CREATIVE ARTS-BASED INTERVENTIONS FOR PERSONS WITH DEMENTIA IN RESIDENTIAL FACILITIES: EVIDENCE FROM A SCOPING REVIEW AND A MIXED-METHODS SYSTEMATIC REVIEW

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Preface / Author’s Notes

As you read this thesis, I implore you to think about your needs, wants, and what makes you, you. Take a moment and out loud, say who you are and what is it that you enjoy. Now for a brief second, pretend what you said, you can no longer identify with and it no longer exists in your life…how does that make you feel?

People with dementia have through the ages lost support for their needs, wants, and lived experiences. In fact, they are treated as those who are ‘losing’ their mental capacities or are only capable of cognitive and/or behavioural disturbances. This thesis will turn its attention to the creative aspects of arts-based interventions that play a massive role on the life of people with dementia.

For me, the arts have always been an important aspect of my life. When the going got tough or I was faced with a difficult situation, I found solace in the arts and in expressing my creativity. The arts have been an outlet for me, even as a child, therefore I hope that even as I age, I have the opportunity to stay creative and participate in artistic endeavours. I hope the same for everyone that appreciates various art and uses it as an outlet. I also hope that you are always able to partake in your own creative passions even as you age; never let them go!

Acknowledgements

Land Acknowledgement – We are standing on unceded Algonquin, Anishinabek territory. They are the past and present caretakers of the waterways and land that we call Ottawa. I am grateful to have the opportunity to be present in this territory.

I begin my acknowledgements by extending my love, kindness, and humble gratitude to my family, particularly to my parents and my sister, all three of whom have supported me throughout this master’s degree. No matter the situation, no matter the obstacles, these three have always provided me with a shoulder to lean on.

I would also like to set aside a moment to appreciate my grandfather on his life and for his constant love. It is because of him, my drive to work with older adults in any capacity began. His life was a testament to how important creative arts-based interventions were in daily life, especially when he would enjoy listening to his music at all times of the day. You are always in my heart and thoughts.

I extend my deepest gratitude to Sarah Visintini, our Librarian, for being the beacon of light that guided me in every step of the review process. Without whom, my thesis would not be completed, nor would we have found a direction with the work being presented in this thesis.

I thank Stéphanie Breau-Godwin, the real heart and soul of the Master of Interdisciplinary Health Sciences program. No matter the question, Stéphanie always provided her support, guidance, and kindness.

To all the kind and wonderful people, I have come across throughout my Masters, including my peers, friends, professors, and library staff, I value each and every one of you.

I would like to thank my supervisor, Dr. Pascal Fallavollita, and my TAC team of Drs. Dal Bello-Haas, Deonandan, Fraser, and Kuling.

Thank you to both my second reviewers, Tanita Cepalo and Sarah Wells, for their ongoing support and continued efforts throughout the review process.

Finally, I would like to say how humbled I am that each and every day, by the grace of God, I have been able to wake up and continue striving on completing my education and increasing my knowledge base.

Abstract

Background: The Public Health Agency of Canada published a strategic document recognising the elements associated with person-centred dementia care, including interactions with stakeholders and research mandates. One essential element identified was advanced therapies, containing non-pharmacological interventions, such as creative arts-based interventions.

Objective: This thesis investigates the impact of creative arts-based interventions on individuals with dementia, living in residential care through a scoping review (ScR) and a mixed-methods systematic review (MMSR).

Methods: The ScR surveyed the current literature base to identify which creative arts-based interventions improved the personhood, quality of life and well-being of persons with dementia (PwD); five studies were included. The MMSR explored the impact of dance interventions on the symptoms of dementia on persons with Alzheimer's disease and related dementias, as dance was unrepresented in the ScR; three studies were included. Both reviews were narratively synthesized due to the heterogeneity in the results.

Results: Each included study spoke of the impact the creative arts had on the PwD and which element(s) of their health improved. Results also showed that the creative arts were beneficial for the personhood of the PwD (ScR) and for decreasing symptoms while promoting the person (MMSR).

Conclusion: We must continue to look past the condition and recognize that creativity, psychosocial needs, and creative arts are all interconnected in promoting the personhood of PwD. Creative arts-based interventions can be designed to promote the individual creativity of the person and showcase their intact abilities.

Keywords: dementia care, creative arts, QOL, personhood, person-centred care, strategic planning

Résumé

Contexte : L'agence de la santé publique du Canada a publié un document stratégique reconnaissant les éléments associés aux soins de la démence centrés sur la personne, y compris les interactions avec les intervenants et les mandats de recherche. Les thérapies avancées sont un élément essentiel identifié contenant des interventions non pharmacologiques, telles que les interventions basées sur les arts créatifs.

Objectif : Cette thèse étudie l'impact des interventions fondées sur les arts créatifs sur les personnes avec la démence, vivant dans des soins résidentiels, par le biais d'une revue exploratoire et d'une revue systématique à méthodes mixtes.

Méthodes : La revue exploratoire a examiné la base de littérature actuelle afin de déterminer quelles interventions fondées sur les arts créatifs ont amélioré l'identité individuelle, la qualité de vie et le bien-être des personnes avec la démence; cinq études ont été incluses. La revue systématique à méthodes mixtes a exploré l'impact des interventions de danse sur les symptômes de la démence chez les personnes avec la maladie d'Alzheimer et d'autres démences associées alors que la danse n'était pas représentée dans la revue exploratoire; trois études ont été incluses. Les deux revues ont été synthétisées de manière narrative en raison de l'hétérogénéité des résultats.

Résultats : Chaque étude incluse a discuté l'impact des arts créatifs sur les personnes avec la démence et des éléments de leur santé qui se sont améliorés. Les résultats ont également montré que les arts créatifs étaient bénéfiques pour l'identité individuelle des personnes avec la démence (la revue exploratoire) et pour diminuer les symptômes tout en favorisant la personne (la revue systématique à méthodes mixtes).

Conclusion : Nous devons continuer à regarder au-delà de la condition et à reconnaitre que la créativité, les besoins psychosociaux et les arts créatifs sont tous interconnectés dans la promotion de l’identité individuelle des personnes avec la démence. Les interventions basées sur les arts créatifs peuvent être conçues pour promouvoir la créativité individuelle de la personne et mettre en valeur ses capacités intactes.

Mots clés : soins de la démence, arts créatifs, qualité de vie, l’identité individuelle, soins centres sur la personne, planification stratégique

List of Acronyms and Abbreviations

PwD	People/person(s) with dementia
ADRD	Alzheimer's Disease and related dementias
AD, VaD, FTD, LBD, PDD	Alzheimer's Disease, Vascular Dementia, Frontotemporal Dementia, Lewy Body Dementia, Parkinson's Disease Dementia
MSP	Malignant Social Psychology
PRVHC	Perley & Rideau Veteran's Health Centre
ScR	Scoping Review
MMSR	Mixed-Methods Systematic Review
cABT	Creative arts-based therapies
GCCWBOT	Greater Cincinnati Chapter Well-Being Observation Tool
OMA, AMT, CRS, NOC, NOA	Opening Minds through Art, Art/Music Therapy, Creative Regular Staff, Non-Creative, No-Activity
MIM	Memories in Making
CMAI	Cohen-Mansfield Agitation Inventory
RCT(s)	Randomized Controlled Trial(s)
BPSD	Behavioural and psychological symptoms of dementia
ROB	Risk of Bias
AAT	Alternative Assistive Technologies
ID	Interdisciplinary
QOL	Quality of Life

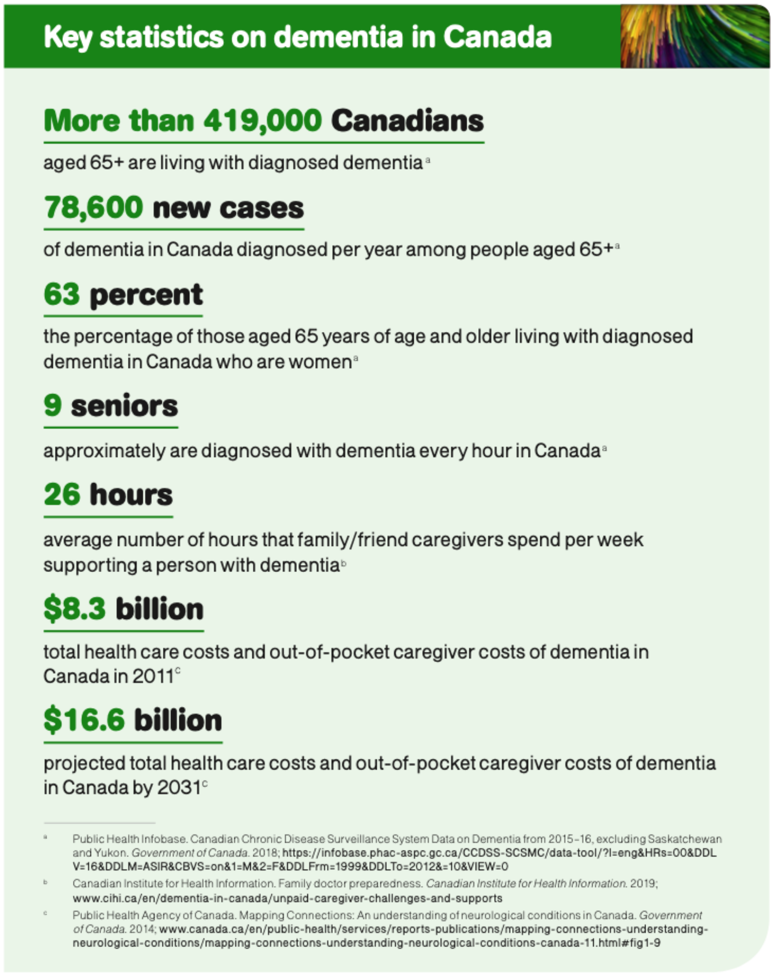
TABLE OF CONTENTS

Chapter 1: Introduction

The Public Health Agency of Canada in 2019 developed *A Dementia Strategy for Canada: Together We Aspire.* This strategy document provided a “focused vision and direction for advancing dementia prevention, care and support in Canada” (Public Health Agency of Canada, 2019, p.1). The strategic plan also involved the three tiers of the government (federal, provincial and territorial, and local government), other organizations, and individuals involved in the care of people with dementia.

Each chapter of the strategy document—seven in total—is dedicated to recognizing the path in bettering the care for persons with dementia, preventing dementia, establishing advance therapies and finding a cure, improving the quality of life (QOL), identifying the pillars involved in effective implementation of the national strategy for dementia, adopting a driven focus on the higher risk and equitable care, and moving towards implementation (Public Health Agency of Canada, 2019).

As it stands, over 400, 000 Canadians sixty-five and older are living with diagnosed dementia and numbers eclipsing fifty million people worldwide (Public Health Agency of Canada, 2019). Health care and out-of-pocket caregiver costs will be close to $16.6 billion by 2031 (Public Health Agency of Canada, 2019). In addition, considering the increase in baby-boomers and the number of new cases (~78 000 per year) in Canada, (Public Health Agency of Canada, 2019), the monumental strain on the health care, people with dementia, and their caregivers will be immensely draining. *Figure One* contain key statistics from the Public Health Agency of Canada (2019, p. 3).



Key statistics on dementia in Canada

More than 419,000 Canadians

aged 65+ are living with diagnosed dementia[a]

78,600 new cases

of dementia in Canada diagnosed per year among people aged 65+[a]

63 percent

the percentage of those aged 65 years of age and older living with diagnosed dementia in Canada who are women[a]

9 seniors

approximately are diagnosed with dementia every hour in Canada[a]

26 hours

average number of hours that family/friend caregivers spend per week supporting a person with dementia[b]

$8.3 billion

total health care costs and out-of-pocket caregiver costs of dementia in Canada in 2011[c]

$16.6 billion

projected total health care costs and out-of-pocket caregiver costs of dementia in Canada by 2031[c]

[a] Public Health Infobase. Canadian Chronic Disease Surveillance System Data on Dementia from 2015–16, excluding Saskatchewan and Yukon. *Government of Canada.* 2018; https://infobase.phac-aspc.gc.ca/CCDSS-SCSMC/data-tool/?l=eng&HRs=00&DDLV=16&DDLM=ASIR&CBVS=on&1=M&2=F&DDLFrm=1999&DDLTo=2012&=10&VIEW=0

[b] Canadian Institute for Health Information. Family doctor preparedness. *Canadian Institute for Health Information.* 2019; www.cihi.ca/en/dementia-in-canada/unpaid-caregiver-challenges-and-supports

[c] Public Health Agency of Canada. Mapping Connections: An understanding of neurological conditions in Canada. *Government of Canada.* 2014; www.canada.ca/en/public-health/services/reports-publications/mapping-connections-understanding-neurological-conditions/mapping-connections-understanding-neurological-conditions-canada-11.html#fig1-9

Figure One. Key Statistics on dementia in Canada. Image taken from the Public Health Agency of Canada's 2019 document titled *A Dementia Strategy for Canada: Together We Aspire* (p. 3).

One can extrapolate that Canada has a direction for the care of persons with dementia and their caregivers as QOL[1], respect and value diversity[2], human rights[3], evidence-informed[4], and results-focused[5] principles are echoed throughout the Public Health Agency of Canada's 2019 document.

Details of each principle (Public Health Agency of Canada, 2019):

[1] living well, access to quality care and supports, and supportive communities

[2] inclusive, distinct indigenous needs, community involvement, and most at risk

[3] human rights lens, inclusion, respects choices, inclusive of voices, and includes caregiver perspectives

[4] best evidence, all forms of knowledge, working together, and informed decision-making

[5] initiatives support reporting, enabling evaluation, measurement, accountability and flexibility to evolve

Effective plans and strategies are therefore needed to establish a plan to decrease stigmatization or social isolation of persons with dementia. The illness/disease is a factor that makes up a minuscule portion of the person. The individual with dementia, in their own right, are still a person with needs and preferences (van der Roest et al., 2007) that can often be overlooked.

Areas of focus in sections 3.2-3.5 of the document (Public Health Agency of Canada, 2019, pp. 23-28) pertain to advancing therapies and even finding a cure for dementia—at least that is the hope of research moving forward. With this in mind, the increased need for dementia research and developing innovative and effective therapeutic approaches are highly important, especially when:

> more can be done to turn research findings on therapies for people living with dementia more quickly into relevant information that can be adapted and adopted in clinical, community and family settings. (Public Health Agency of Canada, 2019, p. 28)

One way of turning research findings into relevant information for the adaptation or adoption for practice is through the use of systematic or scoping reviews. These types of reviews allow for snapshots of the current academic literature (see Arksey & O'Malley, 2005; Page et al., 2020) to be communicated to key stakeholders, leaders, and persons with dementia in dementia care through interdisciplinary research. Reviews afford a glimpse into the gap in literature and perhaps direct researchers into conducting more studies involving persons with dementia. Additionally, current academics can quickly test research findings from reviews, to be used in real-world settings, thereby, allowing clinical or health practice to become aware and supportive of the research from a population health perspective.

Moreover, developing innovative and effective therapeutic approaches that expand on person-centred care rather than focus on the condition is significant for advancement in dementia care. Persons with dementia can:

> bring the perspective as ‘experts’ from their unique experience and knowledge gained through living with a condition or illness, as well as their experiences with treatments and the health care system. Involvement of [persons with dementia] in research increases its quality and, as health care providers utilize research evidence in their practice, increases the quality of care. (Canadian Institutes of Health Research, 2014, p. 6)

The ideology of person-centred care and Tom Kitwood’s personhood (1997 a, b) will be explored later in this chapter and in Chapter 3. Personhood is a foundation framework for this thesis, in combination with effective non-pharmacological interventions for persons with dementia.

Improving QOL remains a critical mandate in dementia care. Drug (pharmacological) therapies and non-drug (non-pharmacological) therapies have been tested on cognitive abilities, behaviour and psychological symptoms of dementia, and limiting the effects of dementia (Public Health Agency of Canada, 2019). However, limited progress on drug therapies demonstrates the need for effective non-drug therapies that have shown promising benefits in persons with dementia (Baird & Samson, 2015; Masopust et al., 2018; McDermott et al., 2013; Public Health Agency of Canada, 2019).

The next sections discuss three main concepts and one foundational framework. The three concepts are: dementia, residential care, and creative arts-based interventions. The framework of personhood is then presented.

1.1 Rationale

1.1.1 Dementia

Dementia is a neurological condition that impacts cognition, memory, thinking, reasoning, behaviours, and emotions (Alzheimer Society, 2016a; Baird & Samson, 2015; Cho, 2016). Further explorations on incidence and prevalence of Dementia are located in the introduction sections of both Chapters 3 and 4.

Alzheimer's Disease (AD) is the most common form of dementia accounting for nearly 60-70% of cases worldwide (World Health Organization, 2020). AD is characterized by the changes in the brain from amyloid plaques and neurofibrillary tangles (tau) which result in loss of neurons and obstructs electrical and chemical signaling that is important for communicating, metabolism, and repair throughout the body (Cho, 2016; National Institute on Aging, n.d. -a, b). Due to a breakage in communication, a person with AD loses their ability to remember, think, and to an extent, live independently (National Institute on Aging, n.d.-a). Eventually, during the final stages of AD, neuronal damage and death throughout the brain may cause brain atrophy (shrinkage), resulting in significant brain volume loss (National Institute on Aging, n.d. -b).

AD progresses in three stages: mild (early), moderate (middle), and advanced[6] (late). In all stages, various forms of impairment to memory, participation of daily life, and reliance on support services varies. For example, in the mild stage independent functioning still occurs, but memory lapses relating to location and familiar words may happen (Alzheimer's Association, n.d. -e). The moderate stage, the longest stage, the need for care increases and symptoms start to

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[6] After a conversation with the research coordinators at the Perley & Rideau Veteran's Health Centre in Ottawa (Manji, Irfan, personal communication, November 2018), they communicated that the word 'severe' negatively categorizes persons with dementia or AD. As a result, I am using the word 'advanced' over 'severe'. This allows for the use of dementia friendly language and is a must when speaking in regard to the target population. Use of language varies based on country of residence (see van der Vleuten et al., 2012 in Chapter 3).

become more pronounced (Alzheimer’s Association, n.d. -e). Expressions of thoughts and routine of daily tasks becomes difficult to do, however, persons living with AD can still participate in daily activities with assistance (Alzheimer’s Association, n.d. -e). Finally, in the advanced stage, responses to the environment (loss of awareness) and the ability to carry conversations changes; loss of control in movement can also occur, therefore, around the clock care is usually required (Alzheimer’s Association, n.d. -e).

Cause of AD, although not fully understood (LoGiudice, 2002; National Institute on Aging, n.d. -a), include risk factors such as age, family history, Down’s syndrome, head injury, lack of education, ethnicity, and the presence of the apolipoprotein E4 (LoGiudice, 2002). Apolipoprotein E4 is a gene that increases the risk of AD in late-onset AD (National Institute on Aging, n.d. -a). Early-onset AD, rarer than late-onset, can be caused by gene changes passed down from parent to child; however, researchers are working to identify other genetic risk variants (National Institute on Aging, n.d. -a).

Vascular Dementia (VaD) is considered the second most common form of dementia after AD accounting for 5-10% of cases worldwide (Cho, 2016). VaD is caused by cerebrovascular, cardiovascular, or other problems associated with inhibiting vascular function (Cho, 2016). Major blood vessels become blocked with VaD, which influences thinking skills (Alzheimer’s association, n.d. -f; Cho, 2016), less so memory losses which is more associated with AD (Cho, 2016). Further, once blood vessels are blocked, blood flow throughout the brain is reduced causing oxygen and nutrient deprivation (Alzheimer’s association, n.d. -f Alzheimer Society, 2016b). Stroke[7] is the most common cause of VaD (Alzheimer's association, n.d. -f; Alzheimer Society, 2016b; Cho, 2016; LoGiudice, 2002).

Lewy Body Dementia (LBD) accounts for 5-20% of cases (Alzheimer's Association, n.d. -b; Cho, 2016); 20% has been noted in Cho (2016) and LoGiudice (2002). In LBD, the individual has abnormal deposits in the protein alpha-synuclein (Alzheimer's Association, n.d. -b; National Institute on Aging, n.d. -c). Tangles and plaques are also seen in LBD, similar to AD (Alzheimer's Association, n.d. -b). Overall, LBD is characterized as a person having visual and auditory hallucinations, Parkinsonism, gait imbalance, and fluctuating cognition (Cho, 2016; LoGiudice, 2002).

Parkinson's Disease Dementia (PDD) is a decline in thinking and reasoning in people living with Parkinson's Disease for at least year (Alzheimer's Association, n.d. -c). Following brain changes caused by Parkinson's Disease, mental functions are affected, including memory, ability to pay attention, make judgements, and plan out tasks (Alzheimer's Association, n.d. -c). Similar to LBD, PDD also occurs due to abnormal deposits of the alpha-synuclein protein (Alzheimer's Association, n.d. -b, c). The alpha-synuclein protein's role in DNA repair is considered crucial in preventing cell death (Alzheimer's Association, n.d. -c).

Frontotemporal Dementia (FTD) is linked to nerve cell degeneration in the frontal and temporal brain lobes (Alzheimer's Association, n.d. -a; Cho, 2016). Ultimately, this leads to deterioration in behaviour, personality, and/or producing incomprehensive language (Alzheimer's Association, n.d. -a). Frontotemporal degenerations can be caused by either a group of brain disorders involving the tau protein or the TDP43 protein (Alzheimer's Association, n.d.

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[7] If you see signs of a Stroke, use FAST (Face, Arms, Speech, Time). Ask questions: Is the face drooping? Can you raise both arms? Is your speech slurred/jumbled? Call 9-1-1 right away if you see the signs (Alzheimer Society, 2016b, p. 3).

-a). This form of dementia occurs in individuals aged 45-65 years old and is considered to be inherited from a first-degree relative (Alzheimer's Association, n.d. -a; Cho, 2016).

1.1.2 Residential Care

Residential care facilities (i.e., care facilities with an inpatient population) are the choice of setting in the entirety of this thesis. Particularly, prior to COVID-19, my intention was to work at the Perley & Rideau Veteran's Health Centre (PRVHC) in Ottawa to develop a gaming platform that incorporated the lived experiences of persons with dementia. The gaming platform was positioned to improve usability and engagement via assistive technologies. Unfortunately, the original thesis project was cancelled during the pandemic, but as a pivot, I continued down the path of residential care and ventured forward into the scope of creative arts and the interventions that came with it. This spoke in volumes with my undergraduate[8] background. Residential care is expanded on in Chapters 3 and 4.

1.1.3 Creative Arts-Based Interventions/Therapies

Creative arts-based interventions, therapies, and sometimes referred to as activities (see Lokon et al., 2019), are creative methods used to engage persons with dementia through non-pharmacological extra-circular modalities. These modalities are usually aimed to manage symptoms and behaviours or cognitive function (Cerejeira et al., 2012; Guseva, 2019), improve well-being and/or QOL (Burnside et al., 2017; Cohen-Mansfield et al., 2011; van Dijk et al., 2012), or target an improvement in overall health (Zeilig et al., 2014).

Sometimes, creative interventions can be categorized as cognitive/emotion-oriented, sensory stimulating, behaviour management, and 'other' psychosocial interventions (Cerejeira et

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[8] Undergraduate degree: Bachelor of Science with Honours Specialization in Health Sciences and a minor in Theatre.

al., 2012; O'Neil et al., 2011). Common forms of creative arts include art creation, dance, music and theatre/drama (Demarin et al., 2016; Megranahan & Lynskey, 2018; O'Neil et al., 2011; Social Care Institute for Excellence, 2020). Chapter 3 considers these interventions and creativity in dementia.

1.1.4 Personhood and Psychosocial Needs

The Public Health Agency of Canada (2019) admits that options for evidence-informed therapies remain limited and majority of the time, research is not person-centred. Person-centred care by definition is built around the needs of the individual and is dependent upon the person's interpersonal relationships (Fazio et al., 2018). It also challenges the traditional medical model that focus more on processes, schedules, staff, and organizational needs (Fazio et al., 2018). Further, person-centred care approaches dementia care by distinguishing between the medical and behavioural mindset and instead, aimed to expand on communication and relationships (Fazio et al., 2018).

One way to approach person-centred care research is through the lens provided by Tom Kitwood's personhood[9]. Kitwood, the pioneer for personhood, identified the importance of care for persons with dementia. He challenged the normative imbalances that were highly focused on the biomedical approaches associated with 'treating' the effects of dementia. Through his readings (see Kitwood 1997a, b), we learn the meaning behind looking past the illness and to envision the person as their own entity capable of more than the defined aspects of their condition (Kitwood, 1997a, b). The very existence of autonomy and self-love (inclusive of self-worth, self-esteem, self-empowerment), remain intact even as the person's severity of illness progresses. In fact, the idea of love is centred around the tenets of psychosocial needs, which

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[9] Personhood will be defined in Chapter 3.

Kitwood names as comfort, attachment, inclusion, identify, and occupation (Kitwood, 1997b). According to Kitwood (1997b) the psychosocial needs are:

> present in all human beings, they are more generally evident in people who are losing their mental powers. Those in this predicament are far more vulnerable and generally less well stabilized by psychological defences; also they are less able to take the initiatives that would lead to their needs being met. The pattern of need that is shown will vary according to personality, and often the intensity of the needs increases with the advance of cognitive impairment. (p. 19)

Unmet needs are obvious in people with dementia who are more vulnerable and less likely to take initiatives that would lead to their needs being met; needs vary from person to person and must be fully brought into the area of moral concern (Kitwood, 1997a). Needs are also addressed as desires that contain cultural meanings and values for the individual (Kitwood, 1997a). As well, the subjective nature of personal well-being (Oberg, 2013) should continue to be a critical standard of practice when implementing studies involving persons with dementia and should be fully cognizant of their psychosocial needs.

Furthermore, Oberg (2013) points out that the chain of ideas central to person-centred care and maintaining personhood, may also be dependent on fostering verbal and non-verbal communicated relationships. By this standard, research that follows the path of personhood would very well be accustomed to relationships between participants, researchers, care staff, therapists, and family. Ideally, warranting relationships to be weighted with significance when considering person-centred care in future studies and policies.

The relationships mentioned in the prior paragraph play an immense role in the care for persons with dementia. Disparities in these relationships may give rise to a concept known as malignant social psychology (MSP). MSP arises when people with dementia are not acknowledged or are invisible in society which challenges their personhood. MSP is a term used by Tom Kitwood to describe a range of behaviours that undermines people with dementia’s personhood and well-being (Mitchell & Agnelli, 2015). MSP is not usually considered to be of malicious intent from nurses, family, and members of the public (Mitchell & Agnelli, 2015), but these tendencies are mostly cultural inheritance and can be seen in the behaviours of others towards persons with dementia (Kitwood, 1997a). A list of elements that make up MSP are on pages 46-47 in Kitwood (1997a).

Last, Kitwood (1997a) envisioned dementia to, “no longer be person-with-DEMENTIA, but PERSON-with-dementia” (p. 7). Simply meaning that the person should have far greater importance than the condition, which can often be overlooked due to MSP or when psychosocial needs are left unmet.

1.2 Thesis Purpose Statement

The purpose of this thesis was to survey the literature through reviews, to generate conclusions on which creative arts-based interventions or therapies (used interchangeably) are designed for the health and care of people/person(s) with dementia (PwD). Further, the thesis aimed to understand the impact the creative arts had on the target population. PwD from here on out, will be inclusive of all types of dementia, and in Chapter 4 PwD are referred to as persons with Alzheimer’s Disease and related dementias (ADRD). I asked the following research questions:

1) Which creative arts-based therapies focus on the personhood of PwD and also, place significance on improving personhood, QOL and well-being for those living in residential facilities? (scoping review)
2) In persons with ADRD living in residential care facilities, what impact do dance interventions have on the symptoms of dementia? (mixed-methods systematic review)

Each research question guided the reviews included in this thesis, in Chapters 3 and 4. The second research question in particular was generated due to a gap found after the completion of the first review in Chapter 3.

1.3 Thesis Structure

This thesis is structured into six chapters and follows a thesis by article approach. Chapter 1 covers the rationale, concepts, and framework that contextualize the thesis. Chapter 2 overviews the current review literature and addresses next steps for future reviews. Chapter 3 (article one) consists of a scoping review based on the premise of personhood through creative arts-based therapies. Chapter 4 (article two) involves a mixed-methods systematic review that builds off a gap from the included studies of article one in Chapter 3. Chapter 5 presents an integrated discussion of the findings from Chapters 3 and 4, followed by the implications, limitations, barriers and conclusions in Chapter 6. Following the chapters, the remaining sections include the references and appendices.

Chapter 2: Existing reviews in the Creative Arts

2.1 Previously Published Reviews

Prior to executing the scoping review (Chapter 3) and mixed-methods systematic review (Chapter 4), it was important to understand and gather the current literature of reviews to better position this thesis. Especially, when developing new ideas in the context of creative arts-based interventions and people/person(s)with dementia (PwD). Search terms such as those in *Table One* were executed in databases Pubmed, SCOPUS, and Medline before starting the two review articles. Had this step not been undertaken, a possibility of duplicated and redundant work might have been processed, thereby adding nothing significant to the current research base. Review articles from the past decade (2010-2020) were identified from the searches.

Table One. *Search Strategy in Pubmed for Creative Art reviews.*

Therapy**	**Population**	**Review Type**
art therapy	dementia OR Alzheimer*	systematic OR scoping OR rapid OR realist

**Other synonyms searched were: theatre or drama, music*, and dance*.

After examining the title and abstracts, the next step was to identify those studies that were focused on the PwD and those which provided creative arts-based therapies to the person. *Figure Two* shows a breakdown of twenty-two review articles and the percentage denoted for each type of creative arts therapy. Significant numbers of creative art reviews have been done in the last ten years with 41% of review articles. Reviews which focused on visual arts (Chancellor et al., 2014), participatory arts (Cavalcanti Barroso et al., 2020; Ward et al., 2020; Zeilig et al., 2014), and those that classified the creative arts under the umbrella term of art therapy (Beard,

2011) or nonpharmacological interventions (Brown Wilson et al., 2019) were categorized under art type review articles.

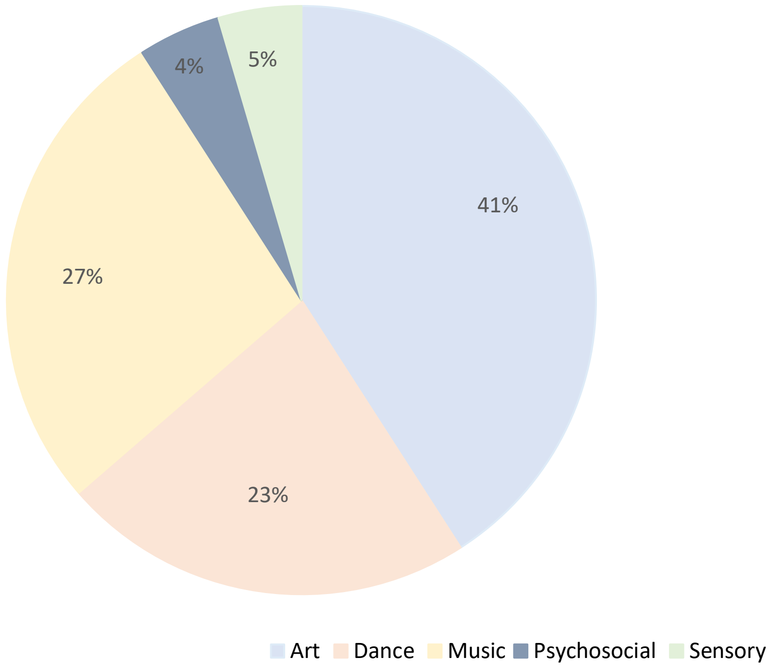

Figure Two. Previous Reviews on Creative Arts-based interventions. A total of twenty-two reviews were extracted from Pubmed, SCOPUS, and Medline databases over the past decade.

