feel motivated and mentally stimulated. One participant noted:

Reading keeps my brain going; it's like exercise for my mind. I look forward to each session, not just for the books but for the discussions. Hearing others' thoughts and sharing my own makes me feel connected and part of something meaningful. It's a highlight of my week, sparking curiosity and giving me a sense of accomplishment [Participant #6, 72 years]. The eReaders allowed participants to explore new topics, fostering curiosity and sustained mental engagement. Participants also reported frequent independent use of eReaders between sessions, indicating high levels of engagement with the intervention. The option to request additional books during the program further enhanced motivation and satisfaction.

Emotional Well-being

Participants reported that reading contributed to positive emotions and mood improvement. Engaging with new stories and ideas provided emotional relief, offering a sense of purpose and meaning. One individual stated:

Even on days I felt low, reading lifted my spirits. It gave me a sense of purpose and something positive to look forward to. The stories distracted me from negative thoughts and brought moments of joy, making my day feel brighter [Participant #4, 57 years]. Another participant reflected that engaging with new books helped them reconnect with positive emotions, contributing to improved mood. The participant commented, "It makes me laugh; even if I'm feeling sad, I can pick up a book, and everything feels lighter. The stories have a way of lifting my mood and bringing joy, turning a tough day into something much brighter" [Participant #2, 79 years].

Social Interaction

Group discussions provided opportunities for meaningful connections with others, promoting emotional support and reducing feelings of loneliness. Participants expressed that talking about books with others made them feel part of a community, which further contributed to their emotional well-being and engagement with the program. The group sessions facilitated meaningful connections among participants. One participant shared, “I enjoyed talking about the books with others, it gave me a sense of connection and made me feel less lonely’ [Participant #8, 90 years]. Sharing our thoughts and hearing different perspectives brought us closer and created a sense of community. One participant commented “There is a social aspect to it. It added to my social interaction with people. I like that” [Participant #2, 57 years]. Another participant stated, “I was able to talk to others about the books I read, which made the experience more engaging and enjoyable. It gave me a chance to connect with people and share ideas, making reading feel like a shared journey” [Participant #11, 81 years].

Program Flexibility

Participants emphasized the importance of program flexibility in enhancing their engagement with the eBook club. Many participants appreciated the opportunity to read independently at their own pace, in addition to participating in weekly group sessions. One participant noted, "I liked that I could read whenever I wanted, without having to follow a strict schedule" [Participant #1, 84 years]. This flexibility allowed residents to integrate reading into their daily routines and provided them with a sense of autonomy. The ability to request new books throughout the program further motivated participants, as it ensured the availability of material aligned with their personal interests. For example, one participant remarked, “I was able to request books I really wanted to read, which made the experience much more enjoyable. Having a choice in what I read made it feel personalized and kept me excited about each session” [Participant #10, 75 years]. Participants also found that pre-loaded eReaders made it easier to access literature without requiring frequent technical support, further enhancing their reading experience.

Discussion

To the best of our knowledge, this is the first study to examine the impact of eBook clubs on reducing apathy among LTCF residents. Findings indicate that group reading sessions effectively reduce apathy by combining cognitive stimulation with social interaction. Unlike interventions focused solely on individual engagement, the structured group format fosters shared experiences and emotional connections, addressing key aspects of apathy such as withdrawal and lack of motivation (Marin, 1991; Starkstein, 2000). While independent reading was available, qualitative feedback and observed outcomes highlight group dynamics as the primary driver of the intervention's success. This is consistent with prior studies suggesting that group activities can reduce apathy in older adults (Theleritis et al., 2017; Zhu et al., 2017).

Our findings further demonstrate that eBook clubs significantly reduce self-reported apathy and enhance emotional and social well-being among LTCF residents. The reduction in apathy suggests that the interactive nature of eReaders, combined with stimulating content, actively contributes to improved health outcomes. Apathy, prevalent in LTCF, is associated with poorer cognitive and functional outcomes (Marin, 1991). By providing engaging activities, eBook clubs mitigate these risks, serving as a proactive tool for managing apathy (Oh et al., 2018; Zhu et al., 2017). Additionally, the emotional and social benefits of reading in LTCF are substantial. While traditionally seen as a solitary activity, eBook clubs foster social interaction, a critical component of emotional health being (O'Neill & Dogra, 2016). Group reading sessions encourage discussions and connections, reducing loneliness and isolation (Weziak-Bialowolska et al., 2013).

This study highlights the feasibility of eBook clubs as a practical non-pharmacological intervention for addressing apathy in LTCF residents. While music therapy reduces apathy and improves mood (Tang et al., 2018), its need for specialized training and instruments limits scalability (Cohen-Mansfield, 2018). Similarly, pet-assisted therapy provides emotional and social benefits (Bernabei et al., 2013), but logistical challenges such as animal care, allergies, and safety concerns restrict its widespread use (Zisselman et al., 1996). In contrast, eBook clubs are cost-effective, requiring only eReaders and minimal staff training, and are highly scalable. They uniquely integrate cognitive stimulation and social interaction, effectively addressing multiple dimensions of apathy while fostering emotional well-being and social connections, making them a more sustainable solution for LTCF.

Despite these potential benefits, the implementation of eReaders must be handled with sensitivity to the unique emotional and psychological needs of users. Some individuals may experience frustration or anxiety when learning new technologies, which could counteract the potential emotional benefits. Therefore, proper training and support are essential to ensure that the transition to digital reading is as smooth as possible (Mitzner et al., 2010). These may include individualized instruction (Charness & Boot, 2009), peer support (Lee & Maher, 2021), and hands-on practice (Czaja & Sharit, 2013). Moreover, care must be taken to select appropriate reading materials that are aligned with the interests and emotional states of the readers. Overly complex or emotionally distressing content could potentially exacerbate feelings of frustration or sadness.

Many participants had limited prior exposure to digital technology, contributing to difficulties in using the devices. This aligns with Andrews et al. (2019), who found that technological literacy significantly impacts older adults' ability to use digital devices.

Addressing these challenges requires targeted training tailored to their cognitive and physical needs (Wu et al., 2015). Additionally, issues such as eReader weight and navigation difficulties highlight the need for user-friendly designs suited for older adults (Kebede et al., 2022). Participants also expressed mixed preferences for digital and physical books, consistent with Lu et al. (2023), who noted older adults' preference for the tactile experience of physical books. These findings underscore the importance of offering both formats to accommodate preferences and ensure inclusivity in eBook club programs.

The program's implementation also revealed critical logistical considerations, such as the need for reliable Wi-Fi infrastructure when downloading books to eReaders or any digital reading devices and consistent scheduling to avoid program interruptions. These aspects are crucial for the seamless integration of technology-based interventions in LTCF (Kebede et al., 2022; Sen et al., 2022). Furthermore, the feedback from residents about the timing and accessibility of reading materials indicates the importance of aligning program logistics with residents' daily routines and seasonal activities to maximize participation and engagement (Smith, 1993).

Strengths and limitations of the study

This study addresses a critical gap in geriatric care literature by examining how technology and reading intersect to mitigate apathy in LTCF residents. However, several limitations should be noted. The small sample size of 20 participants limits the generalizability of findings, as it may not capture the diverse experiences of a larger, more varied population. Additionally, the absence of a control group or alternative conditions (e.g., independent reading) makes it difficult to isolate the specific effects of group interaction. Future studies should adopt comparative designs to better distinguish the contributions of group and individual reading.

The reliance on self-reported data collected using the GDS-3A to assess engagement and mood is another limitation. Incorporating standardized apathy measures in future research would enhance the robustness of findings. The study also did not explore how device features, such as screen glare or battery life, influence user experience, which could impact satisfaction and effectiveness. Furthermore, the role of staff and the structure of reading activities were not fully examined, despite their potential influence on outcomes. Lastly, the short follow-up period precluded an assessment of the long-term benefits of eBook clubs, highlighting the need for longer-term studies to evaluate their sustained impact on residents' well-being.

Implications for practice

To boost participation in eBook clubs among LTCF residents, technology should be tailored to their needs with simplified interfaces, larger icons, high-contrast colors, and lightweight, easy-to-grip eReaders. Features such as text-to-speech and adjustable text sizes enhance accessibility (Bernard et al., 2001). Scheduling sessions strategically and offering both eReaders and physical books cater to diverse preferences, increasing satisfaction and fostering social interaction through hybrid formats. Apathy, linked to reduced neural connectivity in reward and motivation centers (Jang et al., 2021), may be counteracted by engaging stories and group discussions that stimulate these networks. Integrating eBook clubs into LTCF routines provides residents with meaningful engagement, improving quality of life.

Conclusion

The results demonstrate the potential of eBook clubs to reduce apathy among LTCF residents. By promoting social interaction and emotional engagement, they offer a scalable and cost-effective alternative to pharmacological treatments. eBook clubs also address accessibility challenges of traditional books through eReaders with adjustable fonts and backlighting, alleviating visual strain in older adults. Additionally, eReaders provide access to extensive literary content, overcoming physical library limitations and enhancing cognitive engagement. Future research should explore the long-term effects of eBook clubs and investigate their integration with other therapeutic activities to maximize their impact on residents' well-being.

Characteristics	**% (n)**
Age (years)	
50-60	15 (3)
61-70	10 (2)
71-80	30 (6)
81-90	35 (7)
90+	10 (2)
Gender	
Man	25 (5)
Woman	75 (15)
Other	0
Marital status	
Married	15 (3)
Never married	15 (3)
Widowed/Separated/Divorced	70 (14)
Education	
College/University	20 (4)
High School	30 (6)
Grade 7-9	45 (9)
Grade 1<6	5 (1)
Change in Reading habits	
No change	45 (9)
Read less	25 (5)
Read more	30 (6)
Years spent reading	
Below 5 years	15 (3)
Over 5 years	85 (17)
No of times reading per week	
Everyday	85 (17)
Once a week	15 (3)
Prior use of technology	
No	25 (5)
Yes	75 (15)

Table 6: Sample Characteristics

Quantitative Findings	**Qualitative Themes**	**Interpretation**
Apathy scores decreased from 1.6 (SD = 0.99) to 0.9 (SD = 0.71). Cohen's d = 0.85 indicates a large effect.	Cognitive Stimulation: Participants found the reading material mentally engaging. Quote: "Reading keeps my brain going."	The reduction in apathy reflects how mental engagement fostered motivation and provided participants with meaningful activity.
The proportion of participants classified as apathetic decreased from 55% to 35% after the intervention.	Emotional Well-being: Reading helped participants feel emotionally uplifted. Quote: "Even on hard days, reading gave me something to look forward to."	Participants reported improved emotional well-being, explaining the observed decline in apathy.
87% average attendance rate across weekly sessions indicates high engagement.	Social Interaction: Group discussions fostered a sense of belonging. Quote: "Talking about books made me feel connected with others."	Social interaction through group reading sessions contributed to reduced isolation, enhancing emotional health and engagement.
Participants reported frequent independent reading between sessions.	Program Flexibility: Participants appreciated the ability to read independently at their own pace. Quote: "I liked being able to read whenever I wanted."	The flexibility of the eReaders encouraged independent participation, further reinforcing cognitive and emotional engagement.

Table 7: Key factors contributing to apathy reduction

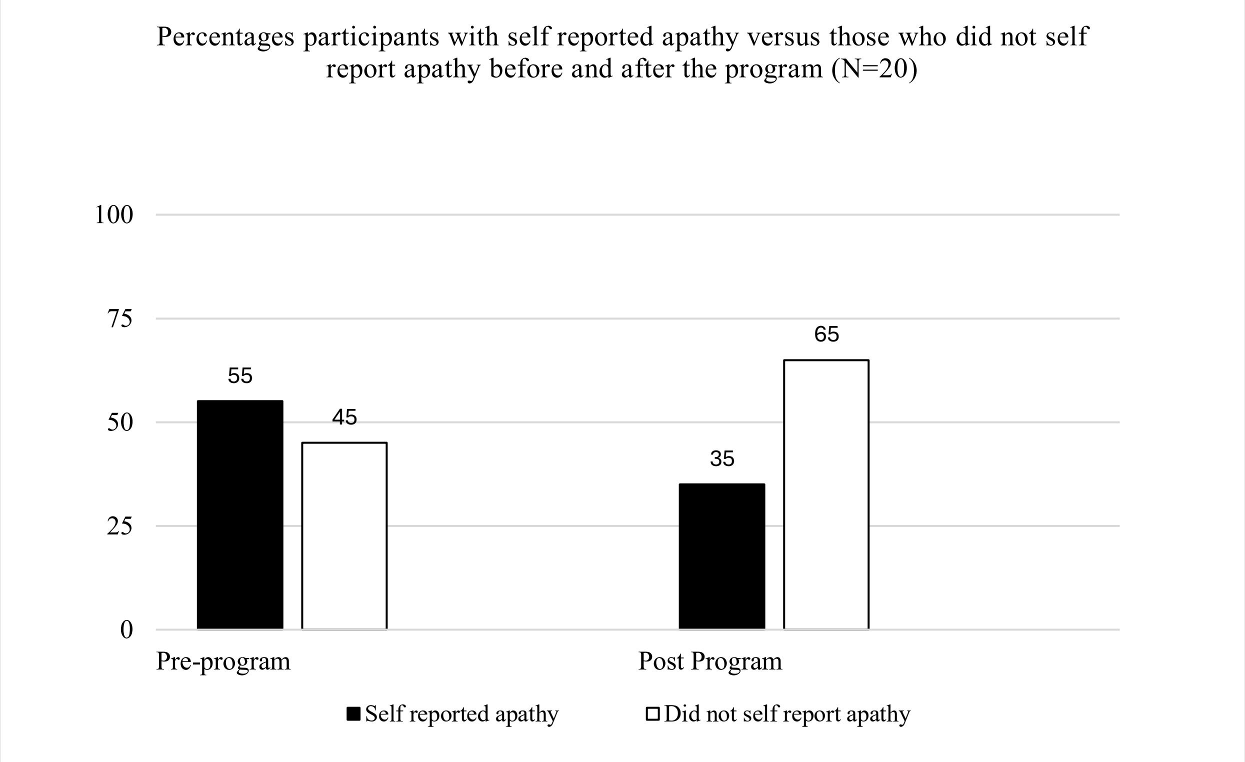


Figure 10: Prevalence of apathy before and after the program

Chapter Eight: Impact of eBook Club Implementation on Apathy Among Community Dwelling Older Adults in Rural Canada: A Mixed Method Study

This chapter addressed RQ 5 “What impact (s) does eBook club has on apathy among community dwellers in rural Northern British Columbia?” and has been submitted to the Journal of Applied Gerontology for publication. It is currently under review.

Abstract

Background: Apathy is prevalent among older adults, especially in rural areas, where social isolation and limited resources can intensify disengagement from meaningful activities. This study assessed the impact of eBook club participation in reducing apathy among older adults in rural communities and identified mitigation strategies to support successful program implementation.

Method: This mixed-method study collected quantitative data using the Apathy Subscale of the Global Depression Scale (GDS-3A) and qualitative insights from semi-structured interviews guided by Socioemotional Selectivity Theory (SST). The eBook club involved both independent and group reading sessions, with each participant provided with an eReader preloaded with books aligned to their preferences.

Results: Twenty-eight older adults (60-86 years) from three rural communities participated, with a majority being women (89%) and avid readers (100%). Half of participants had a high school education level. The findings revealed use of the eReaders and participation in eBook clubs significantly reduced apathy among participants, decreasing from 54% at baseline to 11% post-program. Participants noted emotional satisfaction, convenience, and renewed interest in reading with the use of eReaders, alongside improved social interaction through group reading sessions. Participants described creative mitigation strategies employed to adapt and use the eReader technology sustainably.

Conclusion: Participation in eBook clubs has the potential to reduce apathy by promoting emotionally meaningful activities, close-knit relationships and adaptation to age related decline. Thus, enhance the overall well-being of community dwelling older adults.

Implications for Practice: Implementing eBook club programs in rural communities can mitigate apathy in older adults. Ensuring robust technical support and addressing physical accessibility needs will further enhance the success and inclusivity of such programs.

Introduction

In Canada, individuals aged 65 years and older currently represent approximately 18.9% of the population, a figure that has been steadily rising due to the aging baby boomer generation and increased life expectancy (Statistics Canada, 2023). This trend is expected to continue, with projections suggesting that by 2073, the proportion of older adults could range from 21.9% to 32.3%, depending on various growth scenarios (Statistics Canada, 2023). In British Columbia (BC), the growth in the older adults' population mirrors national trends. In 2022, older adults aged 65 years and older made up 19.9% of the province's population, exceeding one million residents. This aging trend is projected to accelerate, with BC's overall population expected to reach 7.9 million by 2046, a 49% increase from 2022 (BC Stats, 2024). In Northern BC, the demographic is also growing steadily. For instance, in the Cariboo region, individuals aged 65 years and older accounted for 16.5% of the population in 2021, with significant growth expected through 2046 (BC Stats, 2024). These trends underscore the increasing need for innovative strategies to support the aging population, particularly, in rural communities.

Apathy is an increasingly recognized health issue among older adults, both with and without cognitive impairments (Brodaty et al., 2012; Lanctot et al., 2017; Onyike et al., 2007). Evidence suggests that apathy is not a normal part of aging but rather represents a complex neuropsychiatric geriatric syndrome that requires thorough assessment and care (Agboji et al., 2024; Lanctôt et al., 2023). Apathy is primarily characterized by a significant decline in motivation or interest in goal directed activities, which can manifest in various ways, including diminished initiation, reduced emotional expression, and a lack of goal-directed behavior (Marin, 1991; Robert et al., 2012). Thus, individuals with apathy often show a lack of initiative, do not pursue activities they enjoy, and may seem emotionally flat or indifferent (Marin, 1990). This can significantly impair their daily functioning, as they may neglect basic self-care tasks, lose interest in social interactions, and become increasingly isolated (Lanctot et al., 2017; Marin, 1991; Robert et al., 2012). This condition, therefore, poses serious implications for the well-being of older adults, particularly those in rural areas where access to social and recreational activities may be limited.

Engagement in intellectual, social, and leisure activities has been shown to reduce cognitive decline and improve well-being of older adults (Almeida-Meza et al., 2021; Foubert-Samier et al., 2014). For instance, Wilson et al. (2012) found that frequent participation in cognitively stimulating activities, including reading, was associated with a reduced risk of Alzheimer’s dementia in older adults. Social activities and networks also have a positive impact on cognitive functioning, as demonstrated by Kelly et al. (2017), underscoring the potential value of social interaction on cognitive health. Traditional social outlets, such as book clubs, offer both intellectual engagement and social connection, helping older adults stay mentally active and emotionally engaged (Toepoel, 2013).

As technology becomes more integrated into daily life (Freeman, 2020), digital platforms such as eBook clubs present new opportunities for engagement. eBook clubs offer unique benefits, including (a) accessibility: eReaders provide convenient access to a broad range of reading materials, with adaptable settings for visual or physical limitations (Katz et al., 2012; Lu et al., 2023); (b) cognitive stimulation: reading and discussing books in a group promotes mental engagement, which may help maintain cognitive function (Chang et al., 2021; Oh et al., 2018); and (c) social interaction: regular meetings create opportunities for social connection and discussion, combating isolation often linked to apathy (Weziak-Bialowolska et al., 2013).

Despite these advantages, research on the use of eReaders and the role of eBook clubs in reducing apathy among older adults remain limited. While studies have shown that reading can enhance cognitive function and emotional well-being (Bavishi et al., 2016), the potential for eBook clubs to extend these benefits has not been fully explored. For rural-dwelling older adults, where social and intellectual engagement opportunities are often limited, addressing apathy is a critical concern for caregivers, healthcare professionals, and policymakers (Agboji et al., 2024). This study aims to bridge these gaps by investigating how participation in eBook clubs can reduce apathy among older adults in rural community settings. To achieve this aim, the study addresses the following research questions: (a) What is the impact of eBook club participation on apathy among rural, community-dwelling older adults? and (b) What are the challenges and solutions for successfully implementing eBook clubs in rural communities?

Methodology

Theoretical framework

This study is grounded in Socioemotional Selectivity Theory (SST) (Carstensen et al., 1999), which provides a framework for understanding the behavioral and emotional priorities of older adults as they age. SST posits that with an increased awareness of life's finitude, individuals shift their focus from future-oriented goals, such as knowledge acquisition or broad social exploration, toward emotionally meaningful activities that enhance well-being. This shift encourages older adults to prioritize experiences and relationships that bring immediate emotional satisfaction and support psychological health (Carstensen, 2006). In the context of aging, apathy can arise when individuals lack engagement in activities that fulfill these emotional needs (Marin, 1991). SST therefore offers a valuable lens for understanding and designing interventions aimed at reducing apathy in older adults. By focusing on activities that foster emotional engagement and social connection such as eBook clubs, older adults might have the natural tendency to seek purpose and satisfaction in daily life.

Sample/settings

This study was conducted over six months (March to September 2023) in three rural communities in Northern British Columbia (BC), Canada. Northern BC is a vast, sparsely populated region characterized by rugged landscapes, a resource-based economy, and diverse communities (BC Stats, 2024; Kornelsen et al., 2021). Covering approximately 70% of BC's land area but home to less than 10% of the provincial population, the region exemplifies the low population density typical of rural areas (BC Stats, 2024). One of the primary challenges facing rural Northern BC is limited access to healthcare services; geographic isolation often necessitates long-distance travel for medical care, leading to delays in treatment and potential health complications (Freeman et al., 2022). Participants were recruited using purposive sampling through social media, community bulletin boards, and word of mouth. Eligibility criteria included an interest in reading, proficiency in reading and speaking English, willingness or ability to use digital technology, and the capacity to provide informed consent. Ethical approval for the study was granted through the Harmonized Ethics Review process in collaboration with the Institutional Research Ethics Board. Capacity to consent was determined using the University of California, San Diego Brief Assessment of Capacity to Consent (UBACC) tool (Jeste et al., 2007). This tool was administered by the first author to ensure participants understood the research protocol, appreciated the risks and benefits, and could provide informed consent. The assessment was repeated before each data collection point to confirm ongoing consent and understanding, ensuring inclusivity for participants with varying cognitive abilities.

Study Design

This study used a quasi-experimental mixed-methods design, combining quantitative and qualitative data to comprehensively understand participants' experiences with the eBook club program. Data collection occurred at two time points: baseline (week 0) and post-intervention (week 6). These time points were chosen to capture changes in apathy levels throughout the program. Quantitative data was collected through a self-report apathy questionnaire, while qualitative data was gathered via two semi-structured interviews. The first interview, conducted after informed consent was obtained, collected demographic information, reading preferences, and initial thoughts on using eReaders, establishing a baseline understanding of participants' backgrounds and expectations. The second interview, conducted post-program, focused on participants' reflections on their experiences with the eBook club and their perspectives on the use of eReaders. The interviews provided valuable qualitative insights into participants' emotional responses, challenges, and suggestions for improving program implementation. The open-ended, semi-structured format also allowed participants to express their thoughts freely while ensuring key topics were covered and additional points of interest could be explored.

For quantitative data, analysis was performed using the Statistical Package for the Social Sciences (SPSS version 29) (IBM Corp., 2022). Descriptive statistics identified the proportions of participants with and without apathy pre- and post-intervention. A McNemar's test was conducted to assess the statistical significance of changes in apathy following the program. Thematic analysis of the interview transcripts using NVivo 12 software (QSR, 2018) was conducted by the first and second authors, with Socioemotional Selectivity Theory (SST) guiding framework the interpretation of findings. Conflicts were resolved by the third author. Thematic analysis allows researchers to organize and interpret data in a way that reveals underlying meanings and insights about participants' experiences, perceptions, and behaviors (Braun & Clarke, 2006).

Apathy measures

A self-report questionnaire consisting of three items from the Global Depression Scale (GDS-15), known as the Apathy Subscale of the GDS or GDS-3A, was used to measure apathy before and after the program. The three items used to assess apathy included the following questions: "Have you dropped many of your activities and interests?"; "Do you prefer to stay in your room rather than going out and doing new things?"; and "Do you feel full of energy?". The scoring method for these questions was as follows: for questions 1 and 2, a "Yes" response was given a score of 1, while for question 3, a "No" response was given a score of 1. This scoring system was designed to capture key elements of apathy, such as loss of interest and lack of motivation to engage in new activities. The GDS-3A subscale has been widely used in research (Adam, 2001; Bertens et al., 2017; Grool et al., 2014; Ligthart et al., 2012). The validity of the GDS-3A as a measure of apathy has been established in populations of older adults with and without depression (Bertens et al., 2017).

Although the three items in the GDS-3A do not capture all dimensions of apathy, they are valuable for screening purposes (Bertens et al., 2017). In addition, the three items provide psychometric benefits, achieving a balance between brevity and reliable screening results, which is more effective than a single-item approach (Szymkowicz et al., 2022). A cut-off score of ≥2 indicates the presence of apathy, a threshold based on prior research linking such scores to clinically significant apathy symptoms in older adults (Bertens et al., 2017). For analytical purposes, apathy scores were converted into a binary variable, where scores of 2 or above signified "apathy" and scores below 2 represented "no apathy."

Overview of the intervention

Before the start of the eBook club program, participants were provided Kobo eReaders (Kobo Libra H20) and free access to the Rakuten Kobo eReader platform (www.kobo.com), which included a selection of free eBooks. A tutorial session was held to guide participants on loading eBooks onto their devices and navigating the eReader features. The intervention consisted of two main components: independent reading sessions and facilitated group discussions. Independent reading was designed to provide cognitive engagement and emotional satisfaction, while group discussions aimed to enhance social interaction and support. Group reading sessions, facilitated by the first author, were held once a week for six weeks, with each session lasting 45 to 60 minutes. Attendance ranged from four to eight participants per session, providing a supportive environment for engaged discussion and shared reading experiences.

Results

Sample characteristics

Table 8 displays the sample characteristics of the 28 older adults who participated in this study. The age range of participants varied, with the most represented age groups being 60 to 80 years (86%). The majority were women (89%). Many participants had a “College/University” (46%) or “High School” (50%) education. A significant proportion were married (57%) and three participants were formally diagnosed with dementia (11%). With regards to reading habits and preferences of the participants, the majority reported to be regular readers (71%). The most preferred book genre among the participants was fiction, with a total of 75% of participants indicating a preference for some form of fictional literature, including genres such as travel adventure, romance, mystery, and other combinations of fiction. About a third of the participants used digital devices such as phones, tablets, or eReaders for reading, while one in three (32%) did not have prior experience using eReaders or other reading technology.

