Performing (Ab)normal: Reframing Ageing, Dementia, and Temporality

by

Heunjung Lee

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Abstract

In response to the broader discourse that scrutinises cultural constructions of dementia, this thesis investigates how performance theories and theatrical practices can disrupt, reshape, and transform the stigmatised cultural imaginary of persons living with dementia. By bridging Performance Studies, Age Studies, and Critical Disability Studies, this dissertation engages in activism and advocacy to rethink living with dementia as an alternative way of being and living.

More specifically, by focusing on alternative perception of time and reality experienced by people with dementia, this thesis engages in a sharp critique of discourses and representations that contrast normal versus abnormal experiences of consciousness. This study provides critiques of ableist assumptions in medical terms and cultural rhetoric framing the temporality of dementia, including notions of disorientation, asynchrony, and atemporality. Furthermore, by analysing theatrical representations of alternative temporal and reality experience of people living with dementia, this thesis demonstrates how theatre and performance can offer embodied and affective understanding of the experience of a syncopated time and an inter(in)animation between different times, memories, multiple age-selves, and realities. It suggests that theatre and performance can challenge the dominant, normative, and ableist perspective imposed on people with dementia and promote a more inclusive approach.

Additionally, this research problematises the ideas of normative ageing which cast out older adults with illnesses and disabilities from desirable ageing futures. By analysing three case studies of age-critical performance, this thesis demonstrates how theatre can disrupt normative cultural scripts of ageing and old age and expand and reshape our consciousness and imaginations of old age. Specifically, by showcasing the performative strength of older community performers in the analysed productions who convey intricate realities of ageing, this research considers the implications of dementia futurity in theatre and performance, advocating for a reimagining of theatre to include people with dementia as creators and performers. This dissertation concludes by introducing my own artwork that encapsulates my activist point of view regarding persons living with dementia. By examining the performance of dementia in both aesthetic and everyday contexts, this study highlights the unique contribution of Theatre and Performance Studies to the rethinking and reimagining of ageing and living with dementia.

Preface

This dissertation is an original, independent work by Heunjung Lee with respect to the identification and design of the research program, the conduct of all parts of the research, and the analysis of the research subjects and results.

An expanded article version of Chapter 4's section on Florian Zeller's play *The Father* is published in the peer-reviewed journal, *Contemporary Theatre Review*.[1] The author holds the copyright for this article.

A version of the Chapter 5's section discussing the concept of "experts of age/ing" and the critical analysis of Mammalian Diving Reflex's performance *All the Sex I've Ever Had* has been published in the peer-reviewed journal, *Theatre Research in Canada*.[2] The author retains the copyright for this article.

A version of the Chapter 5, providing a critical analysis of Tuuli Helkky Helle, a Finnish aged-disabled artist, and her dance, has been published as a book chapter in the anthology, *Aging Experiments: Futures and Fantasies of Old Age* (2023).[3] The author holds the copyright for the book chapter.

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[1] Lee, Heunjung. "Theatrical Affordances to Stage the Perceived-Experienced Reality of People with Dementia: Florian Zeller's Dramaturgy of Porosity in *The Father*." *Contemporary Theatre Review*, Vol. 23, No. 3, 2023, pp. 203-217. https://doi.org/10.1080/10486801.2023.2249395.

[2] Lee, Heunjung. "En/Countering Ageism Together: *All the Sex I've Ever Had* by Mammalian Diving Reflex." *Theatre Research in Canada*, Vol. 44, No. 1, 2023, pp. 82-102. https://www.utpjournals.press/doi/abs/10.3138/tric-2022-0004.

[3] Lee, Heunjung. "Dancing Relational Bodyhood: Older Disabled Artist-Activist Tuuli Helkky Helle (1933-2018)." In *Aging Experiments: Futures and Fantasies of Old Age*, Edited by João Paulo Guimarães, Transcript Verlag, 2023, pp. 97-124.

Some of the ideas from the Chapter 5's section, analysing laGeste's dance piece *Gardenia*, have been incorporated into an article published in the peer-reviewed journal, *European Journal of Theatre and Research*, with the author serving as the first author of the article.[4]

The image and description of "Across Time through Dementia" were featured in the 2021 University of Alberta Library's Images of Research competition and are published on the University of Alberta's Education and Research Archive (ERA) with the following DOI: https://doi.org/10.7939/r3-1yzh-1910.

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[4] Lee, Heunjung, and Xavia A. Publius. "Getting Our Flowers Now: Ageing Trans and Queer Bodies in *Gardenia* (2010) and *Gardenia – 10 Years Later* (2021)." *European Journal of Theatre and Performance*, Vol. 6, 2023. pp. 126-169, https://journal.eastap.com/eastap-issue-6/.