Music and Dance yielded 27% and 23% of the review articles, respectively. Psychosocial and sensory interventions were seen as 4% and 5%, respectively. No review articles outright had developed a theatre or drama related review. This thesis was on a different trajectory and was unable to further investigate in the realm of theatre or drama related reviews.

Once the twenty-two articles were identified, they were then summarized, and data was extracted from the articles to ascertain the gaps and to find areas to build on. *Table Two* contains essential data points from each of the review articles. Data extraction items such as, study details, setting, population, research aims, eligibility criteria in the reviews, number of included studies, and key findings were included in this table.

Through the reviews, interventions for the PwD were mostly related to symptomatic changes (Aleixo et al., 2017; Brown Wilson et al., 2019; Clare & Camic, 2019; Cowl & Gaugler, 2014; Dowson et al., 2019; Karkou & Meekums, 2017; van der Steen et al., 2018), isolated for only randomized controlled trials (Blackburn & Bradshaw, 2014; Brown Wilson et al., 2019; Deshmukh et al., 2018; Karkou & Meekums, 2017; van der Steen et al., 2018), looked at more than one setting (Alexio et al., 2017; Chatterton et al., 2010; Clare & Camic, 2019; Deshmukh et al., 2018; van der Steen et al., 2018), did not clearly state setting (Beard, 2011; Cavalcanti Barroso et al., 2020; Chancellor, et al., 2014; Cowl & Gaugler, 2014; Dowson et al., 2019; Jiménez et al., 2019; Klimova et al., 2017; Mabire et al., 2019; Ruiz-Muelle & López-Rodríguez, 2019; Salisbury et al., 2011; Zeilig et al., 2014), and/or gave more emphasis to the caregivers, staff, or therapists involved (Chatterton et al., 2010; Smith & D'Amico, 2020). Some reviews returned low results which could be explained by a narrow search strategy or due to the paucity of available research.

Some reviews suggested that creative arts interventions are positive interventions that can help people with dementia in various facets of their life. However, the low amount of health or well-being oriented studies (Dowson et al., 2019; Ward et al., 2020; Zeilig et al., 2014) show that even though we are moving towards a holistic approach with the creative arts, the state of the literature remains steadfast on the various symptoms and behavioural disturbances that are associated with dementia, instead of focusing on the needs of the person.

Table Two. Previous Review Works on Creatives Arts-based Interventions for People with Dementia summarized.

Art

Study	Setting	Population	Research Aims	Eligibility	Included Studies	Key Findings
Beard (2011)	Not stated	Alzheimer’s disease	This review aimed to critique evidence base of art therapies including music, visual arts, drama, and dance/movement. The author asked four research questions: 1. What is the focus of the empirical base on using AT with persons who have DAT? 2. (How) have these studies been designed and evaluated? 3. What findings are reported? 4. What does this tell us about the potential of AT for enriching the lives of people with dementia?	Inclusion: • evidence base of art therapies (music, visual arts, drama, dance/movement) from 1990 to 2010	Unclear	Empirical weakness: unclear study designs, activity descriptions, methods used; poorly identified or unspecified; too much emphasis on clinical outcomes; a lack of systematic analysis of data. Omissions within dementia-specific work: lack of accounts self- reports; lack of tailored therapies to persons in the early stages versus late-stage; imbalanced attention between persons living at home versus nursing facilities; product focused versus process focused or quality of life focused.
Brown Wilson et al. (2019)	Nursing Home	Dementia	This review aimed to assess the effectiveness of nonpharmacological interventions used in reducing anxiety symptoms. The authors asked: 1. Are nonpharmacological interventions effective in reducing anxiety symptoms in older adults with comorbid dementia?	Inclusion: • older people with dementia, Parkinson’s disease with dementia • residential aged care, Assisted living, specialist dementia unit • psychotherapeutic intervention • randomized control trials • use of a validated tool that measures anxiety • English only Exclusion: • people without dementia, people with mild cognitive impairment, • caregivers	13	Few studies looked at anxiety as the primary outcome; some studies considered anxiety as part of the construct for mood, or behaviour and psychological symptoms of dementia. Anxiety was only a primary outcome in studies focused on a music intervention. Music therapy was the most consistent approach in reducing anxiety (six out of thirteen included articles).

			2. If so, which nonpharmacological interventions demonstrate the greatest effectiveness in reducing anxiety symptoms in older adults with comorbid dementia?	• other mental health issues • population-based studies • home care, primary care, memory clinic, Inpatient or outpatient of a hospital, Community-dwelling • drug intervention • individual case studies/case reports • prevalence studies • case–control studies, Randomized control trial protocol, Narrative reviews or systematic reviews, Opinion pieces or commentary • global or subjective assessment of anxiety • cognitive assessment only		
Cavalcanti Barroso et al. (2020)	Not stated	Dementia	Report and summarize on the effects of visual participatory arts activities in dementia research. Evidence included quantitative, qualitative, and mixed-methods study designs.	Inclusion: • Art should be created by the person and not just observed or discussed • Empirical evidence using quantitative, qualitative, and mixed-methods designs • People living with dementia and participatory art interventions, peer-reviewing (in English), and publications before Jan 2019 Exclusion: • Research without participants with dementia or related cognitive disorders, other interventions not visual arts related • cases studies/dissertations/conference papers	20	Participatory visual arts have a positive effect on cognition, social, and psychological functioning of people with dementia. Although, the heterogeneity of the studies provided an inconsistent evidence of an overall positive effect. Participants thought interventions were enjoyed and engaging. Included studies were classified into the following outcome areas: program evaluation, psychological aspects, well-being, and social aspects.
Chancellor, et al. (2014)	Not stated	Alzheimer’s Disease and other dementias	The authors explored art therapy’s usefulness in dementia.	Inclusion: • years 1980 to 2013 • visual art therapy	16	Proposed a three-level framework on art therapy for persons with dementia: art therapy relies on preserved abilities and not on correcting disabilities; allows for emotional expression, especially when verbal communication is a difficulty; visual art opens a state of ‘flow’, potentially enhancing well-being.
Cowl & Gaugler (2014)	Not stated	Alzheimer’s Disease and Dementia	The goal of this review is to determine the efficacy and benefits of arts	Inclusion: • in English	112	Data was split into quantitative and qualitative works.

			therapies (visual arts, music, drama, dance movement, song writing, and poetry) for persons with Alzheimer’s disease and dementia.	• creative arts therapy as at least one of the interventions • participants with Alzheimer’s Disease/dementia Exclusion: • unspecified participants for whom outcomes were measured or developed • not specified with Alzheimer’s disease or dementia • not original work • described changes or characteristics of individuals’ artwork as their disease progressed without describing the therapeutic benefits of art participation for the individual		Twelve out of fourteen randomized control trials provided that creative art therapies are potentially effective. The three categories of outcomes (cognitive, behavioural, and emotional) varied in capacity to improve symptoms in participants.
Deshmukh, et al. (2018)	Community or any form of institutional care	Dementia	Aimed to review the effects of art therapy as an adjunctive treatment for dementia compared to standard care and other non-pharmacological interventions.	Inclusion: • randomized controlled trials • participants with a formal diagnosis of dementia • intervention was to be a minimum of five sessions	2	Limited information on the effectiveness of art therapy due to the small number of studies included.
Salisbury et al. (2011)	Not stated	Dementia	Scoping review aims to identify published and grey literature relating to art therapy program effectiveness, review and summarize research evidence, and identify gaps in the research.	Inclusion: • peer reviewed • in English • available in March 2010 • grey reports	42	Themes seen: promoting well-being, reducing isolation, positive effects and cost savings, arts appreciation, self-expression, Art therapy, Rewarding the brain, and Preventing cognitive decline Benefits seen were: an increase in quality of life and well-being, improved communication (non-verbal and verbal), reminiscence opportunities, and encouraging meaningful conversation, sense of self was regained, and helped carers gain an insight into the experiences of those they care for.
Ward et al. (2020)	Community	People with dementia	This review had the following objectives: • offer a descriptive overview of the different participatory arts	Inclusion: • people living with early to moderate stages of dementia in the community • carers or partners of people living with early or mid-stage dementia. • participatory arts-based interventions (singing, playing, and making music,	26	Three key areas of interest: *The Individual; The Group*; and *Space, Place and Objects*. The individual focused on: person-centered and personalized activities, participation, and communication, "In

			• consider holistic benefits of participatory arts by exploring: the role of the “individual”, “group”, and the role of space, place, and objects.	dancing and movement, drama and theatre, storytelling, creative writing, or visual arts) • outcome measures (effectiveness, participation, or health and wellbeing) • research designs including quantitative, qualitative, or mixed methods • in English • publication date between 2008 and 2019. Exclusion: • advanced dementia • residential care settings, hospitals, and hospices • therapy or clinical based • One-to-one interventions not in a group setting. • Invasive/biological testing or measurements using blood sample, x-rays, or scans. • other formats of publication (book reviews, commentaries, literature reviews and meta-analyses, dissertations, or theses)		the moment" (allowed participants to freely use their imaginations to reconnect and make sense of the fragments that remain as aspects in person), attention and cognitive stimulation. The group found importance on social cohesion and togetherness and in new and existing relationships. Space, place, and objects underlined the benefits in semi-public spaces where there are less distractions, compared to a residential home, and provided a sense of societal contribution.
Zeilig et al. (2014)	Not stated	Dementia and Alzheimer’s Disease	To strengthen the knowledge surrounding the efficacy of art-based approaches for persons with dementia and to investigate the question: 1. What is the value of arts and culture for people living with a dementia?	Inclusion: • reference to creative activities that involved persons with dementia • role of museums and/or art galleries • participatory arts activities that aim to enhance well-being or quality of life • participatory arts activities that focused on aesthetic appreciation • activities that did not include therapies of any kind • systematic data/meta-analyses about the value of the arts for older people, including one Cochrane Review on music therapy for PWD	63	Participatory arts contribute positively to persons with dementia, including improving communication, encouraging residual creative abilities, new learning, enhancing cognitive function, increasing confidence/self-esteem/social participation, and sense of freedom in creation. Arts act as a way to uncover and communicate with the inner worlds of the persons with dementia.

Dance

Study	Setting	Population	Research Aims	Eligibility	Included Studies	Key Findings
Jiménez et al. (2019)	Not stated	Adults aged 60 and older with a mental health disorder	The aim of this systematic review was to identify and appraise studies on dance movement therapy interventions with adults aged over 60, who have mental health disorders.	Inclusion: • people from 60 years of age with mental disorders • dance movement therapy • studies that reported patient relevant parameters and patient relevant data • published empirical studies (quantitative and qualitative) or systematic reviews. • in English, French, German, or Spanish Exclusion: • studies that evaluated dance inventions without involvement of a qualified dance movement therapist • studies on expert opinions, literature reviews which were not systematically conducted • grey literature	16	Majority of studies were of older people with dementia; one study focused on depression.
Karkou & Meekums (2017)	No restrictions	People with dementia	The authors aimed to assess the effects of dance movement therapy on behavioural, social, cognitive, and emotional symptoms of people with dementia in comparison to no treatment, standard care, or any other treatment. They also aimed to compare different forms of dance movement therapy.	Inclusion: • randomized controlled trials • people with dementia – no age or setting restrictions • any language • dance movement therapy delivered by a therapy practitioner with formal training • included both group, individual, and family/couple dance movement therapy	0	Zero studies were included. The authors believed that relevant trials may exist in the grey literature. Possibility exists that dance movement therapy is defined differently in each country based on history, legal frameworks, and training.
Klimova et al. (2017)	Not stated	People with dementia	The purpose of this study is to explore the efficacy of dancing on people with dementia, as well as listing the benefits and limitations of dancing therapy for this population.	Inclusion: • explored sources of clinical trials, qualitative descriptive studies, review studies • reports written exclusively in English • focused on the issues of dancing therapy with respect to dementia • years of 2010 up to 2015	6	Benefits of dancing include: improved physical state, cognitive functions, physiological health, social interaction, autonomy, quality of life, a type of non-invasive treatment, lower costs, and delay of institutional care, reduces caregivers’ burden

						Limitations of dancing include: lacks randomized clinical trials, small sample sizes, short-term trials, non-pharmacological therapies are shown to be more effective for middle-aged health individuals
Mabire et al. (2019)	Not Stated	Dementia	This review aimed to a) analyze studies on dance interventions for people with dementia and b) identify practice recommendations for the development of these interventions.	Inclusion: • any study design that used dance interventions for people with dementia • dance interventions can be combined with other interventions if dance was the main intervention	14	Four categories of processes (physical, cognitive, psychological, and social) were seen in the studies. None of the included studies compared the effectiveness of different styles of dance. See table 4 in Mabire et al. (2019) for list of practice recommendations.
Ruiz-Muelle & López-Rodríguez (2019)	Not stated	Alzheimer's Disease	The purpose of this study is to review the current literature identifying clinical trials that explore the effects of dancing on psychological and physical outcomes, functionality, cognitive function, and quality of life in patients diagnosed with Alzheimer's disease. Additionally, the review wishes to assess the quality of studies that perform dance therapy.	Inclusion: • pilot or clinical trials • effect of dancing on people with Alzheimer's disease • in English, French, Portuguese, Italian or Spanish • no age, gender, or stage of illness restrictions • published from July 2000	12	The type of dancing intervention impacts the person different (e.g., Waltz versus elder clown) Frequency and duration of dancing intervention varied. Outcomes including physical outcomes, functionality, cognitive function, psychological outcomes, quality of life, burden of care, and other outcomes (language, ethnic interaction, and ethnic identity), influenced persons with Alzheimer's disease differently.

Music

Study	Setting	Population	Research Aims	Eligibility	Included Studies	Key Findings
Aleixo et al. (2017)	Nursing or residential homes; in treatment in-day	Dementia, Alzheimer's Disease, Vascular Dementia,	Assessed the efficacy of Music Therapy in the neuropsychiatric	Inclusion: • Alzheimer's Disease, Vascular Dementia, mixed or frontotemporal dementia, in all stages of severity.	12	Studies indicated the efficacy of music therapy on the decline of delusions, agitation, anxiety, apathy, irritability, aberrant motor activity, night-time

	center, tertiary hospital and hospice program	mixed dementia with mild-severe severity	symptoms of people with dementia.	- cross-sectional or longitudinal studies, randomized or nonrandomized, with or without a control group The studies were categorized according to its efficacy on the neuropsychiatric symptoms. Exclusion: - with no casuistic, clinical trials about pharmacologic interventions - studies about MT among people with other pathologies or children, young adults or elderly people without dementia - studies developed in mental health institutions, - use of music or other non-pharmacological interventions only with caregivers		disturbances, other neuropsychiatric symptom, behaviour, and depression. Cognitive functioning improved. Various assessments tools were used to assess neuropsychiatric symptoms. Studies used active group, active individual, receptive group, and receptive individual Music Therapy interventions.
Blackburn, & Bradshaw (2014)	Residential Care	Dementia/Alzheimer's Disease	Identify if Music Therapy is beneficial for use with dementia patients.	Inclusion: - randomized controlled trials - participants diagnosed with dementia as defined by the Mini-Mental State Examination or equivalent diagnostic rating scale - conducted in residential care Exclusion: non-English-language publications.	6	Two studies utilized passive MT techniques. Four studies used active MT interventions. Methodological quality may be considered a weakness. However, findings suggest that Music Therapy *may* reduce depression, anxiety, agitation, and improved cognitive functioning and quality of life.
Chatterton et al. (2010)	Residential care facility and at home	Caregivers, Music Therapists, Persons with Dementia	This review sought to investigate who sings to people with dementia and with what objectives and effects to answer: which is more effective, the singer or the singing? Sub-questions were: who sings individually with PWDs? What were their objectives and effects?	Inclusion: - one-to-one singing interactions with a people with dementia using only live singing, not recorded music - in English - full texts Exclusion: - review articles - if singing was undertaken in a situation other than individual person-to-person	16	It was noted that caregivers' primary objective using singing was to improve the quality of life. Whereas music therapists sought to address cognitive, behavioural, physiological, and social factors through one-to-one singing. More weight fell on the singing versus the singer based on the included studies. However, singing interventions depend on both the

				• articles describing an individual PWD singing or being sung to while part of a group were not included		goals of the singers and perceptions of the persons with dementia.
Clare & Camic (2019).	Residential and Community	Dementia	Research questions: 1. What impact does group music intervention, with active participation, have on: cognitive function, behavioural or psychological symptoms, physiological responses, quality of life and communication? 2. Is there a difference in impact on these outcomes according to whether live or recorded music is used?	Inclusion: • group music • intervention focused on music rather than related interventions such as singing on its own • the intervention involved an opportunity for active participation using instruments • participants were people with any type of dementia • peer reviewed works in English	15	Positive impact seen on behavioural and psychological 201, quality of life, communication, and some aspects of cognitive function. The use of recorded music resulted in more positive behavioural and psychological outcomes. Interventions using live music reported a benefit to communication and relationships.
Dowson et al. (2019)	Not Stated	Various types of Dementia with a range of severity	The aim of this paper was to provide a detailed picture of music and dementia published since 1980, including important contextual data about study design, sample size, types of dementia and where music interventions take place.	Inclusion: • English, peer-reviewed between 1980-2018 • research with people with dementia • use of live or recorded music intervention where the goal is to promote health and/or well-being • music intervention paired with another intervention can be included only if musical component was distinguishable • if studies used participants with and without dementia, results were included for persons with dementia Exclusion: • other types of articles were excluded if they were not clear on participants or intervention	163	Evaluated domains included music-related responses, quality of life, neuropsychiatric symptoms, cognitive function, and physiological changes (see Figure 2 in Dowson et al., 2019). Findings show that neuropsychiatric symptoms have been prioritized in music and dementia research, however music has the potential to support and strengthen relationships, provide 'in the moment' experiences, and the meet the psychosocial needs of people with dementia.
van der Steen et al. (2018)	Nursing homes, residential homes and hospital wards	Persons with dementia included according to Diagnostic and Statistical Manual of	The review aimed to assess the effects of music-based therapeutic interventions on the	Inclusion: • randomized controlled trials of music-based therapeutic interventions (at least five sessions)	22	Providing at least five sessions of music-based therapeutic intervention probably reduces depressive symptoms

		Mental Disorders-IV, International Classification of Diseases-10, or other accepted diagnostic criteria	emotional well-being, quality of life, mood disturbance or negative affect, behavioural problems, social behaviour, and cognition for persons with dementia at the end of therapy and four or more weeks after the end of treatment	• measured outcomes of interest (van der Steen et al., 2018, pp. 7-8) • control groups either received usual care or other activities with or without music • diverse settings, all severities of dementia, and no age restrictions • active or receptive music interventions delivered in groups or to individuals • music intervention met *at least* two of the following criteria/indicators: 1. therapeutic objective which may include communication, relationships, learning, expression, mobilization, and other relevant therapeutic objectives; 2. music matches individual preferences; 3. active participation of the people with dementia using musical instruments or singing; 4. participants had a clinical indication for the intervention or were referred for the intervention by a clinician. • music should be a main element of the intervention • control groups could receive activities in which music was used, but they could not receive any music-based therapeutic intervention • all assessments tools accepted • outcomes were sought a minimum of four weeks after the treatment to assess long-term effects		and improves overall behavioural problems at the end of treatment. Sessions may improve emotional well-being and quality of life and reduce anxiety, however, they may have little or no effect on agitation, aggression, or cognition. Uncertainty on social behaviour and about long-term effects.

Psychosocial

Study	**Setting**	**Population**	**Research Aims**	**Eligibility**	**Included Studies**	**Key Findings**
Lawrence et al. (2012)	Nursing Home	Dementia	Through a qualitative synthesis,	Inclusion: • English-language articles that reported qualitative research	39	Benefits associated with a psychosocial intervention: enabled people with dementia to connect with others;

			understanding the successful in implementing psychosocial interventions in care homes. See page 345 for a list of psychosocial interventions (Lawrence et al. 2012)	• articles looking at the use and effectiveness of psychosocial interventions from perspectives with persons with dementia, relatives, or care staff • no restrictions placed on type of dementia • participants residing in a residential facility		enabled the feeling of making a meaningful contribution; provided an opportunity to reminisce Focus on staff: supervision provided as a way to reflect on caregiving style and aided for some to look beyond the illness.

Sensory

Study	Setting	Population	Research Aims	Eligibility	Included Studies	Key Findings
Smith & D'Amico (2020)	Residential Facilities	Dementia and Alzheimer's Disease	The purpose of this review was to explore the evidence of sensory-based occupational therapy interventions persons with dementia and Alzheimer's Disease.	Inclusion: • published between 2002 and September 2017 • full-text English and peer-reviewed • sensory-based intervention, within the occupational therapy scope of practice Exclusion: • studies based in the community or home, extenuating author biases (monetary benefit), and study participants with compounding diagnoses such as schizophrenia	47	Sensory- based therapy focused on vision, auditory, olfactory, gustatory, vestibular, and tactile. Sensory Stimulation: Light (vision) Aromatherapy (olfactory) Massage (tactile) Snoezelen (multi-sensory stimulation) Environment-based intervention: Art (visual environment-based intervention) Music (auditory) Visual + Auditory Occupation-based intervention: dance and yoga (proprioceptive & vestibular) gardening (occupation based) mealtime (gustatory and occupation) animal assisted therapy (tactile) Montessori intervention (multi-sensory and occupation based)

2.2 Next Steps for new Review works

Table Three identifies potential next steps that may be undertaken prior to starting review work using creative arts-based interventions for PwD. Not all the next steps were implemented in this thesis, but major ideas were considered.

Beard (2011) had isolated the literature from 1990-2010, therefore a gap exists in the last ten years of data on creative arts-based interventions. As well, some reviews (Beard, 2011; Ruiz-Muelle & López-Rodríguez, 2019) chose to include persons with Alzheimer's Disease (AD) as this form of dementia makes up 60-70% of the cases worldwide (World Health Organization, 2020). This still leaves another 30-40% of dementia individuals and studies involving them out of the included studies pool. A future search strategy should capture key words like dementia and AD to be more inclusive of the target population. Both Chapters 3 and 4 included this modification.

The findings in Aleixo et al. (2017) and Dowson et al. (2019) mainly evaluated music on neuropsychiatric symptoms. However, Dowson et al. (2019) suggested that music can also support and strengthen relationships, provide in the moment experiences, and meet psychosocial needs of PwD. Next steps would be to create a design that is not focused on symptoms but rather focuses on the person more, as seen in the residual impacts from Dowson et al. (2019). Chapter 3 investigates this through personhood.

Six of the twenty-two reviews only focused on research containing randomized controlled trials (RCTs). Although by research standards RCTs are considered the gold standard, they can be filled with limitations when utilizing them for PwD (see de Medeiros & Basting, 2013). These limitations are explored in Chapter 3. As a result, no study design restrictions should be placed in the eligibility criteria for upcoming reviews.

Table Three. *Suggested Next Steps for future review works.*

Study	**Next Step(s)**
Art	
Beard (2011)	Explore the years 2010-2020. Include persons with dementia and not only Alzheimer's. Move away from clinical approaches and include different study designs.
Brown Wilson et al. (2019)	Include more than randomized controlled trials If need be, exclude studies based on quality (follow guiding documents before doing so). Research that understands the perspectives of lived experience is needed.
Cavalcanti Barroso et al. (2020)	Identify quality assessment tools that are valid for psychosocial interventions, not for drug or medical trials. Identify a comprehensive synthesis strategy (e.g., narrative versus meta-analysis) which recognizes the differences between the included studies' elements of design and outcomes of the intervention.
Chancellor, et al. (2014)	Expand art therapies past visual arts. Include persons with dementia from residential care facilities
Cowl & Gaugler (2014)	Looking at benefits aside from improving symptoms through creative arts therapies.
Deshmukh, et al. (2018)	Include more than randomized controlled trials. Expand to databases other than ALOIS.
Salisbury et al. (2011)	Target benefits to arts-based interventions that are not symptomatic related and enhance the person.
Ward et al. (2020)	Continue with having no study design restrictions and focusing on the health and well-being of persons with dementia
Zeilig et al. (2014)	Expand on participatory arts to include creative arts-based interventions including art, music, and drama which were missing in Zeilig et al. (2014).
Dance	
Jiménez et al. (2019)	Include persons who facilitate dance with all or no qualifications. Specify target population as persons with dementia
Karkou & Meekums (2017)	Include more than randomized controlled trials and be inclusive of all persons who delivery dance movement therapy
Klimova et al. (2017)	Include more study designs and account for the years 2016-2020
Mabire et al. (2019)	Investigate what symptoms or outside factors that can impact the four processes
Ruiz-Muelle & López-Rodríguez (2019)	Expand on the study designs, other related dementias, and published date. Continue: no age, gender, or stage of illness restrictions
Music	
Aleixo et al. (2017)	Look at creating a design that is not focused on neuropsychiatric symptoms only.
Blackburn, & Bradshaw (2014)	Include more than randomized controlled trials
Chatterton et al. (2010)	More focus in this article was on the caregivers and music therapists' delivery and how it differed or could be combined to better future music intervention approached. Future studies should look at the person with dementia and how they benefit from their experiences.

Clare & Camic (2019).	Address more than the behavioural and psychological outcomes. Measurement tools should be considered with caution.
Dowson et al. (2019)	Continue to build on health and/or well-being factors and less so on neuropsychiatric symptoms that may blur the lines between person and dementia symptoms.
van der Steen et al. (2018)	Include more than randomized controlled trials. Restricting interventions to follow-up team of four weeks could have excluded many studies. Focus on other things besides symptomatic change.
Psychosocial	
Lawrence et al. (2012)	Focus more on the person with dementia
Sensory	
Smith & D'Amico (2020)	Move away from the occupational therapy mindset and focus more on the person with dementia

There was a wide range of assessment tools used in the studies found in the reviews, which could benefit from further investigation. Specifically on which tools are more common for which type of creative arts interventions. The works of Algar et al. (2016), Bowling et al. (2015), Missotten et al. (2016), and Ready and Ott (2003) have summarized various assessment tools but even they agree that the tools are chosen based on the definitions and aims of the study. Chapter 3 highlights the measurements tools used for PwD.

Finally, some published reviews state that a creative arts-based intervention be administered and monitored by a professional therapist (Brown Wilson et al., 2019; Chatterton et al., 2010; Karkou & Meekums, 2017). This approach may exclude primary caregivers or staff members at local residential facilities and could also be costly to the facility. As well, comfort levels vary amongst PwD, therefore, not all interactions could be valued as being pleasant (Manji, Irfan, personal communication with PRVHC, February 2020). Next steps would be to expand the type of intervention provider to not only trained therapists but also to caregivers, staff members, family, and any other individual that may be around the PwD.

2.3 Final Thoughts

Extensive body of work on reviews pertaining to creative arts-based interventions have been published in the last ten years, however, gaps exist in the current literature, not only in review works but also in other published studies. This chapter aimed to show the many reviews up-to-date, as well as how research in dementia care is undeniably important and needed, especially through creative non-pharmacological interventions.

New reviews should include all PwD, explore into the person more than the condition and highlight personhood and creativity, expand on the type of study designs, incorporate a variety of arts facilitators, and be inclusive of assessment tools which can track changes in condition, if necessary. These next steps were integrated in the review articles located in Chapters 3 and 4.

Chapter 3: Scoping Review

Article 1

With the next steps identified in Chapter 2, Chapter 3 investigated personhood, quality of life, and well-being outcomes through the arts from years 2010-2020. A scoping review was chosen to provide an overview on the current literature base on creative arts-based therapies for persons with dementia living in residential care facilities. The reviews of Beard (2011) and Deshmukh et al. (2018) are further explored and built on in this chapter.

Personhood, QOL and well-being in People with Dementia undergoing Creative Arts-based Therapies: A Scoping Review

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Abstract

Objectives: Creative art-based therapies (cABT) provide a creative non-pharmacological approach in therapy to people with dementia. This review identifies creative arts-based therapies (cABT) that focuses on the personhood of persons with dementia living in residential facilities and determines how quality of life (QOL) or well-being were assessed.

Methods: A scoping review was conducted using databases PubMed, Medline (Ovid), EMBASE, CINAHL (EBSCO), PsycINFO (OVID), and SCOPUS. cABT, in this review, encompassed art, theatre/drama, music, and dance.

Results: An overall of five studies were included and, in these studies, art programs were seen in the form of water painting, an intergenerational art program, live music performances, and medical clowns. QOL and well-being were assessed using the Greater Cincinnati Well-being Observation Tool, a QOL checklist, and transcribed from conversations to develop themes on participation and mental well-being.

Conclusion: Personhood was promoted through self-expression and self-creativity. Increased number of participants are required for future cABT to further understand the impact the arts may have on personhood and on the QOL and well-being for people with dementia.

Keywords*:* creative art-based therapies, personhood, QOL, well-being, residential care

3.1 Introduction

3.1.1 Dementia and Alzheimer's disease

Dementia impacts almost fifty million people around the world and each year, approximately ten million new cases of dementia are diagnosed (World Health Organization, 2020). The global prevalence of dementia for the ages of 65 to 85 doubles every five years and continues that increase after the age of 90 (Lopez & Kuller, 2019). Incidence of dementia after the age of 60 doubles every ten years (Lopez & Kuller, 2019). Further, incidence in men and women show very little difference, however, due to different life expectancy trends, numbers for women older than 85 with dementia or Alzheimer's Disease (AD) differs from men (Fitzpatrick et al., 2004; Lopez & Kuller, 2019). AD is the most common form of dementia and, accounts for approximately 60-70% of cases world-wide (Standing Senate Committee on Social Affairs, Science and Technology, 2016; World Health Organization, 2020). Overall, incidence rates vary depending on the type of dementia being studied, but the common finding amongst the literature confirms that increase in dementia incidence was related to age (Fitzpatrick et al., 2004).

Dementia can affect adult brain function (Public Health Agency of Canada, 2019) and can impact memory, judgement, reasoning, behaviour, and emotions (Alzheimer Society, 2016a). As the disease progresses, the ability to perform activities of daily living become difficult to maintain and further, recognition of loved ones begins to change (Cao et al., 2020; Torpy et al., 2010).

3.1.2 Residential Care

Residential facilities can provide twenty-four-hour supervision which is increasingly important when dementia progresses into the later stages (Alzheimer's Association, n.d. -d). In Canada, about one-third of adults under 80 live in residential facilities and that number rises to

42% of adults aged 80 and above living in care homes (Canadian Institute for Health Information, 2018a). Further, cost of care varies depending on country of residence. For example, in Ontario, Canada, personal and nursing costs are expensed by the provincial government but boarding and room is the responsibility of the individual and their families (Ontario, 2014). In the United States on average, to reside in a living facility it costs $51, 600 per year, with costs reaching over $100, 000 for private care (Alzheimer's Association, n.d. -d). Due to the high demand on health care systems, persons with dementia are often poorly treated and in recent times, a person-centred care approach has been suggested (Canadian Institute for Health Information, 2018b). Furthermore, as dementia progresses, personhood (Kitwood, 1997a) also becomes impacted.