Characteristics	**Participants, % (n)**
Age	
60-70	43 (12)
71-80	43 (12)
81-90	14 (4)
Gender	
Man	11 (3)
Woman	89 (25)
Marital status	
Married	57 (16)
Never married	4 (1)
Widowed/Separated/Divorced	39 (11)
Education	
College/University	46 (13)
High School (Grade 10-12)	50 (14)
Grade 7-9	4 (1)
Change in reading habits over time	
No change	18 (5)
Read less	29 (8)
Read more	53 (15)
Years spent reading	
Below 5 years	0 (0)
Over 5 years	100 (28)
No of times reading per week	
Everyday	71 (20)
Once a week	21 (6)
Three times a week	4 (1)
Occasionally	4 (1)
Dementia Diagnosis	
Yes	11 (3)
No	89 (25)
Prior use of technology	
No	32 (9)
Yes	68 (19)
Favorite Genre	
Fiction	21 (6)
Non-fiction	75 (21)
Both	4 (1)

Table 8:Characteristics of study participants (N=28)

Impact of participation in eBook clubs on apathy

Figure 11 shows the number of participants with self reported apathy before and after the program while Figure 12 is a joint display of the qualitative themes that explain why and how the observed reduction in apathy occurred. The reduction in apathy was treated as a dependent variable, analyzed using McNemar’s test to assess changes from baseline to post-intervention (Fagerland et al., 2013), with additional exploration of qualitative themes as mediating factors influencing the observed outcomes. Prior to the intervention, 54% of participants (n = 15) reported apathy, while 46.4% (n = 13) did not meet the GDS-3A threshold for apathy and were subsequently categorized as "no apathy." Following the intervention, only 11% of participants (n = 3) continued to report in the "apathy" category, with 89% (n = 25) reported the "no apathy" group. No new participants reported apathy at follow-up. Therefore, this shift suggests a notable reduction in apathy post-intervention. The McNemar’s test result showed a highly significant effect, with an exact p-value of < .0001 (Figure 12), indicating that the intervention was effective in reducing apathy levels among participants.

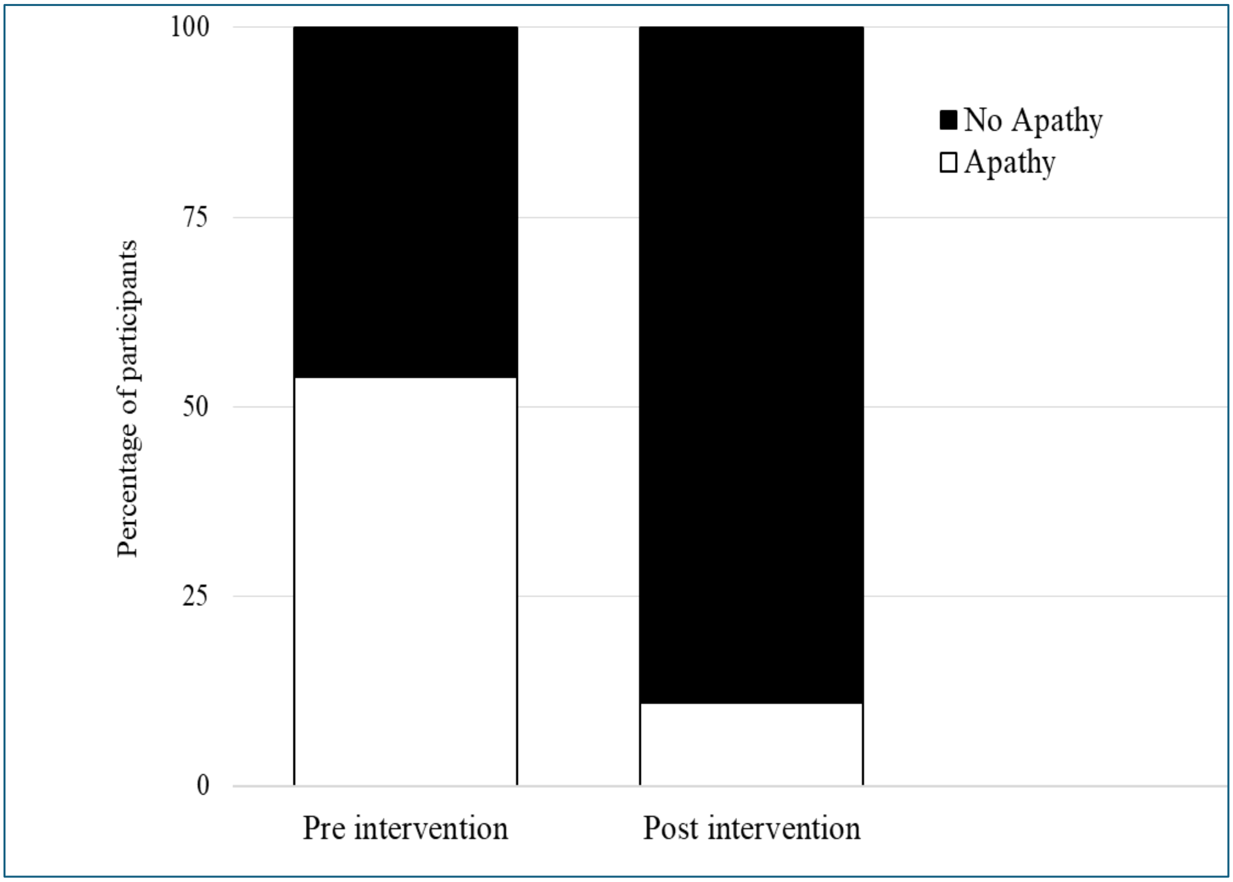


Figure 11: Percentages of participants with self reported apathy vs no apathy pre and post intervention.

Three themes emerged from participants' perspectives, each broken into subthemes that offered a deeper understanding of the observed reduction in apathy among those who initially self-reported apathy: (1) the positivity effect, which highlighted a shift toward emotionally fulfilling activities; (2) selective pruning of social networks, reflecting participants' focus on cultivating meaningful social connections; and (3) adaptation to physical and cognitive decline, demonstrating how participants utilized the eBook club to accommodate and actively engage with the challenges of aging (Figure 12).

Positivity Effect: Focus on emotionally fulfilling activities

Participants emphasized the focus on positive and emotionally meaningful experiences they experienced during the eBook club. Participants reported that reading provided emotional satisfaction and moments of joy, helping them shift attention from negative emotions and reduce feelings of apathy. The group reading sessions created opportunities to share uplifting stories and emotionally fulfilling discussions, reinforcing the positivity effect. As one participant stated,

Honestly, reading these books just brought me this real sense of relief and joy. They became kind of like a little escape for me, you know? A way to set my worries aside and just get lost in something light and positive. It was like each page gave me this small break from the usual stresses, letting me dive into a world that felt safe and, honestly, just really uplifting. And it wasn't only about the stories themselves. It was more about this comforting feeling they gave me a kind of warmth and reassurance that lifted my mood and just made everything feel a bit better, even if only for a little while [Participant #3, 71 years]. Another participant remarked,

When I read, I feel truly alive again. Each story stirs memories of better times, moments I might have forgotten in the daily rush. It's more than just entertainment, it's a reminder of warmth, hope, and the person I am beneath all the noise. It's exactly what I needed. [Participant #5, 69 years].

Selective Pruning of Social Networks: Focus on meaningful connections

Participants placed high value on selective social interactions through the group reading sessions. The eBook club fostered small, intimate group interactions, allowing participants to form deeper social bonds with fellow members. These close-knit relationships provided emotional support and mitigated social isolation, helping participants maintain a sense of connection despite a shrinking social network. This process was evident in how participants described their relationships with other group members. For example, one participant shared,

> I used to be part of bigger groups, but this small reading group felt much more intimate. I genuinely connected with everyone; it was like we all showed up for each other, creating a space where we could share openly and supportively. It felt special" [Participant #9, 70 years].

Another participant reflected,

> We weren't just discussing the books; we were sharing pieces of our lives, which made the experience so much more meaningful. It became more than a reading group—it was a place for connection and understanding, where each story sparked deeper conversations about our own experiences [Participant #11, 60 years].

Adaptation to physical and cognitive decline: Coping with age related changes

The participants described how they adapted to physical and cognitive challenges by engaging in emotionally meaningful activities, particularly reading with the eReaders. SST emphasizes that older adults can maintain or even enhance their subjective well-being by focusing on emotionally meaningful experiences, even as future-oriented goals become less relevant (Löckenhoff & Carstensen, 2004). Many participants reported that using eReaders made it easier to engage in reading despite physical challenges such as arthritis or vision impairments. Features such as adjustable text size and lightweight design facilitated sustained engagement, highlighting how participants adapted to their limitations while continuing to enjoy emotionally meaningful activities. One participant noted,

> "I used to struggle with holding books because of my arthritis, but the eReader changed everything. I could read comfortably again, and it was such a relief to enjoy my books without

the pain. It brought back the simple joy of reading that I thought I had lost" [Participant #27, 81 years].

Another participant commented,

"Despite all the limitations I face now and the activities I've had to give up, reading remains something I can still do and truly enjoy. It's a comforting constant, a reminder that I still have something meaningful to hold onto. Being able to lose myself in a story, to experience new worlds or perspectives even from my own home, gives me a sense of independence and joy that I cherish deeply." [Participant #10, 78 years].

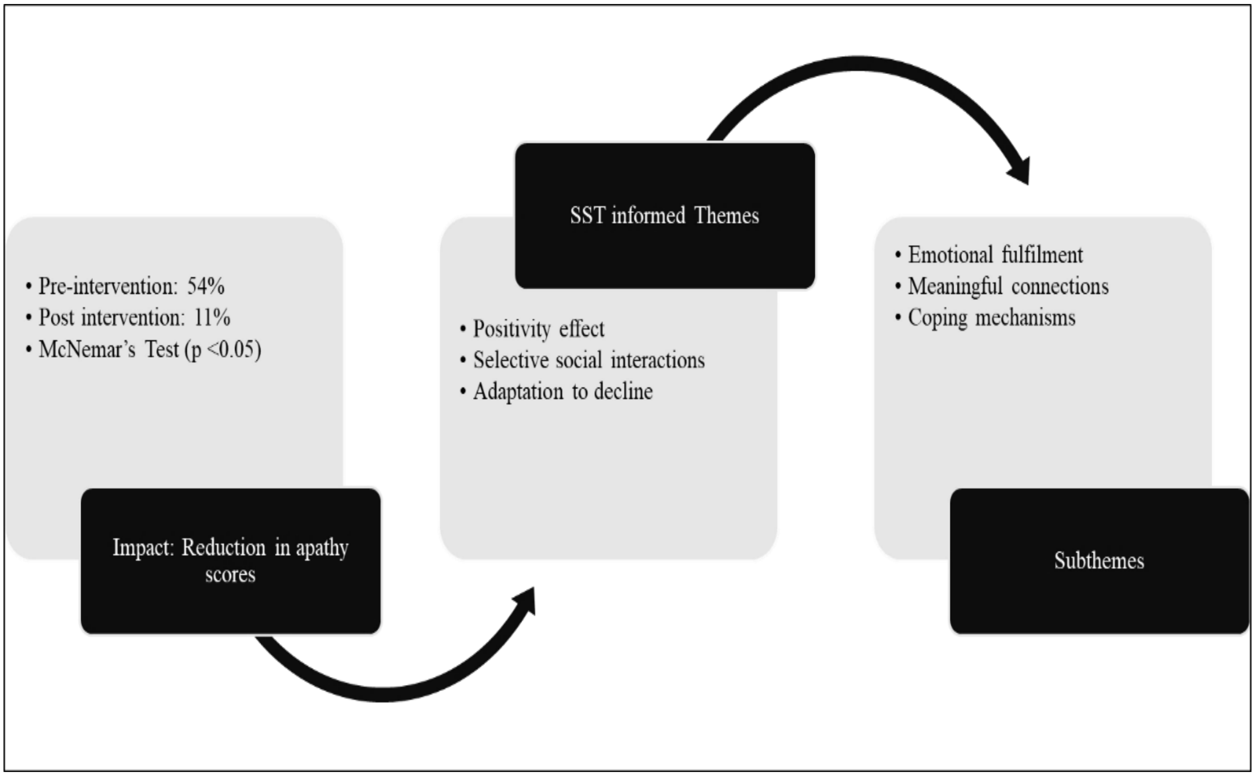


Figure 12:Joint display of qualitative and quantitative findings on the impact of the eBook clubs on apathy.

Mitigation Strategies to successful implementation of eBook clubs

The implementation of eBook clubs among rural, community-dwelling older adults provided valuable insights into a range of creative solutions developed for successful implementation of digital reading programs for this demographic. Themes identified included strategies to: address technological setup and usability, understand eReader use instructions, group engagement, and personalization.

Technology set up and Usability

For some, the experience of setting up and navigating the Kobo eReaders was new. Participants described need to learn how to connect to Wi-Fi, skills in downloading books, and ways to safely locate free content. As one participant noted,

"Setting it up was not that easy… I need to meet with someone to help me do it." [Participant #13, 86 years].

These experiences highlighted the value for additional support, often provided by peers, to help participants become familiar with the device. Physical challenges were also common, with some participants finding it a new sensation to hold the eReader for extended periods or to read comfortably in bed. Tailored, hands-on assistance during setup, including in-person support provided by family or friends for troubleshooting and device handling, was suggested as a potential solution. Additionally, the lightweight device option provided through use of the Kobo eReaders as compared to large print books and access to supportive holders were found to alleviate physical strain and improve usability for participants with limited mobility.

Understanding Instructions

Participants expressed a desire for comprehensive, easy-to-understand guidance. Suggestions included visual aids such as photo infographics or step-by-step guides that could help clarify the device's features. As one participant stated,

"If I had the notes explaining everything about the Kobo from the start, it might have been easier." [Participant #21-, 69 years].

Participants recommended that these materials should cover both basic navigation and advanced functionalities, such as accessing Overdrive and Libby, to enhance user confidence. Comprehensive, visually supportive guides were identified as a useful strategy to empower participants to independently address technological issues by having ample resources to refer back to as needed, helping them independently troubleshoot common issues and also to explore the full capabilities of the eReader.

Group Engagement

The eBook club aimed to foster a sense of community. For some participants participation in a group eReader club was challenging and it took time for some participants to fully connect with the group. By the time of follow-up, many participants expressed a desire for more collective activities. However, for one participant they remained challenged to connect with others through the group:

> "I couldn't really get part in with the whole group," indicating a gap in group cohesion. [Participant #8, 63years].

Others expressed interest in more structured social opportunities, suggesting that shared reading sessions or facilitated group discussions could strengthen engagement and encourage a sense of belonging. Regular, structured group activities such as weekly discussions, icebreakers, or group reading sessions could be incorporated to foster deeper social connections and make the experience more enjoyable and interactive.

Reading pace and content

Participants were enthusiastic to engage in the reading activities and often desired to read ahead. Having a weekly chapter limit occasionally felt restrictive, with some members preferring to read at a faster pace and expressed eagerness to find out what happened next in the book. Feedback such as,

“I would have liked to read more than five chapters at a time,” emphasized a desire for flexibility in the reading schedule as well as an enthusiasm to embrace eReader technology. [Participant #1, 70 years].

Programs could address this by offering customizable reading plans, allowing participants to set their own pace and progress based on individual preferences, and encouragement to read more than one book at a time. Additionally, some participants suggested adding audiobook functionality to accommodate different learning preferences. Incorporating audiobook options could make the program more accessible for participants who prefer auditory engagement or face visual limitations, enhancing satisfaction and inclusivity.

Opportunity	**Mitigation Solutions**
Need to newly set up and navigate the Kobo eReaders devices	Provide tailored, hands-on support during setup, including in-person assistance for familiarizing participants with eReader functions including connecting to Wi-Fi, downloading books, finding free content, and troubleshooting.
Adjustment to read in bed or hold device for long periods.	Consider lightweight device options or eReader holders for easier handling, especially for those with limited mobility.
Need to learn and understand text-based instructions	Create a step-by-step guide with images, covering basic and advanced eReader functionalities, including Overdrive and Libby. This would allow participants to refer back to instructions as needed.
Need to navigate the device and leverage its full range of features	Offer printed or digital support materials with a focus on frequently used features, making it easier for participants to troubleshoot on their own.

Group engagement	Incorporate structured group activities, such as weekly discussions, icebreakers, or collective reading sessions, to foster social connections and a sense of community. Schedule group reading or discussion sessions that encourage shared experiences and allow for reflection on common themes.
Varied reading pace and content	Offer customizable reading plans, allowing participants to set their own pace and progress based on their preferences. This flexibility can accommodate different reading speeds and engagement levels.
Vision and mobility issues	Consider incorporating audiobook features to increase accessibility for participants with visual limitations or those who prefer auditory learning, enhancing engagement and satisfaction.

Table 9: Practical solutions to the challenges encountered during the eBook club implementation

Discussion

Use of eReaders and participation in an eBook club reduced self reported apathy among community dwelling older adults in northern BC. The significant reduction in apathy scores over the course of the program, highlights the potential impact that eBook club can have on apathy among rural community dwelling older adult. Consistent with SST's positivity effect, which posits that as individuals age, they increasingly focus on positive emotional experiences to regulate their mood and well-being (Carstensen et al., 1999), participants in our study reported that reading, both independently and in a group setting, provided emotional satisfaction and a sense of accomplishment, helping them shift away from negative emotions and reduce feelings of apathy. Some participants also expressed that reading gave them a sense of joy and provided a mental escape from the stresses of daily life. In addition, participants prioritized reading as an enjoyable activity, reinforcing the positivity effect described in SST. The shared nature of reading, combined with the flexibility of using eReaders, created opportunities for participants to engage in positive emotional experiences that helped improve their overall mood and engagement.

This selective social interaction was evident in the participants' experiences during the eBook club. This key process emphasized by SST includes the selective pruning of social networks, where older adults tend to focus on maintaining emotionally significant relationships while cutting back on less meaningful social connections (Carstensen, 2006). Rather than forming new and superficial connections, participants formed deeper, more meaningful relationships with other group members. These interactions provided emotional support and a sense of connection, which is critical in managing apathy. Additionally, participants highlighted the value of the small group discussions, where they felt comfortable sharing their thoughts and experiences. This process allowed them to form meaningful bonds, reinforcing their sense of belonging. As older adults often face social isolation, particularly in rural settings, the ability to maintain and nurture emotionally meaningful relationships through the eBook club helped reduce feelings of loneliness and social disengagement, which are common contributors to apathy.

In this study, participants demonstrated how they were able to adapt to age-related challenges, such as declining vision or arthritis, by using the eReaders to continue engaging in reading. SST also emphasizes the importance of adapting to physical and cognitive decline by focusing on emotionally meaningful activities (Löckenhoff & Carstensen, 2004). The adjustable text size and lightweight features of the Kobo eReaders helped participants overcome barriers that would have otherwise limited their ability to enjoy reading. This ability to adapt highlights SST's principle that older adults prioritize emotionally meaningful activities that are aligned with their physical and cognitive capacities. Even as some participants faced difficulties related to memory or physical health, the accessibility of the eReader allowed them to remain engaged in reading, maintaining a sense of purpose and avoiding apathy. The ease of use of the eReaders also reduced frustration for participants, ensuring that reading remained a fulfilling activity despite the challenges of aging.

While the eBook program demonstrated great opportunity to engage older adults through reading and social interaction, several needs were identified that needed to be addressed to ensure access to and continued use of the Kobo eReaders and involvement in the program. Mitigation strategies were created by participants to address difficulties they experienced with the initial setup and navigation of the Kobo eReaders. This included challenges to initially learn and start using the eReaders as well as need to understand how to connect to Wi-Fi, borrow books from the library, or access learning the other functionalities of the device. These experiences when adapting to a new technology are not uncommon, particularly among older adults who may have limited experience with technology. Previous research has shown that older adults often face challenges when adopting new technologies, including difficulties with interface design, learning new functions, and troubleshooting problems independently (Heart & Kalderon, 2013). The unfamiliarity with digital devices can lead to frustration suggesting the initial hurdles indicate that more robust support may be necessary during the onboarding process. However, in our study, many participants eventually overcame these challenges. Further, the challenges related to accessing free eBooks is consistent with previous studies which noted that older adults often require simplified, step-by-step instructions to successfully engage with new technologies (Czaja & Sharit, 2013; Mitzner et al., 2010). To address the initial difficulties participants faced with setting up the eReaders, the study incorporated hands-on support sessions and provided detailed step-by-step guides. For future implementations, incorporating a peer-support model where tech-savvy participants assist others could further enhance user confidence and engagement.

Although eReaders are designed to be lightweight and portable. There are features built into the Kobo eReader that participants used in this. For example, participants were able to push button instead of swipe on screen when navigating to the next page. This finding echo broader concerns in gerontechnology research, where physical ease of use is a key factor in determining the success of technology adoption among older adults. Devices that are not optimized for the physical capabilities of older users can hinder engagement and discourage long-term use (Czaja & Lee, 2007). Addressing these physical challenges by offering adaptations or ergonomic tools may help improve the experience for users and encourage more consistent participation.

Some participants expressed desire for more opportunities to interact with others in a collective setting. Participants desired longer engagement in the eReader clubs than the initial 6-week duration during this study. The desire for more frequent or structured group reading activities could suggest that participants might have benefited more from the program if offered a greater variety of group interaction opportunities. For instance, smaller, more intimate reading circles or one-on-one discussions. This further aligns with SST, which posits that older adults often prefer deeper, more emotionally meaningful interactions over broader social networks as they age (Carstensen, 2006).

Strengths and limitations

One of the key strengths of this study was that it was conducted immediately post-COVID, a time when many older adults were emerging from extended periods of isolation and reduced social interaction. The study offered participants a valuable opportunity to reconnect socially and re-engage in meaningful activities, addressing both emotional and cognitive challenges that may have been exacerbated during the pandemic. Additionally, the use of eReaders and reading groups provided a flexible, accessible means for participants to interact, which was particularly beneficial considering the technological adaptations many had adopted during the pandemic. The timing of the study also allowed for insights into how digital tools can be used to foster social connections and reduce apathy among older adults in a post-pandemic world. While the study provides valuable insights into the use of eBook clubs for mitigating apathy, there are several limitations that should be acknowledged. The study relied on self-reported measures of apathy, which may be subject to bias. More objective measures, such as observational data, could provide further validation of the findings. Further, the length of the intervention varied between participants, ranging from four to six weeks. While this flexibility accommodated different schedules and allowed for individualized participation, it may have led to some nuances in participants' experiences being overlooked. A longer duration was desired by participants and a longer standardization might have provided greater consistency in capturing the longer-term outcomes.

Implications for Practice

This study demonstrates the feasibility and potential impact of digital interventions such as eBook clubs in reducing apathy among rural older adults. By aligning the program with Socioemotional Selectivity Theory, the findings provide evidence for the importance of fostering emotionally meaningful activities and social connections. Practitioners should consider incorporating accessible technology, such as eReaders, to support older adults to continue engaging in activities that bring them joy, even when facing physical limitations. Furthermore, the emphasis on small group interactions reflects the importance of fostering close social relationships, rather than encouraging superficial social networks, as a means of enhancing emotional well-being. Future programs may consider integrating peer support models in which more tech-savvy participants help others navigate the devices and troubleshoot problems, fostering a sense of community while addressing technical challenges. These modifications could enhance the accessibility and inclusivity of eBook club programs, ensuring that all participants feel supported and able to engage fully in both the technological and social aspects of the intervention.

Conclusion

Use of eReaders and participation in eBook clubs were successful to reduce apathy among older adults. As described through the lens of SST, by engaging in emotionally meaningful reading and fostering close, supportive relationships within the eBook club, participants were able to regulate their emotions, maintain social connections, and adapt to the challenges of aging. These processes helped participants remain engaged, fulfilled, and emotionally balanced, effectively mitigating apathy and enhancing their overall well-being. Future studies could explore the role of other emotionally meaningful activities, beyond reading, in reducing apathy among older adults in different settings. Understanding how technology can be tailored to meet the needs of individuals with more advanced cognitive impairments could expand the applicability of such interventions.

Chapter Nine: Results and Major contributions

The primary goal of this dissertation was to investigate apathy as a distinct clinical syndrome in older adults, with and without dementia, across diverse care settings. To this end, a multimethod approach was employed to answer five research questions. The first question (RQ 1) addressed the barriers and facilitators to apathy management. The second and third questions (RQ 2 and 3) focused on the prevalence and predictors/risk factors of apathy among residents with and without dementia in LTCF. The third and fourth questions (RQ 3 and 4) explored the impacts of eBook clubs on apathy among individuals living in LTCF and community settings. The findings are presented as follows:

RQ 1: What are the barriers to and facilitators of apathy among older adults across various settings?

The first study (Chapter Four) focused on understanding the barriers and facilitators to optimal care for older adults with apathy, particularly in the context of its detection and management. This integrative review synthesized findings from 34 studies conducted across Europe, North America, and Australasia, examining the challenges faced by caregivers and healthcare professionals in identifying and addressing apathy in older adults with and without dementia. On one hand, the review revealed that a major barrier to optimal care for apathy was the absence of a universally accepted definition (Agboji et al., 2024a). This lack of consensus on what constitutes apathy leads to inconsistencies in diagnosis and treatment (Caeiro et al., 2013; Mele et al., 2020). In addition, it was noted that apathy is often confused with other conditions such as depression or fatigue, making it challenging for healthcare providers to distinguish it as a distinct syndrome (Agboji et al., 2024a). These overlapping symptoms further complicate accurate detection and can delay appropriate interventions (Agboji et al., 2024a). The review highlighted significant methodological limitations in the studies reviewed, including small sample sizes, varied diagnostic tools, and a lack of blinding in treatment protocols, which made it difficult to establish clear, reliable guidelines for treating apathy (Agboji et al., 2024a).

On the other hand, the review identified several facilitators that can improve care for individuals with apathy including active involvement of both patients and caregivers in the diagnostic and treatment process (Agboji et al., 2024a). By including caregivers in the decision-making process, healthcare providers are more likely to capture a comprehensive picture of the patient's symptoms, improving the accuracy of diagnosis and the relevance of interventions (Agboji et al., 2024a). Additionally, the review emphasized the need for better education and training for healthcare professionals, particularly those working in LTCF (Agboji et al., 2024a). Increased awareness of apathy among healthcare providers can lead to earlier identification and more effective treatment (Agboji et al., 2024a). Furthermore, the adoption of new screening methods, particularly those using ICT, can improve the efficiency of detecting apathy and enable healthcare providers to monitor symptoms more accurately (Agboji et al., 2024a).

However, despite the agreement with existing evidence, the review identifies some gaps in the literature that remain unaddressed. One significant gap is the ongoing lack of a standardized definition and diagnostic criteria for apathy. While efforts to establish a universally accepted definition are ongoing, the absence of such a framework continues to create ambiguity in both research and clinical practice. This gap contributes to inconsistent measurement and hinders the development of effective, universally applicable interventions (Mele et al., 2019). Despite various attempts to standardize assessment tools, apathy’s multifaceted nature remains difficult to capture consistently (Borsje et al., 2018; Tay et al., 2021).