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The completion of this dissertation was facilitated by the support of professors, colleagues, and the administrative team in the U of A Drama Department. Dr. Stefano Muneroni and Dr. Donia Mounsef, in particular, helped me shape my dissertation by providing insightful ideas and advice. I am also grateful for the editorial assistance provided by my PhD colleagues: Lily Climenhaga, Xavia A. Publius, Lebogang Disele-Pitso, John Battye from the Drama Department, and Annika Rosanowski from the English Department.

I extend my gratitude to scholars from other institutions, especially Dr. Julia Henderson from UBC, for their generous contributions and encouragement to my scholarly growth. Their keen interest and willingness to share knowledge and resources have significantly enriched my academic journey. Special thanks to Dr. Valerie Barnes Lipscomb, Dr. Aagje Swinnen, Dr.

Christel Stalpaert, Dr. Kim Sawchuck, Dr. Stephen Katz, Dr. Benjamin Gillespie, and Dr. Micahel Davidson for their support.

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Last, but certainly not least, I would like to thank my family and friends both in Canada and South Korea, for their resolute love and support. Special thanks go to my parents, Mi-Suk Kim and Jin-Hyung Lee, who have been steadfast supporters, encouraging me to pursue my dream. This lengthy endeavour would not have been possible without their unconditional belief and love, all the way from South Korea. I also extend my appreciation to my in-laws, Winnie, and Peter Lam, for supporting and fostering an environment for my educational pursuits. I would like to thank my grandmother and my husband's grandparents, all of whom have been a great source of inspiration for my research. Additionally, I am deeply grateful for my dog, Flora, who has been my emotional caretaker, and to my precious daughter, Nadine Lam, who encouraged me to complete the final leg of this journey from inside of my belly!

Finally, above all others, from the bottom of my heart, I want to extend my deepest thanks to my husband, Andy Lam. His unceasing support, sincere interest, encouragement, and respect for my work have been truly invaluable. He always dedicated his time to read and edit my work over multiple iterations, consistently providing thought-provoking questions and comments that pushed me beyond my boundaries. All of my greatest accomplishments have been achieved together with him. I could not have asked for a better person to be by my side.

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Chapter One: Introduction

1.1 Performance and Activism: Challenging Normativity and Rethinking Dementia

Performance Studies, through its various theories and practices, is interested in accounting for the lived experiences of people and in particular, at least according to some scholars, those of the marginalized: as a discipline which is itself consciously positioned as marginalized and liminal (Bell 1993; Bial 2004). Bial states that "because this liminal position is often understood as a space for transgression or resistance (ideas and acts that go against the mainstream), many Performance Studies scholars have come to consider social activism a defining characteristic of the field" (5).

This project takes an original approach to this activism: it engages in an investigation of cultural imaginaries of ageing[5] and dementia by bridging Performance Studies, Age Studies, and Critical Disability Studies. One of the commonalities of these three disciplines is that they question *norms*. Performance Studies scholar Diana Taylor (2015) writes "the only rule we might apply is the following: breaking norms is the norm of the performance" (71) and "if the norm of performance is breaking norms, the norm of Performance Studies is to break disciplinary boundaries" (200). Therefore, research on ageing and dementia from a Performance Studies perspective must engage in a sharp critique of discourses and representations that divide what are normal and abnormal experiences of ageing and of consciousness. Regarding the growing

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[5] In Canada and the U.S., the preferred spelling is aging. British usage favours the variant ageing, which is also accepted in Canada. In this dissertation, I have chosen to spell ageing with 'e,' but I retrained North American spelling when used in direct citations. This is because I often use "age/ing" to combine both the idea of age and ageing; specifically, this is used in my conceptualization of "experts of age/ing." Thus, British spelling is more consistent with my use of"age/ing." Second, by using less familiar British spelling, this research responses to Gullette's call for revealing and noticing the automatic decline connotation in the term aging. In the same sense, when it is possible, I use precise variants of the gerund such as like 'ageing toward retirement', 'ageing beyond midlife, or 'ageing into old age' (see Gullette 2018).

number of people with dementia,[6] I suggest that Performance Studies can and should examine what kinds of social norms frame and regulate people with dementia, and intervene in normative discourse, knowledge, practices, and systems theoretically as well as aesthetically.