3.1.3 Conceptual Foundations

3.1.3.1 Personhood Framework

Tom Kitwood describes personhood as, "a standing or status that is bestowed upon one human being, by others, it implies recognition, respect and trust" (Kitwood, 1997a, p. 8). Personhood was established to provide people/person(s) with dementia (PwD) with an enhanced well-being (Mitchell & Agnelli, 2015). Kitwood (1997b) developed the model of needs to describe how PwD express psychosocial need. The model is ever-present in human beings, especially in those with dementia. Kitwood's model is composed of comfort, attachment, inclusion, occupation, and identity, all revolved around maintaining personhood and love (1997b). Love was defined as a 'child-like yearning' (Kitwood, 1997b, p. 19) that can have positive emotional impacts for the person with dementia. The notion of personhood shifts the focus to the person and moves away from their condition.

Over the last thirty years academics have argued against (Adams, 1996), acknowledged the flaws (Dewing, 2008), or enhanced the use of personhood (Buron, 2008). Some even consider the framework of personhood to be evolving and non-linear (Berenbaum et al., 2017). For example, Buron (2008) developed the *Personhood Model of Dementia Care* (p. 325) and later, Berenbaum et al. (2017) built from Buron's conceptual framework and developed the *Sustained Personhood Model for Dementia Care* (p. 7). Both models are divided into three levels (L) of personhood: L1 is Biologic, L2 Individual, and L3 Sociologic. This was significant in dementia literature as the two sets of studies (Berenbaum et al., 2017; Buron, 2008) visualized that as dementia progressed, it became more common for L2 and L3 to dissipate and then more attention was placed on L1, the Biologic personhood. In other words, the biomedical definition of symptoms of the disease came to the forefront, when in reality, the individual and their sociability remained intact (Kitwood, 1997b; Kontos, 2011; Sabat, 2002, 2019).

Sabat (2019) exhibited two examples where the biomedical approach is flawed and limited, as the model only takes into consideration the person's perceived symptoms. As with most of Sabat's literature, we follow the case study of Dr. M, an individual who was diagnosed with AD. Sabat illustrates the wrong diagnosis given to Dr. M regarding her gait patterns. When Dr. M was assessed by a physician, the doctor concluded that the gait change was related to Dr. M's AD. However, on occasion Sabat would join Dr. M for regular walks and would notice her moving well with no issues. Instead, Sabat had a difficult time keeping up with Dr. M. He noted with this example that Dr. M's nervousness could have influenced the conclusions made by the physician, thus concluding with a wrong diagnosis. This example also shows how the biomedical model ignores anything but the biology or symptoms, which are existent upon face value. In another case, Sabat (2019) demonstrates an example in which a patient used the word 'hear' rather than ‘see’: “It is good to hear the doctor” (p. 165). This could easily be a case of paraphasia (unintended language error) or as the woman’s primary caregiver (her daughter) informed Sabat, the woman was subjected to verbal abuse during her marriage, therefore she most definitely *heard* the doctor. Providing a diagnosis of paraphasia on face value is understandable if the doctor is unaware of the patients’ history. However, lived experiences play an important role in determining behaviour and actions. Something quite evidently ignored from a biomedical perspective.

In both the examples above, the physicians expected and even forced to see a pathology finding based on AD. This level of misinterpretation is common in diagnoses (Sabat, 2001, 2019). As a result, the biomedical model refuses to acknowledge that there are problems that stem from outside the normal symptoms. Consequently, the issues for Dr. M or the patient, can easily be cases of nervousness, worrying, or abuse that could have caused the results. In other words, the two illustrations show how the physician, or a diagnosis labels a person by the way they acted but it does not, at any point, tell the researcher *why* the person acted in that manner (Sabat, 2019). In both of Sabat’s examples, the two persons with AD have their comfort, occupation, and agency impacted by the preconceived notions from the symptoms that arise from AD. The definitions of the tenets of the model of needs are described in the next paragraph.

Kitwood’s model of needs are: *comfort*, defined by the feeling of trust from others; *attachment* is a sense of security; *inclusion* provides the individuals with a sense of community and the level of involvement in the lives of family or friends; *occupation* includes the involvement of a normal life; *identity* is a sense of expressing individual self-identity; and finally, *agency* provides the individuals with a sense of self-efficacy and self-worth (Kaufmann & Engel, 2016; Kitwood, 1997b; Mitchell & Agnelli, 2015). Agency, recently added by

Kaufmann and Engel (2016), was derived from self-reports of well-being by PwD with moderate to advanced levels of dementia. As a result, Kaufmann and Engel's (2016) study emphasized that PwD are representatives in reporting and discussing their own well-being. The framework also took into consideration the emotional aspects of the person and their ability to participate in daily life (Kaufmann & Engel, 2016). Moreover, Kaufman and Engel (2016) defined well-being as an indicator of quality of life (QOL), insofar as making QOL a construct in their conceptual framework.

Dewing (2008) revisited the ideas of personhood in dementia by assessing the positives and limitations in the work presented by Kitwood. Dewing (2008) acknowledged the fundamentals of personhood on the needs of PwD, as well as a philosophy that is critical in protecting and nurturing personhood in dementia care. Dewing (2008) also cites criticisms and responses to Kitwood's ideas (Dewing, 2008). Dewing (2008) also cites criticisms to Kitwood's ideas by succinctly calling to light the problems of rigor, problems for application into practice, and problems with the personhood philosophy itself (Dewing, 2008). Firstly, Dewing (2008) reasons that personhood is unrefined and does not leave a clear audit trail. For instance, Kitwood's work with psycho-biographies is limited and unfinished (Adams, 1996). Secondly, Kitwood's work may blur the lines between person-centred versus person-focused, meaning that Kitwood ignores the ideas of carers, families, or staff in his approach (Adams, 2001 and Bender & Cheston, 1999, as cited in Dewing, 2008). Additionally, Kitwood's ideas are not adequately translated into action, something which is absent from his work when arguing for his personhood approach (Dewing, 2008). And finally, the philosophy of personhood is criticized because, even though personhood is defined by the standing or status, it makes the philosophy vulnerable to an inclusion and exclusion criteria that he himself was fighting against (Dewing, 2008). However, Kitwood does ground his theory into social being and relationships, something that inevitably stresses the importance of responsibility on the others, those who surround the PwD (Dewing, 2008). Personhood has had a journey where it not only describes the fundamental attributes of a person, but it also extends the notion that PwD are not any less than those around them.

Sakamoto et al. (2017) conducted a study to understand the experiences of early-onset dementia (before age 65) in four adults. Their experiences were summarized into six themes, all of which highlight the subjective feeling and understanding of the stigma, care, and social structures in place. The authors found it necessary to understand how the adults perceived themselves and experienced the disease. They concluded that the idea of personhood is not measured objectively but rather explained through conversations and observations; in other words, subjective feelings were important to discuss. Although this study was designed for early-onset dementia, the ideas and themes can be extrapolated into supporting the importance of a person's personhood and their psychosocial needs in the context of the five components outlined by Kitwood (1997b), and the one additional component (agency) added by Kaufman and Engel in 2016. Agency in the literature is mentioned as being 'lost' (not included) and with Kaufmann and Engel (2016), we recognized that this added component to the model of needs, is another important facet in understanding the foundation of personhood.

There is little doubt that Kitwood's work in dementia care is influential (Dewing, 2008). In the grand scheme of things, personhood has had a journey where it not only describes the fundamental attributes of a person, but it also extends the notion that PwD are not any less than those around them. In fact, they are persons who contain values, ambitions, and non-cognitive attributes versus the conventional cognitive focus.

3.1.3.2 Creativity

The discourse on creativity postulates multiple definitions and thought processes. Kharkhurin (2014) constructed four criteria for creativity: novelty (originality), utility (use in society), aesthetics (value), and authenticity (self-cultivation of individual). Kharkhurin (2014) also emphasized the differences in the viewpoints between Western and Eastern societies as each provide different dogmas on creativity. Glãveanu's (2013) five A's framework (actors, actions, artifacts, audiences, and affordances) built off the four P's of creativity by Rhodes in 1961. Glãveanu (2013) argues that:

> [d]iscussing creativity in terms of actors, actions, artifacts, audiences, and affordances is different from focusing on aptitudes, processes, products, and the environment: The former set clearly emphasizes the distributed nature of creativity and its articulation in concrete sociocultural settings; the latter focuses on rather disparate personal and social aspects of the phenomenon. (p. 76; see Glãveanu, 2013, p. 71, Figure 1 for more differences)

In addition, the five A's accentuate creative expression from every day to celebrated experiences (Glãveanu, 2013). A third set of researchers, Kaufman & Beghetto (2009), conceptualized their four C model of creativity: little-c (everyday creativity, e.g., arranging family photos (p. 1)), big-c (eminent creativity, e.g., wining a prestigious award which takes time (p.2)), mini-c (creativity inherent in the learning process, e.g., fourth grader learning about the planets (p.3)), and pro-c (professional level creativity, e.g., professional creator who has not reached eminent status (p.4)). These three frameworks of creativity demonstrate that creativity follows the person throughout their lives, into old age and is present during dementia.

Creativity and creative expression vary depending on the severity of dementia (Camic et al., 2018). Artistic expression can change during dementia (see Crutch et al., 2001 for case study) but remains intact even though cognitive abilities decline. Artistic creativity has the possibility to continue developing due to the everyday creativity (little-c) or creativity inherent of the learning process (min-c), when aging or dementia onset occurs. This allows a PwD's creativity to progress even with dementia, as there exists a motivator or drive to express artistic creativity (Crutch at al., 2001). Additionally, creativity in dementia focuses on the characteristics and capacities of the individual (Osborne, 2003 as cited in Camic et al., 2018).

Creative arts-based expressions using visual arts or music interventions for PwD has the capacity to satisfy participants when using an artistic modality to create works of art and, shows to reinforce a positive self-image (Ullán et al., 2012). The ability to create art, when PwD use their own hands, indicated that dementia is not an obstacle, as creativity, enjoyment, learning, and communication (Ullán et al., 2012) are possible, especially in social environments. Creativity allows an individual to cope better with the aging process, providing structure and purpose, and can also be seen as a coping mechanism to promote positive aging (Price & Tinker, 2014). Moreover, creative activities can influence self-worth, maintain mental and physical health, and promote social interaction (Price & Tinker, 2014).

3.1.4 Creative Arts-based Therapies

The Social Care Institute for Excellence[10] (2020) describes the creative arts as developments that celebrate the person instead of focusing on the disease and its' problems. They provide examples of poetry, singing and music, museums, and drama and interactive theatre (Megranahan & Lynskey, 2018; Social Care Institute for Excellence, 2020). Each arts approach influences therapy in their own way by cultivating exploratory creative environments, allowing for self-expression, creativity and imagination, and stimulating one or more senses (Lo et al., 2018).

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[10] The Social Care Institute for Excellence contributes to development and implementation that is aimed at bettering care, support, and safeguarding at national and local levels. More on the Institute can be found via this link: https://www.scie.org.uk/about

Creative art interventions and arts-based therapies, in general, can enhance well-being (Young et al., 2016), for a PwD, and those in their environment (staff, therapists, and carers) to build a relationship with one another (Chancellor et al., 2014). Therefore, establishing engagement and person-to-person contact (Salisbury et al., 2011; Schall et al., 2018) and enacting a positive role in PwD's creativity (Zeilig et al., 2014). The creative arts can improve QOL in the individual as it: a) does not rely on the use of pharmaceutical interventions; b) is based on the assumption that art delivers social activities and increases aesthetic pleasing; and c) provides external simulation that affects emotional and physical memories (Zeilig et al., 2014). These approaches can result in maintenance and preservation of self-identity and residual abilities (Schall et al., 2018). Participation can be passive (e.g., listening to music or attending a museum) or active (e.g., painting). Participation with the creative arts provides PwD an opportunity to be stimulated in creative roles in environments where they would otherwise be restricted (Swinnen & de Medeiros, 2018). Failure free programs offer increased expression and building of meaningful relationships that complement connection and belonging (Swinnen & de Medeiros, 2018). Moreover, the ability for participants to create their own art initiates "spontaneity, originality, and expression of personal thoughts and feelings" (Cowl & Gaugler, 2014, p. 283) which is essential for health and well-being outcomes in PwD.

McGreevy (2016) shared a case study to elicit the importance of creative arts in a patient with AD named Betty. To summarize, Betty was admitted to a care home following a hospital stay due to a fractured femur. While on medication, Betty was seen to be withdrawn, isolated, and was unable to effectively communicate, in turn reducing her well-being (McGreevy, 2016). Upon seeing her condition, members of the care staff learned that Betty loved dancing and was a part of a church choir. Eventually, Betty was introduced to therapies that focused on her dancing and singing, alone and in a group, to the point where Betty's independence grew, and she was less isolated (McGreevy, 2016). Correspondingly, her reliance on heavy medications decreased. Because of a creative arts approach, we see that Betty found herself and became an important member of her care home. She no longer relied on a pharmacological intervention to aid in her distress.

3.1.5 QOL & Well-being

Current literature situates the definition QOL on the areas of life influenced by health or condition, treatment, social care, and functioning (Bowling et al., 2015). QOL has also been defined and recognized to be inclusive of life satisfaction, socioeconomic status, well-being, objective and subjective judgements, and other concepts that do not solely rely on the biomedical or physical models of health (Bowling et al., 2015; Ettema et al., 2005). Well-being, often paired with QOL, tends to reflect states of being (Edvardsson et al., 2019) that take long-term illnesses into account (Huber et al., 2011). Namely, psychological, social, physical, spiritual, environmental, and cognitive levels of well-being are common in the literature and are linked to many existing QOL measurement scales (Kelley-Gillespie, 2009). Additionally, well-being is intrinsically linked to "improving society, cultivating close relationships and personal development rather than extrinsic materialist goals" (Tyack & Camic, 2017). QOL, well-being, and personhood are common data elements which contain dimensions relating to physical, psychological, social, and environmental aspects that are pivotal in addressing the overall care of health for PwD in long-term care (Edvardsson et al., 2019).

Kelley-Gillespie (2009, p. 260) presented an integrated model of QOL that considered the six major life domains: social-, physical-, psychological-, cognitive-, spiritual-, and environmental-well-being. These six life domains are critical concepts for successful aging, especially as personhood's paradigm interconnects human life to relationships, feelings, and emotions (Ettema et al., 2005; Kelley-

Gillespie, 2009). Social well-being posits that PwD have a social network that is inclusive of the political and social environments, material resources, and the meanings attached to the person's life (Kelley-Gillespie, 2009). Physical well-being works closely with the biomedical/medical model of well-being which is focused on the physical and functioning conditions of the person (Kelley-Gillespie, 2009). Psychological well-being is inclusive of personal autonomy, subjective satisfaction, and personality (Bond, 1999 as cited in Kelley-Gillespie, 2009). Spiritual well-being revolves around the relationship with God, self, community, and environment which is inclusive to personal values or morals, conduct, and spiritual beliefs (Moberg, 1990 as cited in Kelley-Gillespie, 2009). Cognitive well-being encompasses thinking processes, management skills, and intellectual capacity to make decisions and judgements (Kelley-Gillespie, 2009). Finally, environmental well-being relates to the housing or institutional living, i.e., the physical environment and access to various facilities such as shopping, public transport, and leisure activities (Bond, 1999; Kelley-Gillespie, 2009). These six domains add to the taxonomy of personhood, QOL, and well-being, as these three variants are responsible for understanding a person and their expressive needs, especially when diagnosed with dementia.

3.1.6 Assessment tools

Many authors have conducted reviews on the various QOL assessment tools available to use for PwD (see *Table 1* for the list of tools from the authors' reviews). Ready and Ott (2003), for instance, identified quantitative measurement tools to assess the outcomes of QOL of a PwD. The tools allowed the viewer to observe a combination of behaviour, self-awareness, feelings, mood, enjoyment, engagement, affect, physical/psychological satisfactions, self-esteem, and well/ill-being (Ready & Ott, 2003). Ready and Ott (2003) state that the importance of assessing QOL calls to, "attention [the] positive states and 'personhood' in dementia, in contrast to most other measures of dementia that focus on deficits and pathology" (p. 7). Assessments help observers determine whether or not an intervention can help improve QOL, primarily for PwD in residential facilities.

Missotten et al. (2016) conceptually developed frameworks related to dementia-specific QOL instruments. They aimed to follow the instruments' evolution over time and thus, provided thought on QOL concepts within dementia and its evaluation of the instruments (Missotten et al., 2016). They categorized the tools into self-rated, proxy[11], and tools that use both self-ratings and proxy evaluations. In their assessment of the dementia-related QOL instruments, they concluded that the choice of instrument should be chosen based not only on the psychometric characteristics but also on the theoretical basis of each tool (Missotten et al., 2016). In doing so, the authors highlighted a major importance in the current literature on QOL tools. The concept of QOL is defined and explained differently for each tool, meaning that with the varying definitions, it confirms that QOL does not have a definition that is uniquely its own (Bowling et al., 2015; Ettema et al., 2005 and Ready et al., 2002 as cited in Missotten et al., 2016). Rather it is defined exclusively to the instrument and the author(s) goals when evaluating PwD.

Algar et al. (2016) studied observational measures within art interventions, specifically for the creative activities and visual arts. These measures looked at the QOL and well-being of PwD. This article reviewed different scales with only the DCM overlapping with Ready and Ott (2003). Algar et al. (2016) suggested that quantitative observational tools should include a qualitative portion to gain a higher understanding of the perspectives of the population being tested. Qualitative measures can rely on content analysis that derive themes or coding to understand the emotions and subjective feelings of the

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[11] Perception of QOL in the eyes of 'healthy' person on someone with an illness can differ from the person with the illness itself (Ettema et al., 2005). Proxies, therefore, can misjudge or underestimate QOL of a PwD (Addington-Hall & Kalra, 2001). A disability paradox ultimately comes to the forefront, as QOL is specific to an individual (Carr & Hagginson, 2001). However, cases where individuals are diagnosed with advanced stages of dementia, a proxy can provide information that the PwD is unable to do so in their current state (Addington-Hall & Kalra, 2001). The debate on proxies and power of attorneys is an important perspective to consider but is not the focus of this review.

Table 1. Assessment tools found in the reviews of Ready and Ott (2003), Missotten et al. (2016), Algar et al. (2016), and Bowling et al. (2015).

Ready and Ott (2003)	• Affective and activity ratings • Alzheimer Disease Related Quality of Life (ADRQL) • Cornell-Brown Scale for Quality of Life (CBS) • Dementia Care Mapping (DCM) • Dementia Quality of Life (DQoL)	• Psychological Well-Being in Cognitively Impaired Persons (PWB-CIP) • Quality of Life in Late-Stage Dementia (QUALID) • Quality of Life-Alzheimer's Disease (QOL-AD) • Quality of Life Assessment Schedule (QOLAS)
Missotten et al. (2016)	• DCM • Activity and affect indicators of quality of life (AAIQoL) • Community dementia quality of life profile (CDQLP) • QOL-AD • ADRQL • DQoL • QUALID • QOLAS • Quality of life instrument for the Japanese elderly with dementia (QLDJ) • CBS	• Quality of life in (for) dementia scale (QoL-D) • The Vienna List • The Dementia Quality of Life questionnaire (DEMQOL/DEMQOL-proxy) • A dementia specific quality of life instrument (QUALIDEM) • Bath assessment of subjective quality of life in dementia (BASQID) • Observing QOL in dementia (OQOLD) / observing QOL for dementia advanced (OQOLDA) • Dementia quality of life instrument (DQI) • DEMQOL-U / DEMQOL-Proxy-U
Algar et al. (2016)	• AwareCare • Behaviour observation • Bradford well-being Profile • Creative-Expressive Abilities Assessment tool (CEAA) • DCM • Greater Cincinnati Well-being Observation Tool (GCCWBOT)	• INTERACT • Menorah Park Engagement Scale (MPES) • Observed Emotion Rating Scale (OERS) • Positive Response Schedule for Severe Dementia (PRES) • Quality of Interaction Scale (QUIS)
Bowling et al. (2015)	• QOL-AD • DQoL • ADRQL • DEMQOL • QUALIDEM • QUALID • Observational DCM • BASQID	• CBS • Activity and Affect rating scales • Pleasant events schedule • QoL-D • QOLAS • Observational OQOLD / OQOLDA • Progressive Deterioration Scale Psychological well-being in cognitively impaired persons

individual (Green & Thorogood, 2018). These approaches facilitate conversation and build relationships at a face value. Finally, Bowling et al. (2015) identified sixteen measurements for QOL and evaluated their psychometric properties relating to acceptability, reliability, and validity (see Bowling et al., 2015, Tables 1 and 2). Bowling et al. (2015) also assessed the measurements efficacy on effectively measuring QOL. Similar QOL measurement tools seen in Ready and Ott (2003), Algar et al. (2016), and Missotten et al. (2016) were seen in Bowling et al. (2015).

Information from Algar et al. (2016), Bowling et al. (2015), Missotten et al. (2016), and Ready and Ott (2003) presented a varying amount of assessment tools, scales, instruments, or techniques used to measure QOL outcomes. These tools can be used as measures to either evaluate the efficacy of a creative arts-based intervention, be added as a screening measure for inclusion or exclusion of PwD in the study, or impactfully evaluate the therapy's influence on the QOL and well-being of PwD. The need for measuring QOL is important as researchers can ensure a PwD can 'live well' with dementia, and that their care and support up to death [is maintained]" (Bowling et al., 2015, p. 28).

3.1.7 Currently published reviews

A systematic review by Deshmukh et al (2018) focused on art therapy and included only randomized controlled trials (RCTs) as they cited in their review that RCTs, "aims to summarise higher- quality evidence of its effects from randomised controlled trials" and the effects of art on PwD is required for "future clinical applications and research directions regarding this form of therapy" (Deshmukh et al., 2018, p. 6). They placed no restrictions on the setting in which the PwD resided. Their results examined scales which measured two sets of outcomes, primary and secondary. Primary outcomes measured cognition, affect and emotional well-being, social functioning, behaviour, and adverse effects; secondarily they measured death, QOL, and economic outcomes. The Mini-Mental State Examination and the Cornell Scale for Depression in Dementia were the two main scales used to assess the outcome measures. This systematic review concluded that due to the low number of yielded studies (two included studies in total), that if change occurred it was at miniscule amounts and that more research is required regarding RCTs and art therapy (Deshmukh et al., 2018).

Beard (2011) conducted a systematic review that critiqued the evidence base of art therapies, including music, visual arts, drama, and dance/movement therapies in dementia care. The author reviewed the literature from 1990-2010 and noted that art therapy was defined as:

> (1) creative and enriching activities of self-expression without words or a priori assumptions about how the final product will turn out; and (2) a potential avenue for occupying people's time with the intended outcome of managing behaviors deemed undesirable by in/formal providers of care. (Beard, 2011, p. 636)

As such, art is a process that promotes wellness, hope, healing, and an increased QOL (Beard, 2011). The findings of Beard's work support the argument that the creative arts for PwD are important in promoting increased QOL through creative means.

3.1.8 Rationale for the Scoping Review

This scoping review (ScR) recognized that personhood is impacted in PwD and thus, by extension affecting the QOL or well-being of the person. Predictors of QOL and well-being denote an importance on emotional aspects, functional capacity, relationships (personal and social), an active lifestyle, and the spiritual beliefs of the individual; all of which perceive overall health (Kaufmann & Engel, 2016). The underlying principles of personhood and the non-pharmacological modes of person-centered care directed us to creative arts-based therapies that are used as modalities to improve personhood and supplement creativity in PwD. We realize that the concept of personhood still holds an important foundation in understanding the needs of PwD.

Further, non-pharmacological interventions are being explored with an aim of improving the QOL of PwD (Algar et al., 2016; Canadian Institute for Health Information, 2018c). These avenues contain alternative modes of therapy that improve or enhance the QOL and well-being of PwD by maintaining and improving residual abilities (Bonté, 2014). As such, non-pharmacological interventions provide support for self-expression and fostering relationships and exchanges that can counter the negative affect associated with dementia (Dupuis et al., 2009 as cited in Galbraith et al., 2015). These interventions avoid the use of the typical drug-associated adverse effects and thus, provide as a substitute to pharmacological means (Deshmukh et al., 2018).

Unfortunately, by attempting to eliminate the impact of various dementia related symptom(s), through medications, there is an offsetting chance that other side effects can harm the PwD (Kongpakwattana et al., 2018; Kupfer, 2005). Creative arts allow for residential care homes to forego the reliance on heavy medications and any subsequent substance misuse (Megranahan & Lynskey, 2018). As a result, creative arts interventions—which may seem unorthodox when comparing them to the traditional format of intervention delivery—abstain from the mindset that primarily revolves around the biomedical health model as seen in the examples above from Sabat (2019).

3.2 Materials and methods

3.2.1 Objectives

The purpose of this ScR was to identify creative arts-based therapies (cABT) that focus on the personhood of PwD living in residential facilities. We also wanted to understand the significance of the arts in relation to PwD's QOL and well-being by determining how those two outcomes were assessed. We posed the following questions to guide our search:

1. Which studies touch upon personhood for PwD living in residential facilities (including mentions in cABT, or in the tools used)?
2. Which specific cABT are provided to PwD in residential facilities?
3. How are the outcomes of QOL or well-being assessed? Which assessment tools are being used, if any?

3.2.2 Search strategy and selection criteria

The framework for ScRs established by Arksey and O'Malley (2005) provided a foundation for the methodological approach of this ScR. The framework guided our research with its' five stages: 1) identifying the research question, 2) identifying the studies, 3) selecting the studies, 4) data charting, and 5) collating, summarizing, and reporting the results (Arksey & O'Malley, 2005, p. 22).

We aimed to summarize and disseminate research findings from the field of health sciences, arts interventions, and the care of individuals with dementia. In addition, we sought to highlight research gaps that may exist in understanding the importance of personhood for individuals who are diagnosed with dementia. A ScR was chosen over a systematic review because we aimed to see an indication of the volume of literature at a broad overview (Munn et al., 2018). Moreover, we approached our review to identify concepts that provided a map of the evidence relating to the research questions (Munn et al., 2018).

An initial exploratory search was conducted using PubMed, Medline (Ovid), and SCOPUS in July of 2020. A systematic search, with additional databases, was conducted in June of 2021. We searched Medline (Ovid), EMBASE, CINAHL (EBSCO), PsycINFO (OVID), and SCOPUS, to capture articles from 2010-2020.

Search terms were divided into three main concepts: creative arts-based therapy (intervention), dementia or AD (population), and residential facilities (setting). *Table 2* illustrates the search strategy inputted in Medline (Ovid). Additional search strategies are located in *Appendix C*. We avoided including personhood, QOL, or well-being in the search strategy as we approached our strategy broadly early on and then, narrowed it as we approached the full-text readings. This is common practice when executing reviews and was supported by our University's Librarian (SV).

The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist (Tricco et al., 2018) was used to monitor the key sectional elements needed in a ScR. See *Appendix A* for the PRISMA-ScR checklist.

Table 2. Search Strategy within the Medline (Ovid) database.

Concept	*#*	*Search Terms*
Intervention	1	Dance Therapy/
	2	Movement/
	3	Dancing/
	4	danc*.ti,ab.
	5	((body or authentic) adj3 movement*).ti,ab.
	6	(movement adj3 therap*).ti,ab.
	7	art therapy/ or music therapy/ or play therapy/
	8	Art/
	9	art*.ti,ab.
	10	Creativity/
	11	Paintings/
	12	visual art.mp.
	13	Person-Centered Psychotherapy/
	14	exp sensory Art Therapies/
	15	psychotherap*.ti,ab.
	16	((art or danc* or sensory or perform* or music or creativ* or play or movement* or theatre or drama) adj3 (therap* or program*)).ti,ab.
	17	music.ti,ab.
	18	musicking.ti,ab.
	19	theatre.ti,ab. or drama.ti,ab.
	20	theatre therapy.mp.
	21	Psychodrama/

	22	creative art*.ti,ab.
	23	(creative art* adj3 intervention*).ti,ab.
	24	*1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23*
Population	25	Dementia/
	26	Alzheimer disease/
	27	dementia.ti,ab.
	28	Alzheimer*.ti,ab.
	29	*25 or 26 or 27 or 28*
Setting	30	residential facilities/ or homes for the aged/
	31	long-term care/
	32	nursing home*.ti,ab.
	33	long-term care.ti,ab.
	34	ag?ing home*.ti,ab.
	35	Nursing Homes/
	36	senior? home*.ti,ab.
	37	senior? residence*.ti,ab.
	38	dementia care facilit*.ti,ab.
	39	((nursing or ag?ing or senior? or long-term) adj3 (home* or facility* or residenc*)).ti,ab.
	40	*30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39*
	41	***24 and 29 and 40***
	42	***limit 41 to yr="2010 - 2020"***

3.2.3 Inclusion and Exclusion Criteria

The following inclusion criteria were used:

- cABT for persons with dementia or Alzheimer's disease
- Studies from 2010-2020
- English only
- Creative arts provided in residential facilities, nursing homes, retirement homes, long-term care, and veterans' health centre with an inpatient population
- QOL or well-being assessed either with an assessment tool or through content analysis
- A focus of personhood
- Peer-reviewed articles

We identified the literature of the last decade, by building on the years from Beard (2011) who had uncovered data from mainly two decades, 1990-2010. We also extended our study design restriction comparably to Deshmukh et al. (2018) we had only investigated RCTs paired with art therapy studies. As a result, our search captured the scope of the data from 2010-2020.

English only articles were included because neither reviewer (IM & TC) was fluent in the languages that turned out in the searches (Italian, Mandarin/Cantonese, Dutch, and German were commonly seen). Recreational centres and veterans' health centres were included under residential facilities if they had an inpatient population. As well, we did not place a restriction on who would complete the tools of evaluation because as seen in Missotten et al. (2016) there are three levels of evaluation: self-rated, proxy, or a combination. Therapy providers were not restricted to only a therapist; we welcomed delivery by researchers, therapists, caregivers, or family members. For qualitative works, personhood, QOL, or well-being outcomes, could be measured or identified through the perspectives provided from transcribed conversations and data points identified from any level of content analysis.

The following exclusion criteria were used:

- Studies focusing on reducing behavioural and psychological symptoms of dementia (BPSD) or other related symptoms
- Palliative care or end-of-life
- Dyad-focused or burden of care for the caregiver
- Community/in-home dwelling of PwD
- Opinion or commentary pieces with no dataset

Studies focusing on BPSD and palliative care were excluded because they focused on the symptoms themselves and not on personhood. Articles were rejected if they were dyad focused, as the burden of care of the caregiver was more central to the study compared to the well-being of PwD (see Burnside et al., 2017). Articles were also rejected if they did not contain a dataset to analyze. Any dwelling that was not a residential facility with an in-patient population was excluded.

3.2.4 Charting the data and data items

Covidence was used to manage citations, remove duplicate studies, and complete the screening of the titles/abstracts and full-text readings. To ensure credibility and decrease any potential biases, each screening phase was conducted by two reviewers (IM & TC), independently. Discussions were undertaken to resolve disagreements until a consensus was reached.