Another notable gap identified in the existing literature is the lack of Canadian studies focusing specifically on the prevalence and risk factors for apathy among older adults. While much of the research on apathy in dementia and LTCF has been conducted internationally, there is a paucity of research specific to the Canadian context (Agboji et al., 2024a). This lack of localized research is particularly concerning given the unique healthcare system, demographic composition, and care environments in Canada (Martin et al., 2018). Factors such as cultural diversity, regional variations in healthcare delivery, and the growing aging population may contribute to the manifestation and management of apathy in distinct ways across Canadian provinces and territories (Agboji et al., 2024a). This gap prompted the need to establish the prevalence and risk factors for apathy in Canadian LTCF to inform healthcare policies, improve care practices, and tailor interventions to meet the needs of older adults in Canada.

RQ 2: What is the prevalence and what are the risk factors for apathy among the Canadian LTCF residents?

The second study (Chapter Five) sets out to examine the prevalence of apathy and identify its key predictors among residents newly admitted to LTCF across Canada. Using data from the InterRAI Minimum Data Set (MDS 2.0), the study analyzed a sample of 157,596 residents across six provinces and one territory.

The study established a prevalence of apathy in 12.5% of the residents, with younger residents (under 65 years) displaying a higher prevalence (14.2%) in contrast to older residents (85 and above), where the rate was 11.9%. The prevalence of apathy was notably higher in smaller LTCFs compared to larger ones (19.6% vs. 11.3%), and geographic location played a role, with prevalence rates ranging from 6.8% in Yukon to 25.6% in Saskatchewan (Agboji et al., 2024b). These findings point to the importance of considering institutional and regional factors when addressing apathy in LTCF (Agboji et al., 2024b).

The study also identified several predictors of apathy across biological, psychological, and social domains. Biologically, age was a significant predictor, with younger residents being more likely to exhibit apathy compared to older residents (Agboji et al., 2024b). Sensory impairments, particularly hearing and vision difficulties, were also found to increase the likelihood of apathy, with severe impairments showing the strongest associations (Agboji et al., 2024b). Weight loss was another biological factor linked to higher odds of apathy (Agboji et al., 2024b), which is consistent with previous studies that have suggested a relationship between functional decline and emotional disengagement (Volicer et al., 2013). Psychologically, cognitive impairment emerged as the strongest predictor of apathy (Agboji et al., 2024b). Severe cognitive impairment was associated with the highest risk, which aligns with existing research that links cognitive decline to the development of apathetic symptoms (Agboji et al., 2024b). Socially, the study found that residents who spoke French or other languages were more likely to exhibit apathy (Agboji et al., 2024b), suggesting that language concordance between residents and caregivers might influence the recognition and management of apathy. Marital status, facility size, and provincial location were also significant social predictors of apathy, indicating the complex interplay of personal, institutional, and regional factors in its prevalence (Agboji et al., 2024b).

These findings align with much of the existing literature on apathy in LTCF including studies by Aguera-Ortiz et al. (2015), Ayers et al. (2017) and Starkstein et al. (2009) which suggest that apathy is common among residents with cognitive decline, particularly among people with dementia, and that it contributes to adverse outcomes such as increased dependency and higher mortality risk. Additionally, the finding that apathy is more prevalent in smaller LTCF is also consistent with previous research suggesting that the quality of care and staff-to-resident ratios impact the emotional well-being of residents (Chaudhury et al., 2017). However, some aspects of this study's findings diverge from existing research. For instance, the finding that younger residents (under 65) have a higher prevalence of apathy than older residents is somewhat unexpected, as most studies suggest that older adults, particularly those with advanced dementia, are more likely to experience apathy (Selbaek et al., 2014). This discrepancy may be attributed to the unique challenges faced by younger residents, who may experience factors such as early-onset dementia or greater difficulties adjusting to institutional care. (Agboji et al., 2024b). This finding highlights the need for more targeted research to explore the specific needs and interventions across different aged LTCF resident cohorts.

Despite the valuable insights offered by this study, gaps still exist in the literature regarding apathy in LTCF. The MDS 2.0 dataset lacks a predefined apathy scale or assessment tool, which led to the innovative approach of combining two variables to define and measure apathy, which was referred to as the Apathy Index in this study. In spite of the usefulness of this approach, it does not fully capture all dimensions of apathy, particularly the emotional and cognitive aspects. Future research should focus on developing more comprehensive assessment tools that consider the full spectrum of apathy symptoms. Further, although this study identified several predictors of apathy, its cross-sectional design limits the ability to establish causal relationships. Longitudinal studies are necessary to better understand how these factors interact over time and how early interventions may help prevent the development of apathy.

RQ 3: What is the prevalence and what are the risk factors for apathy among the Canadian LTCF residents with dementia?

The third study (Chapter Six) investigated the prevalence of apathy in residents with dementia in LTCF across Canada. Using data from 97,789 newly admitted residents from 2015 to 2019, the study explored the biopsychosocial characteristics associated with apathy, employing the biopsychosocial model of care (Engel, 1977).

Apathy was found to be prevalent in 13.1% of the sample, with notable differences in prevalence based on age, language, and facility size. Interestingly, younger residents (under 65 years) exhibited higher rates of apathy (17%) compared to older residents (12%) aged 85 and over, suggesting that apathy may present differently in younger individuals with dementia (Agboji et al., 2024c). In addition, the study showed that apathy was more prevalent among English-speaking residents and those in smaller LTCF (Agboji et al., 2024c). Biologically, apathy was strongly linked to factors such as pain, psychotropic medication use, and cognitive impairment (Agboji et al., 2024c). Residents who experienced severe pain showed a higher prevalence of apathy, with those on psychotropic medications also exhibiting increased odds of apathy (Agboji et al., 2024c). Cognitive impairment, measured by the CPS, was another significant predictor of apathy in dementia (Agboji et al., 2024c). Psychologically, depression and aggression were the most prominent factors associated with apathy (Agboji et al., 2024c). The study also found that residents with moderate to severe depression were significantly more likely to exhibit apathy (Agboji et al., 2024c). Social factors also played a key role. Apathy was inversely related to engagement in various activities, such as music, exercise, and card games. Residents who participated in these activities were less likely to experience apathy (Agboji et al., 2024c). Further, the study found that facility size influenced the prevalence of apathy, with smaller facilities reporting higher rates of apathy (Agboji et al., 2024c).

The findings of this study align with previous research, which has consistently reported that apathy is a common neuropsychiatric symptom in dementia and is associated with a range of psychological, cognitive, and environmental factors (Lanctot et al., 2023; Marin, 1991; Roberts et al., 2006; Starkstein et al., 2006; Steffen, 2022; Volicer et al., 2013). Despite these valuable insights, there are gaps that needed to be addressed in future research. Longitudinal studies are needed to examine how apathy evolves over time and interacts with other dementia symptoms. Additionally, there is need to examine the role of other neurodegenerative diseases, such as Parkinson's disease or Huntington's disease, in the development of apathy. Including a broader range of co-morbidities in future research would provide a more comprehensive understanding of the factors contributing to apathy in dementia.

RQ 4: What impact (s) does eBook club has on apathy among LTCF residents in rural Northern British Columbia?

The fourth study (Chapter Seven) explored eBook clubs as a novel, non-pharmacological intervention to mitigate apathy among older adults residing in LTCF. This study addressed the dual goals of reducing apathy and promoting digital inclusion by introducing accessible eReaders and structured reading sessions. A total of 20 participants, aged 51 to 98 years, engaged in weekly eBook club sessions over an eight-to-twelve-week period. Results demonstrated a significant reduction in self-reported apathy, with prevalence rates declining from 55% to 35%. In addition to these quantitative findings, qualitative feedback highlighted the intervention's cognitive, emotional, and social benefits. Participants consistently reported increased mental stimulation, enhanced mood, and a sense of belonging through shared reading experiences (Agboji et al. 2025). Many expressed enjoyment in learning to use eReaders, challenging stereotypes about older adults' reluctance to adopt new technologies (Mitzner et al., 2010).

Accessibility features, such as adjustable font sizes and backlighting, were particularly valued for overcoming physical barriers such as vision impairments.

Despite its success, the intervention faced challenges, including initial hesitation to technology and occasional difficulties navigating eReaders. These findings brought into fore the importance of providing targeted training and ensuring usability when introducing digital tools to older adults. Participants' overall positive reception of the eBook clubs suggests that intellectual engagement, coupled with social interaction, is a powerful strategy for mitigating apathy in LTCF settings. This study further demonstrates the potential of eBook clubs to serve as a scalable, cost-effective intervention for addressing apathy in LTCF. By combining technology with social engagement, the program alleviates apathy and fosters digital literacy and empowerment among older adults. Future implementations could expand these efforts by incorporating hybrid formats that include both digital and physical books to accommodate diverse preferences.

RQ 5: What impact (s) does eBook club has on apathy among community dwellers in rural Northern British Columbia?

The fifth study (Chapter Eight) explored the impact of eBook clubs as a novel, non-pharmacological intervention for apathy among community dwelling older adults in rural Northern BC. Guided by SST, the intervention aimed to foster emotional engagement and social connection through reading activities. At baseline, the study found apathy prevalence to be 54%, underscoring the challenges older adults face in rural areas, where access to social and recreational opportunities is limited. After participating in the eBook club intervention, apathy prevalence dropped significantly to 11%, demonstrating the effectiveness of this approach. Participants further described three primary mechanisms through which the intervention reduced apathy: emotional stimulation, enhanced social connections, and the ability to overcome physical barriers.

While the intervention was largely successful, some participants encountered initial challenges, including apprehension about using eReaders and variability in reading pace. These issues were addressed through hands-on support from facilitators and peer mentorship, emphasizing the importance of personalized approaches in program implementation. Participants also recommended flexible session structures to accommodate individual preferences and ensure inclusivity. The findings underscore the value of integrating similar initiatives into community care programs, particularly in rural areas where older adults often face limited opportunities for engagement. To enhance the success of such interventions, community organizations and healthcare providers should prioritize accessibility, provide robust training and support, and tailor activities to meet participants' diverse needs.

Discussion

Across all five studies in this dissertation, apathy was present among individuals in both institutional and community settings, with variations across age groups and cognitive impairment levels. For example, studies two and three found that younger residents (under 65) exhibited higher rates of apathy than their older counterparts, challenging the conventional belief that apathy is primarily a symptom of advanced age or dementia (Agboji et al., 2024b; 2024c). These findings highlight the need for interventions that account for a broader range of demographic and cognitive profiles. In addition, the results underscore the importance of tailored interventions to support older adults in diverse environments, including LTCF and rural communities, where opportunities for social engagement and mental stimulation are often limited (Brodaty et al., 2010; 2012; Jao et al., 2019).

Furthermore, studies two and three collectively identified a range of biological, psychological, and social factors that serve as predictors of apathy in LTCF. Biologically, cognitive impairment emerged as one of the strongest predictors of apathy, with residents who had severe cognitive decline exhibiting higher rates of apathy. This is consistent with existing literature, which suggests that apathy is closely linked to neurodegenerative processes such as dementia (Starkstein et al., 2006). In addition to cognitive impairment, sensory deficits, particularly hearing and vision problems, were associated with increased likelihood of apathy. These findings emphasize the need for comprehensive assessments that take into account not only cognitive health but also sensory and physical impairments, which may significantly impact older adults' ability to engage with their environment. Psychologically, depression and aggression were strongly associated with apathy in LTCF. The overlap between apathy and depression has been well-documented (Lanctot et al., 2023; Levy et al., 1998; Marin et al., 1993; Steffen et al., 2022), and these studies further emphasize the importance of careful differential diagnosis. Effective treatment of apathy requires distinguishing it from mood disorders such as depression, as both share symptoms including withdrawal and lack of motivation but have different underlying mechanisms (Steffens et al., 2022). Social factors also played a crucial role in the development and mitigation of apathy. Specifically, social engagement and participation in structured activities were key factors in reducing apathy. This result reinforces the usefulness of novel intervention such as an eBook club in mitigating apathy among residents in LTCF.

As demonstrated in studies four and five, the eBook club interventions facilitated emotional engagement and social connection through shared reading experiences, and these elements were repeatedly highlighted by participants as pivotal to the intervention’s success. These findings also underscore the importance of fostering social interactions and emotional connections in any intervention aimed at addressing apathy. Additionally, participants in these studies highlighted the need for flexible session structures that could accommodate individual preferences, further emphasizing the value of personalized approaches to care.

The Biopsychosocial Model and Socioemotional Selectivity Theory in combination provided a comprehensive lens for understanding and addressing apathy in older adults. The Biopsychosocial Model guided the quantitative analysis by framing apathy as the result of interacting biological, psychological, and social factors while the Socioemotional Selectivity Theory supported the intervention phase by explaining why older adults prioritize emotionally meaningful activities, helping to interpret participants' engagement with the eBook club. Together, these frameworks enhanced the study's ability to identify risk and design interventions tailored to the emotional and social needs of aging populations. By aligning each theoretical framework with distinct methodological strands, this study maintained conceptual clarity while generating a more comprehensive understanding of apathy.

Moreover, lessons learned from studies four and five highlight that designing an eBook club requires careful consideration of the participants' needs and preferences to ensure engagement and inclusivity. A successful program begins by identifying the target audience and understanding their demographic and individual needs. This includes assessing physical, cognitive, and sensory capabilities such as vision, hearing, mobility, and cognitive processing (Wu et al., 2015) to determine suitable features that enhance participation. For example, individuals with poor eyesight may benefit from devices with adjustable font sizes or text-to-speech functionality, while those with cognitive impairments might prefer simplified or segmented materials (Saredakis et al., 2021; Moyle et al., 2013).

Understanding participants' interests is equally important for fostering engagement in an eBook club. Surveys or informal discussions can help facilitators identify preferred genres, authors, or topics that resonate with the group, creating a sense of excitement and ownership. Tailored group formations can further enhance participation. For example, specialized groups for individuals with dementia may benefit from abridged or visually enriched texts, while thematic groups, such as one for veterans, might focus on military history or travel memoirs. Book selections should accommodate diverse preferences, including light fiction, poetry, and short stories, which are well-suited for individuals with limited attention spans (Billington et al., 2013). Rotating monthly themes such as mystery novels or inspiring memoirs keeps the experience fresh and engaging. Additionally, interactive eBooks featuring annotations or discussion prompts can deepen engagement, providing facilitators with structured material to guide conversations.

Technology plays a dual role as both an enabler and potential barrier, making accessibility an important design element when implementing an eBook club among older adults. User-friendly eReaders or tablets with features such as high-contrast displays, large fonts, and audio narration can accommodate a wide range of needs. Providing hands-on technical support, including tutorials and troubleshooting, ensures participants feel confident using the devices (Czaja & Sharit, 2013). For group reading sessions, shared equipment such as projectors or TV screens can display eBooks for collective reading, fostering inclusivity. In addition, virtual eBook clubs hosted on platforms such as Zoom or Microsoft Teams can accommodate participants unable to attend in person. Interactive applications that enable note-sharing and annotations encourage active participation. Multimedia elements, such as videos or audio clips related to the book, add depth to discussions and keep participants engaged.

Structured sessions form the backbone of effective eBook clubs (Kebede et al., 2022; Sen et al., 2022). Warm-up activities, such as sharing favorite books or authors, can break the ice and create a comfortable environment. A mix of silent reading, group reading, and facilitator-led excerpts caters to diverse preferences and can promote inclusivity. Thematic discussions allow participants to connect the book's content to their own experiences (Carney et al., 2023), while creative activities like drawing, writing reflections, or sharing personal stories inspired by the book enhance engagement (Smith, 1993).

Facilitators (recreational staff, care givers, research assistants or project directors) play a key role in the smooth functioning of eBook clubs. They should be trained in active listening, encouraging participation, and managing diverse group dynamics (Billington et al., 2013). Empathy training is important, serving as a cornerstone for equipping facilitators to support individuals with cognitive or emotional challenges effectively. Flexibility is also important; facilitators should adapt their approach based on the group's energy levels, shifting from discussions to lighter activities if needed (Billington et al., 2013).

Strengths and Limitations

This dissertation provides the first comprehensive, multidimensional study of apathy among older adults in Canada, particularly those in LTCF and rural communities. A key strength of this research is its holistic approach: combining quantitative and qualitative methods not only allowed for measuring the prevalence and predictors of apathy but also provided deeper insight into how interventions, such as eBook clubs, influence residents' emotional, cognitive, and social well-being. In addition, the integration of objective data with participants' lived experiences captured the full complexity of apathy, underscoring the importance of person-centered care.

The focus on non-pharmacological interventions, specifically, eBook clubs, is a significant strength. By demonstrating that eBook clubs can reduce apathy while promoting digital inclusion, social interaction, and cognitive engagement, this research contributes valuable evidence to the growing body of knowledge surrounding non-pharmacological interventions for apathy (Cai et al., 2020; Oba et al., 2022). The effectiveness of these interventions in the context of reducing isolation and fostering social bonds, shows promise for scalable and cost-effective solutions to apathy in both institutional and community settings. These findings align with previous literature that emphasizes the importance of cognitive and social engagement for enhancing the quality of life for older adults (Mitzner et al., 2010). Further, the inclusion of both urban and rural communities adds depth to the findings, demonstrating that apathy is a widespread issue that affects older adults across various settings. This broadens the scope of this research, making it relevant to different healthcare settings and regions.

Despite these strengths, several limitations must be acknowledged. One of the main challenges across the studies is the cross-sectional design employed in some of them, which limits the ability to make causal inferences. While the findings regarding the prevalence and predictors of apathy are robust, cross-sectional data can only establish associations rather than causal relationships. Longitudinal research would be valuable in understanding the progression of apathy over time and determining the long-term effectiveness of interventions such as eBook clubs.

Moreover, although participants from diverse settings were included in these studies, there is limited ethnic and cultural diversity among participants. The studies primarily focused on English-speaking populations, and demographic factors such as ethnicity, socioeconomic status, and cultural background were not sufficiently explored. As a result, the findings may not be fully applicable to more diverse populations, particularly in regions where cultural factors play a more significant role in care dynamics. Future research should aim to include a broader range of participants from diverse cultural backgrounds to ensure that the findings are more universally applicable.

Another limitation relates to the challenges associated with technology adoption (Mitzner et al., 2019). While the eBook club interventions were largely successful, some participants initially struggled with using eReaders, highlighting the barriers that older adults face in adopting new technology. Resistance to technology, difficulties navigating devices, and variability in digital literacy were noted as challenges that needed to be addressed through targeted training and ongoing support. These issues are particularly relevant for older adults with limited prior exposure to digital devices. The need for accessible, user-friendly technologies and comprehensive training programs is crucial for ensuring the success of such interventions.

The studies also relied on a standardized tools such as the MDS 2.0 and GDS-3A to measure apathy. While the MDS 2.0 is widely recognized as a valid and reliable assessment instrument, they do not capture the full spectrum of apathy, particularly its emotional and cognitive dimensions. Apathy is a complex, multidimensional condition, and the assessment tools used in these studies may not fully encompass its varied manifestations. While leveraging pre-collected data enhances efficiency and enables large-scale analyses, it restricts the ability to incorporate nuanced diagnostic criteria or capture all relevant dimensions of apathy. For example, while Marin’s criteria require the exclusion of apathy caused by physical disabilities or substance effects, these details may not be available in secondary datasets. In addition, the MDS 2.0 primarily focuses on the behavioral and social dimensions of apathy, potentially neglecting its emotional and cognitive aspects. This narrow focus may result in an incomplete assessment of apathy. Additionally, some items within the MDS 2.0 have demonstrated questionable reliability and validity, which could affect the accuracy of apathy measurements (Morris et al., 1999). Similarly, while the GDS-3A has high specificity, accurately identifying non-apathetic individuals, its low sensitivity suggests it is not reliable for determining the prevalence of apathy in specific populations, reduces its effectiveness as a screening tool for apathy (Bertens et al., 2017). Future research could benefit from developing more comprehensive and nuanced assessment tools that better reflect the emotional and cognitive aspects of apathy.

Lastly, the studies did not include long-term follow-up data to assess whether the positive effects of eBook clubs and other interventions were sustained over time. While the interventions showed short-term success in reducing apathy, it remains unclear whether the benefits would last or if continued participation is necessary to maintain improvements. Long-term follow-up is needed to understand the sustainability of these interventions and to determining whether they can be effectively integrated into ongoing care plans.

Chapter Ten: Implications and Key Recommendations

The findings emphasize several implications essential for improving the management of apathy in individuals both in LTCF and community settings.

Clinical implications

First, there is an urgent need to standardize the definition and assessment of apathy using validated tools to ensure consistent diagnosis and treatment (Agboji et al., 2024a). Increased awareness and targeted training for healthcare providers and caregivers are essential in distinguishing apathy from related conditions such as depression. While these conditions may share overlapping symptoms, understanding their distinct characteristics is important for accurate diagnosis and appropriate intervention (Agboji et al., 2024a).

Caregivers play a pivotal role in apathy assessment, and their involvement can enhance diagnostic accuracy and intervention planning. Technology-based solutions, including interactive platforms and digital tools, offer promising avenues for scalable, patient-centered engagement, reducing caregiver burden (Saredakis et al., 2020). Tailored interventions that consider individual cognitive and functional capacities, such as art and music therapy, are particularly important for addressing the unique needs of individuals with varying levels of dementia (Saredakis et al., 2020). Interventions that integrate caregiver perspectives could provide dual benefits for both patients and caregivers (Agboji et al., 2024b; Jao et al., 2019).

Policy-level interventions are necessary to promote the integration of apathy management protocols across care facilities and regions. Public awareness campaigns and research into diverse populations and long-term intervention outcomes are needed to address current gaps and ensure evidence-based practices. Collectively, these strategies can enhance the quality of care and life for older adults while empowering caregivers and healthcare professionals (Agboji et al., 2024).

Implications for future research

Future research on apathy among older adults should focus on deepening the understanding and improving care outcomes for older adults experiencing apathy. Firstly, the development of standardized, reliable, and validated multidimensional apathy diagnostic tools is essential. Such tool should accurately differentiate apathy from overlapping conditions including depression and cognitive decline to facilitate more precise treatment. Additionally, future studies must include diverse populations, addressing geographic, cultural, and demographic differences, to ensure findings are broadly applicable and sensitive to cultural nuances. Longitudinal research plays a pivotal role in deepening our understanding of the progression of apathy over time and its effects on quality of life, disease advancement, and caregiver burden. Further exploration of the neurobiological, psychological, and social mechanisms underlying apathy could yield insights into targeted interventions. For instance, investigating neural pathways linked to motivational deficits may guide the development of effective pharmacological treatments. Intervention research should emphasize evaluating the long-term effectiveness of both traditional and innovative approaches.

Technology-driven solutions, such as virtual reality and robotics, as well as personalized non-pharmacological therapies, warrant rigorous testing to determine their utility in different care settings to prevent and mitigate apathy (Theleritis et al., 2017). Equally important is enhancing the role of caregivers in apathy management (Agboji et al., 2024a). Research should explore the development of caregiver training programs aimed at enhancing their ability to support affected individuals while reducing caregiver strain. On a systemic level, studies should investigate the integration of apathy assessment and management into standard care protocols and policies. This includes examining the cost-effectiveness and scalability of interventions across diverse care environments. Furthermore, ethical and practical challenges, such as obtaining informed consent from individuals with severe cognitive impairments and implementing solutions in resource-constrained settings, should be prioritized in future research.

Key Recommendations

To improve care for residents in LTCF and enhance the quality of life of older adults dwelling in the community setting, the following recommendations are made:

Recommendations for Nursing Practice

Implement Routine Apathy Screening for Older adults

Apathy is underdiagnosed in older adults due to its subtle presentation and overlap with other conditions, such as depression or cognitive decline. To address this, routine screening for apathy should become a standard component of care for older adults in both LTCF and community settings. Given the absence of a scale to assess apathy in the MDS 2.0, the Apathy Index used in this study can be embedded into the assessment to provide a standardized and consistent method for measuring apathy in LTCF) residents (Agboji et al., 2024b; Agboji et al., 2024c; Volicer et al., 2013). By formally recognizing apathy, the inclusion of this scale would enable healthcare providers to better identify and address this condition, leading to the development of more comprehensive and holistic care plans. This would facilitate ongoing research by standardizing the measurement of apathy, contributing to improved care strategies and enhanced quality of life for individuals affected by apathy.

Address Apathy as Integral to Person-Centered Care

Effectively managing apathy in older adults requires interventions that are customized to the individual's unique needs, preferences, and capabilities. The findings highlight the importance of person-centered care, which emphasizes understanding each resident's personal history, interests, and cognitive abilities (van der Ploeg et al., 2013). Nurses and care providers should adopt a proactive approach in gathering detailed personal histories to inform care plans and ensure that interventions resonate with residents on a deeper, more personal level. Such interventions may simultaneously reduce apathy and enhance emotional well-being and social interaction, contributing to an improved overall quality of life (Cohen-Mansfield et al., 2012; Edvardsson et al., 2014). Additionally, integrating residents in meaningful daily activities, such as reading, gardening, or crafting, can provide them with a sense of purpose and accomplishment, which are essential for alleviating apathy (Agboji et al., 2024c).

Collaborate with caregivers

Caregivers, whether professional or familial, should be recognized as a vital part of the care team to effectively manage apathy (Agboji et al., 2024a). Nurses should collaborate closely with caregivers to gain a comprehensive understanding of the patient's baseline behavior, personality, and preferences. This information is invaluable in designing interventions that are both meaningful and effective. Additionally, caregivers often serve as the primary observers of changes in the resident's behavior, making their insights crucial for tracking progress and adjusting care plans (Agboji et al., 2024a). Nurses can support caregivers by providing them with education on recognizing apathy and strategies to engage older adults (Agboji et al., 2024a). This collaborative approach ensures that the care plan is holistic, addressing both the patient's needs and the caregiver's role in delivering effective care.

Integrate Technology into care of older adults

Incorporating technology into the care of older adults with apathy can provide innovative and scalable solutions. Interactive tablets with engaging applications, robotic companions, and VR experiences offer new avenues for stimulating motivation and reducing apathy (Manera et al., 2020; Saredakis et al., 2020). For example, VR can immerse residents in enjoyable or familiar environments, such as a virtual forest walk or a visit to a childhood hometown, rekindling interest and engagement. Robotic pets or humanoid robots can provide companionship and interactive stimulation, especially for individuals with limited mobility or cognitive impairments (Moyle et al., 2013). These technology-based solutions can complement traditional care approaches, offering diverse and personalized options for reducing apathy in older adults.

Adopt interdisciplinary approach to care

Apathy in older adults often stems from a combination of psychological, social, and physical factors, requiring a interdisciplinary approach to address effectively (Agboji et al., 2024a). Nurses should work closely with other healthcare professionals, such as psychologists, occupational therapists, and social workers, to develop comprehensive care plans (Agboji et al., 2024b). Psychologists can provide expertise in motivational therapies and cognitive-behavioral interventions, while occupational therapists can suggest activities tailored to the patient’s functional capabilities. Social workers can address environmental and relational factors, such as family dynamics and community engagement, that may influence apathy. By collaborating across disciplines, nurses can ensure that care plans are well-rounded and address the multifaceted causes of apathy, leading to better outcomes for residents.

Recommendations for Nursing Education

Incorporate Apathy specific modules

Apathy remains underrecognized in clinical settings, partly due to a lack of emphasis on its unique characteristics in nursing education. To bridge this gap, nursing curricula should include dedicated modules that focus on apathy, its clinical manifestations, and its differentiation from similar conditions such as depression and fatigue (Agboji et al., 2024b; 2004c). These modules should provide students with a comprehensive understanding of the underlying causes of apathy, including neurological, psychological, and social factors. Additionally, the training should emphasize the use of validated diagnostic tools and highlight effective, evidence-based management strategies. Early incorporation of apathy-specific training in nursing programs will better equip future nurses to address this pervasive yet overlooked condition (Agboji et al., 2024a).

Integrate simulation-based learning

Simulation-based education offers a practical and immersive way for nursing students to develop their skills in identifying and managing apathy. Through carefully designed scenarios, students can observe and respond to simulated cases of apathy, practicing interventions in a controlled and low-risk environment. For instance, scenarios could include managing a resident with dementia exhibiting apathy or designing an engagement plan for a community-dwelling older adult. This hands-on approach not only enhances clinical competency but also fosters critical thinking and decision-making (Chabrera et al., 2024). By integrating simulation-based learning into nursing education, students can build confidence and proficiency in handling complex cases involving apathy.

Amplify continuing professional development

Given the evolving nature of healthcare, practicing nurses need access to ongoing education on emerging trends and tools for apathy management. Regular workshops, seminars, and certification programs can help nurses stay informed about the latest evidence-based practices, including advancements in technology-assisted interventions and novel therapeutic approaches (Gallagher, 2007). For instance, sessions on the use of virtual reality in apathy reduction or updates on pharmacological treatments can be incorporated. Offering these opportunities as part of professional development ensures that nurses remain at the forefront of best practices, ultimately improving care outcomes for older adults.

Focus on Older Adult Care

Nursing education programs should place a stronger emphasis on older adult care, as the aging population continues to grow globally. Within this focus, addressing the unique challenges associated with apathy in older adults, both with and without dementia, is essential (Agboji et al., 2024a). Courses should cover the impact of apathy on quality of life, caregiver burden, and healthcare resource utilization. Additionally, training should explore age-appropriate interventions, cultural considerations, and ethical dilemmas in managing apathy in older populations.

Recommendations for Policy

Standardized Apathy Management Protocols

National policies should prioritize the development and implementation of standardized guidelines for the assessment and management of apathy in long-term care and community care settings. These protocols should include the use of validated diagnostic tools, such as the Apathy Evaluation Scale (Marin et al., 1991) or Lille Apathy Rating Scale (Sockeel et al., 2006) or

Apathy Index (Agboji et al., 2024b; 2024c; Volicer et al., 2013) and provide clear recommendations for evidence-based interventions. Standardized guidelines will help ensure consistency in care delivery across diverse settings, promoting equity in the identification and treatment of apathy. Policymakers should collaborate with healthcare organizations, professional bodies, and academic institutions to develop these protocols and integrate them into existing care frameworks.

Provide funding for innovative interventions

To address the multifaceted nature of apathy, governments should allocate dedicated funding to support the research, development, and implementation of innovative interventions. Technology-driven solutions, such as virtual reality, robotics, and interactive digital platforms, have shown promise in engaging older adults and reducing apathy symptoms. Policymakers should provide financial incentives to LTCF and home care services to adopt and integrate these technologies into routine care. Ensuring affordability and accessibility will help bridge gaps in care, especially in underserved or resource-limited communities.

Emphasize equity in training programs

Policymakers should include funding and support for training programs to equip healthcare professionals and caregivers with the knowledge and skills to effectively address apathy. These initiatives should target a wide audience, from nurses and social workers to informal caregivers, providing them with practical tools and strategies for apathy management. Training programs should also emphasize the importance of cultural sensitivity and address the unique needs of diverse populations. Personalized engagement is central to culturally sensitive care. Tailoring activities such as reading, or group discussions to reflect residents' cultural backgrounds fosters emotional connection and cognitive engagement, making these interventions more meaningful and effective (Cai et al., 2020) helping to reduce apathy (Tang et al., 2018). Culturally sensitive care also improves communication between staff and residents. When caregivers are trained to understand and respect cultural differences, they can build trust and better respond to residents’ unique needs, reducing feelings of disconnection and isolation that often exacerbate apathy (Lanctôt et al., 2017). Family involvement in care planning ensures that interventions align with residents' cultural identities and histories, increasing their effectiveness. This enhances the emotional and social well-being of residents as well as strengthens their sense of belonging and purpose within the LTCF community (Moyle et al., 2013). By investing in education, policymakers can build a well-prepared workforce capable of delivering high-quality, person-centered care.

Implement public awareness campaigns

Apathy remains a misunderstood and often stigmatized condition (Baber et al., 2021). Public awareness campaigns are vital tools for educating communities about apathy, its impact on individuals and caregivers, and the importance of early detection and intervention. These campaigns should leverage various media platforms to reach a broad audience, dispelling myths and encouraging proactive care. Highlighting personal stories and successes in managing apathy can further humanize the condition and motivate individuals to seek help for themselves or their loved ones.

Establish quality monitoring systems

To ensure the effectiveness of apathy management protocols and interventions, national policies should include mechanisms for quality monitoring and accountability. Metrics such as rates of apathy assessment, intervention uptake, and patient outcomes should be tracked across LTCF and community care settings. Regular audits and reporting can help identify gaps in care delivery and areas for improvement. Establishing a national database on apathy-related outcomes can further support research and policy development, fostering a culture of continuous improvement in care practices.

Chapter Eleven: Conclusion

This study provided a comprehensive exploration of apathy among older adults living in LTCF and community settings. By presenting the barriers and facilitators to managing apathy in Chapter Four, it has highlighted the multifaceted nature of this condition and the pivotal need for innovative, person-centered approaches to address it. The findings discussed in Chapters Five and Six underscore the importance of recognizing apathy as not merely a symptom of aging or cognitive decline but a distinct condition that affects younger people and significantly impacts quality of life, caregiver burden, and healthcare outcomes. The research emphasizes the importance of early identification through standardized tools such as the Apathy Index, which can serve as a reliable screening method to detect apathy in diverse populations. Furthermore, in Chapters Seven and Eight, non-pharmacological interventions such as eBook clubs have shown promise in mitigating apathy and fostering engagement. These interventions, when combined with caregiver support and interdisciplinary collaboration, provide a holistic approach to managing apathy effectively. In addition to practical applications, this study calls for systemic changes at the policy level. Recommendations include the development of national guidelines for apathy management, increased funding for research and innovative interventions, and widespread education programs for healthcare professionals and caregivers. Public awareness campaigns are also vital to destigmatize apathy and encourage proactive care-seeking behavior.

Looking ahead, future research should focus on refining diagnostic tools, understanding the neurobiological underpinnings of apathy, and evaluating the long-term effectiveness of various interventions. Inclusion of diverse populations and longitudinal studies will further enrich our understanding and improve the generalizability of findings. By implementing the insights and recommendations from this study, we can improve the quality of care and enhance the lives of older adults, empowering them to remain engaged, motivated, and socially connected in their later years. This research serves as a stepping stone toward a more compassionate and effective approach to managing apathy in diverse care settings.

References

Aalten, P., de Vugt, M. E., Jaspers, N., Jolles, J., & Verhey, F. R. J. (2005). The course of neuropsychiatric symptoms in dementia. Part I: Findings from the two-year longitudinal Maasbed study. *International Journal of Geriatric Psychiatry, 20*(6), 523–530. https://doi.org/10.1002/gps.1316

Adams K.B. (2001) Depressive symptoms, depletion, or developmental change? Withdrawal, apathy, and lack of vigor in the geriatric depression scale. Gerontologist, 41(6),768–777. https://doi:10.1093/geront/41.6.768

Adan, A. & Guàrdia, J. (1993) Circadian variations of self-reported activation: A multidimensional approach*. Chronobiologia, 20* (3), 233–244. https://pubmed.ncbi.nlm.nih.gov/8131672/

Agboji, A., Freeman, S., Banner, D., Duchesne, A., Armstrong, J., & Martin-Khan, M. (2024a). Apathy in older adults with and without dementia: An integrative review of barriers and facilitators to care. Sage Open, 14(2), 1-25. https://doi.10.1177/21582440241241882.

Agboji A, Freeman S, Banner D, Armstrong J, Martin-Khan M.(2024b). Investigating the Prevalence and Predictors of Apathy among the Canadian Long-Term Care Residents: A Secondary Data Analysis. *Canadian Journal of Nursing Research,56*(4):468-482. https://doi:10.1177/08445621241276613.

Agboji, A., Freeman, S., Banner, D., Armstrong, J., & Martin-Khan, M. (2024c). The prevalence and risk factors of apathy among the Canadian long-term care residents with Alzheimer's disease and related dementias. *Journal of Alzheimer's Disease: JAD*, *102*(2), 382–395. https://doi.org/10.3233/JAD-240370

Agboji, A., Freeman, S., Banner, D., Armstrong, J., & Martin-Khan, M. (2025). Value of ereaders to mitigate apathy and reduce the digital divide in long-term care settings. *Journal of the American Medical Directors Association*, *26*(1), 105362. https://doi.org/10.1016/j.jamda.2024.105362

Andrews, J. A., Brown, L. J., Hawley, M. S., & Astell, A. J. (2019). Older Adults' Perspectives on Using Digital Technology to Maintain Good Mental Health: Interactive Group Study. *Journal of Medical Internet Research*, *21*(2), 1-11. https://doi.10.2196/11694.

Aguera-Ortiz, L., Gil-Ruiz, N., Cruz-Orduna, I., Ramos-Garcia, I., Osorio, R. S., Valenti-Soler, M., Olazaran-Rodriguez, J., Dobato-Ayuso, J. L., Lanctot, K., & Martinez-Martin, P. (2015). A novel rating scale for the measurement of apathy in institutionalized persons with dementia: The APADEM-NH. *American Journal of Geriatric Psychiatry, 23*(2), 149–159. https://doi.org/10.1016/j.jagp.2013.01.079

Almeida-Meza, P., Steptoe, A., & Cadar, D. (2021). Markers of cognitive reserve and dementia incidence in the English Longitudinal Study of Ageing. *The British Journal of Psychiatry, 218*(5), 243-251. https://doi.org/10.1192/bjp.2020.54

Altintas, E., De Benedetto, G., & Gallouj, K. (2017). Adaptation to nursing home: The role of leisure activities in light of motivation and relatedness. *Archives of Gerontology and Geriatrics*, *70*, 8-13. https://doi.10.1016/j.archger.2016.12.004.

Alzheimer Society of Canada. (2022). *Landmark study report #1: Navigating the path forward for dementia in Canada*. Alzheimer's Society of Canada. Ontario, CA.

Ang, Y.-S., Lockwood, P. L., Kienast, A., Plant, O., Drew, D., Slavkova, E., Tamm, M., & Husain, M. (2018). Differential impact of behavioral, social, and emotional apathy on

Parkinson's disease. *Annals of Clinical and Translational Neurology, 5*(10), 1286–1291. https://doi.org/10.1002/acn3.626

Appelhof, B., Bakker, C., Van Duinen-Van Den, I. J. C. L., Zwijsen, S. A., Smalbrugge, M., Verhey, F. R. J., De Vugt, M. E., Zuidema, S. U., & Koopmans, R. (2019). Differences in neuropsychiatric symptoms between nursing home residents with young-onset dementia and late-onset dementia. *Aging & Mental Health, 23*(5), 581–586. https://doi.org/10.1080/13607863.2018.1428935

Arnold, D. S., Rosse, R. B., Dickinson, D., Benham, R., Deutsch, S. I., & Nelson, M. W. (2004). Adjuvant therapeutic effects of galantamine on apathy in a schizophrenia patient. *The Journal of Clinical Psychiatry*, *65*(12), 1723-1724. https://doi.:org/10.4088/JCP.v65n1219e

Atchley, R. C. (1989). A continuity theory of normal aging. *The Gerontologist, 29*(2), 183–190. https://doi.org/10.1093/geront/29.2.183

Ayers, E., Shapiro, M., Holtzer, R., Barzilai, N., Milman, S., & Verghese, J. (2017). Symptoms of apathy independently predict incident frailty and disability in community-dwelling older adults. *Journal of Clinical Psychiatry, 78*(5), e529–e536. https://doi.org/10.4088/JCP.15m10113

Azhar, L., Kusumo, R. W., Marotta, G., Lanctôt, K. L., & Herrmann, N. (2022). Pharmacological Management of Apathy in Dementia. *CNS drugs, 36*(2), 143–165. https://doi.org/10.1007/s40263-021-00883-0

Bakker, C. M., de Vugt, M. E., van Vliet, D. M., Verhey, F. R. J., Pijnenburg, Y. A. M., Vernooij-Dassen, M. J. F. J., & Koopmans, R. T. C. M. (2013). Predictors of time to institutionalization in young- versus late-onset dementia: Results from the Needs in

Young Onset Dementia (NeedYD) study. *Journal of the American Medical Directors Association, 14*(4), 248–253. https://doi.org/10.1016/j.jamda.2012.09.011

Barch, D. M., Pagliaccio, D., & Luking, K. (2016). Mechanisms underlying motivational deficits in psychopathology: Similarities and differences in depression and schizophrenia. *Behavioral Neuroscience of Motivation, 27*, 411–449. https://doi.org/10.1007/7854_2015_376

Bauhuis, R., Mulders, A., & Koopmans, R. (2020). The course of neuropsychiatric symptoms in institutionalized patients with early onset dementia. *Aging Mental Health, 24*(3), 439–444. https://doi.org/10.1080/13607863.2018.1531379

Batail, J. M., Palaric, J., Guillery, M., Gadoullet, J., Sauleau, P., Le Jeune, F., Vérin, M., Robert, G., & Drapier, D. (2018). Apathy and depression: Which clinical specificities? *Personalized Medicine in Psychiatry, 7*(8), 21-26. https://doi.:org/10.1016/j.pmip.2017.12.001

Bavishi, A., Slade, M. D., & Levy, B. R. (2016). A chapter a day: Association of book reading with longevity. *Social Science & Medicine, 164*, 44-48. https://doi.org/10.1016/j.socscimed.2016.07.014

Bazeley, P., & Jackson, K. (2013). *Qualitative Data Analysis with NVivo* (2nd ed.). Sage.

BC Stats (2024). Sustaining Growth: Population and Demography for B.C. and Canada. Available at https://www2.gov.bc.ca/assets/gov/data/statistics/people-population-community/population/sustaining_growth_population_demography.pdf (Accessed September 27, 2024).

Beasley, C. M., Hamilton, S. H., Crawford, A. M., Dellva, M. A., Tollefson, G. D., Tran, P. V., Blin, O., & Beuzen, J. (1997). Olanzapine versus haloperidol: Acute phase results of the international double-blind olanzapine trial. *European Neuropsychopharmacology*, *7(2)*, 125-137. https://doi.:org/10.1016/S0924-977X(96)00392-6

Benoit, M., Berrut, G., & Doussaint, J. (2015). Apathy in late-life depression: Clinical correlates and impact on treatment. *Aging & Mental Health, 19*(1), 1–8. https://doi.org/10.1080/13607863.2014.915920

Bernabei, V., De Ronchi, D., La Ferla, T., Moretti, F., Tonelli, L., Ferrari, B., Forlani, M., & Atti, A. R. (2013). Animal-assisted interventions for elderly patients affected by dementia or psychiatric disorders: a review. *Journal of Psychiatric Research*, *47*(6), 762–773. https://doi.org/10.1016/j.jpsychires.2012.12.014

Bertens A.S., Moonen J.E.F., de Waal M.W.M, et al. (2017) Validity of the three apathy items of the Geriatric Depression Scale (GDS-3A) in measuring apathy in older persons. *International Journal of Geriatric Psychiatry, 32*(4):421–428. https://doi.10.1002/gps.4484.

Blundo, C., & Gerace, C. (2015). Dopamine agonists can improve pure apathy associated with lesions of the prefrontal-basal ganglia functional system. *Neurological Sciences : Official Journal of the Italian Neurological Society and of the Italian Society of Clinical Neurophysiology*, *36*(7), 1197–1201. https://doi.:org/10.1007/s10072-014-2061-5

Borsje, P., Lucassen, P. L. B. J., Wetzels, R. B., Pot, A. M., & Koopmans, R. T. C. M. (2017). Neuropsychiatric symptoms and psychotropic drug use in patients with dementia in general practices. *Family Practice, 35*(1), 22-28. https://doi.org/10.1093/fampra/cmx061

Bolton, D., & Gillett, G. (2019). *The biopsychosocial model of health and disease. new philosophical and scientific developments*. Palgrave Open Access. https://www.palgrave.com/gp/book/9783030118983

Bortolon, C., Macgregor, A., Capdevielle, D., & Raffard, S. (2018). Apathy in schizophrenia: A review of neuropsychological and neuroanatomical studies. *Neuropsychologia, 118*(Pt B), 22-33. https://doi..org/10.1016/j.neuropsychologia.2017.09.033

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101.

Brodaty, H., Altendorf, A., Withall, A., & Sachdev, P. (2010). Do people become more apathetic as they grow older? A longitudinal study in healthy individuals. *International Psychogeriatrics, 22*(3), 426-436. https://doi:10.1017/s1041610209991335

Brodaty, H., & Burns, K. (2012). Nonpharmacological management of apathy in dementia: a systematic review. *American Journal of Geriatric Psychiatry, 20*(7), 549-564. https://doi..org/10.1097/JGP.0b013e31822be242

Burgon, C., Goldberg, S. E., van der Wardt, V., Brewin, C., & Harwood, R. H. (2021). Apathy Measures in Older Adults and People with Dementia: A systematic review of measurement properties using the cosmin methodology. *Dementia and geriatric cognitive disorders, 50*(2), 111-123. https://doi.:org/https://dx.https://doi.:org/10.1159/000515678

Burrows, A. B., Morris, J. N., Simon, S. E., Hirdes, J. P., & Phillips, C. (2000). Development of a minimum data set-based depression rating scale for use in nursing homes. *Age and Ageing, 29*(2), 165–172. https://doi.org/10.1093/ageing/29.2.165

Bieliauskas, L. A. (2005). Neuropsychological assessment of apathy and other symptoms of dementia. *Clinical Neuropsychology, 19*(1), 89–99. https://doi.org/10.1080/13854040490507299

Billington, J., Carroll, J., Davis, P., Healey, C., & Kinderman, P. (2013). A literature-based intervention for older people living with dementia. *Perspectives in public health*, *133*(3), 165-173. https://doi: 10.1177/1757913912470052

Caeiro, L., Ferro, J. M., & Costa, J. (2013). Apathy secondary to stroke: A systematic review and meta-analysis. *Cerebrovascular Disorder*, *35*(1), 23-39. https://doi.:10.1159/000346076

Cai, Y., Li, L., Xu, C., & Wang, Z. (2020). The effectiveness of non-pharmacological interventions on apathy in patients with dementia: A Systematic review of systematic reviews. *Worldviews on Evidence-Based Nursing*, *17*(4), 311–318. doi.org/10.1111/wvn.12459

Calabrese, J. R., Fava, M., Garibaldi, G., Grunze, H., Krystal, A. D., Laughren, T., Macfadden, W., Marin, R., Nierenberg, A. A., & Tohen, M. (2014). Methodological approaches and magnitude of the clinical unmet need associated with amotivation in mood disorders. *Journal of Affective Disorder, 168*, 439-451. https://doi..org/10.1016/j.jad.2014.06.056

Calderon, J., Perry, R. J., Erzinclioglu, S., Berrios, G. E., Dening, T. R., & Hodges, J. R. (2001). Perception, apathy and depression in Alzheimer's disease: A longitudinal study. *Behavioural Neurology, 13*(2), 79–91. https://doi.org/10.1155/2001/121571

Canadian Institute for Health Information. (2013). *When a nursing home is home: how do canadian nursing homes measure up on quality?* Retrieved January 2, 2021, from http://publications.gc.ca/collections/collection_2013/icis-cihi/H118-84-2013-eng.pdf

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada. (2018). *Tri-Council Policy Statement: Ethical conduct for research involving humans* (TCPS 2). https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2018.html

Carney, G. M., Lugea, J., Fernandez-Quintanilla, C., & Devine, P. (2023). "Sometimers, Alzheimer's? I love that! That's definitely me": Readers' Responses to Fictional Dementia Narratives. *The Gerontologist*, *63*(10), 1610–1618. https://doi.org/10.1093/geront/gnad055

Carnes-Vendrell, A., Deus, J., Molina-Seguin, J., Pifarré, J., & Purroy, F. (2019). Depression and Apathy After Transient Ischemic Attack or Minor Stroke: Prevalence, Evolution and Predictors. *Scientific reports*, *9*(1), 16248. https://doi.org/10.1038/s41598-019-52721-5

Carrozzino, D. (2019). Clinimetric approach to rating scales for the assessment of apathy in Parkinson's disease: A systematic review. *Program Neuropsychopharmacology Biology Psychiatry, 94*, 109641. https://doi..org/10.1016/j.pnpbp.2019.109641

Carstensen, L. L. (2006). The influence of a sense of time on human development. *Science*, *312*(5782), 1913–1915. https://doi.org/10.1126/science.1127488

Carstensen, L. L., Isaacowitz, D. M., & Charles, S. T. (1999). Socioemotional selectivity theory: An emotional regulation framework for aging. *Journal of Personality and Social Psychology*, *76*(3), 325–346. https://doi.org/10.1037/0022-3514.76.3.325

Castro, F. G., Kellison, J. G., Boyd, S. J., & Kopak, A. (2010). A Methodology for Conducting Integrative Mixed Methods Research and Data Analyses. *Journal of Mixed Methods Research*, *4*(4), 342-360. https://doi.org/10.1177/1558689810382916

Chabrera, C., Aldomà, M., Bazo-Hernández, L., Faro, M., Farrés-Tarafa, M., Gil-Mateu, E., Gómez-Ibáñez, R., Insa, E., Medel, D., Peñataro-Pintado, E., Puiggrós-Binefa, A., Rascón, C., Sarria-Guerrero, J. A., Ricart, M., Suris, C., Fernández, P., & Rodríguez, E. (2024). The Use of Simulation in Nursing Education Programs: A Cross-Sectional

Interuniversity Study. *Nursing Forum*, *2024*(1), 1091530. https://doi.org/https://doi.org/10.1155/2024/1091530

Chang, Y. H., Wu, I. C., & Hsiung, C. A. (2021). Reading activity prevents long-term decline in cognitive function in older people: evidence from a 14-year longitudinal study. *International Psychogeriatrics*, *33*(1), 63-74. https://doi.org/10.1017/s1041610220000812

Charness, N., & Boot, W. R. (2009). Aging and information technology use: Potential and barriers. *Current directions in Psychological Science*, *18*(5), 253-258. http://cdp.sagepub.com/content/18/5/253

Chaudhury, H., Cooke, H. A., Cowie, H., & Razaghi, L. (2017). The influence of the physical environment on residents with dementia in long-term care settings: A review of the empirical literature. *The Gerontologist, 58*, e325–e337. https://doi.org/10.1093/geront/gnw259

Chase, T. N. (2011). Apathy in neuropsychiatric disease: diagnosis, pathophysiology, and treatment. *Neurotox Research, 19*(2), 266-278. https://doi..org/10.1007/s12640-010-9196-9

Clarke, D. E., Ko, J. Y., Kuhl, E. A., van Reekum, R., Salvador, R., & Marin, R. S. (2011). Are the available apathy measures reliable and valid? A review of the psychometric evidence. *Journal of Psychosomatic Research, 70*(1), 73-97. https://doi..org/10.1016/j.jpsychores.2010.01.012

Clarke, D. E., Reekum, R. V., Simard, M., Streiner, D. L., Freedman, M., & Conn, D. (2007). Apathy in Dementia: An examination of the psychometric properties of the apathy evaluation scale. *The Journal of Neuropsychiatry and Clinical Neurosciences*, *19*(1), 57–64.https://doi.:org/10.1176/jnp.2007.19.1.57

Clarke, D. E., Ko, J. Y., Kuhl, E. A., van Reekum, R., Salvador, R., & Marin, R. S. (2011). Are the available apathy measures reliable and valid? A review of the psychometric evidence. *Journal of Psychosomatic Research, 70*(1), 73–97. https://doi.org/10.1016/j.jpsychores.2010.01.012

Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences* (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum Associates.

Cohen-Mansfield, J., Dakheel-Ali, M., Jensen, B., Marx, M. S., & Thein, K. (2012). An analysis of the relationships among engagement, agitated behavior, and affect in nursing home residents with dementia. *International Psychogeriatrics*, *24*(5), 742–752. https://doi:10.1017/S1041610211002535

Cohen-Mansfield, J. (2018). Non-pharmacological interventions for persons with dementia: what are they and how should they be studied? *International Psychogeriatrics, 30*(3), 281–283. doi:10.1017/S104161021800039x.

Creswell, J. W., & Poth, C.N., V. L. (2018). Qualitative inquiry and research design: Choosing among five approaches. (4th ed.). Sage Publications.

Creswell, J. W., & Plano Clark, V. L. (2018). Designing and conducting mixed methods research (3rd ed.). Sage Publications.

Cummings, J., Friedman, J. H., Garibaldi, G., Jones, M., Macfadden, W., Marsh, L., & Robert, P. H. (2015). Apathy in neurodegenerative diseases: Recommendations on the design of clinical trials. *Journal of Geriatric Psychiatry and Neurology, 28*(3), 159–173. https://doi.org/https://https://doi.org/10.1177/0891988715573534

Cummings, J. L., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D. A., & Gornbein, J. (1994). The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia. *Neurology, 44*(12), 2308–2314. https://doi.org/10.1212/wnl.44.12.2308

Czaja, S. J., & Sharit, J. (2013). *Designing training and instructional programs for older adults*. (1st ed), Boka Rato, FL: CRC Press.