A data extraction system was created by the first author (IM) to chart relevant and necessary study information such as, study characteristics, outcomes, recommendations, strengths, limitations, and identified variables that corresponded with the research objective. Charting was completed on Microsoft Excel. Summarized and charted data were narratively synthesized.

3.3 Results

3.3.1 Study Selection

The searches produced 7339 articles, with 3529 duplicates removed and 3810 articles entered the Title/Abstract screening phase. From here, 3716 were excluded as they did not meet the inclusion criteria. Ninety-four studies entered the full-text assessment. The next step required the reviewers, done in duplicate and independently, to read each text to evaluate the inclusion criteria at a deeper level; eighty-four articles were excluded with various reasons such as, wrong outcomes, wrong setting, wrong patient population, wrong intervention, or incomplete study. Once the removal of duplicates and the conduction of the eligibility assessments were completed, a total of five studies, all non-randomized observational studies, were analyzed. *Figure 1* summarizes the selection process using the PRISMA Flow Diagram.

3.3.2 Forms of Creative Arts-based Therapies

During the screening phases, (IM & TC) recognized the many forms and categories of cABT. The domains of cABT were categorized as: art (museum visiting, poetry, visual arts), music, drama/theatre, and dance. As well, we noticed that researchers interchangeably used the words therapy and activity when defining and administering their interventions (e.g., Lokon et al. 2019; Sauer et al., 2016).

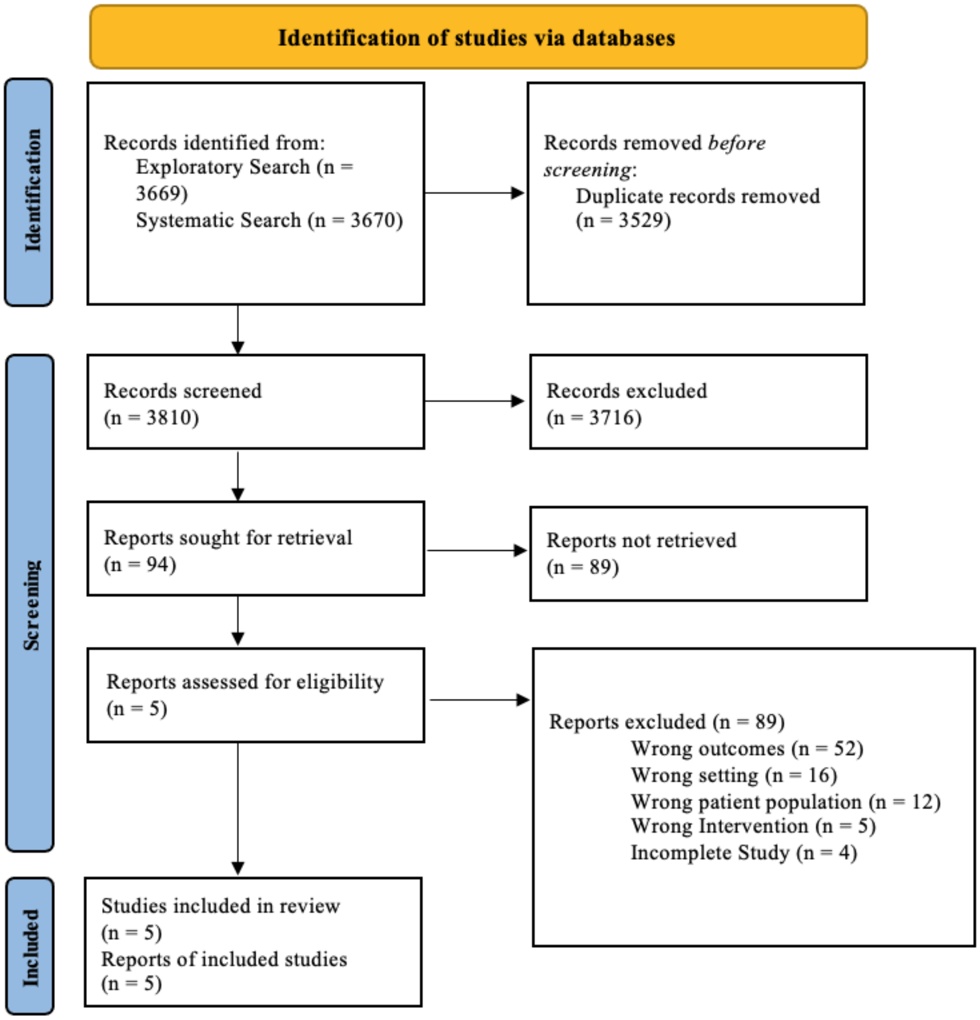

Figure 1. PRISMA Flow Diagram (Adapted from Page et al., 2021)

3.3.3 Study characteristics

A total of 295 participants across all studies were diagnosed with varying levels of dementia. Three studies were conducted in the United States (Gross et al., 2015; Lokon et al., 2019; Sauer et al., 2016), one in Sweden (Ramgard et al., 2012), and another in the Netherlands (van der Vleuten et al., 2012). Three studies focused on visual arts (Gross et al., 2015; Lokon et al., 2019; Sauer et al., 2016), one explored theatre/drama in the form of medical clowns (Ramgard et al., 2016), and another used intimate live music performances as their intervention (van der Vleuten et al., 2012). The longest study ran for fifteen months (Sauer et al., 2016); durations of three studies (Gross et al., 2015; Lokon et al., 2019; Ramgard et al., 2016) ranged from four to twelve weeks; and, a final study was not based on weeks, but rather on seventeen performances carried out by professional singers (van der Vleuten et al., 2012). All studies conducted their cABT in residential facilities.

Among the included studies, four were quantitatively- and one was qualitatively-designed. One of the four quantitative studies (van der Vleuten et al., 2012) followed a quasi-experimental design using observational ratings that assessed the intimacy of live music performances on the QOL of PwD (N = 54) with mild (n = 29) and severe (n = 16) forms of dementia. van der Vleuten et al. (2012) focused on participation and mental well-being as their QOL domains, which were both outlined by Arcares (2005) and Poortvliet et al. (2006) (as cited in van der Vleuten et al., 2012). Within participation, subscales relating to human contact and care relationship were identified. Within, mental well-being negative and positive emotions/affect were the subscales. Finally, communication was a subscale that overlapped both participation and mental well-being.

A second study observed PwD (N = 76) using a well-being tool (Gross et al., 2015) for Memories in Making (MIM). The final two quantitative studies (Lokon et al., 2019; Sauer et al., 2016) observed levels of well-being or ill-being when residents with dementia participated in Opening Minds through Art (OMA). Lokon et al.'s (2019) study had sixty-seven participants and Sauer et al.'s (2016) study had thirty-eight participants, with a subsample of ten that were videorecorded during traditional visual arts intervention.

The only qualitative study (Ramgard et al., 2016) used an ethnographic approach that observed the interaction strategies by medical clowns in a culturally diverse residential care setting and of PwD (N = 60). Ramgard et al. (2016) did not use a QOL assessment tool. Data was obtained from Swedish-born and foreign-born PwD, and observations were concluded by an overt observer while the clowns interacted with the PwD. An overall theme of *Being tuned in and attentive* emphasized the distinctive life history relating to the person's sense of self.

None of the included studies used a QOL assessment tool that were stated in Bowling et al. (2015), Missotten et al. (2016), or Ready and Ott (2003). Algar et al. (2016) identified the Greater Cincinnati Well-being Observation Tool (GCCWBOT) as the most common tool for creative arts/visual arts observation instrument due to a good inter-rater reliability; this tool (and its' variations) were seen in all the creative visual arts-based interventions.

Three studies used the GCCWBOT or a modified version of it. For Gross et al. (2015), the tool focused on interest, attention, pleasure, negative affect, sadness, self-esteem, and normalcy. In Sauer et al. (2016), the modified version of GCCWBOT split well-being (interest, engagement, and pleasure) and ill-being (disengagement, negative affect, sadness, and confusion). Last, in Lokon et al. (2019), the authors used the Scripps Modified GCCWBOT

Table 3. Summary of included studies in the review.

Study	Country	Population	Intervention	Objective(s)	Duration	Assessment	Outcome	Key findings
Gross et al. (2015)	United States	N = 76 AD and other dementias living in four long-term care facilities	Visual Arts - *Memories in Making (MIM)*	• Evaluated MIM • Looked at the carry over effects beyond temporal boundaries of MIM sessions • Examined psychometric qualities of GCCWBOT	12 weeks	GCCWBOT	Well-being	Mean scores across the 12-week MIM program, showing change in GCCWBOT domains (repeated ANOVA measures) Staff (Beginning, Middle, End) *Pleasure* (2.40, 2.44, 2.49)* *Negative Affect** (1.46, 1.48, 1.35)* *Sadness** (1.06, 1.19, 0.98)* Interns (Beginning, Middle, End) *Sustained Attention* (1.73, 2.30, 2.14)* *Pleasure* (1.56, 2.00, 2.26)* *Self-Esteem* (0.94, 1.38, 1.50)* *Normalcy*(0.59, 1.25, 1.49)* *Higher scores in *Interest, Sustained Attention, Self-Esteem, & Normalcy* indicates higher levels of well-being **Lower scores in *Negative Affect and Sadness* indicates higher levels of well-being
Lokon et al. (2019)	United States	N = 67 Moderate/severe dementia in a Midwestern continuing care retirement community and a skilled nursing facility	Visual Arts - *OMA* *Activities:* *OMA, AMT, CRS, NOC, NOA*	• Compared impacts of creative and non-creative activities	4 weeks	Scripps Modified GCCWBOT	Well-being	Intensity and Frequency scores in mean % below follow. Intensity - mean % (overall well-being) OMA – 86% AMT – 73% CRS – 66% NOC – 63% NOA – 48% Frequency - mean % (overall well-being) OMA – 80% AMT – 75% CRS – 67% NOC – 63% NOA – 46%

Notes: AD - Alzheimer's Disease; MIM - Memories in Making; QOL - Quality of Life; GCCWBOT - Greater Cincinnati Chapter Well-Being Observation Tool; OMA - Opening Minds through Art, AMT - Art/Music Therapy, CRS - Creative Regular Staff, NOC - Non-Creative, NOA - No-Activity; ENG - Engagement; PLE - Pleasure; DIS - Disengagement; M - Mean

Table 3 continued…

Study	Country	Population	Intervention	Objective(s)	Duration	Assessment	Outcome	Key findings
Ramgard et al. (2016)	Sweden	N = 60 People with dementia in two nursing homes	Medical Clowns	• Aimed to identify strategies for interactions employed by medical clowns in activities for older people with dementia.	10 weeks	Ethnographic Observation (field notes)	Well-being	**Theme***:* Being tuned in and attentive *Sub-themes:* a) Using Sensory Triggers b) Encouragement and confirmation in the interaction c) Paying attention to places in the past d) Use of Music as a joining activity in shared spaces. Medical clowns contributed to health, well-being, and to the environment of the older adult. Use of objects in the environment acted as identity triggers which strengthened the residents' sense of self. Further, stimulus to cues from the past (music/dances/places) enhanced social interactions.
Sauer et al. (2016	United States	N = 38 (subsample, n = 10) Moderate/ advanced dementia in three long-term care facilities in Ohio	Visual Arts - *OMA*	• Extent at which persons with dementia express well-/ill-being • Compared OMA to traditional arts/crafts at the three facilities	15 months	Adaptation of GCCWBOT	Well-being	Well-being domains at moderate to high Intensity remained relatively high from start to finish of OMA; above 50% (N = 38). Ill-being was close to zero throughout the OMA sessions as only DIS rose to 5% near the end of the OMA session (N = 38). Paired sample t-test on the total combined well-being was higher than traditional arts (OMA M = 8.81; traditional arts M = 5.49) but no significant difference was seen in combined ill-being. OMA Paired sample t-test on n = 10 demonstrated higher intensity scores for ENG (M = 4.15) and PLE (M = 2.10), and lower intensity for DIS (M = 0.06) during OMA compared to traditional art activities. No differences found in social interest, negative affect, sadness, and confusion.

Notes: AD - Alzheimer's Disease; MIM - Memories in Making; QOL - Quality of Life; GCCWBOT - Greater Cincinnati Chapter Well-Being Observation Tool; OMA - Opening Minds through Art, AMT - Art/Music Therapy, CRS - Creative Regular Staff, NOC - Non-Creative, NOA - No-Activity; ENG - Engagement; PLE - Pleasure; DIS - Disengagement; M - Mean

Table 3 continued…

Study	**Country**	**Population**	**Intervention**	**Objective(s)**	**Duration**	**Assessment**	**Outcome**	**Key findings**
van der Vleuten et al. (2012)	Netherlands	N = 54 (only provided data for 45) Mild and Severe dementia in six nursing homes	Music - Live performances from professional singers	• Assessed the effect intimate live music performances can have on the QOL	17 performances	QOL observation list	QOL	One sample t-tests; mean (M) score compared to baseline as M = 2. Participation *Mild (M = 2.24)* *Severe (M = 2.13)* Mental well-being *Mild (M = 2.23)* *Severe (M = 2.10)* Subscales (mild / severe) Human Contact: M = 2.27 / M = 2.11 Care relationship: M = 2.17 / M = 2.09 Communication: M = 2.23 / M = 2.10 Positive affect: M = 2.39 / M = 2.24 Negative affect: M = 2.10 / M = 2.05

Notes: AD - Alzheimer's Disease; MIM - Memories in Making; QOL - Quality of Life; GCCWBOT - Greater Cincinnati Chapter Well-Being Observation Tool; OMA - Opening Minds through Art, AMT - Art/Music Therapy, CRS - Creative Regular Staff, NOC - Non-Creative, NOA - No-Activity; ENG - Engagement; PLE - Pleasure; DIS - Disengagement; M - Mean

and thusly, identified well-being's four subdomains to be inclusive of social interest, engagement, pleasure, and disengagement. The ill-being in their study was reliant on three subdomains, namely, negative affect, sadness, and confusion (Lokon et al., 2019).

3.3.4 Results of individual studies

The summary of included studies can be found in *Table 3*. Included studies contained variations of cABT (music, theatre/drama, and visual arts). Each included therapy type provided support in a creative or engagement format and the PwD were observed by artists, researchers, staff, or family members. Included studies delivered some sort of impact on the personhood of the participants, as described by the authors of their respective studies. Studies either described their population as AD and other dementias, mild/severe, moderate/severe, moderate/advanced dementia, or as PwD. We will refer to the target population as PwD.

3.3.4.1 Visual Arts

3.3.4.1.1 Memories in Making (MIM). Gross et al. (2015) evaluated MIM, assessed the carry over effects beyond temporal boundaries of MIM, and examined the psychometric qualities of the GCCWBOT. MIM's participants used "watercolor or acrylic paints, brushes, and paper, and [were] encouraged by a facilitator to either copy a picture that is provided as a model, or to paint freestyle" (Gross et al., 2015, p. 31). The art became a tangible expression of the artist's expression—artist in this case refers to the PwD—and allowed for PwD to communicate experiences that may be difficult to express with words (Gross et al., 2015). In addition, MIM had four goals for the participants: to enhance sensory stimulation, pleasure from being involved in a creative process, enriched sense of well-being, and increased self-esteem and QOL from the result of creating something of value (Gross et al., 2015, p. 30).

Seventy-six persons with AD and other dementias living in four long-term care facilities underwent MIM for twelve weeks. Of the seventy-six, thirteen were male and sixty-three were female, with a mean age of 84.28 years. Art classes were facilitated by university student interns who had an educational background in psychology and art (Gross et al., 2015). Facility staff and interns evaluated the residents using the GCCWBOT. Staff ratings were taken from a broad sampling of behaviour outside the art sessions. Intern ratings were established from beginning, middle, and end observation of the MIM activities. The interns also kept journal notes from each session with the residents. The residents worked with the same interns throughout the twelve-week program as to maximize familiarity, something which was more common between staff and PwD already.

The effects of MIM art activities on residents' well-being was rated on the seven domains of psychological well-being on the rating scale of GCCWBOT. The domains were: interest, sustained attention, pleasure, negative affect, sadness, self-esteem, and normalcy (Gross et al., 2015). Psychological well-being was derived from Lawton's (1996) work, and through this understanding Rentz (2002, as cited in Gross et al., 2015) examined art activity's contribution to well-being in PwD. Rentz's work showed that active engagement in artistic activity had a positive effect on psychological functioning, thereby improving expressions of pleasure and self-esteem, in addition to engagement (Gross et al., 2015). The GCCWBOT was scaled on a five-point Likert scale (0-4) (see Gross et al., 2015, Table 1).

The Interns reported significant improvements from beginning (b), middle (m), and end (e) across the twelve-week MIM program[12]. Change was seen in the mean scores in the domains

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[12] Note that higher scores in *Interest, Sustained Attention, Self-Esteem, & Normalcy* indicated higher levels of well-being and lower scores in *Negative Affect and Sadness* indicated higher levels of well-being (see Gross et al., 2015, Table 3).

of: Sustained Attention (b=1.73, m=2.30, e=2.14), Pleasure (b=1.56, m=2.00, e=2.26), Self-Esteem (b=0.94, m=1.38, e=1.50), and Normalcy (b=0.59, m=1.25, e=1.49). Staff reported no significant change in well-being across the 12 weeks outside of intervention, except for decreases in scores in Negative Affect (b=1.46, m=1.48, e=1.35) and Sadness (b=1.06, m=1.19, e=0.98). Slight change was seen in Pleasure (b=2.40, m=2.44, e=2.49).

3.3.4.1.2 Opening Minds through Art (OMA). OMA is an intergenerational art program for PwD to create art with the support of trained volunteers, in a one-on-one facet (Lokon et al., 2019). This means that one volunteer is assigned to each PwD, but the volunteer does not complete the art for the PwD. Additionally, OMA is based on Kitwood's person-centred care philosophy (1997a, b) in which the psychological needs for attachment, comfort, inclusion, identify, and occupation are met, due in large part to the failure-free structure of OMA (Sauer et al., 2016).

3.3.4.1.2.1 Sauer et al. (2016). During a fifteen-month period, Sauer et al. (2016) administered OMA for thirty-eight (N = 38) PwD with moderate to advanced dementia (30 women, 8 men). The whole sample was videotaped during OMA at three different long-term care facilities. A subsample of ten (n = 10) was videotaped participating in traditional arts and crafts (8 women, 2 men). An adaptation of the GCCWBOT was used to measure well-being (social interest, engagement, and pleasure) and ill-being (disengagement, negative affect, sadness, and confusion) in PwD participating in OMA and traditional arts and crafts activities. Art sessions ran for forty mins and scores were given as [intensity/frequency] 0 – not observed, 1 – low/infrequently, 3 – moderate/some of the time, 5 – high/most of the time in five min intervals (Sauer et al., 2016). Missing data was aggregated when someone walked in front of the camera or participant(s) left the session. Sauer et al. (2016) averaged the data from the five-minute observation periods and as a result, one data set per participant was reflected across the sessions, for both well- and ill-being.

Well-being intensity scores for social interest, engagement, and pleasure ranged from 50-75% in intensity. On the other hand, ill-being value intensities were close to negligible, except for disengagement which rose to five percent in the final interval of the OMA sessions (N = 38). A paired sample t-test validated that the total combined well-being was higher in OMA (M = 8.81) than in traditional arts (M = 5.49). No significant difference was seen in combined ill-being. Another paired sample t-test, on n = 10, demonstrated higher scores in engagement (M = 4.15) and pleasure (M = 2.10) and a lower intensity for disengagement (M = 0.06). No differences were seen in the remaining well- or ill-being subdomains. Overall, N = 38 confirmed that OMA showed considerable well-being when compared to traditional arts activities. The inter-rater reliability was estimated to be a mean Kappa coefficient of 0.799 when coding the OMA tapes.

3.3.4.1.2.2 Lokon et al. (2019). Lokon et al. (2019) had two predetermined aims of their study. The first was to investigate the validity of the Scripps Modified GCCWBOT. Therapists and staff used the Scripps Modified GCCWBOT to systematically observed PwD. The instrument measured the intensity and frequency of two domains: well-being (social interest, engagement, and pleasure), and ill-being (disengagement, negative affect, sadness, and confusion) (Lokon et al., 2019). However, upon completing a principal component analysis and a reliability check, Lokon et al. (2019) determined that disengagement would be analyzed as part of the well-being domain, and henceforth, will be shown associated with well-being. Ill-being was barely detected by the Scripps Modified GCCWBOT. Scores were marked as [intensity/frequency] never/none (0), low/infrequently (1), moderate/sometimes (3), and high/most of the time (5) (Lokon et al., 2019, p. 477). Observations were coded in five-minute intervals for up to sixty minutes (=twelve intervals). The second part of the study was to compare the impact of five activities on the well-being of PwD: Art/Music Therapy (AMT), OMA, Creative regular staff (CRS), Non-creative (NOC), and No activity (NOA). AMT was conducted by certified and licensed art/music therapists. OMA was administered by teaching artists. CRS activities were led by non-artists (regular activities staff). NOC was guided by activities professionals, and NOA, was not conducted by anyone and was considered as no activity at all.

Activities were administered to sixty-seven individuals (54 females, 13 males) all with moderate to severe dementia in a continuing care retirement community and nursing facility (Lokon et al., 2019). Intensity mean percentage for overall well-being showed that:

- OMA (86%) had a significantly higher impact on well-being compared to AMT (73%), CRS (66%), NOC (63%), and NOA (48%)
- AMT had a higher percentage compared to NOC and NOA.
- CRS was higher than both NOC and NOA
- NOA had a lower intensity percentage in comparison to OMA, AMT, CRS, and NOC

Frequency mean percentage for overall well-being showed:

- OMA (80%) was higher in frequency compared to AMT (75%), CRS (67%), NOC (63%), and NOA (46%)
- AMT was higher than CRS, NOA, NOC
- NOA had the lowest frequency score for overall well-being

All values were statistically significant at $p > 0.05$ (see Lokon et al., 2019, Tables 4 & 5). Lokon et al. (2019) also noted no major differences between creative and non-creative activities, conducted by staff. This could mean that any activity that pre-occupied the PwD may have been beneficial in addressing personhood through QOL or well-being measures. The ability to maintain attention and engagement is as important as the type and style of activity being delivered and how stimulating an environment is.

OMA was designed to provide one-on-one support between the trained OMA volunteer and the PwD. As a result, Lokon et al. (2019) conducted ratios for each activity type based on the number of observations (e.g., 99 observations of OMA) and of staff assigned to each resident(s). A mean score of one (M =1) was seen in OMA to confirm a 1:1 ratio. For AMT, four to five residents were assigned to an art and music therapist (M = 0.23). CRS was observed to show five to six residents per staff member (M = 0.18) and NOC saw four to five residents per staff (M = 0.22). No data exists for NOA as the researchers were only interested in staff ratios for activity-based endeavours (Lokon et al., 2019). However, increasing staff to PwD ratios must be done with careful thought as passive roles or uncomfortable interactions with PwD would not automatically increase well-being (Lokon et al., 2019).

3.3.4.2 Medical Clowns

Medical clowns provide a form of clown therapy that is performance-based and can be considered a parody to the work of doctors and nurses (Warren & Spitzer, 2011). Clown-based therapy is shown to encourage communication, interaction, and laughter in residential homes and care settings (Warren & Spitzer, 2011). In the context of Ramgard et al. (2016), the medical clowns used verbal and non-verbal interactions to engage with residents with dementia from two nursing homes in Sweden. From a cultural standpoint, stimulation of cultural activities that involve music, dance, or even drama have shown to be important activities that link closely with life histories, personal identities, and strengthening of older people’s sense of self and corporeality (Ramgard et al., 2016). The medical clowns in Ramgard et al. (2016) wore recognizable clown clothing (big shoes, baggy trousers, a red nose).

The study aimed to identify interaction strategies through medical clowns in culturally diverse dementia care facilities. Two nursing homes were chosen through convenience sampling;

one nursing home, in an urban area, had many foreign-born residents and the second home, in a rural area, had mostly Swedish-born residents. Before the start of the interactions, nursing staff provided a background of each PwD to the medical clowns and researchers (Ramgard et al., 2016). Over the course of ten weeks, with sessions lasting for three to four hours, an ethnographic approach was initiated for sixty PwD (Ramgard et al., 2016). One of the authors, acted as an overt observer, with no interaction with the clowns or the PwD. Observations were of the interactions between the participant and the clown (Ramgard et al., 2016).

Ramgard et al. (2016) transcribed conversations and developed themes where aspects of QOL and well-being were concentrated on the person and on how they reacted to external stimuli. The overall theme generated was coded as *Being tuned in and attentive* (needs at a personal level and thus, building a relationship) (Ramgard et al., 2016). From the theme, subthemes were identified by Ramgard et al. (2016): *using sensory triggers* (use of accessories to invoke senses that initiate and support interaction), *employing encouragement and confirmation in the interaction* (encouragement and confirmation in a positive manner), *paying attention to places in the past* (connecting to places that were prominent earlier in the individual’s life), and the *use of music as a joining activity in shared spaces* (usage of different music, instruments, and songs).

One creative strategy to connect with a resident, from a Middle Eastern background, was demonstrated by the clowns. The clowns added a shawl (sensory trigger) around their hips to signify a belly dancer, as was evident in the example of a resident named ‘Nina’ (Ramgard et al., 2016, p. 4). The clowns watched as Nina reacted and expressed themselves through facial expressions. A second strategy saw the use of different kinds of music through instruments and songs with residents located in shared spaces (e.g., dining room) (Ramgard et al., 2016). In this space, residents responded to the clowns and suggested songs they could sing or partake in. Their rhythmic and bodily movements to the music connected them to their surroundings and to social interactions between them and the clowns.

Interactions sparked a development of relationships and used the spatial environment and objects to initiate conversation. The clowns attentively listened to what the individual had to say and used various kinds of music to connect with them. Emphasis was placed on the person and subsequently, emphasized their sense of self. Further, once the PwD expressed contentment, the clowns would initiate other interactions, thus, stimulating the senses first and then using encouragement or confirmation to speak with the PwD. As such, empowerment mechanisms (comfort domain) and social interactions (inclusion, identity, and agency domains) were stimulated in the environment of the PwD.

3.3.4.3 Live Performances using Music

van der Vleuten et al. (2012) directed their efforts to a quasi-experimental observational study that provided intimate live music performance by Diva Dichtbij, an organization that provides complementary care for chronically ill individuals (p. 485). Singers from Diva Dichtbij performed across the Netherlands and aimed to establish positive effect on people through their singing and from authentic human contact (van der Vleuten et al., 2012). A balanced approach to produce eye contact, interaction, and be close enough to get a positive reaction was an experience that Diva Dichtbij wanted for their participants (van der Vleuten et al., 2012). In nursing homes, Diva Dichtbij combined singing and authentic human contact (van der Vleuten et al., 2012).

A sample of Fifty-four PwD were selected from six nursing homes; only data for forty-five respondents was included in this study (van der Vleuten et al., 2012). Of the sample, thirty were women and fifteen were men and, twenty-nine had mild dementia and sixteen were diagnosed with severe dementia (van der Vleuten et al., 2012). Participants were exposed to live music performances where an observational rating scale completed by the caregivers or family following a live musical performance (van der Vleuten et al., 2012).

Two dependent variables were identified: participation and mental well-being. Participation included human contact, the care relationship, and communication; mental well-being's subscales were the positive and negative emotions, and communication, which lead to the creation of the observation lists based on the theoretical approaches by Götell et al. (2003, 2009) and Holmes et al. (2006). Communication was inclusive in both the participation and mental well-being dimensions of QOL (van der Vleuten et al., 2012) as music was noted to have positive impacts on the communication of the individual.

The QOL scale that was used by the caregivers or family was different based on the severity of dementia. Familiar caregivers were chosen as the observers because they knew the residents' best when recognizing "the effect of the performance" (van der Vleuten et al., 2012, p. 486). Participants with a mild dementia had a QOL list with forty-five items, compared to those with severe dementia who had a list with thirty items (van der Vleuten et al., 2012). Reasoning for two observation lists was cited as "the severe observation list excluded some items that were not valid for this group (e.g., 'The person speaks more' because people with severe dementia often can no longer speak)" (van der Vleuten et al., 2012, p. 486).

Scoring was completed using a three-point scale to assess behaviour for each item as: (1) deteriorated/declined, (2) no change, and (3) improved/increased (see van der Vleuten et al., 2012, Appendix A). Observations were completed one day following the live music performance as a day was considered sufficient by van der Vleuten et al. (2013) to avoid a short-term immediate effect.

Effects of the performances on both the QOL dimensions for the whole dataset (N = 45) was stated as a mean score of 2.20 for participation and a mean score of 2.18 for mental well-being, with a mean at baseline set as two (M = 2) (van der Vleuten et al., 2012, Table 2). Once the data was split into mild (n = 29) and severe (n = 16) dementia groups, participation and mental well-being mean scores were higher in the mild group compared to the severe group (2.24 and 2.23 versus 2.13 and 2.10) (see van der Vleuten et al., 2012, Table 3). The effects of the music performances showed to be higher than the baseline in both groups.

Additionally, van der Vleuten et al. (2012) calculated the effect of the subscales of each QOL dimension to further understand the effects of live music performances on PwD. Overall, positive change was seen in all subscales (human contact, care relation, communication, and positive affect) in the mild dementia group. On the other hand, not much difference was visualized in the severe group, except for positive affect having a mean score of 2.24 (see van der Vleuten et al., 2012, Table 4). Satisfaction for watching the live music performances was seen in 80% of the participants and was based on two yes/no choice questions (van der Vleuten et al., 2012).

3.4 Discussion

Current literature situates cABT's to reduce behaviour and psychological symptoms (Bajantri et al., 2018; Burnside et al., 2017), depression (Byrne & MacKinlay, 2012), and identified cognitive functioning (Cohen-Mansfield et al., 2011; Low et al., 2016) as the main causes of concern for affecting the QOL and well-being, not personhood. Further, some studies provided cABT to only PwD in the community or day center setting (Choo et al., 2019; Pérez-Sáez et al. 2018; Swinnen, 2016), and not to the PwD living in residential care as inpatients. As the numbers of those with dementia (Alzheimer's Association, 2019) continue to rise, the care through creative arts for PwD in residential facilities continues to be important.

Residential care facilities are objective environments which can alter the QOL of a PwD. Lawton (1983) suggests we separate the environments into personal-, small-group-, suprapersonal-, social-, and physical-environments. When a PwD is living in a care home, we often forget about the person and tend to focus on the objective placements rather than thinking of multiple environments that can make up the person's life (Lawton, 1983). Further, Lawton's (1996) approach to psychological well-being stipulates the importance placed on the self-evaluated level of a person's competence and self (pp. 327-328). The consensual aspects of psychological well-being include neuroticism or negative affect, happiness, positive affect, and congruence between desired and attained goals (Lawton, 1983, p. 351), all of which influence a PwD's ability to participate in daily life or activities.

In residential care facilities, creativity in the arts can be seen as a way to "sharpen the capacity of the senses and the patients' propensity to act themselves" (Hannemann, 2006, p.59). As the severity of dementia progresses, individuals sometimes lose themselves, their autonomy, and state of being (Kitwood, 1997a). In turn, creative activity reduces negative affect and offers power of choice and decisions, as well as "opening windows to people's emotional interiors" (Hannemann, 2006, p. 59).