Davis, R. J., & Tremont, G. (2007). Neuropsychiatric aspects of apathy in Alzheimer's disease: Implications for caregivers. *Psychogeriatrics, 7*(4), 183–189. https://doi.org/10.1111/j.1479-8301.2007.00149.x

Dening, T., Baber, W., Chang, M., & Yates, J. (2021). The struggle of apathy in dementia. *Aging & Mental Health*, *26*(10), 1909–1911. https://doi.org/10.1080/13607863.2021.2008309

Deci, E. L., & Ryan, R. M. (2000). The "what" and "why" of goal pursuits: Human needs and the self-determination of behavior. *Psychological Inquiry, 11*(4), 227–268. https://doi.org/10.1207/S15327965PLI1104_01

Desouza, C. V., Padala, P. R., Haynatzki, G., Anzures, P., Demasi, C., & Shivaswamy, V. (2012). Role of apathy in the effectiveness of weight management programmes. *Diabetes, obesity & metabolism, 14*(5), 419–423. https://doi.org/10.1111/j.1463-1326.2011.01544.x

Diehl-Schmid, J., Pohl, C., Perneczky, R., Förstl, H., & Kurz, A. (2006). Behavioral disturbances in the course of frontotemporal dementia. *Dementia and geriatric cognitive disorders*, *22*(4), 352–357. https://doi.org/10.1159/000095625

Dickson, S. S., & Husain, M. (2022). Are there distinct dimensions of apathy? The argument for reappraisal. Cortex, 149, 246-256. https://doi..org/10.1016/j.cortex.2022.01.001

Drijgers, R. L., Verhey, F. R., Leentjens, A. F., & Kohler, S. (2011). Neuropsychological correlates of apathy in mild cognitive impairment and Alzheimer’s disease: The role of executive functioning. International Psychogeriatric, 23(8), 1327–1333. https://doi.org/10.1017/S1041610211001037

Drye, L. T., Scherer, R. W., Lanctôt, K. L., Rosenberg, P. B., Herrmann, N., Bachman, D., & Mintzer, J. E. (2013). Designing a trial to evaluate potential treatments for apathy in dementia: The apathy in dementia methylphenidate trial (admet). The American Journal of Geriatric Psychiatry, 21(6), 549–559. https://doi.org/10.1016/j.jagp.2012.12.018

Duffy, J. F., Zitting, K. M., & Chinoy, E. D. (2015). *Aging and Circadian Rhythms. Sleep medicine clinics, 10*(4), 423–434. https://doi.org/10.1016/j.jsmc.2015.08.002

Dujardin, K., Langlois, C., Plomhause, L., Carette, A. S., Delliaux, M., Duhamel, A., & Defebvre, L. (2014). Apathy in untreated early-stage Parkinson disease: Relationship with other non-motor symptoms. Movement Disorders: *Official Journal of the Movement Disorder Society, 29*(14), 1796–1801. https://doi.org/10.1002/mds.26058

Ellis, J. M., Doyle, C. J., & Selvarajah, S. (2016). The relationship between apathy and participation in therapeutic activities in nursing home residents with dementia: Evidence for an association and directions for further research. *Dementia (London, England)*, *15*(4), 494–509. https://doi.org/10.1177/1471301214527300

Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. Science *(American Association for the Advancement of Science), 196*(4286), 129-136. https://doi:10.1126/science.847460

Erikson, E. H. (1959). *Identity and the life cycle*. International Universities Press.

Esposito, F., Gendolla, G. H. E., & Van der Linden, M. (2014). Are self-efficacy beliefs and subjective task demand related to apathy in aging? *Aging & Mental Health, 18*(4), 521-530. https://doi.:10.1080/13607863.2013.856865

Fagerland, M.W., Lydersen, S. & Laake, P. (2013). The McNemar test for binary matched-pairs data: mid-*p* and asymptotic are better than exact conditional. *BMC Medical Research Methodology, 13*(1), 91-98. https://doi.org/10.1186/1471-2288-13-91

Fahed, M., & Steffens, D. C. (2021). Apathy: Neurobiology, assessment and treatment. *Clinical Psychopharmacology and Neuroscience, 19*(2), 181–189. https://doi.org/10.9758/cpn.2021.19.2.181

Feng, Y., Barakova, E., Yu, S., Hu, J., & Rauterberg, G. W. M. (2020). Effects of the level of interactivity of a social robot and the response of the augmented reality display in contextual interactions of people with dementia. *Sensors, 20*(13), 3771. https://dx.doi.org/10.3390/s20133771

Ferrero-Arias, J., Goni-Imizcoz, M., Gonzalez-Bernal, J., Lara-Ortega, F., da Silva-Gonzalez, A., & Diez-Lopez, M. (2011). The efficacy of nonpharmacological treatment for dementia-related apathy. *Alzheimer Disease and Associated Disorders, 25*(3), 213-219. https://doi.:10.1097/WAD.0b013e3182087dbc

Finlay, L. (2002). “Outing” the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research, 12*(4), 531–545. doi.org/10.1177/104973202129120052

Flavell, J., & Nestor, P. J. (2022). A Systematic Review of Apathy and Depression in Progressive Supranuclear Palsy. *Journal of Geriatric Psychiatry Neurology, 35*(3), 280-292. https://doi..org/10.1177/0891988721993545

Foubert-Samier, A., Le Goff, M., Helmer, C., Pérès, K., Orgogozo, J.-M., Barberger-Gateau, P., Amieva, H., & Dartigues, J.-F. (2014). Change in leisure and social activities and risk of dementia in elderly cohort. *The Journal of Nutrition, Health & Aging, 18*(10), 876-882. https://doi.org/10.1007/s12603-014-0505-9

Frakey, L. L., Salloway, S., Buelow, M., & Malloy, P. (2012). A randomized, double-blind, placebo-controlled trial of modafinil for the treatment of apathy in individuals with mild-to-moderate alzheimer's disease. *The Journal of Clinical Psychiatry, 73*(6), 796–801. https://doi.:10.4088/JCP.10m06708

Freeman, S., Bishop, K., Spirgiene, L., Koopmans, E., Botelho, F. C., Fyfe, T., Xiong, B., Patchett, S., & MacLeod, M. (2017). Correction to: Factors affecting residents transition from long term care facilities to the community: A scoping review. *BMC Health Services Research, 17*(1), 694–707. https://doi.org/10.1186/s12913-017-2636-y

Freeman, S., Spirgiene, L., Martin-Khan, M., & Hirdes, J. P. (2017). Relationship between restraint use, engagement in social activity, and decline in cognitive status among residents newly admitted to long-term care facilities. *Geriatrics & Gerontology International, 17*(2), 246-255. https://doi:10.1111/ggi.12707

Finlay, L. (2002). “Outing” the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research, 12*(4), 531–545. https://doi.org/10.1177/104973202129120052

Fries, B. E., Morris, J. N., Bernabei, R., Finne-Soveri, H., Hirdes, J., & interRAI consortium (2007). Rethinking the Resident Assessment Protocols. *Journal of the American Geriatrics Society*, *55*(7), 1139–1140. https://doi.org/10.1111/j.1532-5415.2007.01207.x

Frodl, T., & O’Keane, V. (2013). Apathy and its neurocognitive basis in major depressive disorder. *CNS Spectrums, 18*(4), 233–239. https://doi.org/10.1017/s1092852913000386

Gallagher, L. (2007). Continuing education in nursing: a concept analysis. *Nurse Educ Today*, *27*(5), 466-473. https://doi.org/10.1016/j.nedt.2006.08.007

Gerritsen, D. L., Achterberg, W. P., Steverink, N., Pot, A. M., Frijters, D. H. M., & Ribbe, M. W. (2008). The MDS challenging behavior profile for long-term care. *Aging & Mental Health, 12*(1), 116–123. https://doi.org/10.1080/13607860701529882

Gerritsen, D. L., Jongenelis, K., Steverink, N., Ooms, M. E., & Ribbe, M. W. (2005). Down and drowsy? Do apathetic nursing home residents experience low quality of life? *Aging and Mental Health, 9*(2), 135–141. https://doi.org/10.1080/13607860412331336797

Ghaemi, S. N. (2009). The rise and fall of the biopsychosocial model. British Journal of Psychiatry, 195(1), 3–4. https://doi.org/10.1192/bjp.bp.109.063859

Ginsberg, T. B., Powell, L., Emrani, S., Wasserman, V., Higgins, S., Chopra, A., Cavalieri, T. A., & Libon, D. J. (2019). Instrumental activities of daily living, neuropsychiatric symptoms, and neuropsychological impairment in mild cognitive impairment. *Journal of the American Osteopathic Association, 119*(2), 96–101. https://doi.org/10.7556/jaoa.2019.015

Goris, E. D., Ansel, K. N., & Schutte, D. L. (2016). Quantitative systematic review of the effects of non-pharmacological interventions on reducing apathy in persons with dementia. *Journal of advanced nursing, 72*(11), 2612-2628. https://doi.:10.1111/jan.13026

Gracia-García, P., Modrego, P., & Lobo, A. (2021). Apathy and neurocognitive correlates: review from the perspective of 'precision psychiatry'. *Current Opinion in Psychiatry, 34(2)*, 193-198. https://doi..org/10.1097/yco.0000000000000677

Grool AM, Geerlings MI, Sigurdsson S, et al. (2014) Structural MRI correlates of apathy symptoms in older persons without dementia: AGES-Reykjavik Study. *Neurology, 82*,1628–1635.

Grossman, H. T., Sano, M., Aloysi, A., Elder, G. A., Neugroschl, J., Schimming, C., Soleimani, L., & Zhu, C. W. (2022). Prevalent, persistent, and impairing: Longitudinal course and impact of apathy in Alzheimer's disease. *Alzheimer's & dementia (Amsterdam, Netherlands)*, *13*(1), 1-10. https://doi.org/10.1002/dad2.12169

Harrison, F., Aerts, L., & Brodaty, H. (2016). Apathy in Dementia: Systematic Review of Recent Evidence on Pharmacological Treatments. *Current Psychiatry Report, 18*(11), 1-12. https://doi..org/10.1007/s11920-016-0737-7

Havighurst, R. J., & Albrecht, R. (1953). *Older people*. Longmans, Green.

Heart, T., & Kalderon, E. (2013). Older adults: Are they ready to adopt health-related ICT? *International Journal of Medical Informatics*, *82*(11), e209-e231. https://doi.org/https://doi.org/10.1016/j.ijmedinf.2011.03.002

Hesse-Biber, S., & Johnson, R. B. (2015). *The Oxford Handbook of Multimethod and Mixed Methods Research Inquiry*. New York, NY: Oxford University Press.

Herrmann, N., Rothenburg, L. S., Black, S. E., Ryan, M., Liu, B. A., Busto, U. E., & Lanctôt, K. L. (2008). Methylphenidate for the Treatment of Apathy in Alzheimer Disease. Journal of clinical psychopharmacology, *28*(3), 296-301. https://doi.:10.1097/jcp.0b013e318172b479

Hirdes, J. P., Ljunggren, G., Morris, J. N., Frijters, D. H., Finne Soveri, H., Gray, L., Björkgren, M., & Gilgen, R. (2008). Reliability of the interrai suite of assessment instruments: A 12-country study of an integrated health information system. *BMC Health Services Research, 8*(1), 277–288. https://doi.org/10.1186/1472-6963-8-277

Holmes, C., Knights, A., Dean, C., Hodkinson, S., & Hopkins, V. (2006). Keep music live: Music and the alleviation of apathy in dementia subjects. *International Psychogeriatrics, 18*(4), 623-630. https://doi.:10.1017/S1041610206003887

Holtta, E. H., Laakkonen, M.-L., Laurila, J. V., Strandberg, T. E., Tilvis, R. S., & Pitkala, K. H. (2012). Apathy: Prevalence, associated factors, and prognostic va lue among frail, older inpatients. *Journal of the American Medical Directors Association, 13*(6), 541–545. https://doi.org/10.1016/j.jamda.2012.04.005

Horning, S. M., Melrose, R., & Sultzer, D. (2014). Insight in Alzheimer's disease and its relation to psychiatric and behavioral disturbances. *International Journal of Geriatric Psychiatry*, *29*(1), 77–84. https://doi.org/10.1002/gps.3972

Hsueh, L., Hirsh, A. T., Maupomé, G., & Stewart, J. C. (2021). Patient–provider language concordance and health outcomes: A systematic review, evidence map, and research agenda. *Medical Care Research and Review, 78*(1), 3–23. https://doi.org/10.1177/1077558719860708

Makimoto, K., Kang, Y., Kobayashi, S., Liao, X. Y., Panuthai, S., Sung, H. C., Suzuki, M., Terada, S., & Yamakawa, M. (2019). Prevalence of behavioural and psychological symptoms of dementia in cognitively impaired elderly residents of long-term care facilities in East Asia: a cross-sectional study. *Psychogeriatrics: The Official Journal of the Japanese Psychogeriatric Society*, *19*(2), 171–180. https://doi.org/10.1111/psyg.12380

Massimo, L., Kales, H. C., & Kolanowski, A. (2018). State of the Science: Apathy as a Model for Investigating Behavioral and Psychological Symptoms in Dementia. *Journal of the*

American Geriatrics Society, *66 Suppl 1*(Suppl 1), S4–S12. https://doi.org/10.1111/jgs.15343

IBM Corp. (2023). *IBM SPSS Statistics for Windows, Version 29.0* [Computer software]. IBM Corp.

Ishii, S., Weintraub, N., & Mervis, J. R. (2009). Apathy: a common psychiatric syndrome in the elderly. *Journal of the American Medical Directors Association, 10*(6), 381–393. https://doi.org/10.1016/j.jamda.2009.03.007

Ishizaki, J., & Mimura, M. (2011). Dysthymia and apathy: Diagnosis and treatment. *Depression Research and Treatment, 2011*(1), 893–905. https://doi.org/10.1155/2011/893905

Jao, Y. L., Algase, D. L., Specht, J. K., & Williams, K. (2015). The association between characteristics of care environments and apathy in residents with dementia in long-term care facilities. Gerontologist, 55(Suppl 1), S27–S39. https://doi.org/10.1093/geront/gnu166

Jao, Y.-L., Liu, W., Chaudhury, H., Parajuli, J., Holmes, S., &Galik, E. (2020). Function-focused person-environment fit for long-term care residents with dementia: Impact on apathy. *The Gerontologist, 61*(3), 413–424. https://doi.org/10.1093/geront/gnaa111

Jao, Y. L., Mogle, J., Williams, K., McDermott, C., & Behrens, L. (2018). Real-time observation of apathy in long-term care residents with dementia: Reliability of the person-environment apathy rating scale. *Journal of Gerontological Nursing, 44*(4), 23–28. https://doi.org/10.3928/00989134-20180131-02

Jao, Y. L., Williams, K., Mogle, J., Behrens, L., & McDermott, C. (2019). Assessing apathy in long-term care residents with dementia: Who should be the rater? *Dementia (Basel, Switzerland), 18(*6), 2220–2229. https://doi.org/10.1177/1471301217745104

Jeste, D. V., Palmer, B. W., Appelbaum, P. S., Golshan, S., Glorioso, D., Dunn, L. B., Kim, K., Meeks, T., & Kraemer, H. C. (2007). A New Brief Instrument for Assessing Decisional Capacity for Clinical Research. *Archives of General Psychiatry*, *64*(8), 966-974. doi.10.1001/archpsyc.64.8.966

Kebede, A. S., Ozolins, L.-L., Holst, H., & Galvin, K. (2022). Digital Engagement of Older Adults: Scoping Review [Review]. *Journal of Medical Internet Research 24*(12), e40192. https://doi.org/10.2196/40192

Kelly, M. E., Loughrey, D., Lawlor, B. A., Robertson, I. H., Walsh, C., & Brennan, S. (2014). The impact of cognitive training and mental stimulation on cognitive and everyday functioning of healthy older adults: a systematic review and meta-analysis. *Ageing Research Reviews*, *15*, 28-43. https://doi.org/10.1016/j.arr.2014.02.004

König, A., Linz, N., Zeghari, R., Klinge, X., Tröger, J., Alexandersson, J., & Robert, P. (2019). Detecting apathy in older adults with cognitive disorders using automatic speech analysis. *Journal of Alzheimer's Disease: JAD, 69*(4), 1183–1193.https://doi.org/10.3233/JAD-181033

Kornelsen, J., Carthew, C., Míguez, K., Taylor, M., Bodroghy, C., Petrunia, K., & Roberts, D. (2021). Rural citizen-patient priorities for healthcare in British Columbia, Canada: findings from a mixed methods study. *BMC Health Services Research*, *21*(1), 987. https://doi.org/10.1186/s12913-021-06933-z

Kuhlmei, A., Walther, B., Becker, T., Müller, U., & Nikolaus, T. (2013). Actigraphic daytime activity is reduced in patients with cognitive impairment and apathy. *European Psychiatry, 28*(2), 94-97. https://doi:10.1016/j.eurpsy.2011.04.006

Lanctôt, K. L., Agüera-Ortiz, L., Brodaty, H., Francis, P. T., Geda, Y. E., Ismail, Z., Marshall, G. A., Mortby, M. E., Onyike, C. U., Padala, P. R., Politis, A. M., Rosenberg, P. B., Siegel, E., Sultzer, D. L., & Abraham, E. H. (2017). Apathy associated with neurocognitive disorders: Recent progress and future directions. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association, 13*(1), 84–100. https://doi.org/https://https://doi.org/10.1016/j.jalz.2016.05.008

Lanctôt, K. L., Scherer, R. W., Li, A., Vieira, D., Coulibaly, H., Rosenberg, P. B., Herrmann, N., Lerner, A. J., Padala, P. R., Brawman-Mintzer, O., van Dyck, C. H., Porsteinsson, A. P., Craft, S., Levey, A., Burke, W. J., & Mintzer, J. E. (2021). Measuring Apathy in Alzheimer's Disease in the Apathy in Dementia Methylphenidate Trial 2 (ADMET 2): A Comparison of Instruments. Am J Geriatr Psychiatry, 29(1), 81-89. https://doi..org/10.1016/j.jagp.2020.05.020

Lavretsky, H., Reinlieb, M., St Cyr, N., Siddarth, P., Ercoli, L. M., & Senturk, D. (2015). Citalopram, methylphenidate, or their combination in geriatric depression: A randomized, doubleblind, placebo-controlled trial. *American Journal of Psychiatry, 172*(6), 561–569. https://doi.org/10.1176/appi.ajp.2014.14070889

Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist, 9*(3), 179–186. https://doi.org/10.1093/geront/9.3.179

Lee, L., & Maher, M. L. (2021). Factors affecting the initial engagement of older adults in the use of interactive technology. *Int J Environmental Research for Public Health*, *18*(6), 1-22. https://doi.org/10.3390/ijerph18062847

Leontjevas, R., Fredrix, L., Smalbrugge, M., Koopmans, R. T. C. M., & Gerritsen, D. L. (2018). Bayesian Analyses Showed More Evidence for Apathy than for Depression Being Associated with Cognitive Functioning in Nursing Home Residents. Journal of the *American Medical Directors Association, 19*(12), 1110–1117. https://doi.org/10.1016/j.jamda.2018.06.008

Leontjevas, R., Teerenstra, S., Smalbrugge, M., Vernooij-Dassen, M., Bohlmeijer, E., Gerritsen, D., & Koopmans, R. (2013). More insight into the concept of apathy: A multidisciplinary depression management program has different effects on depressive symptoms and apathy in nursing homes. *International Psychogeriatrics, 25*(12), 1941-1952. https://doi:10.1017/S104161021300144

Le Heron, C., Apps, M. A. J., & Husain, M. (2018). The anatomy of apathy: A neurocognitive framework for amotivated behaviour. *Neuropsychologia, 118*(Pt B), 54–67. https://doi.org/10.1016/j.neuropsychologia.2017.07.003

Leone, E., Deudon, A., Bauchet, M., Laye, M., Bordone, N., Lee, J.H., Piano, J., Friedman, L., David, R., Delva, F., Brocker, P., Yesavage, J., & Robert, P. H. (2013). Management of apathy in nursing homes using a teaching program for care staff: The STIMEHPAD study. *International Journal of Geriatric Psychiatry, 28*(4), 383–392. https://doi.org/10.1002/gps.3836

Leung, D. K. Y., Chan, W. C., Spector, A., & Wong, G. H. Y. (2021). Prevalence of depression, anxiety, and apathy symptoms across dementia stages: A systematic review and meta-analysis. *International Journal of Geriatric Psychiatry, 36*(9), 1330–1344. https://doi.org/10.1002/gps.5556

Levy, M. L., Cummings, J. L., Fairbanks, L. A., Masterman, D., Miller, B. L., Craig, A. H., Paulsen, J. S., & Litvan, I. (1998). Apathy is not depression. *The Journal of Neuropsychiatry and Clinical Neurosciences, 10*(3), 314–319. https://doi.org/10.1176/jnp.10.3.314

Levy, R., & Dubois, B. (2006). Apathy and the Functional anatomy of the prefrontal cortex-basal ganglia circuits. *Cerebral Cortex, 16*(7), 916–928. https://doi.org/10.1093/cercor/bhj043

Ligthart, S. A., Richard, E., Fransen, N. L., Eurelings, L. S., Beem, L., Eikelenboom, P., van Gool, W. A., & Moll van Charante, E. P. (2012). Association of vascular factors with apathy in community-dwelling elderly individuals. *Archives of General Psychiatry, 69*(6), 636–642. https://doi.org/10.1001/archgenpsychiatry.2011.1858

Löckenhoff, C. E., & Carstensen, L. L. (2004). Socioemotional selectivity theory, aging, and health: The increasingly delicate balance between regulating emotions and making tough choices. *Journal of Personality, 72*(6), 1395–1424. https://doi.org/10.1111/j.1467-6494.2004.00301

Lopez, F. V., Eglit, G. M., Schiehser, D. M., Pirogovsky-Turk, E., Litvan, I., Lessig, S., & Filoteo, J. V. (2019). Factor analysis of the apathy scale in Parkinson’s disease. *Movement Disorders Clinical Practice, 6*(5), 379–386. https://doi.org/10.1002/mdc3.12767

Lu, S. Y., Yoon, S., Yee, W. Q., Heng Wen Ngiam, N., Ng, K. Y. Y., & Low, L. L. (2024). Experiences of a Community-Based Digital Intervention Among Older People Living in a Low-Income Neighborhood: Qualitative Study. *JMIR Aging, 7*, e52292-e52314. https://doi.org/10.2196/52292

Lueken, U., Seidl, U., Völker, L., Schweiger, E., Kruse, A., & Schröder, J. (2007). Development of a short version of the apathy evaluation scale specifically adapted for demented nursing home residents. *The American Journal of Geriatric Psychiatry, 15*(5), 376–385. https://doi.org/10.1097/jgp.0b013e3180437db3

Lyketsos, C. G., Carrillo, M. C., Ryan, J. M., Khachaturian, A. S., Trzepacz, P., Amatniek, J., . . . Miller, D. S. (2011). Neuropsychiatric symptoms in alzheimer's disease. Alzheimers Dementia, 7(5), 532-539. https://doi:10.1016/j.jalz.2011.05.2410

Ma L. (2020). Depression, Anxiety, and Apathy in Mild Cognitive Impairment: Current Perspectives. *Frontiers in Aging Neuroscience, 12*(9), 1-8. https://doi:/10.3389/fnagi.2020.00009

Manera, V., Abrahams, S., Agüera-Ortiz, L., Bremond, F., David, R., & Fairchild, K., … P. Robert (2020). Recommendations for the nonpharmacological treatment of apathy in brain disorders. *The American Journal of Geriatric Psychiatry, 28*(4), 410–420. https://doi.org/10.1016/j.jagp.2019.07.014

Mansbach, W. E., Mace, R. A., Clark, K. M., & Firth, I. M. (2016). Meaningful activity for long-term care residents with dementia: A comparison of activities and raters. *The Gerontologist, 57*(3), 461–468. https://doi.org/10.1093/geront/gnv694

Marin, R. S. (1990). Differential diagnosis and classification of apathy. *The American Journal of Psychiatry, 147*(1), 22–30. https://doi.org/10.1176/ajp.147.1.22

Marin, R. S. (1991). Apathy: A neuropsychiatric syndrome. The Journal of Neuropsychiatry and Clinical Neurosciences, 3(3), 243–254. https://doi.org/10.1176/jnp.3.3.243

Marin, R., & Wilkosz, P. (2005). Disorders of diminished motivation. *The Journal of Head Trauma Rehabilitation, 20*(4), 377–388. https://doi.org/https://doi.10.1097/00001199-200507000-00009

Martin, D., Miller, A. P., Quesnel-Vallée, A., Caron, N. R., Vissandjée, B., & Marchildon, G. P. (2018). Canada's universal health-care system: Achieving its potential. *Lancet (London, England), 391*(10131), 1718–1735. https://doi.org/10.1016/S0140-6736(18)30181-8

Masdrakis, V. G., Markianos, M., & Baldwin, D. S. (2023). Apathy associated with antidepressant drugs: A systematic review. *Acta Neuropsychiatrica, 35*(4), 189–204. https://doi.org/10.1017/neu.2023.6

Masanic, C. A., Bayley, M. T., vanReekum, R., & Simard, M. (2001). Open-label study of donepezil in traumatic brain injury. *Archives of Physical Medicine and Rehabilitation, 82*(7), 896-901. https://doi.:10.1053/apmr.2001.23833

Matmati, J., Verny, C., & Allain, P. (2022). Apathy and Huntington's Disease: A Literature Review Based on PRISMA. *Journal of Neuropsychiatry Clinical Neuroscience, 34*(2), 100-112. https://doi..org/10.1176/appi.neuropsych.21060154

Md Hussin, N. S., Karuppannan, M., Gopalan, Y., Tan, K. M., & Gnanasan, S. (2023). Exploration of non-pharmacological interventions in the management of behavioural and psychological symptoms of dementia. *Singapore medical journal, 64*(8), 497–502. https://doi.org/10.11622/smedj.2021125

Mele, B., Goodarzi, Z., Hanson, H. M., & Holroyd-Leduc, J. (2019). Barriers and facilitators to diagnosing and managing apathy in Parkinson's disease: A qualitative study. *BMC Neurology, 19*(1). https://doi.:10.1186/s12883-019-1329-z

Mele, B., Van, S., Holroyd-Leduc, J., Ismail, Z., Pringsheim, T., & Goodarzi, Z. (2020). Diagnosis, treatment and management of apathy in parkinson's disease: a scoping review. *BMJ open, 10*(9), 1-11. https://doi:10.1136/bmjopen-2020-037632

Miller, D. S., Robert, P., Ereshefsky, L., Adler, L., Bateman, D., Cummings, J., Dekosky, S. T., Fischer, C. E., Husain, M., Ismail, Z., Jaeger, J., Lerner, A. J., Li, A., Lyketsos, C. G., Manera, V., Mintzer, J., Moebius, H. J., Mortby, M., Meulien, D., … Lanctot, K. L. (2021). Diagnostic criteria for apathy in neurocognitive disorders. *Alzheimers Dementia, 17*(12), 1892–1904. https://doi.org/10.1002/alz.12358

Mitzner, T. L., Boron, J. B., Fausset, C. B., et al. (2010). Older adults talk technology: Technology usage and attitudes. *Computers in Human Behavior, 26*(6), 1710–1721.