3.4.1 Personhood in the included studies

Personhood is a term coined by Tom Kitwood that encompasses the social psychology and person-centered care for PwD (1997a). Often, studies have been found to focus on reducing the discomfort of symptoms, which is substantial in the care of PwD, but does not allow for the person to be included in their decisions or does not supplement their needs, as a primary goal. The creative therapies seen in this ScR show that there is a thought process involved in improving the health of the person through creative means. For example, maintaining personhood in Sauer et al. (2016) stemmed from professionals and volunteers that were trained to promote the 'flow' of the individual; the 'flow' indicates that through non-verbal presence and assisting the PwD when needed, can facilitate the creative process for the artist (the PwD) themselves. In other words, promoting self-expression and self-creativity to potentially improve personhood.

The arts provide a way of expression of personhood and self-decision-making skills that are evident even in later stages of dementia, as seen with Gross et al. (2015). For example, the interns did not interfere in the creativity of the PwD. The participants had the full ability to make their own decisions and to exercise their own creative process, which allowed them to communicate and express themselves through the arts. MIM also showed how long-term memories stayed intact when PwD painted images of their memories (Gross et al., 2015). This form of communication was expressed through paint, a medium which was important as words could not be articulated (Gross et al., 2015). The visual arts program afforded the artists with a sense of comfort when working with the interns and built a relationship that maximized the familiarity between the PwD and interns. Moreover, PwD were involved in the process of a normal life (Kitwood, 1997b; Mitchell & Agnelli, 2015) when partaking in the art. The works of art were their own, each distinguished from others as the person's own memories were embedded in their art. Agency was seen remarkably from the 'freedom of action' (Kaufmann & Engel, 2016, p. 784) and self-efficacy when the artists were given the reins to generate their own work. This allowed the artists to interpret their pieces on their own. And so, for MIM, the art was encouraged through social interactions, all while respecting the personhood of the PwD. Gross et al. (2015) implemented a program that would improve self-esteem and generate a creation of value where words or remembering may be lost.

When personhood is not maintained, confidence and self-expression of the PwD is challenged by not only the disease but also by their carer who can sometimes unconsciously re-define the individual as mentally and physically incompetent (Lokon et al., 2019). OMA was designed with Kitwood's person-centered care philosophy and Ronch's strength-based psychology[13] (Sauer et al., 2016). PwD's psychological needs for attachment, comfort, inclusion, identity, occupation, and agency were met from the failure free art offered by OMA for PwD (Sauer et al., 2016). Further, OMA takes a non-interventionist approach which has a goal of life enrichment and improving QOL (Lokon et al., 2019), without the sole focus on reduction of behavioural and psychological symptoms (Beard, 2011). The design and conduction of creative arts for PwD benefits individuals with dementia, and the facilities, but shows society that PwD have the capability to expressive themselves creatively (Lokon et al., 2019). This is imperative as each person is different and unique with their preferences. OMA also provides the PwD with a social interaction that builds on the relationship between themselves and the OMA lead (Lokon et al., 2019; Sauer et al., 2016).

The ethnographic research by Ramgard et al. (2016) exhibited that the medical clown approach was beyond behaviour and psychological symptoms and was more closely linked to the lived experiences and personal identities of PwD. The combined use of creative approaches of

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[13] Strength-based psychology (SBP) is invested in the psychological strengths and assets of people (Scheel et al., 2012). In other words, SBP focuses less on the shortcomings or negatives of a person, instead finds a way to emphasize what is right and helps use it (Psychology Today, n.d.; Scheel et al., 2012, p. 393).

music, dance, and theatre showed to strengthen the PwD's sense of self and corporeality (Ramgard et al., 2016). In the example where the medical clowns used a sensory trigger, like the shawl for Nina, they provided the PwD a chance to a) reminisce and b) interact and share their lived experiences through the short interactions with the clowns. All of which is robust in understanding that the person goes far beyond the condition and can express themselves in social settings. Words of encouragement were used to positively speak with the PwD (Ramgard et al., 2016), something that is often lacking in conversations with PwD.

Lawton (1983) conveys an important example, where a PwD is asked how they are liking their living condition, "It's fine—I have to like it" (p. 355). The negativity and to an extent the sadness associated with this response, unfortunately, shines a light on the lack of self and autonomy, two aspects that are not always considered. The medical clowns (Ramgard et al., 2016) sufficiently connected parts of the past, self and anatomy, of the PwD and brought it to the forefront in their interactions and support mechanisms. As a result, the medical clowns strengthened the PwD's sense of self and increased their well-being by supplementing their needs.

Personhood was seen in van der Vleuten et al.'s (2012) dependent variables of participation and mental well-being. Participation is linked to the social- and psychological-well-being of the person, and is also an asset in the comfort, attachment, inclusion, identity, and agency of the person. Mental well-being becomes reliant on the psychological well-being (Bond, 1999) where emotions, positive or negative, and experience of life are expressed. Communication plays a role in the social nature of human life, in a verbal or non-verbal format. The improvement in communication contributed to the PwD's ability to express themselves and to be involved the 'normal' processes of life.

3.4.2 Limitations

3.4.2.1 Limitations of included studies

Gross et al. (2015) acknowledged that their tool was questionable but continued to use it to generate their data. They claimed the GCCWBOT, “further exacerbated the difficulty of measuring well-being” (Gross et al., 2015, p. 42) which led to confounding when interpreting results and increased the potential for biases when reporting well-being. Interns and Staff spent only thirty minutes training to use GCCWBOT. The inter-rater reliability (IRR) was similar to the average Kappa coefficient value[14] of 0.65 as seen in Kinney and Rentz (2005), when they conducted a similar visual arts study using the GCCWBOT. For Gross et al. (2015), IRR was calculated separately for each of the seven domains of the GCCWBOT but was later aggregated from a one-tailed significance level ($r = 0.63$, $df = 10$, $p = 0.014$). The low Pearson’s coefficient score was common for the GCCWBOT when examining IRR, in this study. In fact, Gross et al. (2015) acknowledged this issue and later suggested that the domains be split into well-being and ill-being to increase IRR and to further understand the significance visual creative arts have on the well-being of PwD. Comparatively, Lokon et al. (2019) and Sauer et al. (2016) modified the GCCWBOT and created well-/ill-being domains to solidify their understanding of well-being. This modification made scoring and observations simpler and improved IRR amongst observers (see Lokon et al., 2019; Sauer et al., 2016).

Gross et al. (2015) recognized that the interns’ ratings may have been influenced by what they ‘wanted’ to see, which potentially inflated certain values. However, based on the values reported, intern ratings would have shown to be higher throughout MIM. Last, data was missing

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[14] More on the Kappa Statistic and understanding IRR in Viera and Garrett (2005).

for some participants, which was required for the repeated-measures ANOVA mean scores. Statistics were only inclusive of cases where *all* data was made available to the researchers.

A small sample size remained the concern and limitation for Sauer et al. (2016). The inability to compare OMA and traditional arts in all thirty-eight PwD was another limitation for Sauer et al. (2016), therefore, data was aggregated when needed. Demographic and health-related descriptors (e.g., age and severity/type of dementia) were missing for the sample, which limited the generalizability of the study (Sauer et al., 2016). Finally, Sauer et al. (2016) stated that a RCT could not be created because the long-term care facilities would not permit the researchers to exclude residents from participating in OMA.

Limitations identified by Ramgard et al. (2016) raised important questions regarding transferability, reactivity, and the lack of experience of the researchers in nursing home or clinical dementia care. On transferability, Ramgard et al. (2016) included PwD from different municipalities and backgrounds, which validated the credibility as well. Credibility was also enhanced during the data analysis process when field notes and categories were thoroughly discussed and reflected upon. Reactivity was seen when one of the authors acted as an overt observer. This could have influenced the behaviour and dynamics of the PwD and the medical clowns' interactions. The overt observer emphasized their presence as being of the observing nature and of someone who was not involved in nursing home activities relating to either tasks or care. Last, the researchers did not have previous experience working in a nursing home or clinical care setting, but as experienced qualitative researchers and nurses, they combatted this limitation to an extent.

van der Vleuten et al. (2012) had data missing for nine PwD with no clear indication of the reasoning behind this. However, the researchers alluded to pre-/post- and follow up measures and control group limitations, which were not clearly specified in their study. An interval of one day had been considered appropriate by the study's authors to avoid short-term immediate effect, although that does not give the reader much data about the long-term effects of the live music performances. Would observation have been better served to be done in incremental time frames (e.g., T=0, T=1, T=2) to see a change in QOL over time in participants? Further, van der Vleuten et al. (2012) acknowledged the positive effect of change in the mild group but in the severe group, only small positive gains were seen. Future research could focus on evaluating how live music performances connect with persons with severe dementia and how that could better serve in improving their participation and mental well-being. As well, future studies could investigate another style of live musical intervention for severe dementia participants to see changes similar to that of the mild dementia group.

3.4.2.2 Limitations of the Scoping Review

This ScR has some limitations. Only observational, non-randomized studies ended up being included in the study which may have been due to the specificity of this study's research objectives. We were ultimately focused on cABT that were offered to PwD in residential facilities with a personhood approach and that assessed QOL or well-being through quantitative or qualitative means; this was the utmost goal of the review. We also recognize that dance was not among the cABT included in our review. This highlights the paucity of studies that have a combined intervention-outcome partnership of dance interventions and personhood, in the last decade. Current dance based literature focuses on behaviour or cognition (see Guzman et al., 2016; Low et al., 2016).

Excluding articles in a language other than English, can be considered as a language bias (Morrison et al., 2009). The 'English-only' inclusion criteria could have overlooked articles that may have fit our objective; however, we did not have the funding necessary to hire a translator. Since we chose to isolate articles from the last decade and chose only English-based literature, these parameters took away from a potential pool of many studies. Although, it is worth noting that primary research conducted on PwD in residential facilities, specifically those that contain a focus on personhood, is scarce. Finally, searches were not performed using any grey literature which could be a source of publication bias.

Our ScR approached personhood as its main focal point, however, we did not take into consideration other synonyms or like-terms to personhood. Specifically, those that have been developed by Steven Sabat (Selfhood - Self1,2,3; see Norberg, 2019; Sabat, 2002, 2005; Sabat & Harré, 1992) and Pia Kontos (Embodied Selfhood; see Kontos, 2004, 2005, 2011). The foundation laid by personhood cannot be ignored and therefore, it is a concept that continues to be prevalent when looking at the current scope of literature. Should this study be replicated, it would be beneficial to include the additional concepts to grasp a full understanding of the theoretical or empirical data influencing the care and well-being for PwD.

3.4.3 Implications for future research

The evidence suggests that a comparison activity may be chosen to validate whether cABT can influence personhood, QOL, and well-being of a PwD (Lokon et al., 2019; Sauer et al., 2016). This further allows art therapists, artists, staff, or family members to individualize cABT for the target population, with a person-centered care approach. RCT studies in research are considered the gold standard when implementing effective research methodologies (Hariton & Locascio, 2018; Spieth et al., 2016). Consequently, de Medeiros and Basting (2013) inform us that a ‘one size fits all’ approach, may not always work for studies relating to the dementia population. For example, an arts intervention tends to focus on the development of individual potential and social meaning, unlike pharmacologic interventions (de Medeiros & Basting, 2013), which can be focused on symptom reduction or symptom management. Therefore, how can both interventions be assessed in the same way (de Medeiros & Basting, 2013)? The idea of measuring meaning for a PwD is a more complicated than agreement ratings or noting affect change, as per de Medeiros and Basting (2013). Meaning varies based on individuals and the levels of meaning differ on intensity, duration, form of expression, and personal connection (de Medeiros & Basting, 2013, p. 351). Sauer et al. (2016) were unable to implement a RCT as the long-term care facilities did not permit exclusion of their residents. That left the researchers with a makeshift approach in a non-randomized study design (subsample created). Future studies should be mindful of the study design and how the inpatient facilities operate with inclusion and exclusion criteria for PwD. They must ask themselves, are the benefits of the RCT going to give me the results based on efficacy or management? Additionally, a future study can compare the impact of an RCT design versus a non-randomized study to determine which study design has the most effectiveness in understanding the delivery of the arts on PwD.

Another research implication is to appropriately choose whether to collect research data quantitatively or qualitatively. Quantitative data can be considered limiting when addressing psychological needs of people as it is based on statistical techniques which “measure observable phenomena and analyze data; it employs an objective lens and is more interested in the outcome of the research rather than process” (Azzara, 2018, p.75). Qualitative research data, in terms of psychology and social psychology, “has performed a crucial role in understanding the impact of person-centered dementia care in assessing individual needs” (Azzara, 2018, p.78). This research approach has also:

> played an important role in gaining a better understanding of dementia by addressing a series of issues relating to the person's perception of his or her dementia, the caregivers' experiences, and the impact of dementia on family and friends. (Azzara, 2018, p. 78)

A combination of both quantitative and qualitative research methods could provide an objective perspective of the data, through mathematical foundations (Azzara, 2018) and also through a lens that understands the needs of PwD (Kitwood's (1997a, b).

A third implication suggests that one-on-one (1:1 ratio) support during interventions be provided (Lokon et al., 2019). This can establish a rapport between the provider of therapy and the PwD. This increases comfort and calmness in the participants, as they can enjoy the creative arts, speak comfortably, and feel safe with other persons in their environment (Morrissey et al., 2016; Raviv, 2014). Last, appropriate training should be afforded to the observers to avoid skewed ratings or analysis which could lead to reliability issues concerning the results (see Gross et al., 2015).

3.5 Conclusion

Person-centered dementia care and the artistic scholarship can agree that creativity enriches the life and well-being of PwD. No longer is the excuse accepted that once the individual is diagnosed with dementia, they are lost or deteriorating (Beard, 2004). In fact, there is a social process that is active during dementia and that is uncovered when prominence is not given to biological or neuropsychiatric markers associated with decline (Beard et al., 2009). The concept of inclusion and dementia care was solidified and maintained with the work in this ScR. We witnessed that there are programs that stimulate interaction and increase levels of personhood, and in turn positively influence QOL and well-being. cABT should be implemented not as set timed or research driven initiatives, but rather, be included as an activity for daily living and enjoyment for PwD, where connections and lived experiences are shared in a safe space.

Four therapy programs were assessed on PwD in residential facilities. MIM provided a creative outlet via visual arts. Participants were given watercolour or acrylic paints to paint a picture from a model provided or to paint whatever they wanted; this promoted tangible creative expression (Gross et al., 2015). OMA was another visual art program that focused on creative self-expressions (Lokon et al., 2019; Sauer et al., 2016). Intimate live music performances were led by professional singers to mild/severe dementia participants in nursing homes (van der Vleuten et al., 2012). Finally, medical clowns deployed strategies to identify social engagement and interaction (Ramgard et al., 2016).

Each of the included studies focused on personhood in some fashion. QOL and well-being were assessed using the GCCWBOT or a modified version, a QOL checklist, and observational field notes which were transcribed into themes. The outcomes of QOL and well-being impacted the needs of the individual's personhood in different quantitative or qualitative study designs that were led and observed by artists, researchers, staff, or family. Results explored outcomes through inferential or descriptive statistics, however, sample sizes on average were under eighty. Data generated from these studies would need to be replicated at a larger scale and/or for a longer period of time.

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3.7 Declarations

3.7.1 Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

3.7.2 Disclosure of interest

The authors report no conflict of interest.

3.7.3 Ethical Considerations

No ethics committee or institutional review board approval was required for this study as this was a ScR.

Chapter 4: Mixed-Methods Systematic Review

Article 2

As dance interventions were not represented in Chapter 3, this chapter will explore how dance impacts persons with Alzheimer’s Disease and related dementias (ADRD) and their symptoms. A mixed-methods systematic review was chosen because our eligibility was open to quantitative and qualitative studies, and this method of analysis and organization would allow for both research designs to be encompassed within this form of synthesis.

Previous dance based reviews had considered only randomized controlled trials or clinical trials which yielded low results (Karkou & Meekums, 2017; Klimova et al., 2017). By expanding the study designs and years of publication, it may help in understanding the impact of dance interventions on persons with ADRD. Further breakdown of three reviews by Karkou and Meekums (2017), Mabire et al. (2019), and Ruiz-Muelle and López-Rodríguez (2019) were completed in Chapter 4.

Impact of Dance Interventions on the Symptoms of Dementia: A Mixed-Methods Systematic Review

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Abstract

Background: Dance allows for expression of self and promotes interactions and forms of communication through a therapeutic medium.

Objectives: This mixed-methods systematic review (MMSR) aimed to determine the impact of dance interventions on the symptoms of dementia for persons with Alzheimer’s disease and related dementias (ADRD) living in residential care. Two objectives, quantitative and qualitative, provided the ability to undergo a convergent segregate narrative synthesis using the JBI approach to MMSRs.

Methods: We searched Medline (OVID), EMBASE, CINAHL (EBSCO), PsycINFO (OVID), Web of Science, AARP Ageline, and Allied and Complementary Medicine (AMED) databases, for studies published between database inception and April 2021. All types of qualitative and quantitative study designs were included. Outcomes included symptoms of dementia which influenced day-to-day function and expression of self. The risk of bias was completed using CASP, ROBINS-I, and ROB-2. The review protocol was registered on PROSPERO (CRD42021220535).

Results: Of the 567 records identified, three studies met the inclusion criteria. One included study used quantitative methods and two used qualitative methods. Symptoms of dementia were affected by the interventions and mainly decreased levels of agitation and aggression.

Conclusions: Due to the small number of studies definitive conclusions cannot be made. The included studies may suggest that dance interventions reduce the symptoms of dementia through increased expressions, emotions, and improved relationships for persons with ADRD.

Keywords: dance interventions, ADRD, dementia, residential care, symptoms of dementia

4.1 Introduction

4.1.1 Dementia and Alzheimer’s disease

Currently, over fifty million people have Alzheimer’s Disease and related dementias (ADRD) worldwide and the numbers have continued to rise, with approximately, ten million new cases per year (World Health Organization, 2020). Alzheimer’s Disease (AD), Vascular Dementia (VaD), Lewy Body Dementia (LBD), and Frontotemporal Dementia (FTD), have been classified as the most diagnosed forms of dementia (Alzheimer’s Association, n.d.-e; Deb et al., 2017). AD contributes to 60-70% of dementia cases globally (Standing Senate Committee on Social Affairs, Science and Technology, 2016; World Health Organization, 2020); VaD and LBD account for approximately 5-10% of cases each (Alzheimer’s Association, n.d.-e, b; Deb et al., 2017); and FTD comprises of 4% of the cases world-wide (Deb et al., 2017). People with Alzheimer’s disease and related dementia (ADRD) have problems associated with memory, thinking and reasoning, behaviour, and daily living activities (Alzheimer Society, 2016a; Petersson & Philippou, 2016; World Health Organization, 2020).

The prevalence of dementia doubles every five years for Canadians from less than 1% for ages 65-69 to 25% in those 85 and older (Canadian Institute for Health Information, 2018c).

4.1.2 Residential Care

Residential care in facilities encompasses a variety of living options for older adults with different supportive needs (Canadian Institute for Health Information, 2018d). Particularly, these care facilities provide persons with ADRD with full-time support (Alzheimer Society, n.d. -b), ranging from personal care and other therapeutic and support services (Canadian Institute for Health Information, 2018d). Persons with ADRD usually begin living in residential care due to a worsening condition, safety concerns, and/or an inability for caregivers to provide full-time care in the home setting (Alzheimer Society, n.d. -a). Residential care facilities can provide twenty-four-hour care and supervision, if required (Alzheimer Society, n.d. -a; National Institute of Aging, 2017).

With increasing number of persons with ADRD, infrastructure costs in residential care facilities will substantially rise due to a demand on the number of beds needed for new residents (Gibbard, 2017). Because of the rising costs and attention to care required for individuals with ADRD, the Public Health Agency of Canada (2019) recommends to "[d]evelop innovative and effective therapeutic approaches" (p. 5) where modes of intervention treat symptoms of the dementia and improve the quality of life (QOL) of persons with ADRD. Care delivery for people with ADRD has also made a shift from a biomedical approach to a more patient/person-centred care approach that recognizes each person's right to participation, dignity, and respect, and emphasizes the importance of relationships (Lee et al., 2021, p. 2).

4.1.3 Symptoms of Dementia

Behavioural and psychological symptoms of dementia (BPSD), including mood disturbances, aggression, agitation, apathy, psychosis, depression, and sleep disturbances, are commonly reported by people with ADRD and their caregivers (Bature et al., 2017; Deardorff & Grossberg, 2019; Dyer et al., 2018). These symptoms can lead to impairments in daily functioning, reduced QOL, and rapid progression of dementia (El-Saifi et al., 2018; Deardoff & Grossberg, 2019). To address these symptoms, there are currently two approaches: pharmacological and non-pharmacological.

4.1.4 Pharmacological interventions

Pharmacological interventions (El-Saifi et al., 2018; Tisher & Salardini, 2019) can provide symptom management (Abraha et al., 2017; Howard et al., 2012), but effectiveness has been found to be inconsistent (Petersson & Philippou, 2016), and side effects can be problematic. For example, one medication given to persons with ADRD is Donepezil. Donepezil is an acetylcholinesterase inhibitor that works to prevent acetylcholine from breaking down, a function to counteract the reduced cholinergic neurons in the brain (enhancing cholinergic neurotransmission) (Birks & Harvey, 2018). This mechanism inhibits the enzyme acetylcholinesterase which may improve the symptoms of dementia; however, Donepezil may cause unwanted effects as acetylcholine can be found in other parts of the body (Birks & Harvey, 2018). Notable side effects include gastrointestinal problems, insomnia, weight loss, dizziness, bradycardia, and syncope (Deardorff & Grossberg, 2019, p. 11). Another drug, Risperidone, aims to treat BPSD, but specifically aggression or hallucinations (Alzheimer's Society, n.d.). It is an atypical antipsychotic drug that can cause higher extrapyramidal symptoms compared to other atypical antipsychotics (Deardorff & Grossberg, 2019, p. 11). As well, Risperidone can increase the risk of cerebrovascular events such as stroke and mortality in persons with ADRD (Davies et al., 2018; Deardorff & Grossberg, 2019). All to say, the use of pharmacological interventions is a method used to treat the symptoms of dementia but with it comes various side effects, it can be harmful to the user.

4.1.5 Non-pharmacological interventions

Non-pharmacological interventions provide therapeutic support and aim to alleviate symptoms of dementia without medications (Abraha et al., 2017; Cohen-Mansfield, 2018; Dyer et al., 2018), and are recommended as the first line of treatment for BPSD (Guideline Adaptation

Committee, Clinical Practice Guidelines for Dementia in Australia, 2016; National Institute for Health and Clinical Excellence-Social Care Institute for Excellence, 2007 as cited in Dyer et al., 2018).

Non-pharmacological interventions can also boost creativity, self-expression, and engagement for persons with ADRD (Chancellor et al., 2014; Meekums et al., 2015). Creative arts interventions are a by-product that enhances human creativity (Demarin et al., 2016) and have shown to enhance a person with ADRD's self-identity (Schall et al., 2018). Non-pharmacological art interventions include music, dance, theatre/drama, and the arts (Beard, 2011; Cavalcanti Barroso et al., 2020; Demarin et al., 2016; Megranahan & Lynskey, 2018; Social Care Institute for Excellence, 2020; Vaartio-Rajalin et al., 2021; Ward et al., 2020). In turn, these arts interventions impact mood and QOL positively, and improve communication and cognition (Broome et al., 2020; Skinner et al., 2018). The main non-pharmacological intervention that will be investigated in this review are dance interventions.

4.1.6 Rationale

4.1.6.1 Dance Interventions

Dance is creative and universal as it allows for bodily expression of self and emotions, and increases interactions with self, others, and the environment (Ravelin et al., 2013). Dance facilitates both verbal and non-verbal communication through various forms of expression (Nyström & Lauritzen, 2005; Ravelin et al., 2013). Furthermore, dance is safe and has shown to have positive benefits on the health and well-being of persons with ADRD and is a popular intervention with rehabilitation (Hackney & Earhart, 2010), therapy (Hokkanen et al., 2003; Low et al., 2016; Sung et al., 2006; Veronese et al., 2017), or daily activity settings (Lee et al., 2015) being most popular.

Interventions using dance for people with ADRD have been appreciated in the form of dance therapy, dance movement therapy, or any form of dance-related intervention that combines music, light exercise, and sensory stimulation (Hokkanen et al., 2003). Dance interventions have also considered practices of various dance styles (ballroom, folk, contemporary) aiming to improve quality of life and other health related outcomes (Koch et al., 2019). Dance interventions can provide pleasure and play (hedonism), aesthetic experiences, authentic expression, non-verbal meaning, enactive transitional space (including agency, self-efficacy, enactments, and transformation), and creation (Koch et al., 2019).

Dance type interventions can be facilitated by dance/dance movement therapists, family members, and caregivers/care staff (Guzmán et al., 2016; Hokkanen et al., 2003; Kontos et al., 2020b; Low et al., 2016; Sung et al., 2006). When dance therapists are involved, they become concerned with embodied therapeutic relationships that can be projected and worked through "verbally, or non-verbally, or both; more or less verbal reflection may take place, depending on the level of cognitive functioning of the participants" (Karkou & Meekums, 2017, p. 4).

4.1.6.2 Previous Reviews

Manji et al. (2021, in preparation) completed a scoping review that investigated the importance of personhood in creative arts-based therapies and how the creative arts impact QOL and well-being for persons with dementia in residential facilities. Included studies in the reviews comprised of visual arts, music, and theatre/drama creative arts-based therapies, but not dance interventions (Manji et al., 2021, in preparation). In other words, published papers to date related to dance interventions for persons with dementia in residential care did not focus on improving personhood as an outcome, but rather have been based on persons with ADRD levels of cognition and behaviours (see Karkou & Meekums; Ruiz-Muelle & López-Rodríguez, 2019).

Systematic reviews that focus on the impacts of dance interventions on persons with ADRD have been conducted in recent years. Karkou and Meekums (2017), assessed the effects of dance movement therapy (DMT) on behaviour, social, cognitive, and emotional symptoms of dementia in comparison to no treatment, standard care, or other treatment (p. 5). This review also aimed to compare the different types of DMT, namely Laban and Chacian styles of dance movement. Karkou and Meekums' (2017) did not exclude studies based on sex, gender or setting. Other eligibility criteria included: randomized controlled trials (RCTs) and having interventions delivered solely from trained DMT practitioners. This systematic review had no included studies and was conducted in 2016.

Another review assessed the effect of dancing on psychological and physical outcomes, such as function, cognitive function, and QOL in persons with AD (Ruiz-Muelle & López-Rodríguez, 2019). This review included pilot or clinical trials (randomized and non-randomized) that were published or were ongoing studies from July 2000 onwards. No restrictions were placed on gender, age, ethnicity or stage of disease. Published work in English, French, Portuguese, Italian, or Spanish were identified. The authors included twelve studies in their final analysis. Of the twelve, only one was determined to be of excellent quality, four were scored as good quality, and six were scored as poor quality (Ruiz-Muelle & López-Rodríguez, 2019). Ruiz-Muelle and López-Rodríguez (2019) only included persons with AD and no other types of dementia, thus a full scope of the literature on ADRD is lacking. In addition, expanding the search prior to the year of 2000 and conducting a mixed-methods approach to incorporate qualitative studies would have been more inclusive.

Last, Mabire et al. (2019) analyzed various dance interventions (dance therapy, DMT, dance programs, and specialized dancing styles like Salsa or Waltz) for persons with dementia.

They also aimed to identify practice recommendations for the development of dance for transposing other psychosocial interventions (Mabire et al., 2019). These authors included all study designs that implemented dance as an intervention for persons with dementia living in nursing/care homes, low-care facilities, and community dwellings (Mabire et al., 2019). Fourteen studies were included in the analysis, which assessed the efficacy of treatment indications ("specificity of patients biological or psychological profiles, dosage, adverse effects and contradictions" (p. 984)), efficacy of dance interventions, and the types of study designs that focused on dance interventions in persons with dementia. The authors also assessed what factors facilitated or posed barriers to the delivery of dance interventions. This particular systematic review was limited in that articles were searched in only three databases and a quality assessment of the included studies was not conducted.

Based on the key information from Manji et al. (2021, in preparation), Karkou and Meekums (2017), Ruiz-Muelle and López-Rodríguez (2019), and Mabire et al. (2019), our review team identified existing gaps in the literature. First, expanding the number of databases when executing the search would allow for data to be pulled from multiple sources and would be more likely not leave out any potential studies. Second, years of publication should be expanded considering the number of yielded studies in previous systematic reviews was relatively low. Third, while RCTs is considered the gold standard in clinical trials, for research pertaining to persons with ADRD, RCT study designs might not always provide the most accurate representation in assessing interventions (de Medeiros & Basting, 2013; Sauer et al., 2016). The 'one size fit all' (de Medeiros & Basting, 2013) may be a restricting feature of the RCT design. Therefore, expanding on the types of study designs to include non-randomized, case studies, and other designs maybe help researchers provide more than quantitative data as lived experiences are also beneficial to research. Fourth, the search strategy for the population, should include keywords such as ‘dementia’ and ‘Alzheimer’s disease’ and other specific dementia types to appropriately capture all persons with ADRD, as recommended by Ruiz-Muelle and López-Rodríguez (2019). Fifth, intervention provided by a therapist may be a limiting factor for some residential care facilities (resources or cost). Therapists may also be disconnected with residents, thus decreasing comfort and trust. Finally, quality assessments to assess risk of bias could inform the quality and biases in the included studies, something lacking in Mabire et al. (2019).

4.1.7 Research Question and objectives

To guide our research, we asked: *In persons with ADRD living in residential care facilities, what impact do dance interventions have on the symptoms of dementia?* We identified two primary objectives:

1. *Quantitative*: Determine whether dance interventions reduce symptoms of dementia for persons with ADRD.
2. *Qualitative:* Investigate if dance interventions improve symptoms from the perspectives of persons with ADRD, intervention provider, or care staff.

4.2 Methods

4.2.1 Design

A mixed-methods systematic review (MMSR) following a convergent, segregated approach was the design of this review, as per the Joanna Briggs Institute (Lizarondo et al., 2020). Our study is reported according to the guidelines from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Page et al., 2020). The PRISMA checklist is attached as *Appendix B.*

4.2.2 Protocol and Registration

The review protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO), registration number: CRD42021220535.

4.2.3 Eligibility

Searches were conducted on published work before April of 2021. Only studies published in English were included, as we did not have a translator on our review team. Qualitative, quantitative, and mixed methods studies were included.

4.2.3.1 Population

Our target population was persons with ADRD living in residential care facilities with an inpatient population e.g., long-term care facilities, nursing homes and veterans' health centres. We did not limit the population based on age, sex, gender, ethnic or racial background, type of dementia or stage of disease.

4.2.3.2 Intervention

We examined dance interventions which can be accompanied with or without music. Dance interventions could be led by a certified dance movement instructor/therapist, caregiver, health-care professional, or staff member.

4.2.3.3 Comparator

If an included study was a RCT or quasi-randomized controlled trial, the comparator was either no treatment or treatment as usual. For qualitative studies, there was no comparator.

4.2.3.4 Outcome

This review investigated the impact of dance interventions on the symptoms of dementia which influence day-to-day functioning and the expression of self. These outcomes included measures of BPSD, or other measures of symptoms that influence mood, aggression, agitation, and memory. Outcomes were reported by a third-party assessor (i.e., care home staff, researcher, or proxy) and/or by people with ADRD.