Mizrahi, R., & Starkstein, S. E. (2007). Epidemiology and management of apathy in patients with Alzheimer's disease. *Drugs & aging*, *24*(7), 547–554. https://doi.:10.2165/00002512-200724070-00003

Mjorud, M., Kirkevold, M., Rosvik, J., Selbaek, G., & Engedal, K. (2014). Variables associated to quality of life among nursing home patients with dementia. *Aging & Mental Health, 18*(8), 1013-1021. https://doi.:10.1080/13607863.2014.903468

Mohammad, D., Ellis, C., Rau, A., Rosenberg, P. B., Mintzer, J., Ruthirakuhan, M., Herrmann, N., & Lanctôt, K. L. (2018). Psychometric Properties of Apathy Scales in Dementia: A Systematic Review. *Journal of Alzheimer's disease: JAD, 66*(3), 1065-1082. https://doi.:10.3233/JAD-180485

Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., Shekelle, P., & Stewart, L. A. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews*, *4*(1), 1-7. https://doi.:10.1186/2046-4053-4-1

Morris, J. N., Fries, B. E., Mehr, D. R., Hawes, C., Phillips, C., Mor, V., & Lipsitz, L. A. (1994). Mds cognitive performance scale(c). Journal of Gerontology, 49(4), M174–M182. https://doi:10.1093/geronj/49.4.m174

Morris, J. N., Fries, B. E., & Morris, S. A. (1999). Scaling adls within the mds. *The Journals of Gerontology: Series A, 54*(11), M546–M553. https://doi.org/10.1093/gerona/54.11.m546

Morris, J. N., Hawes, C., Mor, V., Phillips, C., Fries, B. E., Nonemaker, S., & Murphy, K. (2012). *Resident Assessment Instrument (RAI) RAI-MDS 2.0 User's Manual: Canadian Version,* Canada.

Morris, J. N., Howard, E. P., Steel, K., Perlman, C., Fries, B. E., Garms-Homolová, V., Henrard, J.-C., Hirdes, J. P., Ljunggren, G., Gray, L., & Szczerbińska, K. (2016). Updating the cognitive performance scale. *Journal of Geriatric Psychiatry and Neurology, 29*(1), 47–55. https://doi:10.1177/0891988715598231

Morse, J.M. (2003) Principles of mixed methods and multimethod research design. In: A. Tashakkori and C. Teddie (Eds.) *Handbook of mixed methods in social & behavioral research* (pp. 189–208). Sage, Thousand Oaks.

Morse, J. M., & Niehaus, L. (2009). *Mixed method design: Principles and procedures*. Routledge, New York.

Mortby, M. E., Black, S. E., Gauthier, S., Miller, D., Porsteinsson, A., Smith, E. E., & Ismail, Z. (2018). Prevalence, neurobiology, and treatments for apathy in prodromal dementia. *International Psychogeriatrics, 30*(2), 171-175. https://doi.org/10.1017/S1041610218000042

Mortby, M. E., Adler, L., Aguera-Ortiz, L., Bateman, D. R., Brodaty, H., Cantillon, M., Geda, Y. E., Ismail, Z., Lanctot, K. L., Marshall, G. A., Padala, P. R., Politis, A., Rosenberg, P. B., Siarkos, K., Sultzer, D. L., Theleritis, C., & Istaart Nps, P. I. A. (2022). Apathy as a treatment target in alzheimer's disease: implications for clinical trials. *American Journal of Geriatric Psychiatry, 30*(2), 119-147. https://doi: 10.1016/j.jagp.2021.06.016

Mulders, A. J., Fick, I. W., Bor, H., Verhey, F. R., Zuidema, S. U., & Koopmans, R. T. (2016). Prevalence and correlates of neuropsychiatric symptoms in nursing home patients with young-onset dementia: The BEYOnD study. *Journal of the American Medical Directors Association, 17*(6), 495–500. https://doi.org/10.1016/j.jamda.2016.01.002

Mulders, A. J., Zuidema, S. U., Verhey, F. R., & Koopmans, R. T. (2014). Characteristics of institutionalized young onset dementia patients–the BEYOnD study. *International Psychogeriatrics, 26*(12), 1973–1981. https://doi.org/10.1017/S1041610214001859

Mulin, E., Zeitzer, J. M., Friedman, L., Le Duff, F., Yesavage, J., Robert, P. H., & David, R. (2011). Relationship between apathy and sleep disturbance in mild and moderate alzheimer's disease: an actigraphic study. *Journal of Alzheimer's disease, 25*(1), 85-91. https:// doi:10.3233/JAD-2011-101701

Nijsten, J. M. H., Leontjevas, R., Pat-El, R., Smalbrugge, M., Koopmans, R., & Gerritsen, D. L. (2017). Apathy: Risk factor for mortality in nursing home patients. *Journal of America Geriatric Society, 65*(10), 2182–2189. https://doi.org/10.1111/jgs.15007

Nijsten, J. M. H., Smalbrugge, M., Plouvier, A. O. A., Koopmans, R. T. C. M., Leontjevas, R., & Gerritsen, D. L. (2023). Identifying and managing apathy in people with dementia living in nursing homes: A qualitative study. *BMC Geriatrics, 23*(1), 727–738. https://doi.org/10.1186/s12877-023-04422-y

Njomboro, P., Humphreys, G. W., & Deb, S. (2014). Exploring social cognition in patients with apathy in acquired brain damage. *BMC Neurology, 14*(18), 1-11. https://doi: 10.1186/1471-2377-14-18

Oh, H., Razlighi, Q. R., & Stern, Y. (2018). Multiple pathways of reserve simultaneously present in cognitively normal older adults. *Neurology*, *90*(3), e197-e205.

O'Neill, C., & Dogra, S. (2016). Different Types of Sedentary Activities and Their Association with Perceived Health and Wellness Among Middle-Aged and Older Adults: A Cross-Sectional Analysis. *American Journal of Health Promotion*, *30*(5), 314-322. doi.org/10.1177/0890117116646334

Onyike, C. U., Sheppard, J.-M. E., Tschanz, J. T., Norton, M. C., Green, R. C., Steinberg, M., Welsh-Bohmer, K. A., Breitner, J. C., & Lyketsos, C. G. (2007). Epidemiology of apathy in older adults: The cache county study. *The American Journal of Geriatric Psychiatry, 15*(5), 365-375. https://doi:10.1097/01.JGP.0000235689.42910.0d

Padala, P. R., Burke, W. J., Shostrom, V. K., Bhatia, S. C., Wengel, S. P., Potter, J. F., & Petty, F. (2010). Methylphenidate for apathy and functional status in dementia of the alzheimer type. *American Journal of Geriatric Psychiatry*, *18*(4), 371-374. https://doi.:10.1097/JGP.0b013e3181cabcf6

Padala, P. R., Padala, K. P., Lensing, S. Y., Jackson, A. N., Hunter, C. R., Parkes, C. M., . . . Sullivan, D. H. (2018). Repetitive transcranial magnetic stimulation for apathy in mild cognitive impairment: A double-blind, randomized, sham-controlled, cross-over pilot study. *Psychiatry Research*, *261*, 312-318. https://doi.:10.1016/j.psychres.2017.12.063

Padala, P. R., Padala, K. P., Lensing, S. Y., Ramirez, D., Monga, V., Bopp, M. M., Roberson, P. K., Dennis, R. A., Petty, F., Sullivan, D. H., & Burke, W. J. (2018). Methylphenidate for apathy in community-dwelling older veterans with mild alzheimer's disease: A double-blind, randomized, placebo-controlled trial. *The American Journal of Psychiatry*, *175*(2), 159–168. https://doi.:10.1176/appi.ajp.2017.17030316

Padala, P. R., Padala, K. P., Majagi, A. S., Garner, K. K., Dennis, R. A., & Sullivan, D. H. (2020). Selective serotonin reuptake inhibitors-associated apathy syndrome: A cross-sectional study. *Medicine*, *99*(33), e21497-e21502. https://doi.:10.1097/MD.0000000000021497

Palmer, K., Di Iulio, F., Varsi, A. E., Gianni, W., Sancesario, G., Caltagirone, C., & Spalletta, G. (2010). Neuropsychiatric predictors of progression from amnestic-mild cognitive impairment to Alzheimer's disease: the role of depression and apathy. *Journal of Alzheimers Disease, 20*(1), 175-183. https://doi.:10.3233/JAD-2010-1352

Parrotta, I., Cacciatore, S., D'Andrea, F., D'Anna, M., Giancaterino, G., Lazzaro, G., Arcara, G., & Manzo, N. (2024). Prevalence, treatment, and neural correlates of apathy in different forms of dementia: a narrative review. *Neurological sciences: official journal of the Italian Neurological Society and of the Italian Society of Clinical Neurophysiology*, *45*(4), 1343–1376. https://doi.org/10.1007/s10072-023-07197-7

Peavy, G. M., Salmon, D. P., Edland, S. D., Tam, S., Hansen, L. A., Masliah, E., Galasko, D., & Hamilton, J. M. (2013). Neuropsychiatric features of frontal lobe dysfunction in autopsy-confirmed patients with lewy bodies and "pure" Alzheimer disease. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, *21*(6), 509–519. https://doi.org/10.1016/j.jagp.2012.10.022

Pedersen, K. F., Larsen, J. P., Alves, G., & Aarsland, D. (2009a). Prevalence and clinical correlates of apathy in Parkinson's disease: A community-based study. *Parkinsonism & Related Disorders, 15*(4), 295-299. https://doi.org/10.1016/j.parkreldis.2008.07.006

Pedersen, K. F., Alves, G., Aarsland, D., & Larsen, J. P. (2009b). Occurrence and risk factors for apathy in Parkinson disease: a 4-year prospective longitudinal study. *Journal of Neurology, Neurosurgery, and Psychiatry, 80*(11), 1279–1282. https://doi.org/10.1136/jnnp.2008.170043

Pedersen, K. F., Alves, G., Brønnick, K., Aarsland, D., Tysnes, O. B., & Larsen, J. P. (2010). Apathy in drug-naïve patients with incident parkinson's disease: the norwegian park west study. Journal of neurology, 257(2), 217–223. https://doi.org/10.1007/s00415-009-5297-x

Pedersen, K. F., Larsen, J. P., & Aarsland, D. (2007). Validation of the unified parkinson's disease rating scale (UPDRS) section 1 as a screening and diagnostic instrument for apathy in patients with parkinson's disease. *Parkinsonism & Related Disorders, 14*(3), 183-186. https://doi:10.1016/j.parkreldis.2007.07.015

Perlman, C. M., & Hirdes, J. P. (2008). The aggressive behavior scale: A new scale to measure aggression based on the minimum data set. *Journal of the American Geriatrics Society, 56*(12), 2298–2303. https://doi:10.1111/j.1532-5415.2008.02048.x

Peters, M. D. J. (2017). Managing and coding references for systematic reviews and scoping reviews in endnote. *Medical Reference Services Quarterly, 36*(1), 19-31. https://doi.:10.1080/02763869.2017.1259891

Pinquart, M., & Sörensen, S. (2001). Influences of socio-economic status, social network, and competence on subjective well-being in later life: A meta-analysis. *Psychology and Aging*, *16*(2), 187-224. https://doi.org/10.1037/0882-7974.16.2.187

Plano Clark, V. L., Huddleston-Casas, C. A., Churchill, S. L., O'Neil Green, D., & Garrett, A. L. (2008). Mixed Methods Approaches in Family Science Research. *Journal of Family Issues*, *29*(11), 1543-1566. https://doi.org/10.1177/0192513x08318251

Pluye, P., Bengoechea, E., Granikov, V., Kaur, N., & Tang, D. (2018). A world of possibilities in mixed methods: Review of the combinations of strategies used to integrate qualitative and quantitative phases, results and data. *International Journal of Multiple Research Approaches, 10*, 41-56. https://doi.:10.29034/ijmra.v10n1a3

Polit, D. F., & Beck, C. T. (2017). *Nursing research: Generating and assessing evidence for nursing practice* (10th ed.), Wolters Kluwer.

Poss, J. W., Jutan, N. M., Hirdes, J. P., Fries, B. E., Morris, J. N., Teare, G. F., & Reidel, K. (2008). A review of evidence on the reliability and validity of minimum data set. *Healthcare Management Forum, 21*(1), 33–39. https://doi.org/10.1016/S0840-4704(10)60127-5

Proitsi, P., Hamilton, G., Tsolaki, M., Lupton, M., Daniilidou, M., Hollingworth, P., Archer, N., Foy, C., Stylios, F., McGuinness, B., Todd, S., Lawlor, B., Gill, M., Brayne, C., Rubinsztein, D. C., Owen, M., Williams, J., Craig, D., Passmore, P., Lovestone, S., & Powell, J. F. (2011). A multiple indicators multiple causes (mimic) model of behavioural and psychological symptoms in dementia (BPSD). *Neurobiology of Aging, 32*(3), 434–442. https://doi.org/10.1016/j.neurobiolaging.2009.03.005

QSR International (2018) [Computer software]. Retrieved November 02, 2020, from https://helpnv.qsrinternational.com/12/win/v12.1.99-d3ea61/Content/welcome.htm

Radakovic, R., Harley, C., Abrahams, S., & Starr, J. M. (2015). A systematic review of the validity and reliability of apathy scales in neurodegenerative conditions. *International Psychogeriatrics, 27*(6), 903–923. https://doi.:10.1017/S1041610214002221

Robert, P. H., Berr, C., Volteau, M., Bertogliati, C., Benoit, M., Sarazin, M., Legrain, S., & Dubois, B.; PréAL study. (2006). Apathy in patients with mild cognitive impairment and the risk of developing dementia of Alzheimer's disease: A one-year follow-up study. *Clinical Neurology and Neurosurgery, 108*(8), 733–736. https://doi.org/10.1016/j.clineuro.2006.02.003

Robert, P. H., Clairet, S., Benoit, M., Koutaich, J., Bertogliati, C., Tible, O., Caci, H., Borg, M., Brocker, P., & Bedoucha, P. (2002). The Apathy Inventory: Assessment of apathy and awareness in Alzheimer's disease, Parkinson's disease and mild cognitive impairment. *International Journal of Geriatric Psychiatry, 17*(12), 1099–1105. https://doi.org/10.1002/gps.755

Robert, P., Lanctôt, K. L., Agüera-Ortiz, L., Aalten, P., Bremond, F., Defrancesco, M., Hanon, C., David, R., Dubois, B., Dujardin, K., Husain, M., König, A., Levy, R., Mantua, V., Meulien, D., Miller, D., Moebius, H. J., Rasmussen, J., Robert, G., & Manera, V. (2018). Is it time to revise the diagnostic criteria for apathy in brain disorders? The 2018 international consensus group. *European Psychiatry, 54*, 71–76. https://doi.org/10.1016/j.eurpsy.2018.07.008

Robert, P., Onyike, C. U., Leentjens, A. F., Dujardin, K., Aalten, P., Starkstein, S., Verhey, F. R., Yessavage, J., Clement, J. P., Drapier, D., Bayle, F., Benoit, M., Boyer, P., Lorca, P. M.,Thibaut, F., Gauthier, S., Grossberg, G., Vellas, B., & Byrne, J. (2009). Proposed diagnostic criteria for apathy in Alzheimer's disease and other neuropsychiatric disorders.

European Psychiatry: *The Journal of the Association of European Psychiatrists, 24*(2), 98–104. https://doi.org/10.1016/j.eurpsy.2008.09.001

Robert, P. H., Mulin, E., Malléa, P., & David, R. (2010). Review: Apathy diagnosis, assessment, and treatment in alzheimer's disease. *CNS Neuroscience & Therapeutics*, *16*(5), 263–271. https://doi.:10.1111/j.1755-5949.2009.00132.x

Ruthirakuhan, M. T., Herrmann, N., Abraham, E. H., Chan, S., & Lanctôt, K. L. (2018). Pharmacological interventions for apathy in Alzheimer's disease. *Cochrane Database Systematic Review*, *5*(5), 1-101. https://doi.org/10.1002/14651858.CD012197.pub2

Rosenstock, I. M. (1974). Historical origins of the health belief model. *Health Education Monographs, 2*(4), 328–335. https://doi.org/10.1177/109019817400200403

Roth, R. M., Flashman, L. A., & McAllister, T. W. (2007). Apathy and its treatment. *Current Treatment Options in Neurology, 9*(5), 363–370. https://doi.org/10.1007/s11940-007-0022-5

SAS Institute, Cary, NC, USA (2013). [Computer software].

Santangelo, G., Cuoco, S., Pellecchia, M. T., Erro, R., Barone, P., & Picillo, M. (2018). Comparative cognitive and neuropsychiatric profiles between Parkinson's disease, multiple system atrophy and progressive supranuclear palsy. *Journal of Neurology, 265(11)*, 2602-2613. https://doi:10.1007/s00415-018-9038-x

Santangelo, G., D'Iorio, A., Piscopo, F., Cuoco, S., Longo, K., Amboni, M., . . . Vitale, C. (2017). Assessment of apathy minimising the effect of motor dysfunctions in Parkinson's disease: a validation study of the dimensional apathy scale. *Quality of Life Research, 26*(9), 2533-2540. https://doi:10.1007/s11136-017-1569-6

Santangelo, G., Trojano, L., Barone, P., Errico, D., Grossi, D., & Vitale, C. (2013). Apathy in Parkinson's disease: diagnosis, neuropsychological correlates, pathophysiology and treatment. *Behavior Neurology, 27*(4), 501-513. https://doi:10.3233/BEN-129025

Saredakis, D., Keage, H. A., Corlis, M., & Loetscher, T. (2020). Using virtual reality to improve apathy in residential aged care: mixed methods study. *Journal of Medical Internet Research*, 22(6), e17632-e17646. https://doi.:10.2196/17632

Saredakis, D., Keage, H. A. D., Corlis, M., & Loetscher, T. (2021). Virtual reality intervention to improve apathy in residential aged care: protocol for a multisite non-randomised controlled trial. *BMJ Open*, *11*(2), e046030. https://doi.org/10.1136/bmjopen-2020-046030

Selbaek, G., Engedal, K., Benth, J. S., & Bergh, S. (2014). The course of neuropsychiatric symptoms in nursing-home patients with dementia over a 53-month follow-up period. *International Psychogeriatrics, 26*(1), 81–91. https://doi.org/10.1017/S1041610213001609

Sen, K., Prybutok, G., & Prybutok, V. (2022). The use of digital technology for social wellbeing reduces social isolation in older adults: A systematic review. *SSM - Population Health*, *17*(101020), 1-9. https://doi.10.1016/j.ssmph.2021.101020.

Sepehry, A. A., Sarai, M., & Hsiung, G. Y. R. (2017). Pharmacological therapy for apathy in Alzheimer's disease: a systematic review and meta-analysis. *Canadian Journal of Neurological Sciences*, *44*(3), 267-275

Serretti, A. (2023). Anhedonia and depressive disorders. Clinical Psychopharmacology and Neuroscience, 21(3), 401–409. https://doi.org/10.9758/cpn.23.1086

Smith, M. C. (1993). The reading abilities and practices of older adults. *Educational Gerontology*, *19*(5), 417-432.

Sockeel, P., Dujardin, K., Devos, D., Denève, C., Destée, A., & Defebvre, L. (2006). The lille apathy rating scale (LARS): A new instrument for detecting and quantifying apathy: Validation in Parkinson's disease. *Journal of Neurology, Neurosurgery, and Psychiatry, 77*(5), 579–584. https://doi.org/10.1136/jnnp.2005.075929

Sommerlad, A., Park, H. K., Marston, L., & Livingston, G. (2022). Apathy in UK care home residents with dementia: Longitudinal course and determinants. *Journal of Alzheimer's Disease: JAD, 87*(2), 731–740. https://doi.org/10.3233/JAD-215623

Stanton, B. R., & Carson, A. (2016). Apathy: a practical guide for neurologists. Practical neurology, 16(1), 42-47. https://doi.:org/10.1136/practneurol-2015-001232

Starkstein, S. E. (2000). Apathy and withdrawal. *International Psychogeriatrics, 12*(Suppl1), 135–137. doi.org/10.1017/S1041610200006918.

Starkstein, S. E., Ingram, L., Garau, M. L., & Mizrahi, R. (2005). On the overlap between apathy and depression in dementia. *Neurosurgery, and Psychiatry, 76*(8), 1070–1074. https://doi.org/10.1136/jnnp.2004.052795

Starkstein, S. E., Jorge, R., & Mizrahi, R. (2006). The prevalence, clinical correlates and treatment of apathy in Alzheimer's disease. *European Journal of Psychiatry, 20*(2), 96–106. https://doi.org/10.4321/S0213-61632006000200005

Starkstein, S. E., & Leentjens, A. F. G. (2008). The nosological position of apathy in clinical practice. *Journal of Neurology, Neurosurgery & Psychiatry, 79*(10), 1088–1092. https://doi.org/10.1136/jnnp.2007.136895

Starkstein, S. E., Merello, M., Jorge, R., Brockman, S., Bruce, D., & Power, B. (2009). The syndromal validity and nosological position of apathy in Parkinson's disease. Movement Disorders, *Official Journal of the Movement Disorder Society, 24*(8), 1211–1216. https://doi.org/10.1002/mds.22577

Statistics Canada (2022). *Nursing and residential care facilities in 2020*, Government of Canada, Canada. Available from https://www150.statcan.gc.ca/n1/en/daily-quotidien/221102/dq221102ceng.pdf?st=80LUWtLd. Accessed November 25th, 2023.

Statistics Canada (2023). Annual Demographic Estimates: Canada, Provinces and Territories, 2023. Available at https://www150.statcan.gc.ca/n1/pub/91-215-x/91-215-x2023002-eng.htm (Accessed September 26, 2024)

Steffens, D. C., Fahed, M., Manning, K. J., & Miller, A. (2022). The neurobiology of apathy in depression and neurocognitive impairment in older adults: A review of epidemiological, clinical, neuropsychological, and biological research. *Translational Psychiatry, 12*(525), 1-16. https://doi.org/10.1038/s41398-022-02292-3

Stones, M. J. J., Clyburn, L. D., Gibson, M. C., & Woodbury, M. G. (2006). Predicting diagnosed depression and anti-depressant treatment in institutionalized older adults by symptom profiles: A closer Look at anhedonia and dysphoria. *Canadian Journal on Aging / La Revue Canadienne du Vieillissement, 25*(2), 153–159. https://www.muse.jhu.edu/article/203422

Szymkowicz, S. M., Ellis, L. J., & May, P. E. (2022). The 3-Item "Apathy" Subscale Within the GDS-15 Is Not Supported in De Novo Parkinson's Disease Patients: Analysis of the PPMI Cohort. *Journal of Geriatric Psychiatry Neurology*, *35*(3), 309-316. https://doi.10.1177/0891988720988908

Tan, Shaoying MSa; Lin, Xiaoli MSb; Liu, Zan BDc; Wu, Yao MSd; Xie, Bijiao MSd; Wang, Tao, M.D. D. (2022). Non-pharmacological intervention effects on apathy caused by central nervous system organic diseases: *A Network Meta-analysis. Medicine 101*(35), 1-6. https://doi: 10.1097/MD.0000000000030467.