The qualitative component of this review considered studies that examined perspectives, perceptions and experiences of changes in symptoms through interviews and focus groups by people with ADRD or with other staff, family, and proxy.

4.2.3.5 Exclusion

Participants who received end-of-life or palliative care were excluded. Studies that included persons with ADRD who were not living in residential care facilities were not included in the current review. Further, studies which assessed interventions that were delivered as part of day-program activities (i.e., not facilitated and delivered to in-patients at residential facilities), were excluded.

As per our MMSR protocol, studies containing a high risk of bias in ROB-2 or critical risk of bias in ROBINS-I were excluded. Further details on exclusion is located in the *Assessment of methodological quality* section.

4.2.4 Search Strategy and information sources

A literature search using databases Medline (OVID), EMBASE, CINAHL (EBSCO), PsycINFO (OVID), Web of Science, AARP Ageline, and Allied and Complementary Medicine (AMED) was conducted on 25 September 2020. A second literature search was conducted on 5

April 2021, utilizing the same search terms to ensure we had not missed any studies that had been published in the interim. No date restrictions were placed on the search strategies as dates of inclusion were from database inception to date of the searches.

Backwards and forwards citation searches were completed next. A backwards-citation search screened the reference list of our included articles for further studies that may have met our inclusion criteria; a forward-citation search screened studies which had cited the included articles. Indexing was completed using SCOPUS and Pubmed. Seven articles were retrieved through backwards-citation searching, and another seven articles were retrieved through forwards-citations searching. Of those fourteen, three were removed as duplicates and eleven were kept for continued screening.

The search strategy was configured with the help of a research librarian (SV). The strategy focused around three main search concepts: the intervention (dance), population (dementia/Alzheimer's Disease), and the setting (residential facilities) in which the intervention was delivered. *Table 1* contains an example of the search strategy as it was used in MEDLINE. Refer to *Appendix D* for more search strategies used in the other databases that were searched for this review.

In situations where identified studies were incomplete or were in protocol stages, the first author (IM) reached out to the corresponding author to inquire about the study's status (n = 2). The first author (IM) also contacted the Interlibrary Loan team at the University regarding articles that could not be retrieved from. Unfortunately, because of the COVID-19 pandemic library resources were scarce as some articles could not be retrieved in full (n = 5). The review team marked those articles as "Unable to find" during the screening process.

Table 1. Search Strategy within MEDLINE.

Concept	#	Search Terms
Therapy	1	Dance Therapy/
	2	Movement/
	3	Dancing/
	4	danc*.ti,ab.
	5	((body or authentic) adj3 movement*).ti,ab.
	6	(movement adj3 therap*).ti,ab.
	7	*1 or 2 or 3 or 4 or 5 or 6*
Population	8	Dementia/
	9	Alzheimer disease/
	10	dementia.ti,ab.
	11	Alzheimer*.ti,ab.
	12	*8 or 9 or 10 or 11*
Setting	13	residential facilities/ or homes for the aged/
	14	long-term care/
	15	nursing home*.ti,ab.
	16	long-term care.ti,ab.
	17	ag?ing home*.ti,ab.
	18	Nursing Homes/
	19	senior? home*.ti,ab.
	20	senior? residence*.ti,ab.
	21	dementia care facilit*.ti,ab.
	22	((nursing or ag?ing or senior? or long-term) adj3 (home* or facility* or residenc*)).ti,ab.
	23	*13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22*
	24	***7 and 12 and 23***

4.2.5 Assessment of methodological quality

To assess the quality of the studies we validated the risk of bias (ROB) using three tools: the Critical Appraisal Skills Programme (CASP) for qualitative research (Critical Appraisal Skills Programme, 2019); the revised Cochrane ROB for randomized trials (ROB-2) (Higgins et al., 2019); and finally, the Risk of Bias In Non-randomized Studies - of Interventions (ROBINS-I) (Sterne et al., 2016a, b).

The guidance documents for ROB-2 and ROBINS-I were utilized to help with scoring within each domain and for each overall ROB score (Higgins et al., 2019; Sterne et al. 2016b). Unlike, the ROB-2 (Higgins et al., 2019) or ROBINS-I (Sterne et al., 2016a, b), little guidance was given to assess final levels of risk when including or excluding using the CASP tool (Long et al., 2020). Therefore, all studies using the CASP were included. The CASP is scored by answering 9 questions with Yes, Can’t Tell, and No, and a final question is answered on the research’s value (Critical Appraisal Skills Programme, 2019).

Both the ROB-2 and ROBINS-I asked signalling questions which were answered with Yes/Probably Yes, No/Probably No, and No Information. Scoring for each ROB-2 bias section included: low risk, some concerns, and high risk. Scoring for each ROBINS-I section included: low risk, moderate risk, serious risk, critical risk, and no information. Risk scores were given at the end of each bias section, followed by an overall bias at the end of the ROB-2 and ROBINS-I.

Studies that had an overall ROB score that was either high, ROB-2, (Higgins et al., 2019) or critical, ROBINS-I, (Sterne et al. 2016a, b) were excluded from the final studies in this review, as per our protocol. The ROB-2 guidance document on exclusion of studies, states “[w]e recommend that this be done only when it has been pre-specified in the protocol that trials judged to be at ‘High’ risk of bias will play no role in the synthesis of evidence (Higgins et al., 2019, p. 7). The ROBINS-I says that a critical ROB can be excluded from a study as a critical ROB “is too problematic to provide any useful evidence and should not be included in any synthesis” (Sterne et al., 2016b, p. 17).

4.2.5 Data collection and extraction process

Literature search results were uploaded into Covidence, an internet software that facilitates collaboration and screening among the reviewers. Duplicates were removed by Covidence, followed by independent title/abstract and full-text screening of articles by two reviewers (IM & SW). Any disagreements were resolved via discussion.

A data extraction form was generated by the first author (IM) to gather relevant and necessary study information on Microsoft Excel. Information such as study characteristics, demographics of participants, stage of ADRD, symptoms of dementia, intervention type, outcomes, key findings, recommendations for future studies, strengths, and limitations were included in the extraction form. For the quantitative data, an extraction point was created for measurement tools that had been used to gage pre/during/post measurements of symptomatic changes. For the qualitative data, key themes and important quotations were extracted. For both quantitative and qualitative studies, we obtained important information that underlined the impact of dance interventions on our target population.

4.2.6 Planned methods of analysis

A narrative synthesis was chosen for our review, as a meta-analysis (for the quantitative studies) was not possible due to the low number of studies included in this review. A narrative synthesis is used when statistical meta-analysis is not feasible due to methodological heterogeneity between the studies included (Conserve et al., 2017).

Our MMSR separated the quantitative and qualitative syntheses, which was then followed by an integration of the results from the syntheses (Lizarondo et al., 2020). Further, the universal steps involved in a regular systematic review such as developing review questions, eligibility criteria, conducting a search strategy, critical appraisal of included studies, data extraction, and synthesis also applied to this MMSR (Lizarondo et al., 2020).

4.3 Results

4.3.1 Study Selection

The database searches generated 567 articles. From these articles, 393 duplicates were removed by Covidence and 175 entered the Title/Abstract screening phase. From the Title/Abstract, 136 were excluded by two reviewers (IM & SW), as they did not clearly meet the inclusion criteria. Therefore, 39 studies were examined for full-text screening. Two reviewers (IM & SW) read each article to evaluate the inclusion criteria at a deeper level; 34 articles were excluded for various reasons such as, wrong publication type (e.g., book, periodical), wrong setting, wrong intervention, unable to find, wrong outcomes, wrong patient population, language, or the study's study design was wrong (e.g., protocol with no data).

A total of five studies met the inclusion criteria with full-text screening and were analyzed using the ROB quality assessment tools CASP, ROB-2, and ROBINS-I. After these assessments, three studies were included in the MMSR. *Figure 1* summarizes the selection process using a PRISMA Flow Diagram.

4.3.2 Risk of Bias

Tables 2-4 summarize the ROB assessment scores for each study that met inclusion criteria, as well as the two excluded studies at the full-text screening stage.

4.3.2.1 Included

Two qualitative studies, Goldstein-Levitas (2019) and Guzmán-García et al. (2012) were assessed using CASP (Critical Appraisal Skills Programme, 2019) and both studies were included. However, both studies did not provide a full transcript of how their data was generated (Goldstein-Levitas, 2019; Guzmán-García et al., 2012). This level of selection bias could have restricted the final results and only provided the reader with information that was thought to improve symptoms. One quantitative study, Duignan et al (2009) was assessed using the ROBINS-I tool (Sterne et al., 2016a, b) and was judged to contain a serious risk of bias. There was a potential bias in confounding related to medication changes and selection of participants.

Further, bias in measurement outcomes was caused as the assessors were aware and participated in the intervention.

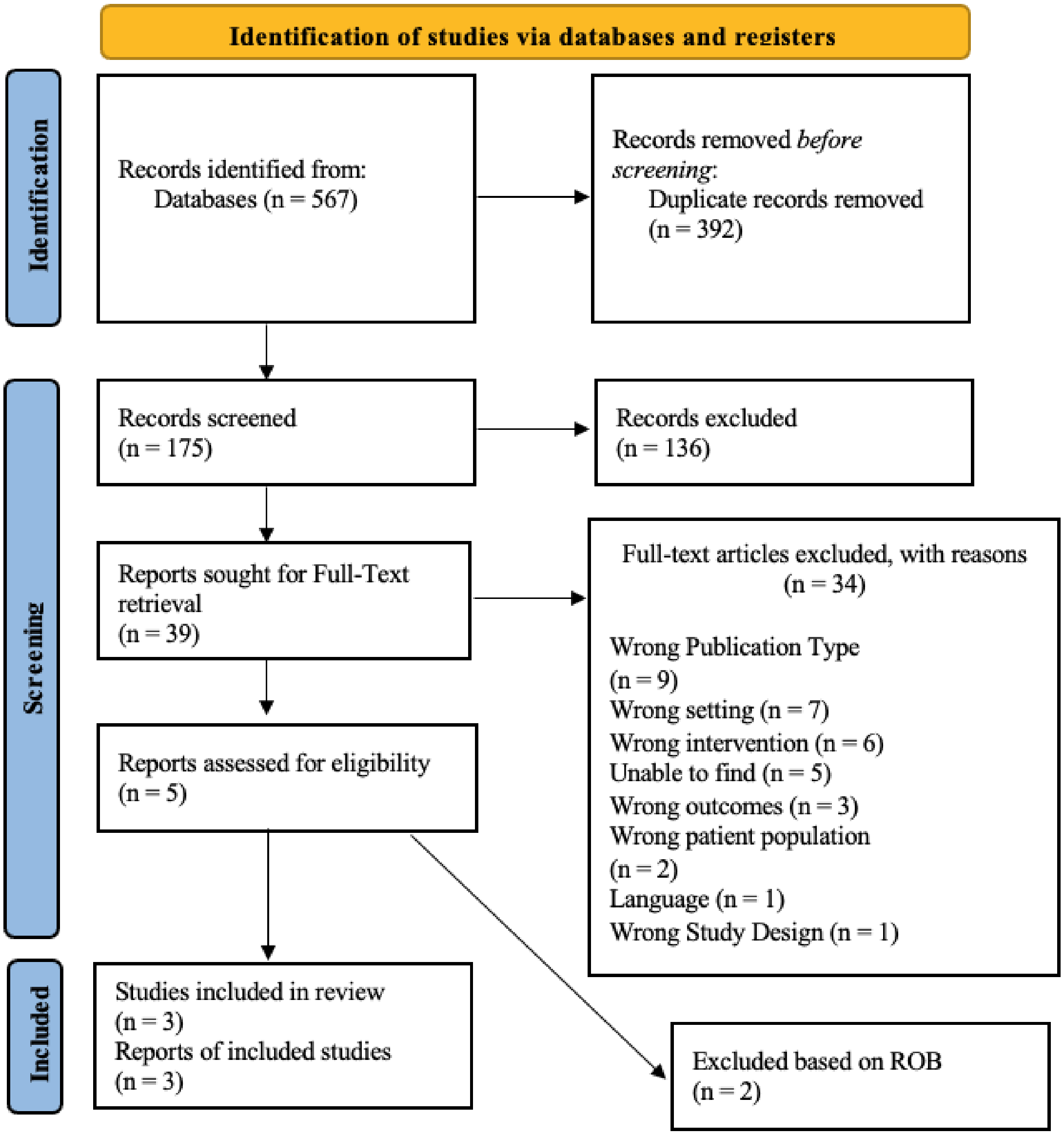

Figure 1. PRISMA Flow diagram (Page et al., 2021).

Table 2. CASP.

Signalling Questions		**Goldstein-Levitas (2019)**	**Guzmán-Garciá (2012)**
Section A	1. Was there a clear statement of the aims of the research?	Yes	Yes
	2. Is a qualitative methodology appropriate?	Can't tell	Yes
	3. Was the research design appropriate to address the aims of the research?	No	Yes
	4. Was the recruitment strategy appropriate to the aims of the research?	No	Yes
	5. Was the data collected in a way that addressed the research issue?	No	Can't tell
	6. Has the relationship between researcher and participants been adequately considered?	No	Can’t tell
Section B	7. Have ethical issues been taken into consideration?	No	No
	8. Was the data analysis sufficiently rigorous?	No	Yes
	9. Is there a clear statement of findings?	No	Can't tell
Section C	10. How valuable is the research?	• DMT was a beneficial intervention for people with ADRD • DMT can be used in the residential facility to improve symptoms of dementia • Author recommends employing Pilot or RCT interdisciplinary studies to conduct DMT at a larger scale and to look at QOL scales which will aid in validating efficacy of DMT for aggression in Dementia adults.	• Danzón provided enjoyment through improved mood, behaviour, mobility, mental stimulation, reminiscence, and socializing and communicating • Dancing enhanced interactions between participants and findings are in line with other studies. • Helped the authors pivot to a larger quantitative study.
Final Decision		**Include**	**Include**

Table 3. ROBINS-I.

Domains	**Duignan et al (2009)**
Bias due to confounding	Serious
Bias in selection of participants into the study	Low
Bias in classification of interventions	Low
Bias due to deviations from intended interventions	Low
Bias due to missing data	Low
Bias due to measurement of outcomes	Serious
Bias in selection of the reported result	Low
Overall Bias	*Serious*
Final Decision	**Include**

Table 4. ROB-2.

Domains	**Sung et al (2006)**	**Guzmán et al (2016)**
Risk of bias arising from the randomization process	Low	Low
Risk of bias due to deviations from the intended interventions (effect of assignment to intervention)	N/A	N/A
Risk of bias due to deviations from the intended interventions (effect of adhering to intervention)	Some concerns	Some concerns
Missing outcome data	Low	Low
Risk of bias in measurement of the outcome	High	High
Risk of bias in selection of the reported result	Low	High
Overall risk of bias	*High*	*High*
Final Decision	**Exclude**	**Exclude**

4.3.2.2 Excluded

Two quantitative studies, Sung et al. (2006) and Guzmán et al. (2016), were excluded due to a high ROB judgement from the ROB-2 quality assessment (Higgins et al., 2019). Sung et al. (2006) was excluded due to bias in the outcome measures domain. Outcomes were measured by nursing home staff, making them aware of the intervention. This may have resulted in biased reporting on the Cohen-Mansfield Agitation Inventory (CMAI) from staff. Guzmán et al. (2016) was also excluded due to bias in the outcome measures. Their study's outcome measures were conducted by staff members. However, level of participation varied amongst the staff. Those who danced and scored may have observed changes in the Dementia Mood Assessment Scale differently compared to those who only observed and scored. In addition, a ROB in the selection of reported results also influenced a high ROB in Guzmán et al. (2016). Multiple eligible outcome measurements were available in the study, including measurement scales and varying time points of intervention and observation, which remained unclear at times.

4.3.3 Study Characteristics

Table 5 provides a summary of the included studies in the review. Studies included in this review were conducted by research teams across the globe. The one quantitative study (Duignan et al., 2009) represented Australia and assessed CMAI scores from pre and post intervention. The two qualitative studies represented the United States (Goldstein-Levitas, 2019) and England (Guzmán-García et al., 2012), respectively. Of the two, one qualitative study (Goldstein-Levitas 2019) reported two narrative case vignettes, whereas the other (Guzmán-García et al. 2012) used a grounded theory methodology.

Across all studies, data was collected from a total of 47 persons with ADRD (Duignan et al., 2009; Goldstein-Levitas, 2019; Guzmán-García et al., 2012). Persons with ADRD were categorized by individual studies as having dementia, mild to severe dementia, and Alzheimer's disease and other forms of dementia. The quantitative study (Duignan et al., 2009) and the one of the two qualitative studies (Guzmán-García et al. (2012) did not mention the severity of ADRD that was experienced by residents, or what stage of ADRD residents were at the time of the intervention. Goldstein-Levitas (2019) mentioned their population ranged from mild to severe dementia in their qualitative study.

Dance interventions lasted between four to six weeks (Duignan et al., 2009; Guzmán-García et al., 2012). One study did not disclose the length of the intervention (Goldstein-Levitas, 2019).

All participants resided in residential facilities. Participants included in the quantitative study by Duignan et al. (2009) recruited participants from a low-care facility. One qualitative study (Goldstein-Levitas, 2019) recruited from a residential facility (Vignette one) and memory care unit (Vignette two). The other, recruited from two private, residential care homes (Guzmán-García et al., 2012).

4.3.3.1 Dance interventions

Each included study investigated a different type of dance intervention. First, the study by Duignan et al. (2009) implemented a Wu Tao intervention which utilized music and subtle movement. Wu Tao was designed by a former ballerina where she combined her interest in people, emotions, and Japanese shiatsu (Duignan et al., 2009). Wu Tao (Duignan et al., 2009), was led by instructors, and persons with ADRD were observed by a senior behaviour consultant. Sessions were held in a therapy room which catered to the needs and comforts of the persons with ADRD (e.g., ability to move, sit, relax, and spacious enough; Duignan et al., 2009). This study lasted for a duration of four weeks with Wu Tao delivered on a weekly basis (Duignan et al., 2009).

Second, Goldstein-Levitas’ (2019) implemented a DMT intervention. DMT is a holistic, psychotherapeutic discipline based on the mind and body; movement provides an outlet for reflection of thoughts and emotions (Goldstein-Levitas, 2019).

Last, Guzmán-García et al. (2012) implemented the Danzón psychomotor intervention. Danzón is a Latin ballroom dancing style practiced by older adults in Mexico and is geared towards pair dancing (Guzmán-García et al., 2012). This small-step paired dance style is of moderate intensity and is defined by starting and stopping at each music bar. A dancer following Danzón can be seen gently moving their hips and body through movements divided into short sections facilitated by a teacher with or without dancing experience (Guzmán-García et al., 2012). Danzón sessions were administered for thirty-five minutes, twice a week, for six weeks by the first author and were facilitated by care staff from the care homes (Guzmán-García et al., 2012).

4.3.4 Findings of the Review

4.3.4.1 Quantitative Evidence

4.3.4.1.1 Wu Tao. Duignan et al. (2009) assessed the impact Wu Tao had on agitation for six ADRD individuals. Consent was received from persons with ADRD and family members were made aware of the sessions (Duignan et al., 2009). Agitation levels were scored using CMAI at pre and post intervention stages.

Table 5. Summary of included studies in the review

Study, *Country*	**Population**			**Intervention**	**Health Outcome**	**Study Design**	**Duration**	**Objectives**	**Key Findings**	**Measurement Tool**
	Sample size	**Type of ADRD**	**Age or Mean age**							
Quantitative Studies										
Duignan et al. (2009), *Australia*	N = 6	Dementia	Mean age = 85.1	Wu Tao	Agitation	Pilot – *quantitative*	4 weeks (weekly)	Evaluate the effectiveness of Wu Tao dance therapy & assess the impact on agitation	• Wu Tao allows for verbal and non-verbal expression that decreases agitation; Agitation scores averaged a reduction of 6.16 Cohen-Mansfield Agitation Inventory scores in the six participants	Cohen-Mansfield Agitation Inventory *Observer: senior behaviour consultant*
Qualitative Studies										
Goldstein-Levitas (2019), *United States*	*Vignette One*: N = 15 *Vignette two*: N = 13	Mild to Severe Dementia	58-96 years 62-93 years	Dance Movement Therapy (DMT)	Aggression, Agitation	Narrative research (vignettes) – *qualitative*s	N/A	Shed light on challenges within the long-term system and affirm that DMT is a beneficial approach for dementia adults	• Encouraging movement to a counting sequence allowed participants to shake out their frustrations. This effectively promoted a stable structure and decreased aggressive behaviour • Sharing of thoughts relaxed the participants • Motown music helped mobilize and excite the residents • Residents who led and followed within DMT sessions showed to have a sense of belonging and helped each other	N/A *Observer: First Author*
Guzmán-García et al. (2012), *England*	N = 13	Alzheimer's Disease (AD); Frontotemporal Dementia (FTD); Vascular Dementia (VaD); Mixed (AD and VaD); Parkinson's Disease Dementia (PDD)	Mean age = 80.5	Danzón (Latin ballroom)	Behaviour and psychological symptoms	Pilot – *qualitative*	6 weeks (35 mins 2x a week)	Analyze the effect of Danzón in two care homes on people with dementia	• Danzón was beneficial for people with various stages of dementia to participate • Residents felt a renewed vigour, sense of fitness, and vitality after participating in Danzón • Dance is easy to learn and increased interaction; social touch suggested tactile stimulation (decreased anxiety); and, Danzón provided a break from daily resident activities, as well as, when delivered by carers provided the residents with familiarity and comfort • Staff reported position impact on the residents and their own levels of well-being and satisfaction • Residents observing the dancing gained benefits as well	N/A *Observer: First Author*

The results show that four out of six participants demonstrated positive changes in their agitation levels following the intervention (Duignan et al., 2009). The two residents who did not show improved results were cited as undergoing medication changes which could have "contributed to their increased scores" (Duignan et al., 2009, p. 10). Overall, mean CMAI score decreased by 6.16 points from initial to follow-up (66.83 reduced to 60.67). A therapeutic bond between the residents and care staff was also reported (Duignan et al., 2009).

The authors deployed a questionnaire to the residents after the intervention, which assessed enjoyment, mood, likelihood to continue Wu Tao, and the effects of having staff participation during (Duignan et al., 2009). A second questionnaire was distributed to care staff, which assessed the perceived benefits of the intervention, job satisfaction, relationships with participants, resident behaviours, and other observation-based questions (Duignan et al., 2009). On both questionnaires, an average of more than 50% of responses reported a 'yes' to a questionnaire question. For example, one question on the residents' questionnaire asked, "Do you feel the dance group has improved your mood, that is, made you happier?" (Duignan et al., 2009, p. 10). 83% of participants with dementia responded with 'yes'. The residents also remarked that they felt happier following the intervention, and that they wanted to participate in Wu Tao again (Duignan et al., 2009). In the staff's questionnaire, one question asked, "Did you notice any changes in residents' behaviours throughout or following the sessions? And, if so, what did you notice?" (p. 12). The staff also responded favourably to this question with 83% saying 'yes'. The staff noted that residents were happy, relaxed, focused, and more settled after the Wu Tao sessions (Duignan et al., 2009).

4.3.4.2 Qualitative Evidence

4.3.4.2.1 DMT. The author recounts two vignettes where they share personal experiences of facilitating DMT in persons with ADRD. Vignette One's target population ranged in age from 58-96 years, and participants were described as having mild to severe dementia. The goal of the intervention described in this vignette was "to promote reminiscence, to decrease aggression, and to discharge and process fear and frustration" (Goldstein-Levitas, 2019, p. 293). The author did so by playing nostalgic music that promoted rhythm and structure which in turn helped to regulate impulse control caused by dementia-associated aggression (Goldstein-Levitas, 2019).

Vignette Two provided therapeutic value in decreasing agitation, frustrations, and loss of control. This Vignette used Motown Music for persons with mild to severe ADRD, aged 62-93 years. Goldstein-Levitas (2019) narrates a story of one individual, Ms. C, who was often distressed and combative. However, once the DMT session began, Ms. C would appear more focused and less agitated through softened facial expressions, an occasional smile, and feet tapping. As a result, When Ms. C was actively engaged with the DMT intervention and her agitation decreased. Other members of the DMT session were also seen to initiate feet tapping, clapping, and singing along with the tunes as a sign of enjoyment and decreased agitation.

4.3.4.2.2 Danzón. Guzmán-García et al. (2012) examined the effect of Danzón on persons with ADRD using a grounded theory methodology. Participants included thirteen care home residents with dementia; eight people were diagnosed with AD, two were diagnosed with FTD, one was diagnosed with VaD, one with mixed (AD and VaD) dementia, and one with Parkinson's Disease Dementia.

Interviews were conducted after the sixth week of the intervention. Of the thirteen persons with ADRD who participated in the intervention, seven participated in the interviews. All nine members of the care staff and residents were interviewed twice (Guzmán-García et al., 2012). Two conceptual models were developed through the grounded theory methodology, one for the residents and one for the staff, which contained the positive and negative responses to Danzón, and reflected on the experiences of each participant (Guzmán-García et al., 2012).

In the conceptual model for the residents, a central theme of Enjoyment emerged, with six sub-themes: mood, behaviour, mobility, mental stimulation, reminiscence, and socializing and communicating. Guzmán-García et al. (2012) noted Danzón promoted a healthy mood and behaviours among participants and facilitated social stimulation between participants. One carer recognized that by undergoing Danzón in the corridor helped aid in reducing a resident's anxiety. Residents expressed their likes and dislikes towards Danzón, which aided in increased competence, pride, and enjoyment. Moments of interactions and dancing improved behaviour, mood, and anxiety in participants with ADRD (Guzmán-García et al., 2012).

4.3.5 Integration of quantitative and qualitative evidence

4.3.5.1 Decreases in Symptoms of Dementia

The quantitative study of Duignan et al. (2009) and the qualitative study of Goldstein-Levitas (2019) found a decrease in agitation. Duignan et al. (2009) saw decreased CMAI scores from pre to post intervention by 6.16. Similarly, in Goldstein-Levitas (2019), with the example of Ms. C, her level of agitation was decreased through the rhythmic structure provided by the nostalgic music and movement associated with DMT. Both studies saw a decrease in agitation.

Guzmán-García et al. (2012) also validated that their findings showed dance interventions can benefit symptoms of dementia, BPSD, through evoking enjoyment in dance. Enjoyment was subjectively measured from the responses' given by the residents and staff.

4.3.5.2 Impact of Dance Interventions

All three included studies recognized the value of dance interventions in persons with ADRD. Duignan et al. (2009) recognized that Wu Tao had the capacity to reduce agitation from treatment and prevention perspectives, which can be beneficial for both residents and staff.

Goldstein-Levitas (2019) showed that DMT acted as a non-pharmacological approach which can aid in reducing aggression and agitation in persons with ADRD. The author underwent a series of dance movements that effectively showed how persons with ADRD respond to stimulation and various redirects to continue movement qualities.

The impact of Danzón in Guzmán-García et al. (2012) exhibited that dancing produced positive emotions and feelings, participants looked forward to dancing, they expressed their likes and dislikes, a sense of identity formed from the group participation, memories were re-imagined, and new ones were created. Furthermore, a renewed sense of fitness, vitality, and vigour were articulated (Guzmán-García et al., 2012). Persons undergoing the intervention provided their thoughts on the intervention and this helped understand the uniqueness and individuality of how different people feel after undergoing dance interventions. Expression is an important benefit that can be shared from verbal and non-verbal cues. Therefore, this qualitative studies evaluated a refreshed understanding on how a person with ADRD might respond to an intervention and its effect on their overall health.

4.4 Discussion

The aim of this MMSR was to evaluate the impact of dance interventions on the symptoms of dementia in persons with ADRD living in residential facilities. To complement our research directives, we established two objectives: 1) determine if dance interventions reduce symptoms of dementia in our target population (quantitative), and 2) investigate the influences of dance interventions from perspectives of persons with ADRD, provider of the intervention, or care staff (qualitative).

A total of three studies were included in this MMSR. The one quantitative study (Duignan et al., 2009) assessed agitation through CMAI scores pre/post of Wu Tao. One qualitative study evaluated DMT on agitation and aggression through two vignettes (Goldstein-Levitas, 2019) and another qualitative study (Guzmán-García et al., 2012) executed a grounded theory methodology to determine the effects of Danzón.

Current research on Wu Tao and Danzón is limited. DMT, a more common type of dance intervention, has previously been studied as an intervention for populations including, but not limited, to persons with dementia, Parkinson's disease (Koch et al., 2016), cancer patients (Bradt et al., 2015), and in adolescents with depression (Jeong et al., 2005; Meekums et al., 2015). These studies support dance as a tool that provided individuals a positive mode of intervention and improved any negative psychological symptoms (Jeong et al., 2005). Goldstein-Levistas' (2019) approach to DMT soothed the participants' aggression and agitation and thus, allowed for the participants to express themselves freely. The ability to discharge frustrations through a creative medium allowed for a) expression of self and emotions and b) created social engagement between participants (Goldstein-Levitas, 2016). This 2019 study's findings were consistent with the findings of other studies concerning the efficacy of DMT (see Goldstein-

Levitas, 2016; Ho et al., 2020). DMT also attains a holistic approach that has the capacity to connect the mind to the body (Goldstein-Levitas, 2016; Ho et al., 2020) and can decrease the harmful effects of symptoms influencing ADRD (Goldstein-Levitas, 2016). In addition, DMT can improve and sustain the well-being and care for persons with ADRD (Ho et al., 2020).

Our MMSR showcased studies that were designed as an intervention for ADRD and aimed to reduce the symptoms of dementia on the individual’s daily life. Particularly, non-pharmacological approaches are needed in complementing and supporting the care of persons with ADRD. Participation through non-pharmacological routes suggests that the implementation of interventions after diagnosis can improve QOL and well-being of persons with ADRD (Choo et al., 2019; Ruiz-Muelle & López-Rodríguez, 2019; Weise et al., 2018).

Interventions for individuals in residential care facilities is increasingly important. Residents commonly report lack of meaning in their lives, limited opportunities for engagement, and paternalistic communication with staff (Theurer et al., 2015). Interventions that engage the perspectives and contributions of residents advances social identity, relationships, and social productivity (Theurer et al., 2015). This provides a sense of purpose, improved self-esteem and behaviours that support well-being, and accessibility that allows for active participation (Theurer et al., 2015). Theurer et al. (2015) developed the Resident Engagement and Peer Support (REAP) model which speaks to developing and designing new programs by and for the residents based on what they believe is meaningful for them. As such, autonomy and decision making from residents, especially those with ADRD, should be considered when designing interventions. The benefit must have the resident’s needs in mind.

Dementia-friendly communities are also necessary (Lin, 2017). These communities include recognizing the value in the setting/place (environment, transport, housing), the people (family, careers, community residents' support), the resources (services and facilities), and the networks in place (planning, communicating, and collaborating action items), thereby being beneficial for persons with ADRD (Lin, 2017).

Often, stigma (Dupuis et al., 2016; Hossain & Mughal, 2021; Kontos et al., 2020a), isolation (Holmén et al., 2000) and/or social exclusion (Biggs et al., 2019; Dupuis et al., 2016), and negligence (Bolt et al., 2019; Cousins et al., 2021; Harding & Peel, 2013) are common issues witnessed in the care of those with ADRD. It is therefore important to continue to not only improve symptoms of dementia but also underline the importance of person-centred care (Kitwood, 1997a, b) for those involved in these dance interventions. The tenets of personhood (Kitwood, 1997), selfhood (Sabat 2002, 2005) and embodied selfhood (Kontos, 2005, 2011), as well as person-centred care are valuable in dementia care.

4.4.1 Limitations

When interpreting the results included in this MMSR, we must exercise caution due to the small number of studies yielded from our search strategy, and the exclusion of some papers due to quality concerns. We were also unable to conduct a meta-analysis as not enough studies provided quantitative data. This meant we could not calculate effect size and this limited our ability to meta-analyze. Furthermore, none of the included studies had a RCT design and therefore, we were unable to assess comparative data (e.g., different intervention).

We included English-only articles which can contribute to a language bias (Morrison et al., 2009) by excluding articles in a different language. However, as this was an unfunded project, we did not have the means necessary to hire a translator to enable the inclusion of studies published in languages other than English. Additionally, we conducted our review during COVID-19, therefore, the availability of some articles during the screening phases was reliant on the Interlibrary Loan system. Due to the pandemic, the accessibility of the Inter Library Loan network was compromised for our research team, and this limited the number of papers that we were able to retrieve for full text review (n = 5). The first author (IM) contacted authors to either request an updated version of a study, or to request a copy of the study be sent outside of the library system (n = 2). Not all contacted authors responded. Moreover, we did not search grey literature, which could contribute to publication bias in our data.

We excluded two studies that were judged to contain a high ROB. These two studies contained biases in the measurement of outcomes and reported results domains in the ROB-2. We would hope that future studies placed a greater emphasis on reducing bias in these domains, as biased data can negatively impact the validity (Pannucci & Wilkins, 2010; Viswanathan et al., 2012) or provides low confidence in the findings of the study. The decision to exclude these two studies further reduced the number of included studies in the review. The small number of studies that met our inclusion criteria demonstrated a paucity of primary research that investigates the impact of dance interventions on the symptoms of dementia in persons with ADRD who live in residential facilities.

4.4.2 Implications for future research

The implementation of dance interventions have been found to have a positive impact on the overall symptoms of dementia in persons with ADRD living in residential facilities. As demonstrated by the findings of this review, there is a scarcity of available research that investigates the extent to which dance interventions contributes to the health of individuals with dementia. Our findings emphasize the need for further research that investigates a robust variety of non-pharmacological interventions through dance, specifically for individuals with dementia residing in residential care. Further, greater emphasis should be placed on the extent to which these interventions affect overall health, self-expression, self-efficacy, self-worth, and on the QOL and well-being of persons with ADRD.

Eventually, dance, other creative arts-based therapies, and participatory based arts will turn to technology and digital delivery (Waycott et al., 2019), as seen recently with Sharing Dance Seniors (SDS) (Kontos et al., 2020b; Kosurko et al., 2020). The remote delivery aspect of SDS allows for flexible delivery of the intervention, which appeals to persons with ADRD who are socially isolated in residential facilities or in rural communities (Kontos et al., 2020b; Kosurko et al., 2020). This has been increasingly important in light of the COVID-19 pandemic. In addition, remote delivery is essential for those who are unable to connect with others in a normal face-to-face environment (Kontos et al., 2020b). Kontos et al. (2020b) highlight the importance of reaching remote settings where person contact is limited and must be done through a virtual medium, such as SDS. The findings of Kontos et al. (2020b) also inform future research into the virtual delivery of dance interventions as dance instructors can now be with the persons with ADRD through virtual means from any location.

Evaluation studies found that assistive technologies improved independence, behavioural symptoms and QOL in persons with ADRD, and reduced stress amongst their caregivers (Meiland et al., 2017). Chen et al. (2017), investigated the acceptance of robot partners in dance-based interventions. This new approach, in theory, provides an alternative to partner dancing; however, robot dancing could remove the “human touch”. Human contact may be important to the success of the intervention, but further research is needed on the utility and acceptability of robots and other assistive technologies, and the influence of human contact on the efficacy of dance interventions.

4.5 Conclusion

Despite the small number of studies included in this MMSR, we found preliminary evidence that three different types of dance interventions (Wu Tao, DMT, and Danzón) demonstrated efficacy in improving the symptoms associated with dementia among persons with ADRD living in residential facilities. Wu Tao positively impacted the symptoms of agitation as seen in the reduced CMAI scores from pre- to post-intervention (Duignan et al., 2009). Goldstein-Levitas (2019) recounted their work with the ADRD population, and how disconnection, distress, and disorientation changed with improved symptoms of aggression and agitation following a DMT session. Danzón was an alternative dance intervention that produced positive change in BPSD amongst persons with ADRD (Guzmán-García et al., 2012). Dance interventions also increased a sense of belonging among participants with ADRD and increased expression, emotions, and social relationships. Additional research is desperately needed that exclusively assesses the potential of alternative forms of non-pharmacological interventions using dance for people with ADRD who live in residential facilities.

4.6 Acknowledgements

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4.7 Declarations

4.7.1 Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

4.7.2 Disclosure of interest

The authors report no conflict of interest.

4.7.3 Ethical Considerations

No ethics committee or institutional review board approval was required for this study as this was a systematic review.

Chapter 5: Discussion

For this thesis, I set out to investigate, through two reviews, creative arts-based interventions in residential care homes for people/person(s) with dementia (PwD)/Alzheimer's Disease and related dementias (ADRD). The concepts of population (dementia), intervention (creative arts), and setting (residential care facilities) were incorporated in the search strategy of both reviews, which can be found in Chapters 3 and 4. The main ideas in this chapter will suggest on improving or complementing the current dementia strategy document discussed in Chapter 1.

5.1 Research endeavours

Once again, the review questions in the articles were as follows:

1) Which creative arts-based therapies focus on the personhood of PwD and also, place significance on improving personhood, QOL and well-being for those living in residential facilities? (scoping review)
2) In persons with ADRD living in residential care facilities, what impact do dance interventions have on the symptoms of dementia? (mixed methods)

5.1.1 Scoping Review

Chapter 3 differed from Chapter 4 simply because the outcomes addressed in the scoping review (ScR) were central to the framework of personhood by Tom Kitwood and to a greater extent, quality of life (QOL) and well-being, which were measured through assessment tools. These tools varied from the Greater Cincinnati Well-being Observation Tool (GCCWBOT), an observation list focusing on QOL in persons with mild and severe dementia, and content analysis of themes through interactions. Visual arts and painting related creative arts seemed to benefit from the use of the GCCWBOT, particularly the version by Lokon et al. (2019). Further research should continue to validate this tool and improve on the IRR that was relatively moderate when reported by Kinney and Rentz (2005). Measurement assessment tools for other creative arts-based therapies (cABT) were rather unclear as they were not as common or seen in the ones identified by Algar et al. (2016), Bowling et al. (2015), Missotten et al. (2016), and Ready and Ott (2003). Personhood and the creative arts worked well together by increasing and supporting the psychosocial needs of comfort, attachment, inclusion, occupation, identify, and agency (Kaufmann & Engel, 2016; Kitwood, 1997a, b). The cABT of Memories in Making (MIM) (Gross et al., 2015), Opening Minds through Art (OMA) (Lokon et al., 2019; Sauer et al., 2016), medical clowns (Ramgard et al., 2016), and live performances of music (van der Vleuten et al., 2012) initiated personhood and maintained it through these interventions.

5.1.2 MMSR

The MMSR addressed the lack of dance related interventions found from the results in Chapter 3 and sought to close the gaps located in current dance literature. As well, the MMSR was established to understand why dance interventions may not have been represented in the first review. Due in large part to dementia care focusing on the symptoms of dementia, the MMSR validated that the drive for dementia and creative arts literature still focused heavily on these symptomatic changes, similar to the conclusions found and summarized in Chapter 2. Those results were re-confirmed in Duignan et al. (2009) as symptomatic change were subjected to visualizing pre- and post-evaluations of change. However, it should be noted, that even though Goldstein-Levitas (2019) and Guzmán-García et al. (2012) were focused on the symptoms, a sense for the person and their abilities was critical to their findings.

5.2 Personhood & Creative Arts

From Chapter 3, we can theorize that personhood in the creatives arts is valuable for PwD. Once the PwD is the main focus in activities or therapies, researchers can better gage the impacts of those arts on the health, QOL, and well-being of individuals undertaking the interventions.

Whether PwD were partaking in visual arts, music, dance, or theatre/drama interventions, there was a level of engagement, identity, and self-importance. This shows that cABT have the capacity to sustain creativity and engagement that is beneficial to the psychosocial needs and personhood of PwD. Although the included studies were less than ten in total, each provided sufficient data to warrant the continuation of the cABT and to continue personhood and person-centred care in conjunction with cABT. This includes an opportunity for PwD to utilize their intact creative mind and express themselves when partaking in creative environments.

Gross et al. (2015), Lokon et al. (2019), and Sauer et al. (2016) utilized the GCCWBOT to measure domains of well-being and ill-being based on a visual arts intervention that supplemented the personhood of the PwD. Although this tool required some work and development, the important data points changed from the version used by Gross et al. (2015) to the one used by Lokon et al. (2019). As these three papers have shown, the correctness and proper validation of a tool can take some time. Future works in dementia care and personhood, should aim to develop assessment tools that become appropriate and validated for future studies.

This thesis provides as an intermediary step and transition for venturing forward using personhood and the creative arts. The work in this thesis acts as a theoretical foundation, however, future work must put thought into developing the correct study with the correct elements of personhood and creative arts.

5.2.1 Creativity and Creative Arts

Creativity and the creative arts are considered essential in communication, engagement, and improving personhood as more autonomous and self-generated decisions are made by PwD. Creativity in dementia involves the ability to produce an original piece of work and is appropriated by the goals (Mumford, 2003; Ochse, 1990; Sternberg & Lubart, 1991 as cited in Palmiero et al., 2012) designed during interventions.

Miller and Miller (2013) primarily looked at creativity and artistic ability in visual arts interventions for persons with variations of progressive aphasia linked to FTD. They concluded that there were tendencies to create even with new onset abilities (changes) in visual and verbal arts (Miller & Miller, 2013). Additionally, even with these new set of abilities, individuals showed an inherent connection to past skillsets in creative pursuits (Miller & Miller, 2013). If artistic ability is continued on even after aphasia from FTD, then it must be true that reinforcing the capacity of creative expressions and creativity are developmentally encoded in each person (Miller & Miller, 2013).

Palmiero et al. (2012) conducted a review that investigated how dementia affects production of art in people with or without artistic backgrounds. The secondary aim was to understand if the relationship between dementia and creativity is expressed with divergent thinking (Palmiero et al., 2012). Divergent thinking is defined as, “an open-ended mental process oriented to find many new and appropriate solutions to a particular problem” (Palmiero et al., 2012, p. 194). In other words, conceptual flexibility and strategic approaches to cognitive process make up divergent thinking (Heart & Wade, 2006 as cited in Palmiero et al., 2012). The final part of their review clarified the overlap between dementia and creativity based on cerebral mechanisms and processes (Palmiero et al., 2012).

Palmiero et al.'s (2012) review showed that creativity can decrease over time, that creativity may help PwD express their emotions and well-being, in creativity the prefrontal cortex seems to be essential, and to conduct behavioural observations, which when carried out, would be more useful when assessing further studies on creativity in dementia.

To counteract the first conclusion made by Palmiero et al. (2012), even when disease progresses, the artist can still incorporate new elements into their paintings and make it relatable to their current feelings. That means that creativity doesn't decrease over time, rather creative artistic value simply changes and is judged by the beholder to be good or bad (see transitional pieces in Miller & Miller, 2013, Figures 1 and 2), not necessarily a decrease in creativity. Expressions of emotions and well-being have been corroborated by the included studies in Chapter 3's ScR, as well as the engagement that promoted any level of creative expression seen in the included studies in Chapter 4's MMSR. Conclusions three and four from Palmiero et al. (2012) were not related to this thesis as prefrontal cortex creativity or assessing creativity were not fully examined.

Combined with the understanding of creativity within the creative arts and the findings from Miller & Miller (2013) and Palmiero et al. (2012) we can conclude that creativity exists when the PwD are given the tools to express their creative sides. With or without verbal expressions, expressions are seen in the creative arts through the colour strokes (for visual arts), through the movements (dance), from humming/singing along (music), and actively participating in interventions (e.g., medical clowns).

5.3. Other theoretical works

In the discussion portion of Chapter 3, I had highlighted two theoretical works, one by Sabat and the other by Kontos, which were not a part of the eligibility or search strategy of the

ScR. However, both selfhood (Sabat) and embodied selfhood (Kontos) are fundamental constructs in dementia care, with each providing their rationale and importance for PwD. The next subsections examines selfhood and then embodied selfhood.

5.3.1 Selfhood

A person's self remains intact despite having a condition like AD. It simply becomes 'lost' when the PwD is viewed and treated differently by others (Sabat & Harré, 1992). There are other aspects of a person relating to the social self (social interactions and relationships) which can also be lost indirectly as a result of the condition (Sabat & Harré, 1992). Through a social constructivist lens[15], the notion of selfhood came into existence. Selfhood remains intact regardless of cognitive deficits and is based on how PwD react and give meanings to a situation (Sabat, 2005). This concept is focused on the person and how they interact and are seen by others.

Sabat (2005) shares a case from Stephen Post's work. In the example, he talks of a devout Islamic woman who had been a widow for ten years and was diagnosed with probable AD. With a habit of walking around at night, the woman had wandered into another resident's room (resident known to have a sexual aggression history), only to be raped by the resident. When the woman's son found out about the assault, he sued the nursing home, to which he was met with a rebuttal from the defending attorney. The attorney stated that the woman would soon forget the incident and casted doubts on the woman's ability to have any genuine religious occupation with her stage of dementia (Sabat, 2005). A standard neuropsychological test positioned her to be incapable of religious commitments, leave her with any memory of the incident, or leave any

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[15] Idea that develops knowledge of the world through a social context and can be perceived through shared assumptions (Vinney, 2019). It also alludes to how the objective reality is socially constructed (Vinney, 2019).

enduring harm as of result of rape. In other words, the attorney concluded that a person with AD is unable to experience harm to their self-identity or experience a significant lasting impression of the incident (Sabat, 2005).

The attorney turned the situation of someone with AD into an example of the lack of memory and lasting impressions for the person; in other words, the person is no longer of 'sound' stature. Rather than asking questions on how the incident impacted the person, the attorney grouped the woman into a section of people that 'cannot remember and therefore, it probably does not count'. The question that he should have asked was, how was she able to share this with her family? How does this impact her? What is she going through? How has her behaviour changed since? Is she able to still pray? Tom Kitwood's approach, PERSON with dementia, was clearly ignored, simply because the nursing home cannot be sued for negligence. Selfhood was lost because of how the woman was viewed and treated through the attorney's arguments. Literature surrounding implicit memory, as discussed by Sabat (2005), shows that even with severe memory issues, events and experiences can still affect the person long-term. It can influence the person even without them having the conscious ability to recall the situation.

Selfhood is divided into three aspects: Self 1, Self 2, and Self 3. Self 1 means to have personal identity and use of self-intact indexical language like 'I, me, myself, mine, my' (Sabat, 2002, 2005; Sabat & Harré, 1992). A person can be diagnosed with dementia but can "still retain an intact Self 1 simply by saying, 'I feel sad. . .'" (Sabat, 2005, p. 1034). Self 2 is considered the part of self, relating to mental and physical attributes (height, eye colour, possession of degrees, and health) (Sabat, 2002, 2005). It also includes one's humour, facility of words, religious and/or political beliefs, and belief in one's attributes (Sabat, 2005). Relating back to the story above, the women's Self 2 was no longer left intact because of the judgements passed on by the opposing lawyer, which devalued the woman. This was because, “[p]roblematic to the person with AD, however, is that others often focus increasingly on defective Self 2 attributes and less on positive attributes” (Sabat, 2005, p. 1034). Last, Self 3 exhibits the social identities constructed with necessary cooperation from others (Sabat, 2005). For instance, an individual could be a spouse, friend, parent, and professional, all of which entail a different behaviour or responses from the person. These social identities are fashioned with the help of another. For PwD, current ideology on social identity remains steadfast on the dysfunctionality of the person rather than other more valued social identities (spouse, friend, parent, and professional) (Sabat 2002, 2005). This level of ignorance shows:

> vulnerability of the social identity of the [PwD, which] does not inhere solely in the neuropathology of the disease, but in the social interactions the person has with others. If others refuse to cooperate with the person with AD in the construction of a valued social identity, the person is restricted to the identity of ‘dysfunctional patient’ and so any ‘loss of social self’ has its roots in the social world, rather than in the brain, of the person in question. (Sabat, 2005, p. 1034)

Selfhood is embedded into personal and social identities, and also into mental and physical attributes which make up belief of the PwD. Selfhood overlaps with Personhood and the psychosocial needs by realizing that PwD are social creatures capable of having their self and needs intact even with cognitive decline. In addition, the creatives arts act as a burgeoning pathway that enhances the identities and the good attributable portions of the person.

5.3.2 Embodied Selfhood

Kontos’ embodied selfhood is based on the theoretical foundations of Merleau-Ponty’s “non-representational or basic intentionality” (2011, p. 311) and Bourdieu’s habitus linking bodily dispositions to the social world structures. Through an ethnographic study, Kontos (2011) observed embodiment in all aspects of body including posture, eye contact, facial expression, gestures, movements, balance, social actions and mannerisms, clothing and style.

Embodied selfhood differentiates itself from selfhood by recognizing that the body is an agent that is intentionally and purposefully separate and distinct from cognition (Kontos, 2005). The body has the ability to communicate and instill its own wisdom (Kontos, 2004). Therefore, the body does not derive its agency from cognition but is rather a fundamental source of selfhood itself (Kontos, 2005).

Embodied Selfhood is defined as “an observable coherence and capacity for improvisation that is sustained at a pre-reflective level by the primordial as well as the socio-cultural significance of the body” (Kontos, 2004, p. 831). The body is considered to reside below the threshold of cognition (Kontos, 2005). Primordial comes from the body’s natural expression and conveys the body’s ability to capture and convey meaning (Kontos, 2004). The social interconnectedness speaks to the body habits, gestures, and actions that support and convey individuality in the sociability context of dementia literature (Kontos, 2011).

The corporeality aspect of embodied selfhood affords the person the ability to understand the experiences of others and allows for empathetic caring and connection (see Kontos, 2011 for ethnographic study). Therefore, body, language, and words, all make up the embodied self. Once again, the embodied body is devoid of reliance on cognition and is intact with the body’s relationship with self and social relations.

Overall, both selfhood and embodied selfhood, are valued aspects in dementia care and in understanding the person, especially when developing creative arts-based interventions for PwD. A combinative approach that attaches the beliefs found in personhood’s psychosocial needs, selfhood's three selves, and embodied selfhood that does not derive its conclusion on isolating the body to cognition, might conclude that these foundations are vital for person-centred care and contingent on the person's overall needs. All three concepts were not in the strategy document highlighted in Chapter 1 and should be considered when developing advanced and innovative therapies that are designed for PwD.

5.4. Strategic Pillars

The Public Health Agency of Canada (2019, p. 43) has established five pillars needed for effective implementation of the national strategy for dementia. These consist of collaboration, research and innovation, surveillance and data, information resources, and a skilled workforce[16].

5.4.1 Collaboration

Collaboration enables knowledge and experience to allow for growth and learning from those with dementia. Thus, making PwD key stakeholders in their own health. This can be gained through policies and programs, research, knowledge translation, and dissemination of knowledge. Academia and clinical research through population-based perspectives can improve dementia care.

A common theme highlighted by both review articles in this thesis, showed how valuable the PwD/ADRD are when considering sociological and population-based understanding over the normalized biomedical perspective. The biomedical perspective in and of itself is problematic, at times, as it concentrates more on the condition and the symptoms, than the person being affected

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[16] *Collaboration* includes all governments and organizations in Canada working on dementia related initiatives; *research and innovation* focus on prevention, therapies and a cure, and QOL; *surveillance and data* aim to improve the impact of dementia, identify, and support efforts which are effective in Canada; *information resources* which are accessible and evidence-based are considered; last, a *skilled workforce* looks at the now and future to provide quality dementia care with an importance placed on research and innovation priorities (Public Health Agency of Canada, 2019, p. 43).

by it (see example of second case in Sabat (2019) paragraph in Chapter 3). Unfortunately, the understanding of the person is commonly judged based on what our eyes can see and not on what may be under the surface. An example of an iceberg comes to the frame of mind when understanding and uncovering ignorance. Much more is located beneath the surface of the water.

In the current scope of mental health and physical health, it is quite common for someone to question another person's disability because it cannot be seen. Mental health is not always considered an integral part of reasoning when needing time off to recover. Since this dichotomy exists, institutions such as the Government of Canada has paired with Not Myself Today[17] to remove stigma from receiving help and support. As a result, this protects and promotes the mental health of employees (Manji, Irfan, personal observation, November 2019).

Likewise, to PwD, a staff member, family member, and the health-care professional see the disturbances, the outbursts, and the cognitive decline but forget that underneath the frustrations is an individual whose needs are not being met. An outburst is a way to express anger or frustrations when verbal forms of language are difficult to express. The collaboration of PwD as stakeholders allows researchers, policy makers, and academia to ask the PwD what they feel and if their needs are being met. This makes the collaboration pillar vital for involving knowledge and experience into dementia care research.

5.4.2 Research and Innovation

Current research situates dementia as a debilitating disease (Sabat, 2002) that mainly harms the person's cognitive and behavioural capacities (Gale et al., 2018). Research is designed to fill gaps in the knowledge base on dementia and to provide the greatest possible positive

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[17] https://www.notmyselftoday.ca/about/. This resource has been implemented at the Fisheries and Oceans department in the federal government.

impact for those living with dementia in Canada. Research and innovation must prioritize investments in preventing, delaying onset of symptoms, enhancing care and therapies, and improving QOL (Public Health Agency of Canada, 2019).

The article in Chapter 3 overviewed the research base to find what had been accomplished in regard to the investments in improving personhood, QOL, and well-being through cABT of those with dementia. Active involvement of those with dementia and their personhood must be considered in the research process, as active involvement for all severities is considered a priority in research and innovation (Public Health Agency of Canada, 2019). The literature, however, shows that some modalities only impact those in early stages of dementia (Lorenz et al., 2019; van der Vleuten et al., 2012), whereas research in advanced stages of dementia are not always considered. The consensus was gathered from PwD in more cognitive, vegetative, or behavioural states and so, made it difficult for researchers to connect or see improvements in PwD with advanced stages. However, a study by Hanser (1999) shared that PwD in advanced stages still have their musicality and essence of the person intact through various vocalizations, humming, and movements that are otherwise hidden, until exposure to creative arts-based interventions.

Barriers in dementia care judge those with advanced stages of dementia with automatic assumptions and that the intervention(s) will not make significant differences to them. This is a major concern that impedes research and innovation into practice. Kitwood (1997a, b) showed that each person is valuable and different in their needs and that should be respected, regardless of severity of dementia or type of dementia seen. Instead, active participation and value on needs should be paramount in the care of those with dementia. Both articles in Chapter 3 and 4 capture the importance of inclusion and increasing the understanding that capacities of PwD are not stagnant due to the condition of dementia. The person exists within the blurred existence of the disease (see example of Dr. M in Chapter 3).

5.4.3 Surveillance and Data

5.4.3.1 QOL and Well-being

The meaning of QOL, throughout health-related research, has changed in definition and understanding. Within the works of Algar et al. (2016), Bowling et al. (2015), Missotten et al. (2016) and Ready & Ott (2003), the definition of QOL has encompassed and overlapped with health statuses including physical, mental, social, and health perceptions. The World Health Organization (2012) defines QOL as:

> ‘individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’. It is a broad ranging concept incorporating in a complex way the persons' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment. (p. 3)

However, with no clear-cut definition, Ettema et al. (2005) say that conceptualizations of QOL vary (particularly in QOL based assessment tools) because each person’s QOL is not the same as the next. These QOL definitions make the assumption that each person is unique, but also showcases how the definition of QOL has some variance.

There have been staggering instances of QOL definitions throughout history, especially when understanding the sacredness of life. Three ethical concepts of the sanctity of life, qualified sanctity of life, and the QOL ethos show where value of life has been placed throughout history—in regard to the euthanasia and assisted suicide conversation. The sanctity of life ethos does not allow a person to hasten death via positive or negative acts (omission versus non-omission) because life is considered to be a loan (stewardship) from God (Dowbiggin, 2003). Therefore, any suffering or hardship causing a downgraded QOL, cannot be modified or ended because of a potential divine wrath faced from God. Because Jesus has suffered, so must the person and that is how the sanctity of life operates. This ideology is very much in line with Christian dominant perspectives.

The second concept is known as the qualified sanctity of life. Here, a person's life cannot be hastened by death through needles or pills, but a person can die with the act of omission from the lack of respiration and food/water (Chambers, 2016). Nature, passive means, must take its course (Chambers, 2011) and as such, the doctrine has now evolved from God's will to nature's will.

Finally, the QOL ethos states the person's death can be hasten through positive and negative acts (Chambers, 2016). Because a person's autonomy comes first, suffering is now considered subjective, and with safety measures in place to protect the person and medical professions from 'killing', the QOL ethos has now become the dominant ideology for assisted suicide[18] in Canada (Chambers, 2011, 2016).

The three ethical concepts are an example of how during the course of history the value of life and QOL have changed based on the perceptions of the generations and evolving definitions associated with life. As of now QOL definitions vary depending on type of tool, severity of dementia, activity, and outcomes measures being sought by researchers. This in turn gives QOL a wide variety of meanings depending on the need of the person executing the intervention.

The history of QOL has been measured by others and not the person: sanctity of life by the church and qualified sanctity of life by biomedical approaches. The final ethos does in fact

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[18] Bill C-14 contains more details of assisted suicide regulations in Canada.

take the persons' wishes into consideration and I believe that stems from the recent definitions of QOL (similar to the WHO definition).

The various definitions of QOL match with the differences that vary from person to person. Each person uniquely defines what their QOL or well-being needs are and how they can be met. Consequently, the surveillance and data pillar could tighten the definition of QOL to be inclusive of all PwD, regardless of severity.

Identifying the tools in both review chapters showed our research teams that some tools are chosen based on behaviours, symptoms, and type of activity. This is important knowledge for future studies as defining the concept beforehand informs the readers of the data being surveilled and how it applies to the research context for PwD as a whole.

Surveillance and data optimize dementia care to provide a more accurate picture of the impact dementia has on Canadians. I included QOL and well-being as topics of discussion in this section particularly because of how definitions can inform the type of research seen. The revolving definition of QOL envisages how assessments are defined and utilized in dementia research and determines if the quality of the data presented does in fact paint a correct picture of how PwD with all severities are included or excluded in studies. In addition, data can assess the impact activities, such as cABT, have on PwD and helps to plan future studies that are concerned with the personhood, QOL and well-being of PwD (the hope).

5.4.4 Information Resources

Information resources that are available when the basis of knowledge can provide reliable, evidence-based information, as well as provide research, educational resources and tools that are culturally inclusive and appropriate (Public Health Agency of Canada, 2019). These then become appreciated when disseminating data to stakeholders and to the population with dementia and their caregivers, care providers, and policy makers (Public Health Agency of Canada, 2019).

The strategic document was a foundational piece in this thesis as it directed me towards alternative interventions; **however, the most striking revelation was that personhood was not mentioned even once in the entire document. Neither was Tom Kitwood and nor were any concepts relating to the self of PwD.** Although, the ideas revolving around the person were reiterated many times in the document, concepts that propagate the person through personhood need to be acknowledged. Because of this problem, I turned to more adept frameworks recognizing the person before the condition. The next paragraphs delve into person-centred care and life trajectories, relating to personhood.

5.4.4.1 Person-centred care

Concepts relating to PwD can educate research personnel into better understanding the major concepts that influence dementia care. As such, “equipping care providers with evidence-based information resources benefits both those receiving and those providing care” (Public Health Agency of Canada, 2019, p. 48).

The definition of person-centred care in Chapter 1 provided the model of care in dementia involving the person and their relationships, their well-being or ill-being, and affirms personhood more than the status of the condition (Fazio et al., 2018; Kitwood & Bredin, 1992; Summer Meranius et al., 2020). A discussion paper by Summer Meranius et al. (2020) looked at the advantages and disadvantages of person-centred care. The advantages have already been stated in this thesis (see Chapter 1), however, the disadvantages to person-centred care tend to be scarce. Data that was found identified increased costs (personal and financial), exclusion of certain groups (e.g., decision making in older persons with limited capacity to make decision), exclusion of staff’s personhood (diminished value leading to poor working conditions and increased turnover rates), compassion fatigue (gradual lessening of compassion and exhaustion; stress on person), and unfairness from empathy (excessive empathy can be selective and unfair to others) (Summer Meranius et al., 2020).

Summer Meranius et al. (2020) concluded that paradoxes be considered during implementation and use of person-centred care. The paradoxes were diluted into four main concepts: patient-, interpersonal-, staff-, and organizational-levels, with each needing to be considered for future works using person-centred care (Summer Meranius et al., 2020).

A threat on the self and personhood is a disabling effect associated with dementia, in addition to the symptoms and condition itself. It is also important to note that dementia varies from person to person and does not progress linearly. General biomedical trajectory identified by Kitwood (see 1997a, Figure 3.3), shows a diagram that is used to loosely define the life of PwD from normal life until death. This process is used to commonly define the path of dementia progression and unfortunately, gives more emphasis to neurological impairment and malignant social psychology related approaches. *Figure Three* is an adapted and simplified version of the spiral image located in Kitwood’s work.

5.4.4.2 Life course and Lifespan

The life course framework, as described by Alwin (2012) states that life course is a construct of time and age, contains life stages, incorporates events, transactions, and trajectories, life-span is part of human development, and last, life course is determined by early life (and their cumulative) influences on adult outcomes later in life. Life course aims to understand the evolutionary components of life as outcomes of institutional regulation and social structural forces (Mayer, 2003). Lived experiences within the life course approach become more imperative and personhood must be protected at the social and institutional living levels. Life course also utilizes the principle of agency allowing individuals to conduct their own lives within social structures by the choices and actions they take (Alwin, 2012).

On the other hand, the lifespan theory looks at the psychological and functional (biological) capacities through life, from birth to death (Mayer, 2003). Domains of lifespan include biological, psychological, and social structures with gains and losses that influence aging (Alwin, 2012; Mayer, 2003). In *Figure Three* the trajectory is a common pathway used to describe disease progression for most individuals with dementia, which is problematic in its own right. Casting PwD into a set of functions is completely contradictory to what personhood and person-centred care address.