Tang, Q., Zhou, Y., Yang, S., Thomas, W. K. S., Smith, G. D., Yang, Z., & Yuan, L. (2018). Effect of music intervention on apathy in nursing home residents with dementia. *Geriatric Nurse, 39*(4), 471–476. https://doi.org/10.1016/j.gerinurse.2018.02.003

Tagariello, P., Girardi, P., & Amore, M. (2009). Depression and apathy in dementia: same syndrome or different constructs? A critical review. *Archives of Gerontology and Geriatrics, 49*(2), 246–249. https://doi:10.1016/j.archger.2008.09.002

Tay, J., Morris, R. G., & Markus, H. S. (2021). Apathy after stroke: Diagnosis, mechanisms, consequences, and treatment. *International Journal of Stroke, 16*(5), 510–518. https://doi.org/10.1177/1747493021990906

Teixeira, A. L., Gonzales, M. M., de Souza, L. C., & Weisenbach, S. L. (2021). Revisiting apathy in alzheimer's disease: From conceptualization to therapeutic approaches. *Behavioral Neurology*, *2021*(6319826), 1-8. https://doi..org/10.1155/2021/6319826

Thant, T., & Yager, J. (2019). Updating Apathy: Using Research Domain Criteria to Inform Clinical Assessment and Diagnosis of Disorders of Motivation. *The Journal of Nervous and Mental Disease, 207*(9), 707–714. https://doi.org/10.1097/NMD.0000000000000860

Theleritis, C., Siarkos, K., Politis, A. A., Katirtzoglou, E., & Politis, A. (2018). A systematic review of non-pharmacological treatments for apathy in dementia. *International Journal of Geriatric Psychiatry, 33*(2), e177-e192. https://doi:10.1002/gps.4783

Theleritis, C. G., Siarkos, K. T., & Politis, A. M. (2019). Unmet needs in pharmacological treatment of apathy in alzheimer's disease: a systematic review. *Frontiers in Pharmacology, 10* (1108), 1-18. https://doi:10.3389/fphar.2019.01108

Tierney, S. M., Woods, S. P., Weinborn, M., & Bucks, R. S. (2018). Real-world implications of apathy among older adults: Independent associations with activities of daily living and quality of life. *Journal of Clinical and Experimental Neuropsychology, 40*(9), 895-903. https://doi.:10.1080/13803395.2018.1444736

Toepoel, V. (2013). Ageing, leisure, and social connectedness: How could leisure help reduce social isolation of older people? *Social Indicators Research, 113 (1)*, 355–372. https://doi.org/10.1007/s11205-012-0097-6

Valembois, L., Oasi, C., Pariel, S., Jarzebowski, W., Lafuente-Lafuente, C., & Belmin, J. (2015). Wrist actigraphy: A simple way to record motor activity in elderly patients with dementia and apathy or aberrant motor behavior. *The Journal of Nutrition, Health & Aging*, *19*(7), 759–764. https://doi.:10.1007/s12603-015-0530-z

van Almenkerk, S., Smalbrugge, M., Depla, M. F., Eefsting, J. A., & Hertogh, C. M. (2015). Apathy among institutionalized stroke patients: Prevalence and clinical correlates. America Journal of Geriatric Psychiatry, 23(2), 180–188. https://doi.org/10.1016/j.jagp.2014.03.011

van der Linde, R. M., Matthews, F. E., Dening, T., & Brayne, C. (2017). Patterns and persistence of behavioural and psychological symptoms in those with cognitive impairment: the importance of apathy. *International journal of Geriatric Psychiatry, 32*(3), 306-315. https://doi.org/https://dx.doi.org/10.1002/gps.4464 van Dalen, J. W., van Wanrooij, L. L., Moll van Charante, E. P., Brayne, C., van Gool, W. A., & Richard, E. (2018). Association of apathy with risk of incident dementia: A systematic review and meta-analysis. *JAMA Psychiatry, 75*(10), 1012–1021. https://doi.org/10.1001/jamapsychiatry.2018.1877

van der Ploeg, E. S., Eppingstall, B., Camp, C. J., Runci, S. J., Taffe, J., & O'Connor, D. W. (2013). A randomized crossover trial to study the effect of personalized, one-to-one interaction using montessori-based activities on agitation, affect, and engagement in nursing home residents with dementia. *International Psychogeriatrics*, *25*(4), 565–575. https://doi.org/10.1017/S1041610212002128

Van Malderen, L., Mets, T., & Gorus, E. (2013). Interventions to enhance the quality of life of older people in residential longterm care: A systematic review. *Ageing Research Reviews, 12*(1), 141–150. https://doi.org/10.1016/j.arr.2012.03.007

van Reekum, R., Stuss, D. T., & Ostrander, L. (2005). Apathy: Why care? *The Journal of Neuropsychiatry and Clinical Neurosciences, 17*(1), 7–19. https://doi.org/10.1176/appi.neuropsych.17.1.7

Van Vliet, D., De Vugt, M. E., Aalten, P., Bakker, C., Pijnenburg, Y. A., Vernooij-Dassen, M. J., Koopmans, R. T., & Verhey, F. R. (2013). Prevalence of neuropsychiatric symptoms in youngonset compared to late-onset Alzheimer’s disease-part 1: Findings of the two-year longitudinal NeedYD-study. *Dementia and Geriatric Cognitive Disorders, 34*(5-6), 319–327. https://doi.org/10.1159/000342824

Vilalta-Franch, J., Calvó-Perxas, L., Garre-Olmo, J., Turró-Garriga, O., & López-Pousa, S. (2013). Apathy syndrome in Alzheimer’s disease epidemiology: Prevalence, incidence, persistence, and risk and mortality factors. *Journal of Alzheimer's Disease: JAD, 33*(2), 535–543. https://doi.org/10.3233/JAD-2012-120913

Villar, F., Chacur, K., Celdrán, M., & Serrat, R. (2021). Managing apathy among people with dementia living in institutional settings: Staff's perceived gap between common and best practices. *Geriatric Nursing, 42*(3), 613-620. https://doi.:10.1016/j.gerinurse.2021.03.014

Volicer, L., Frijters, D. H., & van der Steen, J. T. (2013). Apathy and weight loss in nursing home residents: Longitudinal study. Journal of the American Medical Directors Association, 14(6), 417–420. https://doi.org/10.1016/j.jamda.2012.12.004

Volicer, L. (2016). Management of Apathy in the Long-Term Care Setting. *J Am Med Dir Assoc*, *17*(8), 682-684. https://doi.org/10.1016/j.jamda.2016.05.007

Moyle, M., Marie, C., Elizabeth, B., Cindy, J., Barbara, K., Glenda, C., & Colin, M. G. (2013). Exploring the effect of companion robots on emotional expression in older adults with dementia: A pilot randomized controlled trial. *Journal of Gerontological Nursing, 39*(5), 46-53. https://doi.org/10.3928/00989134-20130313-03

Wetzels, R. B., Zuidema, S. U., de Jonghe, J. F. M., Verhey, F. R. J., & Koopmans, R. T. C. M. (2010). Course of neuropsychiatric symptoms in residents with dementia in nursing homes over 2-year period. *American Journal of Geriatric Psychiatry, 18*(12), 1054–1065. https://doi.org/10.1097/JGP.0b013e3181f60fa1

Weziak-Bialowolska, D., Bialowolski, P., & Sacco, P. L. (2023). Mind-stimulating leisure activities: Prospective associations with health, wellbeing, and longevity. *Front Public Health*, *11*, 1117822. https://doi.10.3389/fpubh.2023.1117822

Whittemore, R., & Knafl, K. (2005). The integrative review: updated methodology. *Journal of Advanced Nursing*, *52*(5), 546–553. https://doi.:10.1111/j.1365-2648.2005.03621.x

Wilson, R. S., Segawa, E., Boyle, P. A., & Bennett, D. A. (2012). Influence of late-life cognitive activity on cognitive health. Neurology, 78(15), 1123-1129. https://doi.org/10.1212/WNL.0b013e31824f8c03

World Health Organization. (2019). *Risk reduction of cognitive decline and dementia: WHO guidelines*. https://iris.who.int/bitstream/handle/10665/312180/9789241550543-eng.pdf. Last updated January 01, 2019, Accessed on October 29, 2023.

Wong, S., Irish, M., Husain, M., Hodges, J. R., Piguet, O., & Kumfor, F. (2020). Apathy and its impact on carer burden and psychological wellbeing in primary progressive aphasia. *Journal of the Neurological Sciences, 416*(117007), 1-6. https://doi.org/10.1016/j.jns.2020.117007

Wood, S., Cummings, J. L., Hsu, M.-A., Barclay, T., Wheatley, M. V., Yarema, K. T., & Schnelle, J. F. (2000). The use of the neuropsychiatric inventory in nursing home residents: Characterization and measurement. *The American Journal of Geriatric Psychiatry, 8*(1), 75–83. https://doi.org/10.1097/00019442-200002000-00010

Wu, Y.H., Damnée, S., Kerhervé, H., Ware, C., & Rigaud, A.-S. (2015). Bridging the digital divide in older adults: a study from an initiative to inform older adults about new technologies. *Clinical Interventions in Aging,10*(1), 193-201.

Yan, H., Wu, H., Cai, Z., Du, S., Li, L., Xu, B., Chang, C., & Wang, N. (2023). The neural correlates of apathy in the context of aging and brain disorders: A meta-analysis of neuroimaging studies. *Frontiers in Aging Neuroscience*, *15*(1), 1-13. https://doi.org/10.3389/fnagi.2023.1181558

Yuen, G. S., Gunning-Dixon, F. M., Hoptman, M. J., Abdelmalak, B., Mcgovern, A. R., & Seirup, J. K. (2014). The salience network in the apathy of late-life depression.

International Journal of Geriatric Psychiatry, 29(11), 1116–1124. https://doi.org/10.1002/gps.4171

Zhao, Q. F., Tan, L., Wang, H. F., Jiang, T., Tan, M. S., Tan, L., Xu, W., Li, J. Q., Wang, J., & Lai, T. J. (2016). The prevalence of neuropsychiatric symptoms in Alzheimer's disease: Systematic review and meta-analysis. *Journal of Affective Disorder, 190*(0), 264–271. https://doi.org/10.1016/j.jad.2015.09.069

Zahodne, L. B., Gongvatana, A., Cohen, R. A., Ott, B. R., Tremont, G., & Alzheimer's Disease Neuroimaging Initiative (2013). Are apathy and depression independently associated with longitudinal trajectories of cortical atrophy in mild cognitive impairment? *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, *21*(11), 1098–1106. https://doi.org/10.1016/j.jagp.2013.01.043

Zhou, Y., Yao, X., Han, W., Wang, Y., Li, Z., & Li, Y. (2022). Distinguishing apathy and depression in older adults with mild cognitive impairment using text, audio, and video based on multiclass classification and shapely additive explanations. *International Journal of Geriatric Psychiatry, 37*(11), 1-12. https://doi:10.1002/gps.5827

Zhu, C. W., Grossman, H. T., & Sano, M. (2019). Why do they just sit? Apathy as a core symptom of Alzheimer disease. *The American Journal of Geriatric Psychiatry, 27(4),* 395–405. https://doi.org/10.1016/j.jagp.2018.12.013

Zisselman, M. H., Rovner, B. W., Shmuely, Y., & Ferrie, P. (1996). A pet therapy intervention with geriatric psychiatry inpatients. *The American Journal of Occupational Therapy: Official Publication of the American Occupational Therapy Association*, *50*(1), 47–51. doi.org/10.5014/ajot.50.1.47

Zuidema, S. U., de Jonghe, J. F., Verhey, F. R., & Koopmans, R. T. (2009). Predictors of neuropsychiatric symptoms in nursing home patients: Influence of gender and dementia severity. *International Journal of Geriatric Psychiatry, 24*(10), 1079–1086. https://doi.org/10.1002/gps.2225

Zuidema, S. U., De Jonghe, J. F., Verhey, F. R., & Koopmans, R. T. (2010). Environmental correlates of neuropsychiatric symptoms in nursing home patients with dementia. *International Journal of Geriatric Psychiatry, 25*(1), 14–22. https://doi.org/10.1002/gps.2292

Appendices

Appendix 1: Letter from Research Ethics Board (Studies One to Three)

UNBC UNIVERSITY OF
NORTHERN BRITISH COLUMBIA

RESEARCH ETHICS BOARD

MEMORANDUM

To: Aderonke Agboji
CC: Shannon Freeman

From: Davina Banner-Lukaris, Chair
Research Ethics Board

Date: August 17, 2020

Re: **E2020.0805.039.00**
The prevalence and predictors of apathy among Canadian Long-Term Care Residents with an without neurocognitive disorders: A secondary data analysis

Thank you for submitting the above-noted proposal to the UNBC Research Ethics Board. Your application has been reviewed and it has been determined that, as presented to us, REB approval is not required.

If you have any questions, or require further clarification, please feel free to contact Isobel Hartley in the Office of Research (reb@unbc.ca or 250-960-6735).

Sincerely,

Dr. Davina Banner-Lukaris
Chair, Research Ethics Board

3333 University Way, Prince George, BC, V2N 4Z9, Telephone (250) 960-6735

Appendix 2: Letter approval from Northern Health Authority (Study Four)

northern health
the northern way of caring

Northern Health Regional Office
600-299 Victoria Street, Prince George, BC V2L 5B8
Telephone (250) 565-2649, Fax: (250) 565-2640
www.northernhealth.ca

June 13, 2022

File # RRC-2021-0043
REB #H21-02006

Via email to: shannon.freeman@unbc.ca

Dr. Shannon Freeman, PhD,
Associate Professor, Nursing
University of Northern British Columbia
3333 University Way
Prince George, BC, V2N 4Z9

Dear Dr. Freeman:

RE: e-Reader Project, A multimethod approach to mitigating apathy among long term care residents and community dwellers with and without neurocognitive disorders in northern BC

On behalf of the Northern Health Research Review Committee, I would like to thank you for submitting your application for research approval.

The study has received ethical approval through BC Harmonized Ethics Review process (Certificate of Approval issued by UNBC Research Ethics Board as the Board of Record dated June 6, 2022) and achieved operational and ethical approval through the Northern Health Research Review Committee.

Please note that **not all sites were approved**. Specifically, the study can't be conducted at Parkside Care, Prince George, BC.

We look forward to hearing about your findings. Please share your results with us at Research@northernhealth.ca at the completion of your project.

Sincerely,

NORTHERN HEALTH

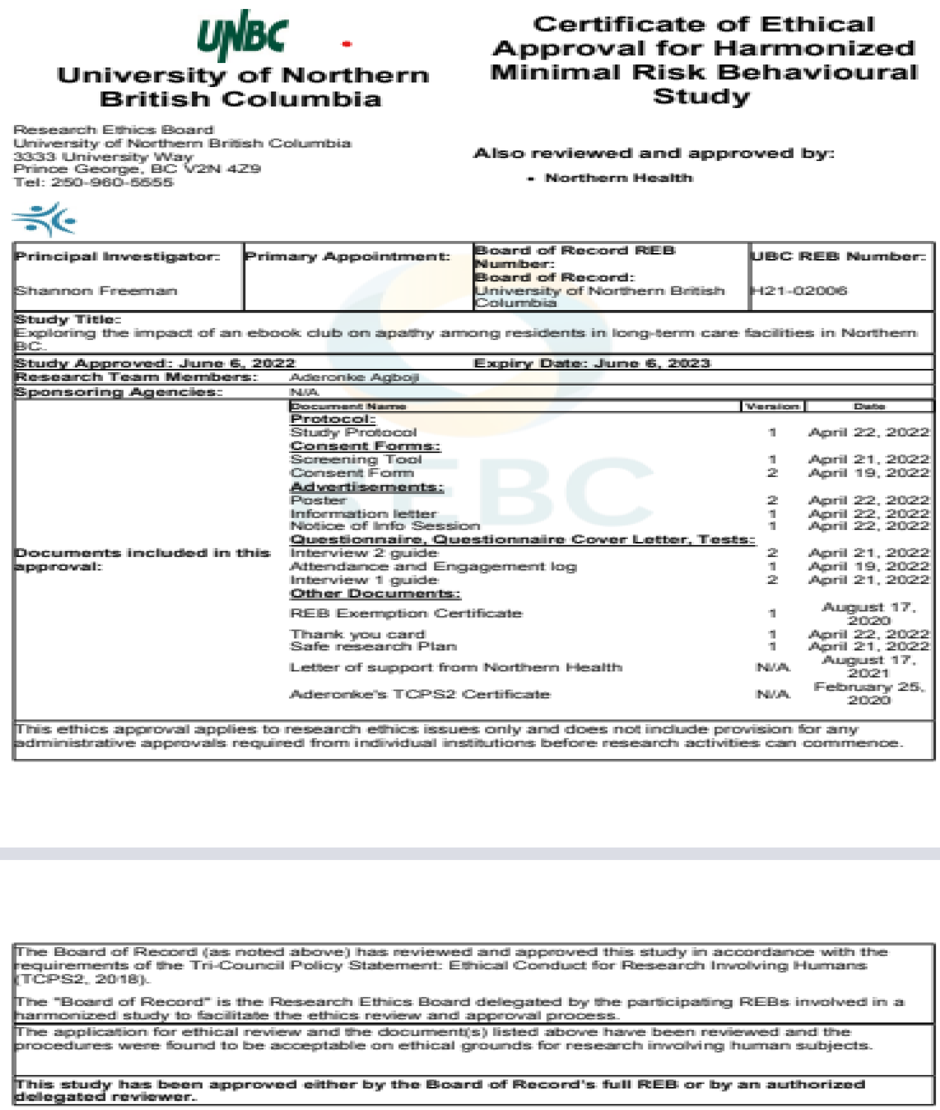
Esther

Dr. Esther Alonso-Prieto,
Chair, Research Review Committee
Lead, Clinical and Research Ethics

EAP/dt

CC: Aderonke Agboji, PhD Student, Health Sciences, Co-PI, UNBC
Tracee Dunn, Strategic Lead for the Elder Services Program, Northern Health

Appendix 3: Certificate of ethical approval (Study Four and Five)



University of Northern
British Columbia

Research Ethics Board
University of Northern British Columbia
3333 University Way
Prince George, BC V2N 4Z9
Tel: 250-960-5555

Certificate of Ethical Approval for Harmonized Minimal Risk Behavioural Study

Also reviewed and approved by:

- **Northern Health**

Principal Investigator:	**Primary Appointment:**	**Board of Record REB Number:** **Board of Record:**	**UBC REB Number:**
Shannon Freeman		University of Northern British Columbia	H21-02006

Study Title:
Exploring the impact of an ebook club on apathy among residents in long-term care facilities in Northern BC.

Study Approved: June 6, 2022 **Expiry Date: June 6, 2023**

Research Team Members: Aderonke Agboji

Sponsoring Agencies: N/A

Documents included in this approval:

Document Name	Version	Date
Protocol:		
Study Protocol	1	April 22, 2022
Consent Forms:		
Screening Tool	1	April 21, 2022
Consent Form	2	April 19, 2022
Advertisements:		
Poster	2	April 22, 2022
Information letter	1	April 22, 2022
Notice of Info Session	1	April 22, 2022
Questionnaire, Questionnaire Cover Letter, Tests:		
Interview 2 guide	2	April 21, 2022
Attendance and Engagement log	1	April 19, 2022
Interview 1 guide	2	April 21, 2022
Other Documents:		
REB Exemption Certificate	1	August 17, 2020
Thank you card	1	April 22, 2022
Safe research Plan	1	April 21, 2022
Letter of support from Northern Health	N/A	August 17, 2021
Aderonke's TCPS2 Certificate	N/A	February 25, 2020

This ethics approval applies to research ethics issues only and does not include provision for any administrative approvals required from individual institutions before research activities can commence.

The Board of Record (as noted above) has reviewed and approved this study in accordance with the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2, 2018).

The "Board of Record" is the Research Ethics Board delegated by the participating REBs involved in a harmonized study to facilitate the ethics review and approval process.

The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

This study has been approved either by the Board of Record's full REB or by an authorized delegated reviewer.

Appendix 4: Consent form

Exploring the impact of an eBook club on apathy in older adults in northern British Columbia

Consent Form for Community Dwelling Older Adults --- Participant Copy

Taking part in this study is entirely voluntary. You have the right to refuse to participate in this study. If you decide to take part, you may choose to withdraw from the study at any time without giving a reason and without any negative impact on your relationship with the organization and/or individuals from which you were recruited. Please read the following carefully:

I have read the information presented in the information letter about the project.	☐YES	☐NO
I have had the opportunity to ask questions about my involvement in this project and to receive additional details I requested.	☐YES	☐NO
I understand that if I agree to participate in this project, I may withdraw from the project at any time with no consequences of any kind.	☐YES	☐NO
I have been given a copy of this form.	☐YES	☐NO
I agree to be recorded in the interviews.	☐YES	☐NO

Your signature indicates that you consent to participate in this study.

____

Participant's Name (print)

____

Participant's Signature Date

____

Research Team Member's Signature Date

____

Research Team Member's Name (print)

If you would like to receive a brief summary of the study findings, please provide your email address:

____

Exploring the impact of an eBook club on apathy in older adults in northern British Columbia

Consent Form for Community Dwelling Older Adults --- Researcher Copy

Taking part in this study is entirely voluntary. You have the right to refuse to participate in this study. If you decide to take part, you may choose to withdraw from the study at any time without giving a reason and without any negative impact on your relationship with the organization and/or individuals from which you were recruited. Please read the following carefully:

I have read the information presented in the information letter about the project.	☐YES	☐NO
I have had the opportunity to ask questions about my involvement in this project and to receive additional details I requested.	☐YES	☐NO
I understand that if I agree to participate in this project, I may withdraw from the project at any time with no consequences of any kind.	☐YES	☐NO
I have been given a copy of this form.	☐YES	☐NO
I agree to be recorded in the interviews.	☐YES	☐NO

Your signature indicates that you consent to participate in this study.

____

Participant’s Name (print)

____

Participant’s Signature Date

____

Research Team Member’s Signature Date

____

Research Team Member’s Name (print)

If you would like to receive a brief summary of the study findings, please provide your email address:

____

Appendix 5: Interview 1 Guide

Participant ID code: ________________________________ Date: __________.

PART 1: Demographic Information

1. How old are you? _________ years
2. What is your gender?
   ☐ Male

   ☐ Female

   ☐ Non-binary

   ☐ Prefer to self-identify, please specify: ___________________________________

   ☐ Prefer not to say
3. What is the highest education you have received?
   ☐ Less than high school, grade completed _______

   ☐ High School

   ☐ College or university degree

   ☐ Post-graduate studies, specify ________________
4. Have you been diagnosed with dementia?
   ☐ Yes

   ☐ No
5. What is your marital status?
   ☐ Never married

   ☐ Married

   ☐ Partner/significant other

   ☐ Widowed

   ☐ Separated

   ☐ Divorced

PART 2: GDS-3A questionnaire

1.. Have you dropped many of your activities and interests?

☐ Yes

☐ No

2. Do you prefer to stay in your room rather than going out and doing new things?

☐ Yes

☐ No

3. Do you feel full of energy?

☐ Yes

☐ No

Positive answers for apathy screening are "yes" to either or both questions

and "no" to ***the 2 questions.*** A score of ***1*** or higher indicates possible ***apathy.***

PART 3: Reading

1. How long have you been reading (years)?
   ☐ less than 1 year
   ☐ 1- 5 years
   ☐ over 5 years
2. How often do you read?
   ☐ Everyday
   ☐ Once a week
   ☐ Once a month
   ☐ Occasionally
3. Can you tell me about your past experiences of reading?
4. Who is your favorite author?
5. What is your favorite book?
6. What types of books do you like to read? Fictional, non-fictional, poetry, religious?
7. How has your reading habit change over time since you came to the long-term care facility/retire?

8. What type of book or author of a book are you hoping to read? Stories, poems, novels, and plays?

PART 4: Reader/eReader

1. Tell me about your experience of using tablets/eReaders to assist with reading.
2. What type of devices have you used to help with reading? Probes: phone, tablets, eReaders?
3. How do you feel about using this device?
4. How do you feel about trying a new reading device?

Appendix 6: Interview 2 Guide

Participant ID code: ______________________________ Date: __________.

PART 1: GDS-3A questionnaire

1.. Have you dropped many of your activities and interests?

☐ Yes

☐ No

2. Do you prefer to stay at home rather than to go out and do new things?

☐ Yes

☐ No

3. Do you feel full of energy?

☐ Yes

☐ No

Positive answers for apathy screening are "yes" to questions **1 and 2**, and "no" ***question 3.*** A score of ***1*** or higher indicates possible ***apathy.***

PART 2: Reading

1. What motivated you to join the eBook club?
    a. What interested you most in the eBook club?
    b. What motivated you to continue to take part in the eBook club?
2. Can you please share with me your experiences during the eBook club?
    a. Do you think that your participation in the eBook club impacted your motivation to do things you've always enjoyed?
    b. Do you think that your participation in the eBook club impacted your motivation to get involved in the group reading activities?
    c. Do you think that your participation in the eBook club impacted your mood?
    d. Do you think that your participation in the eBook club helped you in building relationships with others?
3. Can you please share with me your experiences during eBook club?
    a. Are there aspects of the eBook club that stood out to you?
    b. What is the biggest challenge you encountered during the eBook club?
    c. Was the challenge addressed, and if so, how?

    d. What aspects of the eBook club do you think needs improvement?
4. How often do you read?
    a. Did you read more or less often with the eReader?
5. Please tell me about your experience of reading with the eReader?
    a. Was if fun and relaxing?
    b. Was it interesting and enjoyable?
    c. Did it meet your expectations?
    d. what would you like to change on the eReader? Probes: book layout, font, color, navigation etc.
    e. What would you like to add to the eReader? Probes: book layout, font, color, navigation etc.
    f. What would you like to remove from the eReader? Probes: book layout, font, color, navigation etc.
6. Is there anything that I haven’t asked that you would like to share?
7. How do you feel about trying a new reading device?

Appendix 7: Supplementary tables for Study One

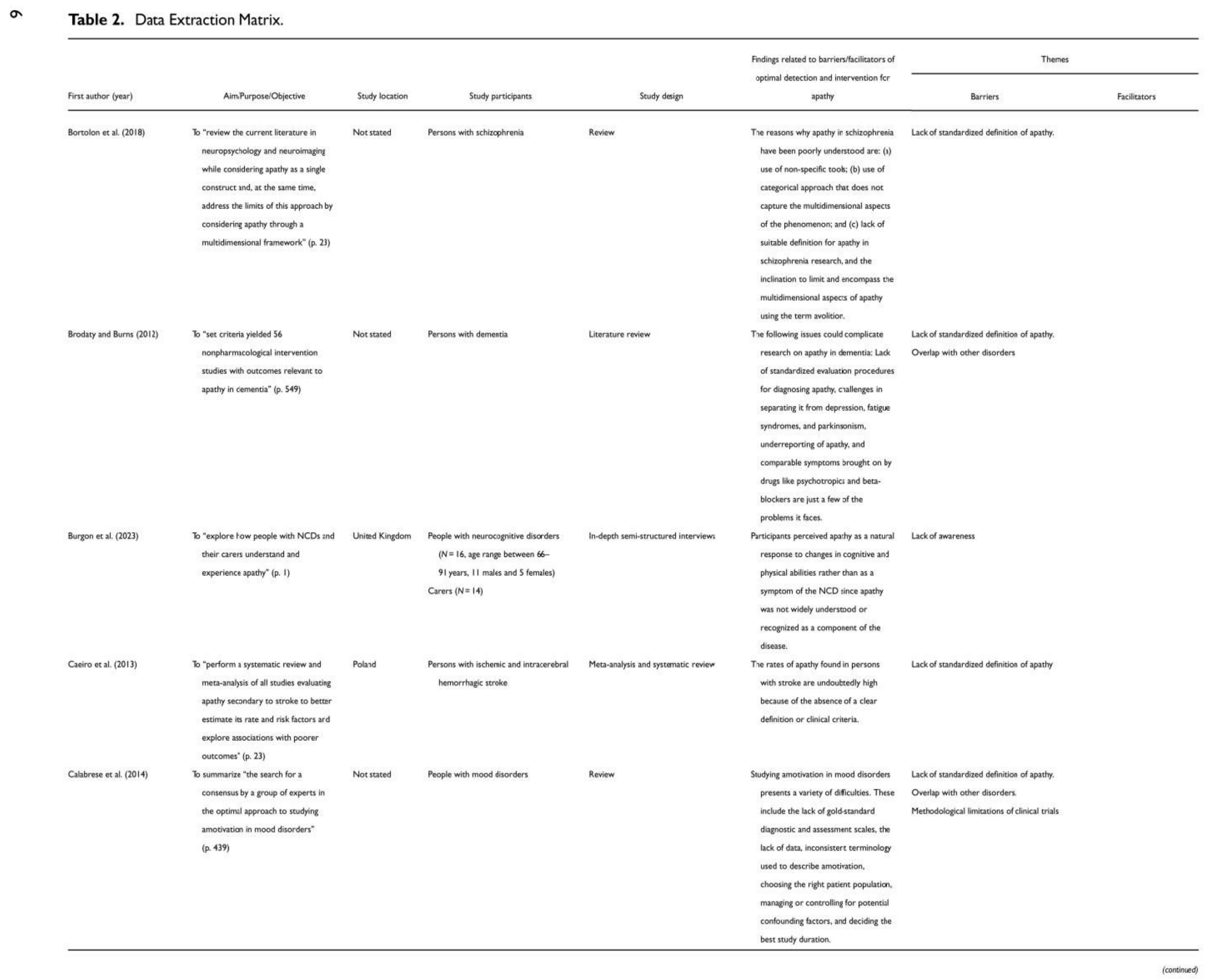


Table 2. Data Extraction Matrix.

First author (year)	Aim/Purpose/Objective	Study location	Study participants	Study design	Findings related to barriers/facilitators of optimal detection and intervention for apathy	Themes	
						Barriers	Facilitators
Bortolon et al. (2018)	To "review the current literature in neuropsychology and neuroimaging while considering apathy as a single construct and, at the same time, address the limits of this approach by considering apathy through a multidimensional framework" (p. 23)	Not stated	Persons with schizophrenia	Review	The reasons why apathy in schizophrenia have been poorly understood are: (a) use of non-specific tools; (b) use of categorical approach that does not capture the multidimensional aspects of the phenomenon; and (c) lack of suitable definition for apathy in schizophrenia research, and the inclination to limit and encompass the multidimensional aspects of apathy using the term avolition.	Lack of standardized definition of apathy.	
Brodaty and Burns (2012)	To "set criteria yielded 56 nonpharmacological intervention studies with outcomes relevant to apathy in dementia" (p. 549)	Not stated	Persons with dementia	Literature review	The following issues could complicate research on apathy in dementia: Lack of standardized evaluation procedures for diagnosing apathy, challenges in separating it from depression, fatigue syndromes, and parkinsonism, underreporting of apathy, and comparable symptoms brought on by drugs like psychotropics and beta-blockers are just a few of the problems it faces.	Lack of standardized definition of apathy. Overlap with other disorders	
Burgon et al. (2023)	To "explore how people with NCDs and their carers understand and experience apathy" (p. 1)	United Kingdom	People with neurocognitive disorders ($N = 16$, age range between 66–91 years, 11 males and 5 females) Carers ($N = 14$)	In-depth semi-structured interviews	Participants perceived apathy as a natural response to changes in cognitive and physical abilities rather than as a symptom of the NCD since apathy was not widely understood or recognized as a component of the disease.	Lack of awareness	
Caeiro et al. (2013)	To "perform a systematic review and meta-analysis of all studies evaluating apathy secondary to stroke to better estimate its rate and risk factors and explore associations with poorer outcomes" (p. 23)	Poland	Persons with ischemic and intracerebral hemorrhagic stroke	Meta-analysis and systematic review	The rates of apathy found in persons with stroke are undoubtedly high because of the absence of a clear definition or clinical criteria.	Lack of standardized definition of apathy	
Calabrese et al. (2014)	To summarize "the search for a consensus by a group of experts in the optimal approach to studying amotivation in mood disorders" (p. 439)	Not stated	People with mood disorders	Review	Studying amotivation in mood disorders presents a variety of difficulties. These include the lack of gold-standard diagnostic and assessment scales, the lack of data, inconsistent terminology used to describe amotivation, choosing the right patient population, managing or controlling for potential confounding factors, and deciding the best study duration.	Lack of standardized definition of apathy. Overlap with other disorders. Methodological limitations of clinical trials	

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Table 2. (continued)

First author (year)	Aim/Purpose/Objective	Study location	Study participants	Study design	Findings related to barriers/facilitators of optimal detection and intervention for apathy	Themes	
						Barriers	Facilitators
Carrozzino (2019)	To "capture the clinimetric properties of these rating scales and to identify the measures, which display clinical validity for the assessment of apathy in PD" (p. 109641)		People with Parkinson's disease	Systematic review	These standards have been confirmed in a variety of patients. Unfortunately, there is still no universally accepted definition of apathy. When performing the ROC analysis from a clinical standpoint, the sensitivity and specificity of a rating scale are determined using the expert clinician's opinion as the benchmark.	Lack of standardized definition of apathy	Education, training, and experience.
Chase (2011)	"To improve our understanding of apathy and to better address the unmet medical needs of those suffering its consequences" (p. 266)	Not stated	Persons with neuropsychiatric disease	Review	There is no clear agreement on the diagnostic standards for the syndrome of apathy. There are already a number of scales available to assess the level of apathy in individuals with neurological and mental illnesses. Unfortunately, due to the absence of widely accepted diagnostic standards, all suffer from the inability to be fully validated against external criteria. Because it is mistaken for depression and other comparable behavioral illnesses, apathy is frequently kept misdiagnosed and, consequently, untreated	Lack of standardized definition of apathy Overlap with other disorders	
Clarke et al. (2011)	To provide "a psychometric review of the most commonly used apathy measures and provides recommendations for use and further research" (p. 73)	Not stated	Persons with neurological, psychiatric, and medical conditions.	Comprehensive review	The primary obstacle to expanding the existing literature in this field may be the lack of a consistent definition and conceptual operationalization of "apathy," as evidenced by the use of terms like "lack or loss of interest," "avolition," "affective flattening," "social withdrawal," and "indifference." This is probably because the DSM doesn't define apathy.	Lack of standardized definition of apathy	

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Table 2. (continued)

First author (year)	Aim/Purpose/Objective	Study location	Study participants	Study design	Findings related to barriers/facilitators of optimal detection and intervention for apathy	Themes	
						Barriers	Facilitators
Clarke et al. (2007)	To reexamine "the factor structure of the three versions of the AES and identifies cutoff scores for apathy…[and] examines the psychometric properties of the three versions of the AES, including sensitivity and specificity, using the identified cutoff scores, and reliability and validity" (p. 58)	Canada	Persons with dementia (N = 121; mean age = 73.7 (SD →9.4) years; 52.9% women)	Quantitative	'It is significant to note that the assessors who administered the clinician version of the AES had bachelor's level training in healthcare-related fields, 1 to 5 years of experience working with dementia patients, and more than 4–6 hr of experience with the scale—a requirement that Marin stated would be sufficient for reliable rating. However, as we noted in our critical evaluation of the AES-C, it's possible that this level of training was insufficient for reliable rating and could account for the AES-C's performance.		Education, training and experience
Cummings et al. (2015)	To "offer key recommendations for the design of clinical studies investigating the management of apathy in AD and PD and, by extension, in a wide range of neuro-psychiatric" (p. 160)	Not stated	Persons with neuropsychiatric disorders	Literature review	The challenges encountered included: limited data due to lack of established diagnostic criteria the presence of confounding factors such as depression, adjuvant medications, and lack of a gold-standard apathy assessment scale	Lack of standardized definition of apathy Overlap with other disorders.	
Dickson and Husain (2022)	To 'critically examine the literature on theoretical frameworks for different domains of apathy' (p. 248)	Not stated	Persons with brain disorders	Systematic review	Apathy scales often focus on the cognitive or executive dimension, but behavioral and emotional dimensions are consistently represented. Research is needed to determine if there is an independent social dimension.	Lack of standardized definition of apathy	
Drye et al. (2013)	To report the challenges encountered while designing the ADMET study	Canada	Persons with dementia (N = 60)	Randomized, double-masked, placebo-controlled multicenter clinical trial	The following issues were encountered: defining and measuring apathy differentiating apathy from depression, determining appropriate intervention recruiting participants and deciding on a suitable method for blinding.	Lack of standardized definition of apathy Overlap with other disorders. Methodological limitations of clinical trials	

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Table 2. (continued)

First author (year)	Aim/Purpose/Objective	Study location	Study participants	Study design	Findings related to barriers/facilitators of optimal detection and intervention for apathy	Themes	
						Barriers	Facilitators
Flavell and Nestor (2022)	To "establish updated prevalence estimates for depression and apathy in patients with PSP" (p. 281).	Not stated	Persons with progressive Supranuclear Palsy	Systematic review	Few studies have employed a rating scale or previously established criteria to evaluate apathy, with 93% of patients being evaluated using merely a screening question. The prevalence rates for apathy varied noticeably between research and assessment techniques as well.	Lack of standardized definition of apathy.	
Gracia-García et al. (2021)	To "identify recent advances in the neurocognitive and biological correlates of apathy" (p. 193)	Not stated	Persons with psychiatric disorders	Systematic review	The diversity of definitional approaches and the clinical heterogeneity of apathy are likely to be the causes of certain discrepant findings in the research.	Lack of standardized definition of apathy.	
Harrison et al. (2016)	To "provide an update and examine recent progress in pharmacological treatment of apathy in dementia" (p. 103)	Not stated	Persons with dementia	Systematic reviews	Despite a recent rise in research interest in apathy in dementia, with a 20% increase in apathy-specific dementia studies over the previous few years, the evidence for pharmaceutical treatment is limited due to the lack of randomized controlled trials that specifically evaluate it.	Methodological limitations of clinical trials	
Jao et al. (2019)	To explore the agreement of apathy assessment using the AES, both the ES-18 and AES-10, among family and clinical caregivers for long term care residents with dementia' (p. 2223).	USA	Persons with dementia ($N = 15$, women = 9, men = 6, mean age = 86 years); family ($N = 15$, all female, mean age=65years); and clinical caregivers ($N = 15$, CNAs mean age = 46 years, LPNs mean age = 31 years, and activity staff mean age=31years)	Cross-sectional, descriptive	Symptoms are subjective, and not as disturbing as other behavioral symptoms. Symptoms overlap with other disorders. Persons with apathy show less awareness of symptoms and find it difficult to understand and answer questions during apathy assessment Small homogenous sample. LPNs are better raters than CNAs but are not ideal raters in NHs. RNs are ideal raters because of their level of training and contact with residents.	Overlap with other disorders. Methodological limitations of clinical trials	Education, training and experience

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Table 2. (continued)

First author (year)	Aim/Purpose/Objective	Study location	Study participants	Study design	Findings related to barriers/facilitators of optimal detection and intervention for apathy	Themes	
						Barriers	Facilitators
König et al. (2014)	To "give an overview of current assessment tools for apathy in clinical practice and new approaches to assessment methods with the help ICT" (p. 345)	Not stated	Persons with dementia	Narrative literature review	The lack of widely accepted diagnostic criteria for apathy as a syndrome result in the lack of a gold standard to evaluate the sensitivity and specificity of scales, among other psychometric features. ICT-based assessment can be mastered over time and readily incorporated into a person's daily life without running the danger of observer bias. Additionally, earlier automated apathy detection may be possible, improving care and possibly increasing the number of early preventive interventions for disease progression.	Lack of standardized definition of apathy.	Adoption of technology for apathy screening and interventions
Lanctôt et al. (2017)	To "summarize research on apathy, as defined using any standardized assessment method, noting how it was defined" (p. 85)	Not stated	Persons with neurocognitive disorders (NCDs) including Alzheimer's disease and mild cognitive impairment.	Review	Technology is currently being evaluated to facilitate apathy assessment and diagnosis in an objective manner. Although apathy has been defined as a syndrome, its definition and measurement still need to be improved, paying special attention to subdomains.	Lack of standardized definition of apathy.	Adoption of technology for apathy screening and interventions
Lanctôt et al. (2021)	To "compare the classification of apathy using the DCA with that using the Neuropsychiatric Inventory-apathy (NPI-apathy) subscale in ADMET 2 Comparisons between NPI-Apathy and Dementia Apathy Interview Rating (DAIR) scale, and DCA and DAIR were also explored" (p. 82)	USA and Canada	Persons with Alzheimer's dementia	Randomized, double-blind, placebo-controlled phase III trial	The absence of defined assessment methods and established definitions of apathy has impeded clinical research. Research results have been difficult to compare between studies due to the vast range of instruments utilized, which is slowing the understanding and treatment of apathy.	Lack of standardized definition of apathy.	
Leone et al. (2013)	To "evaluate the effectiveness of a nursing home (NH) staff education to manage apathy in older individuals with a diagnosis of dementia" (p. 384)	Canada	Nursing home staff and Persons with dementia ($N = 230$, women = 183, men = 47, mean age = 88.3, $SD = 6.3$ years)	Pilot	Due to lack of awareness, NH staff considered apathy as the least difficult behavioral symptoms to manage. It was impossible to avoid issues related to randomization. The strength lies in the use of different types of rating scales by different sets of raters and the standardization of all training materials	Lack of awareness Methodological limitations of clinical trials	

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Table 2. (continued)

First author (year)	Aim/Purpose/Objective	Study location	Study participants	Study design	Findings related to barriers/facilitators of optimal detection and intervention for apathy	Themes	
						Barriers	Facilitators
Manera et al. (2020)	To "provide recommendations for the use of NPT for apathy, and to discuss the role of ICT in this domain, based on opinions gathered from experts in the field" (p. 411)	Not stated	20 experts (researchers and healthcare professionals; Psychiatrists = 8; Psychologists = 8; Neurologists = 2; Speech Therapist = 1, and ICT = 1)	Web Survey	ICT may help with non-pharmacological treatment (NPT) delivery, standardization, and assessment and may open up new opportunities for managing, treating, and intervening with apathy in the future.		Adoption of technology for apathy screening and interventions
Matmati et al. (2022)	To "shed light on apathy in HD, especially regarding its multidimensional aspect and underlying mechanisms" (p. 100)	Not stated	Persons with Huntington's disease	Systematic review	Most researchers agreed that apathy is a complex phenomenon. However, current theories frequently apply to practice and research without considering the various mechanisms underlying apathy. The uncertain relationship between apathy and other psychiatric diseases including anhedonia, abulia, and depression, is another drawback of the categorical approach.	Lack of standardized definition of apathy. Overlap with other disorders	
Mele et al. (2019)	To "assess patient, family caregiver, and health care practitioners" perceptions around the barriers and facilitators to diagnosing and managing apathy in PD" (p. 102)	Canada	Healthcare practitioners (HCPs) (neurologist, psychiatrists, psychologists, nurse, and allied health professional), family caregivers and Persons with PD (*N* = 16, women = 11, men = 4, age range = 59-72 years).	Semi-structured focus groups and interview	Key barriers reported included: Lack of awareness of neuropsychiatric symptoms including apathy. Lack of engagement and insight among those with PD and apathy Lack of a standardized apathy definition belief that apathy is a natural part of aging. No guidelines for care of apathy in PD Reported facilitators are: Increased awareness of apathy as a symptom in PD Increased education on apathy as a symptom in PD Good communication between HCP and family/persons with PD Involvement of family caregivers	Lack of awareness Lack of standardized definition of apathy.	Adequate training, education, and experience Involvement of dyad
Mele et al. (2020)	"To conduct a scoping review of the literature on apathy in Parkinson's disease (PD), to better understand how apathy in Parkinson's disease is diagnosed, treated and managed" (p. e037632)	Not stated	Persons with Parkinson's disease	Scoping review	The major hindrance reported is lack of gold standard criteria for apathy	Lack of standardized apathy definition	

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Table 2. (continued)

					Findings related to barriers/facilitators of optimal detection and intervention for apathy	Themes	
First author (year)	Aim/Purpose/Objective	Study location	Study participants	Study design		Barriers	Facilitators
Saredakis et al. (2020)	To "evaluate the feasibility of using tailored content created for viewing in a VR HMD to deliver reminiscence therapy to older adults in residential aged care" (p.e17634)	Australia	Persons with and without dementia (N = 17, women = 10, men = 7, mean age = 87.3 SD = 6.3 years)	Feasibility study	The absence of a control group receiving no VR intervention and low recruitment of participants with apathy were challenges encountered. The use of sample selected by the staff hindered randomization and could have introduced selection bias.	Methodological limitations of clinical trials	
Stanton and Carson (2016)	To review the strategies for reducing impact of apathy in Persons with chronic neurological disorders	Not stated	Persons with chronic neurological disorders	Review	Apathy is not defined as an independent disorder in the current psychiatric classifications and not mentioned at all in The International Classification of Diseases 10th Revision (ICD-10) Persons with apathy typically have poor insight and might not recognize it at all or perceive it as a problem apathy. The use of other terms to describe similar clinical features of apathy complicates its assessment and management.	Lack of standardized definition of apathy Lack of awareness	
Starkstein et al. (2016)	"To evaluate the efficacy of treatment with nefiracetam compared to placebo in poststroke apathy" (p. 1119)	Australia	Persons with post-stroke (N = 13, Male = 100%, mean age 65.4 SD = 10.3 years).	Parallel group, randomized, placebo controlled, double-blind two-center trial	The results of the findings were non-informative because of the very low recruitment rate.	Methodological limitations of clinical trials	
Steffens et al. (2022)	To "provide a clinical neuroscience-based overview of neurobiological and neuropsychological phenomena related to apathy" (p. 525)	Not stated	Persons with neuropsychiatric disorders	Review	Although neuroimaging studies have identified potential apathy biomarkers, inconsistent results may be caused by the heterogeneity of apathy's expression (variability in which symptoms predominate), the presence of comorbid neuropsychiatric disorders in which apathy is common, or both.	Overlap with other disorders	Adoption of technology for apathy screening and interventions
Tay et al. (2021)	To provide "a contemporary introduction to apathy in stroke for researchers and practitioners" (p.150)	Not stated	Persons with stroke	Systematic review	High-quality research is lacking in helping with post-stroke apathy treatment. Symptoms of depression, in particular, which might behave similarly to apathy, can confuse the diagnosis of apathy.	Methodological limitations of clinical trials Overlap with other disorders.	

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Table 2. (continued)

First author (year)	Aim/Purpose/Objective	Study location	Study participants	Study design	Findings related to barriers/facilitators of optimal detection and intervention for apathy	Themes	
						Barriers	Facilitators
Teixeira et al. (2021)	To "clarify the concept of apathy alongside its assessment and treatment in patients with AD and to identify knowledge gaps" (p.1)	Not stated	Persons with Alzheimer dementia	Scoping review	Self-reported AES have been found to be less accurate than informant- and clinician-based scores, while this finding may be due in part to the diminished awareness seen in AD. Because patients frequently underestimate their level of interest and motivation, participation in personal and social activities, and general level of interest, the assessment of apathy in clinical practice must involve not only the patient but also a relative and/or caregiver. Caregivers may interpret disinterest incorrectly. Family caregivers may view apathy as an oppositional or purposeful conduct with increased degrees of related discomfort, whereas professional carers may not perceive it as a distressing or difficult condition.	Lack of awareness	Involvement of dyad
Thant and Yager (2019)	To examine apathy syndromes in relation to Diagnostic and Statistical Manual ofMental Disorders (DSM) and he Research Domain Criteria (RDoC) frameworks.	Not stated	Persons with psychiatric and neurological disorders	Review	However, neither the index nor the technical words glossary for the DSM-5 define apathy. Clinical professionals typically consider neurodegenerative or general medical disorders, substance use disorders (amotivational states), and/or psychotic disorders (negative symptoms/avolition) when dealing with patients whose primary complaint is apathy. When these elements are absent, diagnostic reasoning frequently shifts to depressive illnesses and sporadically to personality disorder.	Lack of standardized definition of apathy Lack of awareness Overlap with other disorders	

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Table 2. (continued)

First author (year)	Aim/Purpose/Objective	Study location	Study participants	Study design	Findings related to barriers/facilitators of optimal detection and intervention for apathy	Themes	
						Barriers	Facilitators
Theleritis et al. (2018)	To update "the existing literature on the effectiveness of nonpharmacological treatments covering also combined treatments trials" (p. e177)	Not stated	Persons with dementia	Review	Issues with the design (such as randomization and blinding), etc. An effect may be positively skewed by problematic allocation concealment and non-double-blind design. Additionally, the heterogeneity of studies is increased and is influenced by the current dearth of widely accepted standards for apathy measurement.	Methodological limitations of clinical trials Lack of standardized definition of apathy	
Villar et al. (2021)	To 'explore how staff manage apathy involving a person living with dementia (PLWD) (p. 614)	Spain	Nursing home staff (nursing assistants = 21 and technical staff = 21)	Semi-structured interview	Apathy is not properly diagnosed, and staff tend to mistake PLWD with apathy for persons with depression, which could mean that apathy is managed ineffectively or even not at all. This variability could be a sign that there are no unified norms or generally acknowledged standards among experts, who appear to behave based on personal preferences. The reaction that a person with PLWD receives when exhibiting apathy will mainly depend on the individual professional, either technical staff or assistant carer, who is in charge of their care and makes judgments regarding what to do.	Lack of awareness Overlap with other disorders. Lack of standardized definition of apathy	Education, training and experience

Table 3. Critical Appraisal of Included Papers.

Quality assessment of quantitative studies

First author/year	Is the sampling strategy relevant to address the research?	Is the sample representative of the target population	Are measurements appropriate?	Is the risk of non-bias low?	Is the statistical analysis appropriate to answer the research	Rating
Clarke et al. (2007)	Y	Y	Y	Y	Y	H
Drye et al. (2013)	Y	Y	Y	Y	Y	H
Jao et al. (2019)	Y	Y	Y	Y	Y	H
Lanctôt et al. (2021)	Y	Y	Y	Y	Y	H
Manera et al. (2020)	Y	Y	Y	Y	Y	H
Padala, Padala, Lensing, Jackson, et al. (2018), Padala, Padala, Lensing, Ramirez, et al. (2018)	Y	Y	Y	N	Y	H
Starkstein et al. (2016)	Y	Y	Y	Y	Y	H
Villar et al. (2021)	Y	Y	Y	Y	Y	H

Quality assessment of qualitative studies

First author (year)	Is the qualitative approach appropriate to answer the research questions	Are the qualitative data collection methods adequate to address the research questions	Are the findings adequately derived from the data?	Is interpretation of results sufficiently substantiated by data?	Is there coherence between qualitative data sources, collection, analysis and interpretation	Rating
Burgon et al. (2023)	Y	Y	Y	Y	Y	H
Mele et al. (2019)	Y	Y	Y	Y	Y	H

Quality assessment of mixed method studies

First author (year)	Is there an adequate rationale for using a mixed methods design to address the research question?	Are the different components of the study effectively integrated to answer the research question?	Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	Are divergencies and inconsistencies between quantitative and qualitative results addressed?	Do the different components of the study adhere to the quality criteria of each tradition of the method involved?	Rating
Leone et al. (2013)	Y	Y	Y	Y	Y	H
Saredakis et al. (2020)	Y	Y	Y	Y	Y	H

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Table 3. (continued)

Quality assessment of review papers

First author (year)	Did the review address a clearly focused question?	Did the authors look for the right type of papers?	Do you think all the important, relevant studies were included?	Did the review's authors do enough to assess quality of the included studies?	If the results of the review have been combined, was it reasonable to do so?	What are the overall results of the review?	How precise are the results?	Can the result be applied to local population?	Were all important outcome considered?	Are the benefits worth the arm?	Rating
Bortolon et al. (2018)	Y	Y	Y	Y	Y	To gain a better understanding of the neural mechanisms involved in apathy in schizophrenia, it is imperative that future studies consider the multidimensional aspects of apathy.	Very precise	Y	CT	Y	H
Brodaty and Burns (2012)	Y	Y	Y	Y	Y	Non-pharmacological interventions are beneficial, but high-quality research is lacking to guide clinicians and caregivers.	Very precise	Y	Y	Y	H
Caeiro et al. (2013)	Y	Y	Y	Y	Y	Apathy not depression is more prevalent among Persons with stroke	Very precise	Y	CT	Y	H
Calabrese et al. (2014)	Y	Y	Y	Y	Y	Apathy is poorly understood in mood disorders	Very precise	Y	CT	Y	H
Carrozzino (2019)	Y	Y	Y	Y	Y	The WHO-5, Neurasthenia Scale, and LARS are clinically valid for the diagnosis of apathy in PD.	Very precise	Y	Y	Y	H
Chase (2011)	Y	Y	Y	Y	Y	Apathy is a serious condition that can cause disability, but there is no treatment approved to treat it yet.	Precise	Y	CT	Y	H
Clarke et al. (2011)						Research is needed to agree on apathy definition and improve accuracy of tools used to measure apathy	Very precise	Y	Y	Y	H
Cummings et al. (2015)	Y	Y	Y	N	Y	Designing an appropriate clinical trial to investigate apathy in neurogenerative disorder is very challenging	Very precise	Y	Y	Y	H
Dickson and Husain (2022)	Y	Y	Y	Y	Y	While there are some evidence for a social domain of apathy, this concept has not been sufficiently investigated in previous work to draw any valid conclusions	Very precise	Y	Y	Y	H
Flavell and Nestor (2022)	Y	Y	Y	Y	Y	Many Progressive Supranuclear Palsy (PSP) apathy studies use a screening question, which is insufficient. Apathy definitions, tools, and cut-off scores must be agreed upon.	Very precise	Y	Y	Y	H
Gracia-García et al. (2021)	Y	Y	Y	Y	Y	Precision psychiatry may reveal new treatment targets and risk models for apathy.	Very precise	Y	Y	Y	H
Harrison et al. (2016)	Y	Y	Y	Y	Y	Combination of medication and non-medication approaches may be effective in treating apathy.	Very precise	Y	Y	Y	H
Mele et al. (2020)	Y	Y	Y	Y	Y	There is lack of standardized and validated apathy screening tool for apathy in Parkinson's Disease.	Very precise	Y	Y	Y	H
König et al. (2014)	Y	Y	Y	Y	Y	ICT techniques may be useful for assessing apathy.	Very precise	Y	Y	Y	H
Lanctôt et al. (2017)	Y	Y	Y	Y	Y	There is need for refinement in apathy definition and measurement, including subdomains.	Very precise	Y	Y	Y	H
Matmati et al. (2022)	Y	Y	Y	Y	Y	In order to better understand and treat apathy in Huntington's disease, researchers need to use an approach that takes into account multiple factors.	Very precise	Y	Y	Y	H
Stanton and Carson (2016)	Y	Y	Y	Y	Y	Apathy is not defined as an independent disorder, making it difficult to assess and manage.	Very precise	Y	Y	Y	H
Steffens et al. (2022)	Y	Y	Y	Y	Y	Research has identified potential targets and biomarkers for understanding apathy, but methodological issues need to be addressed for more reliable results.	Very precise	Y	Y	Y	H
Tay et al. (2021)	Y	Y	Y	Y	Y	Apathy is linked to a worse prognosis after a stroke, but there are potential treatments such as drugs, behavioral interventions, and transcranial magnetic stimulation.	Very precise	Y	Y	Y	H
Teixeira et al. (2021)	Y	Y	Y	Y	Y	Apathy in Alzheimer's disease is common and linked to worse progression, but there is limited evidence to support treatments.	Very precise	Y	Y	Y	H
Thant and Yager (2019)	Y	Y	Y	Y	Y	Research is needed to define distinct motivational disorders, develop reliable diagnostic methods, identify treatments, and provide evidence.	Very precise	Y	Y	Y	H
Theleritis et al. (2018)	Y	Y	Y	Y	Y	Research is needed to develop tailored treatments for apathy in dementia.	Very precise	Y	Y	Y	H

Y = yes, N = no, CT = can't tell; H = high quality; L = low quality.