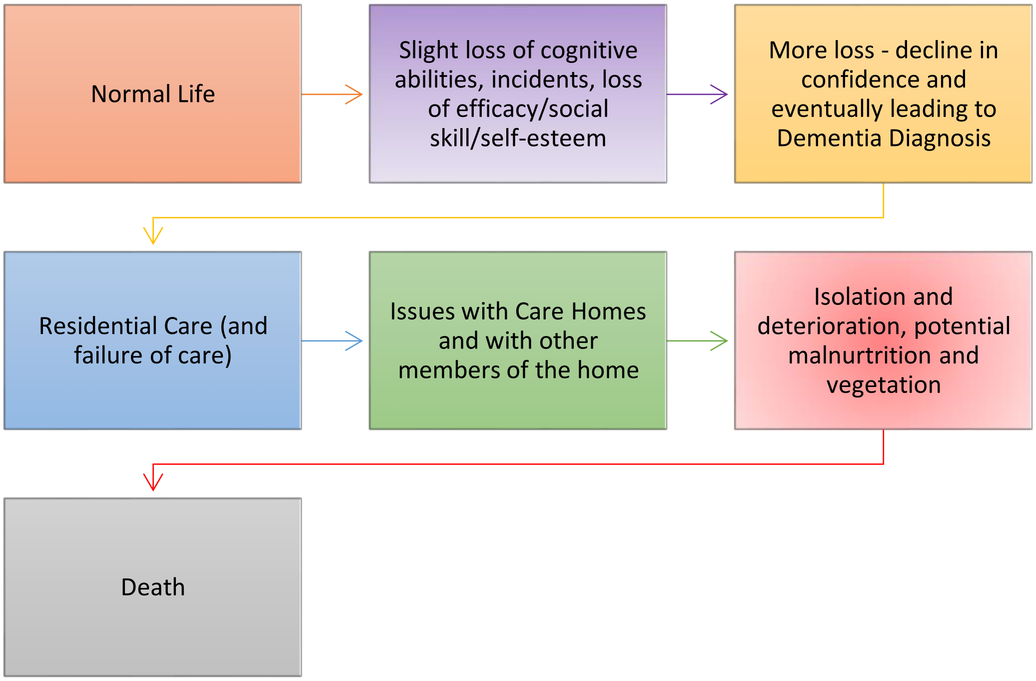

Figure Three. Adapted and simplified from Kitwood (1997a). Concepts are summarized and grouped together to give a closer look at losses and transitions in condition. This path very closely resembles the lifespan approach that is more determinate on functional capacities.

Through a human development and aging lens, aging and time are both irreversible concepts that fill the gaps between birth and death, and symbolize a process of growth (Alwin, 2012). Inter-individual variability determines a person's own course in life which is inclusive of their functional condition, but also the lived experiences up until that point and beyond. The condition should not steal away any level of the psychosocial needs identified to be important for PwD. (Once again, the tenets are comfort, attachment, inclusion, identify, occupation, and the recently added agency). I would recommend that an upcoming Public Health Agency of Canada document further elaborate on person-centred care to include works that support personhood, selfhood, and embodied self-hood paradigms.

5.4.5 Skilled Workforce

5.4.5.1 Technology

As COVID-19 placed the entire global world into a shock and shutdown, it was quite evident that individuals in residential care, and PwD, in particular, were impacted the most (Ickert et al., 2020). It became evidently difficult for outside communication with family or friends, and even care staff were struggling to keep up with the demands of the residential home (Manji, Irfan, personal communication with PRVHC, April 2020).

Previously, under the *Implications for future research* section of Chapter 4, I had alluded to the implementation of technological delivery for future cABT. In that example I had referenced Sharing Dance Seniors which allows for remote delivery of creative dance arts in residential homes, rural communities, and at-home settings (Kontos et al., 2020b). Remote delivery through technology or virtual platforms, can be used for effective delivery of interventions and activities for PwD in isolated environments. The limitation, however, is that technology (e.g., wifi, cost of device) or staff availability might be scarce, thus research for virtual or remote delivery through alternative technologies should be well aware of this drawback. As a result, technology should maximize the use of resources available to PwD without displacing them further and avoid the common issues related to social and geographical isolation for those living in rural or remote areas.

On the other hand, alternative assistive technologies (AAT*)* can contribute to mobility, communication, learning, self-help, and can be vocationally based (Idaho Assistive Technology Project, 1999). AAT are defined as "any item, piece of equipment or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" (Idaho Assistive Technology Project, 1999, p. 5). AAT can also be considered "any service that directly assists an individual with a disability to select, acquire, and use assistive technology" (Idaho Assistive Technology Project, 1999, p. 5). Technologies can be organized into sustaining seven functions: memory support, treatment, safety and security, training, care delivery, social interaction and other (Lorenz et al., 2019) for PwD.

5.4.5.2 Gaming

Another area that can be combined with the creative arts is the gaming world (video games, puzzles, board games) (Chesham et al., 2017), which have proven to be critical tools in non-pharmacological therapy (Stanmore et al., 2017). Gaming can act as a user-friendly and user-focused medium that invokes motivation, focus, and improves executive functions, attentional processing, and visuospatial skills, thereby improving overall health (Barrett, et al., 2016; Chesham et al., 2017). Moreover, games can have choices and actions (Barrett et al., 2016), resulting in various endpoints for the user and allows for more autonomous decision making and in-game challenges, which speaks directly to their personhood.

Creative arts, gaming, and technology—together or on their own—allow the user to create a new social world of play that is described by the time, objects, non-productivity of goods, and rules (Schechner, 2003)[19]. The ability to split the current reality into another engaging and imaginative relationship is a form of creative performance that is undoubtedly created by and for the person involved. This increases the freedom of expression and enhances the idea that "no right or wrong way" (Kontos et al., 2020b, p. 6) exists. This in turn creates a social connection for PwD with their peers and allows for engagement and conversation that is verbal or non-verbal through movements, interactions, and a new world of play. (A world of play was created in Ramgard et al., 2016 when the medical clowns emphasized the person's sense of self through the creative interactions and use of objects).

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[19] The importance of using Schechner's world of play aspects of time, objects, non-productivity of goods, and rules gives the PwD a new imaginative world to live in. For example, take a hockey game into consideration. A hockey game is completely different than real life. In the game, time is split into three 20-minutes periods, instead of twenty-four hour days. Non-productivity refers to the structural elements that differ between environments. The rules are different; in real life you cannot go around hitting, slashing, or tripping people because of real-world consequences. As well, the objects remain different between what is seen in day-to-day—coffee mug versus the puck, sticks, whistles, ice, and boards we see in hockey.

Time, objects, non-productivity of goods, and rules are located in areas of life and performance. They change the environment and give meaning to the person within this new realm. An artistic or gaming platform allows the PwD to manifest a new created world that brings about new interactions and engagement opportunities which can supplement personhood.

Chapter 6: Conclusion

6.1 Contributions of Research

The condition and deficits associated with dementia predominately are viewed from cognitive or behavioural means. This thesis, however, takes another look at dementia care to show how the condition is not always more than the person. Together, the scoping review and the mixed-methods systematic review highlight the positive impact creative arts has on the people/person(s) with dementia (PwD)'s personhood and psychosocial needs, and paves way to being more inclusive to the biographical legacies and autonomy of the target population.

I would like to say that Dementia is not considered to be part of normal aging as participation in daily life and daily activities are affected. The impacts to the brain, are not considered normal either. Nevertheless, PwD have shown time and time again that various properties of their identity remain intact and can be further visualized when exposed to creative arts-based therapies (cABT). This leads me to conclude that not only has the review work in this thesis provided enough evidence to continue creative arts for PwD, but also maximizes the indescribable requirement to pay close attention to the psychosocial needs and other factors that make up the person, not only from a biomedical perception.

6.2 Limitations

Limitations were shared in both review articles but the major overlapping limitation noted, stems from the low number of yielded studies from both reviews in this thesis. One reason for this could be from the search strategies of both reviews having an extensive eligibility criteria, which had been a limitation in some previous reviews that yielded low or no studies (see *Table Two*). This might explain the issue of only eight total studies across both reviews.

However, I would argue that by narrowing in on key points in the eligibility of both reviews, the reviews were positioned to extract information that was not being investigated by other researchers. As a result, the next steps from Chapter 2, addressed gaps in the current review-based literature based.

The reviews in Chapters 3 and 4 could have also been tailored in a different direction. I could have focused more on the lack of theatre/drama therapy reviews; however, personhood and person-centred care are established theories that seem to be fading in the literature in the past decade. This drove my ambition to further connect them back to the creative arts. Further, by recognizing that personhood was unmentioned throughout the strategic document, it provided an extra motivation to address personhood, creativity, and the arts as informants that support advancing non-pharmacological therapies in environments designed for PwD. This also calls to focus the need for tertiary prevention strategies (see Wu et al., 2016) which are vital in improving the quality of life (QOL) for the dementia resident by way of their own needs.

Selection biases within included studies should be considered a limitation, as included participants and their data may be derived from an enriched extraction/sample size. We must be cautious of how we value the positive results from a sample size that may lean positively to the creative arts. Nevertheless, dementia research paired with creative arts-based interventions, are valuable and worthy interventions that do provide benefits aside from symptom relief, as investigated in this thesis.

Due to the language limitations (English only), we recognize that studies with varying cultural approaches and languages were unaccounted for. The differences between the Western and Eastern ideologies and different cultural approaches to dementia care may be an area of study for future research to focus on.

Data on the creative arts are prominently focused on dementia and Alzheimer’s Disease, but research that isolates specifically for the various forms of dementia (Vascular Dementia, Lewy Body Dementia, Frontotemporal Dementia, or Parkinson’s Disease Dementia), should be an area of focus for future research. It would be prudent to also understand how the varying forms of dementia and the creative arts interact with one another and if the benefits are similar or different than what has been reported in literature on dementia and Alzheimer’s disease as standalone forms.

6.3 Barriers to Dementia Care

The strength from the review work confirms that cABT are meaningful modes of intervention for PwD of all severities. However, some barriers exist, which are caused by a dogma engrained in the thought process of some. Kitwood (1997a) recognized how the general population of people has the tendency to consider PwD not persons:

> The highly defensive tactic is to turn those who have dementia into a different species, not persons in the full sense. The principal problem, then, is not that of changing people with dementia, or of 'managing' their behaviour; it is that of moving beyond our own anxieties and defences, so that true meeting can occur, and life-giving relationships can grow. (p. 14)

It is quite clear that many individuals tend to categorize those with dementia as lesser functioning persons. However, through the work provided in the reviews, this level of thinking has evolved and should continue to consider PwD as agents in their own health and well-being.

Dementia care has been known to be impacted by infantilization, stigma, and social exclusion/isolation and loneliness. Infantilization is described as referring to the PwD as a young child and speaking to them in a condescending manner (Hobson, 2019). Further, speaking *for* the PwD when they can do so for themselves is another incidence that is characterized as infantilization. Infantilization is a common example of something that threatens personhood and the person as a whole. It can also be considered as a form of malignant social psychology (Hobson, 2019).

Stigma is central barrier when the PwD are treated like a disease and thusly, becomes alienated (Hobson, 2019). Stigma can be encountered when a lack of understanding or even misconception makes the PwD's condition distinguishable from the rest of the people around them; makes them feel different and decreases their self-worth (Sakamoto et al., 2017). Labels, in particular, can lead PwD to be treated in ways that go against their personhood (Fazio et al., 2018). To combat stigmatization, creative activities like the arts, have shown to maintain self-worth, social interaction, and overall health (Price & Tinker, 2014).

Social exclusion can be reduced through cABT which then allows the PwD to reduce their reliance on pharmacological interventions and simultaneously increase QOL (Price & Tinker, 2014). Exclusion occurs when PwD are treated poorly by their social circles (Biggs et al., 2019). Social exclusion assumes that once the PwD is diagnosed, life stops for them (Biggs et al., 2019). Exclusion can be avoided by creating dementia-friendly environments (Hung et al., 2020; Lin, 2017) that are inclusive to PwD of all severity and avoid isolation or loneliness. Social isolation and loneliness can lead to intensified depression, feelings of despair, and speeds up cognitive decline (Chu et al., 2020; Hung et al., 2020).

There are many other barriers that impede dementia care but through the literature, infantilization, stigma, and social exclusion are commonly mentioned. Future studies should be cognizant of these aspects when developing creative interventions at care homes

6.4 Interdisciplinarity

Interdisciplinary (ID) research involves multiple schools of thought (including professional, community, and the person themselves) working simultaneously together in providing input for a task at hand (Kessel et al., 2008). Repko and Szostak (2017) describe ID endeavours as:

> a process of answering a question, solving a problem, or addressing a topic that is too broad or complex to be dealt with adequately by a single discipline, and draws on the disciplines with the goal of integrating their insights to construct a more comprehensive understanding. (p. 50)

ID approaches provide further insights about how the person's experience, in conjunction with the team's experiences, provides support mechanisms on relationship building and respect for the person (Ciemins et al., 2016). Successful interactions to complex issues are better solved, most times, with ID approaches (Ciemins et al., 2016). ID research can be considered holistic and assesses events that do not occur linearly (Ciemins et al., 2016), as each situation and each person's case varies. One way to understand ID research is by thinking of a pain management clinic. Various specialists and people in the local community meet with the person, at the same time, and develop a unified plan of action that would treat the pain.

ID must not be confused with multidisciplinary approaches as even though a patient might meet with different professionals throughout their treatment time, they do not overlap with each other, rather they provide their findings in the patient's records which are later read by the next health care provider (Kessel et al., 2008). Sometimes no productive conversation occurs and redundant tests can be ordered (Manji, Irfan, personal experience, March 2011).

The research in this thesis opens an opportunity for dialogue between various stakeholders, such as the PwD, staff members of a local residential facility, family members, artists and facilitators, policy makers, and clinician/health care professionals. The combination of these individuals would bring about a clear direction that suggests future policy mandates regarding PwD; similar to the approach taken by the Public Health Agency of Canada (2019) when developing their principles (see pp. 6-7). ID work is paramount if we are to incorporate the needs of PwD in a safe and respectable manner.

6.5 Future Implications

Future policy work should aim to complete a due diligence that involves not only research mandates but also signifies the PwD as important assets in their own well-being. Opportunities for future research should consider the experiences of PwD, as well as the psychosocial needs associated with their personhood, the self (selfhood), and embodied selfhood. Research pertaining to PwD should also work on better defining QOL and refining measurement tools to reflect this new definition. Finally, creative arts programs should be developed not only as interventions but also as daily programming and should be inclusive of a range of activities to choose from. PwD must have the chance of deciding and being involved in an evoking activity that provides benefits to their personhood. This is central to person-centred care and allows for PwD to become principal decision makers and valuable assets in the research being conducted.

6.5.1 COVID-19 and Residential Care

Unfortunately, we cannot move through dementia care literature without acknowledging the detrimental effects of COVID-19, particularly on those living in care homes. Current numbers state that PwD account for 70% of residents in care homes (Hsu et al., 2020). COVID-19 in the Canadian population living in care homes, as of June 1, 2020, claims that almost 92, 000 confirmed cases with 7, 326 deaths (Hsu et al., 2020). This is a sobering number considering from a 2016 consensus that there was a population of 425, 755 people living in facilities (Hsu et al., 2020). That means almost a quarter of the total population has been impacted by COVID-19.

On a more positive note, many areas of deficits have been recognized in the current scope of literature which can help future policy makers, care homes, and other key stakeholders make decisions on improving the efficiency of certain areas. These areas include technology, physical space, resources, and personnel (Hsu et al., 2020; Ickert et al., 2020).

With the isolation felt in residential homes, a dependency on internet and technology infrastructures, as well as the lack of devices and increased costs associated with new forms of technology (Ickert et al., 2020) has been recognized. Because of the lack of face-to-face communication between family and the resident (physical space change), the use of a phone or whiteboards are now needed to communicate between both sides (Ickert et al., 2020). This has also required staff members to help facilitate and transport residents to common areas with a window view to see family (Ickert et al., 2020). The unfortunate aspect of residential care usually sees PwD spending long periods of time without human contact (Kitwood, 1997a). The pandemic increased this issue, but full credit must be given to care home staff who have had to take on many roles such as supporting PwD’s social connections (Ickert et al., 2020).

Recommendations that can be implemented in care homes include more emphasis on staff numbers to balance out activities between residents and staff and technology arrangements. As a result, increasing comfort in PwD, family members, and staff (Ickert et al., 2020). With these recommendations, social connections could be better promoted, and social exclusion can be mitigated all while benefiting the health and well-being of persons living in care homes (Ickert et al., 2020; Jing et al., 2016; Moyle et al., 2015).

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Appendices

Appendix A: PRISMA-ScR checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	31
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	32
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	47
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	48
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	N/A
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	51
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	49
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Table 2
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	49
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	52
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	52
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	N/A
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	53
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Table 3
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Table 3

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	60
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	69
Limitations	20	Discuss the limitations of the scoping review process.	74
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	79
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	81

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

Appendix B: Mixed-methods Systematic Review PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	83
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	84
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	88
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	92
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	93
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	94
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Table 1 / Appendix D
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	97
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	97
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	N/A
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	N/A
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	96
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	98
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	N/A
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	98
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A

Section and Topic	Item #	Checklist item	Location where item is reported
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	103
Study characteristics	17	Cite each included study and present its characteristics.	103 / Table 5
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Table 2-4
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	105 / Table 5
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	105
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	111
	23b	Discuss any limitations of the evidence included in the review.	N/A
	23c	Discuss any limitations of the review processes used.	113
	23d	Discuss implications of the results for practice, policy, and future research.	114
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	93
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	93
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	116
Competing interests	26	Declare any competing interests of review authors.	117
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Appendix

Appendix C: Additional Search Strategies (Chapter 3, Article 1)

EMBASE

Concept	*#*	*Search Terms*
Intervention	1	dance therapy/
	2	"movement (physiology)"/
	3	dancing/
	4	danc*.ti,ab.
	5	((body or authentic) adj3 movement*).ti,ab.
	6	(movement adj3 therap*).ti,ab.
	7	art therapy/ or psychotherapy/ or music therapy/ or play therapy/
	8	art/ or "arts and illustration"/ or drawing/ or painting/
	9	art*.ti,ab.
	10	creativity/
	11	painting/
	12	visual art.mp.
	13	client centered therapy/
	14	exp sensory Art Therapies/
	15	psychotherap*.ti,ab.
	16	((art or danc* or sensory or perform* or music or creativ* or play or movement* or theatre or drama) adj3 (therap* or program*)).ti,ab.
	17	music.ti,ab.
	18	musicking.ti,ab.
	19	theatre.ti,ab. or drama.ti,ab.
	20	theatre therapy.mp.
	21	psychodrama/
	22	creative art*.ti,ab.
	23	(creative art* adj3 intervention*).ti,ab.
	24	*1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23*
Population	25	dementia/
	26	alzheimer disease/
	27	dementia.ti,ab.
	28	Alzheimer*.ti,ab.
	29	8 or 9 or 10 or 11
Setting	30	residential facilities/ or homes for the aged/
	31	long-term care/
	32	nursing home*.ti,ab.
	33	long-term care.ti,ab.
	34	ag?ing home*.ti,ab.
	35	nursing home/
	36	senior? home*.ti,ab.
	37	senior? residence*.ti,ab.
	38	dementia care facilit*.ti,ab.
	39	((nursing or ag?ing or senior? or long-term) adj3 (home* or facility* or residenc*)).ti,ab.
	40	*30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39*
	41	***24 and 29 and 40***
	42	***limit 41 to yr="2010 - 2020"***

CINAHL (EBSCO)

Concept	#	*Search Terms*
Intervention	1	(MH "Dance Therapy")
	2	(MH "Movement")
	3	(MH "Dancing+")
	4	TI danc* OR AB danc*
	5	TI (((body or authentic) N3 movement*)) OR AB (((body or authentic) N3 movement*))
	6	TI (movement N3 therap*) OR AB (movement N3 therap*)
	7	(MH "Performing Arts") OR (MH "Art") OR (MH "Art Therapy") OR (MH "Music") OR (MH "Drama")
	8	(MH: "Art")
	9	TI art* OR AB art*
	10	(MH: "creativity")
	11	(MH: "painting")
	12	"visual art*"
	13	TI psychotherap* OR AB psychotherap*
	14	TI (((art or danc* or sensory or perform* or music or creativ* or play or movement* or theatre or drama) N3 (therap* or program*)) OR AB ((art or danc* or sensory or perform* or music or creativ* or play or movement* or theatre or drama) N3 (therap* or program*))
	15	TI music OR AB music
	16	TI musicking OR AB musicking
	17	TI (theatre OR drama) OR AB (theatre or drama)
	18	"theatre"
	19	(MH: "Psychodrama")
	20	TI creative art* OR AB creative art*
	21	TI (((creative art*) N3 (intervention*) OR AB ((creative art*) N3 (intervention)))
	22	*S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21*
Population	23	(MH "Dementia")
	24	(MH "Alzheimer's Disease")
	25	TI dementia AND AB dementia
	26	TI Alzheimer* AND AB Alzheimer*
	27	*S23 OR S24 OR S25 OR S26*
Setting	28	(MH "Residential Facilities")
	29	(MH "Long Term Care")
	30	TI nursing home* AND AB nursing home*
	31	TI long-term care AND AB long-term care
	32	TI ag#ing home* AND AB ag#ing home*
	33	(MH "Nursing Homes")
	34	TI senior# home* AND AB senior# home*
	35	TI senior# residence* AND AB senior# residence*
	36	TI dementia care facilit* AND AB dementia care facilit*
	37	TI (((nursing or ag?ing or senior? or long-term) N3 (home* or facility* or residenc*))) AND AB (((nursing or ag?ing or senior? or long-term) N3 (home* or facility* or residenc*)))

	38	*S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37*
	39	***S22 AND S27 AND S38***
	40	***Limiters - Published Date: 20100101-20201231***

PsycINFO (OVID)

Concept	*#*	*Search Terms*
Intervention	1	dance therapy/
	2	movement Therapy/
	3	dance/
	4	danc*.ti,ab.
	5	((body or authentic) adj3 movement*).ti,ab.
	6	(movement adj3 therap*).ti,ab.
	7	art therapy/ or creative arts therapy/ or self-expression/
	8	art/
	9	art*.ti,ab.
	10	creativity/
	11	"painting (art)"/
	12	visual art.mp.
	13	client centered therapy/
	14	music therapy/
	15	psychotherap*.ti,ab.
	16	((art or danc* or sensory or perform* or music or creativ* or play or movement* or theatre or drama) adj3 (therap* or program*)).ti,ab.
	17	music.ti,ab.
	18	musicking.ti,ab.
	19	(theatre or drama).ti,ab.
	20	theatre therapy.mp.
	21	psychodrama/
	22	creative art*.ti,ab.
	23	creative art* adj3 intervention*).ti,ab.
	24	drawing/
	25	*1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25*
Population	26	dementia/
	27	alzheimer's disease/
	28	dementia.ti,ab.
	29	Alzheimer*.ti,ab.
	30	*26 or 27 or 28 or 29*
Setting	31	Residential Care Institutions/ or Long Term Care/
	32	nursing Homes/
	33	nursing home*.ti,ab.
	34	long-term care.ti,ab.
	35	ag?ing home*.ti,ab.
	36	senior? home*.ti,ab.
	37	senior? residence*.ti,ab.
	38	dementia care facilit*.ti,ab.
	39	((nursing or ag?ing or senior? or long-term) adj3 (home* or facility* or residenc*)).ti,ab.

	40	*31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39*
	41	***25 and 30 and 40***
	42	***limit 41 to yr="2010 - 2020"***

SCOPUS

Concept	*#*	*Search Terms*
Intervention	1	TITLE-ABS (danc*)
	2	TITLE-ABS ((body or authentic) W/3 movement*)
	3	TITLE-ABS (movement W/3 therap*)
	4	TITLE-ABS (art*)
	5	TITLE-ABS (psychotherap*)
	6	TITLE-ABS ((art or danc* or sensory or perform* or music or creativ* or play or movement* or theatre or drama) W/3 (therap* or program*))
	7	TITLE-ABS (music)
	8	TITLE-ABS (musicking)
	9	TITLE-ABS (theatre)
	10	TITLE-ABS (drama)
	11	TITLE-ABS ("creative art*")
	12	TITLE-ABS ("creative art*" W/3 intervention*)
	13	ALL ("theatre therapy")
	14	ALL ("visual art*")
	15	*#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14*
Population	16	TITLE-ABS (dementia)
	17	TITLE-ABS (Alzheimer*)
	18	*#16 OR #17*
Setting	19	TITLE-ABS ("nursing home*")
	20	TITLE-ABS ("long$term care")
	21	TITLE-ABS ("ag$ing home*")
	22	TITLE-ABS ("senior$ home*")
	23	TITLE-ABS ("senior$ residence*")
	24	TITLE-ABS ("dementia care facilit*")
	25	TITLE-ABS (nursing or ag$ing or senior$ or long$term W/3 home* or facility* or residenc*)
	26	#19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25
	27	***#15 AND #18 AND #26***
	28	***(LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012) OR LIMIT-TO (PUBYEAR , 2011) OR LIMIT-TO (PUBYEAR , 2010))***

Appendix D: Additional Search Strategies (Chapter 4, Article 2)

EMBASE

Concept	#	Search Terms
Therapy	1	dance therapy/
	2	"movement (physiology)"/
	3	dancing/
	4	danc*.ti,ab.
	5	((body or authentic) adj3 movement*).ti,ab.
	6	(movement adj3 therap*).ti,ab.
	7	*1 or 2 or 3 or 4 or 5 or 6*
Population	8	dementia/
	9	alzheimer disease/
	10	dementia.ti,ab.
	11	Alzheimer*.ti,ab.
	12	*8 or 9 or 10 or 11*
Setting	13	residential facilities/ or homes for the aged/
	14	long-term care/
	15	nursing home*.ti,ab.
	16	long-term care.ti,ab.
	17	ag?ing home*.ti,ab.
	18	nursing home/
	19	senior? home*.ti,ab.
	20	senior? residence*.ti,ab.
	21	dementia care facilit*.ti,ab.
	22	((nursing or ag?ing or senior? or long-term) adj3 (home* or facility* or residenc*)).ti,ab.
	23	*13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22*
	24	***7 and 12 and 23***

CINAHL (EBSCO)

Concept	#	Search Terms
Therapy	1	(MH "Dance Therapy")
	2	(MH "Movement")
	3	(MH "Dancing+")
	4	TI danc* OR AB danc*
	5	TI (((body or authentic) N3 movement*)) OR AB (((body or authentic) N3 movement*))
	6	TI (movement N3 therap*) OR AB (movement N3 therap*)
	7	*S1 OR S2 OR S3 OR S4 OR S5 OR S6*
Population	8	(MH "Dementia")
	9	(MH "Alzheimer's Disease")
	10	TI dementia AND AB dementia
	11	TI Alzheimer* AND AB Alzheimer*
	12	*S8 OR S9 OR S10 OR S11*
Setting	13	(MH "Residential Facilities")
	14	(MH "Long Term Care")
	15	TI nursing home* AND AB nursing home*
	16	TI long-term care AND AB long-term care
	17	TI ag#ing home* AND AB ag#ing home*
	18	(MH "Nursing Homes")
	19	TI senior# home* AND AB senior# home*
	20	TI senior# residence* AND AB senior# residence*
	21	TI dementia care facilit* AND AB dementia care facilit*
	22	TI (((nursing or ag?ing or senior? or long-term) N3 (home* or facility* or residenc*))) AND AB (((nursing or ag?ing or senior? or long-term) N3 (home* or facility* or residenc*)))
	23	*S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22*
	24	***S7 AND S12 AND S23***

PsycINFO (OVID)

Concept	#	Search Terms
Therapy	1	dance therapy/
	2	Movement Therapy/
	3	Dance/
	4	danc*.ti,ab.
	5	((body or authentic) adj3 movement*).ti,ab.
	6	(movement adj3 therap*).ti,ab.
	7	*1 or 2 or 3 or 4 or 5 or 6*
Population	8	Dementia/
	9	alzheimer's disease/
	10	dementia.ti,ab.
	11	Alzheimer*.ti,ab.
	12	*8 or 9 or 10 or 11*
Setting	13	Residential Care Institutions/
	14	long term care/
	15	nursing home*.ti,ab.
	16	long-term care.ti,ab.
	17	ag?ing home*.ti,ab.
	18	Nursing Homes/
	19	senior? home*.ti,ab.
	20	senior? residence*.ti,ab.
	21	dementia care facilit*.ti,ab.
	22	((nursing or ag?ing or senior? or long-term) adj3 (home* or facility* or residenc*)).ti,ab.
	23	*13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22*
	24	***7 and 12 and 23***

Web of Science

Concept	#	Search Terms
Therapy	1	TS=danc*
	2	TS=((body or authentic) NEAR/3 movement*)
	3	TS=(movement NEAR/3 therap*)
	4	*#3 OR #2 OR #1*
Population	5	TS=(dementia)
	6	TS=(Alzheimer*)
	7	*#6 OR #5*
Setting	8	TS=(nursing home*)
	9	TS=(long-term care)
	10	TS=(ag?ing home*)
	11	TS=(senior? home*)
	12	TS=(senior? residence*)
	13	TS=(dementia care facilit*)
	14	TS=((nursing or ag?ing or senior? or long-term) NEAR/3 (home* or facility* or residenc*))
	15	*#14 OR #13 OR #12 OR #11 OR #10 OR #9 OR #8*
	16	***#15 AND #7 AND #4***

AARP Ageline

Concept	#	Search Terms
Therapy	1	DE "Dance Therapy"
	2	DE "Movement Therapy"
	3	DE "Dance"
	4	TI danc* OR AB danc*
	5	TI (((body or authentic) N3 movement*)) OR AB (((body or authentic) N3 movement*))
	6	TI (movement N3 therap*) OR AB (movement N3 therap*)
	7	*S1 OR S2 OR S3 OR S4 OR S5 OR S6*
Population	8	DE "Dementia"
	9	DE "Alzheimer’s Disease"
	10	TI dementia AND AB dementia
	11	TI Alzheimer* AND AB Alzheimer*
	12	*S8 OR S9 OR S10 OR S11*
Setting	13	DE "Homes for the Elderly"
	14	DE "Long Term Care"
	15	TI nursing home* AND AB nursing home*
	16	TI long-term care AND AB long-term care
	17	TI ag#ing home* AND AB ag#ing home*
	18	DE "Nursing Homes"
	19	TI senior# home* AND AB senior# home*
	20	TI senior# residence* AND AB senior# residence*
	21	TI dementia care facilit* AND AB dementia care facilit*
	22	TI (((nursing or ag?ing or senior? or long-term) N3 (home* or facility* or residenc*))) AND AB (((nursing or ag?ing or senior? or long-term) N3 (home* or facility* or residenc*)))
	23	*S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22*
	24	***S7 AND S12 AND S23***

Allied and Complementary Medicine (AMED)

Concept	#	Search Terms
Therapy	1	dance therapy/
	2	movement/
	3	dancing/
	4	danc$.ti,ab.
	5	((body or authentic) adj3 movement$).ti,ab.
	6	(movement adj3 therap$).ti,ab.
	7	*1 or 2 or 3 or 4 or 5 or 6*
Population	8	dementia/
	9	alzheimers disease/
	10	dementia.ti,ab.
	11	Alzheimer$.ti,ab.
	12	*8 or 9 or 10 or 11*
Setting	13	residential facilities/ or homes for the aged/
	14	long term care/
	15	nursing home$.ti,ab.
	16	long-term care.ti,ab.
	17	ag?ing home$.ti,ab.
	18	nursing homes/
	19	senior? home$.ti,ab.
	20	senior? Residence$.ti,ab.
	21	dementia care facilit$.ti,ab.
	22	((nursing or ag?ing or senior? or long-term) adj3 (home$ or facility$ or residenc$)).ti,ab.
	23	*13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22*
	24	***7 and 12 and 23***