Biomedically, dementia refers to "a syndrome that can be caused by a number of diseases which over time destroy nerve cells and damage the brain, typically leading to deterioration in cognitive function (i.e., the ability to process thought) beyond what might be expected from the usual consequences of biological ageing."[7] Alzheimer's Disease (AD) is the most common form of dementia (consisting of 60-70% of cases); but there are more than 100 types of dementia including Vascular Dementia, Lewy-body Dementia, Frontotemporal Dementia, Alcohol-related Dementia, Mixed Dementia, etc. Each type of dementia has different paths, symptoms, and outcomes. Dementia is more common among older as compared to younger adults, particularly after the age of 85 (Ott et al. 1988). Dementia disrupts certain ideas and assumptions related to personhood, selfhood, and agency (Higgs and Gilleard 2016). As a research subject in Performance Studies, living with dementia can be situated in the context of broader research fields: the research of the performance of age/ing (e.g., Basting 1998; Gullette 2004; Mangan 2014; Fuchs 2016), the performance of illness and medicine (e.g., Holzapfel 2008; Mermikides and Bouchard 2016; Carel 2016; Weitkamp and Mermikides 2016; Pini and Maguire-Rosier

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[6] Throughout the dissertation, I use the terms 'people/persons with dementia,' 'people/persons living with dementia,' or 'persons/individuals with the lived experiences of dementia.' These terms are preferred over the terms such as 'victim' or 'sufferer,' which convey a negative and tragic view of dementia (Swaffer 2014). I also avoid the biomedically oriented term 'patient' because I am examining dementia as a socio-culturally constructed condition, rather than solely a medical one. The term 'patient' is only used in the context of discussing the doctor-patient relationship when analysing the treatment and documentation of the first patient with Alzheimer's disease in Chapter Two.

[7] The World Health Organization, "Dementia." *The World Health Organization Webpage*, March 15, 2023. https://www.who.int/news-room/fact-sheets/detail/dementia#:~:text=Key%20facts,nearly%2010%20million%20new%20cases. Accessed August 30, 2023.

2021; Sako and Falcus 2022), and the construction of self, identity, and normalcy (e.g., Sandahl and Auslander 2005; Henderson and Ostrander 2013).

With the intention of contributing to these fields of inquiry, this research aims to provide a phenomenological articulation of the altered temporal experiences of persons with dementia from a Humanities perspective. This approach supports the exploration of alternative ways of living and involves a critical examination of mainstream knowledge, social structures, and models of consciousness that tend to marginalize, stigmatize, and suppress different modes of existence. Marlene Goldman (2017) asserts that alarming facts and statistics about dementia, which can be contentious and occasionally overstated, are repeatedly referenced to convey the horrors linked to the "epidemic" of Alzheimer's disease (5). Canadian Gerontologist and Age Studies scholar Stephen Katz has also raised a similar critique of this practice. He argues terrifying statistical numbers contributes to augmenting alarming narratives of dementia and conjuring social and cultural fear related to dementia (Katz 2011). Aligning with these criticisms, this dissertation employs statistics more prudently. When quoting a statistic, the primary objective is to emphasize the urgent requirement for society to alter its stigmatizing perspective toward dementia and those impacted by it. By shedding light on the fact that over 55 million individuals are living with dementia worldwide, with nearly 10 million new cases every year[8] and considering the current lack of a cure for Alzheimer's disease and other forms of dementia, this research argues for a transformation in cultural perceptions and societal structures.

More specifically, this study investigates the cultural imaginary of ageing and living with dementia, questioning how images and perceptions of older people with dementia have been

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[8] The World Health Organization, "Dementia." *The World Health Organization Webpage*, March 15, 2023. https://www.who.int/news-room/fact-sheets/detail/dementia#:~:text=Key%20facts,nearly%2010%20million%20new%20cases. Accessed August 30, 2023.

constructed through health science, social, and cultural practices.[9] After critically reflecting on the current cultural imaginary of dementia, I suggest rethinking living with dementia as an alternative way of being and living. This perspective draws on Critical Disability Studies and Crip theories, which seek to disrupt and destabilise the normative ideas of "the human subject—as we normally understand it—and expound new ways of being and becoming" (Goodley et al., 494). Ageing, illnesses, and disability are intertwined in complex ways, and narratives that celebrate ageing or the lives of older adults often coalesce with an ableist concept that emphasises a triumph over the limits of human bodies and minds (Aubrecht et al. 3-4). Scholars in Critical Disability Studies and Age Studies have identified the complicated relationship between ageing and disability as well as the lack of scholarship exploring the ageing-disability nexus (see Grenier et al. 2016; Gallop 2018; Aubrecht et al. 2020). Aubrecht et al. (2020) argue that "creative and generative possibilities emerge when ageing is situated in a disability politics and when interpretations of disability take account of the weaving of material, social, and cultural relations in and through which the meanings of bodies as young or old are made and unmade" (5).

1.2 Research Questions and Chapter Overview

This dissertation pursues the central research question from the perspective that situates ageing and dementia within the framework of disability politics: What insights can Theatre and Performance Studies provide for rethinking and reimagining ageing and living with dementia?

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[9] Cultural images or imagery of dementia refer to representations and portrayals of dementia within a given society or culture, conveyed through various mediums such as literature, films, arts, theatre, performance, and media. Cultural or social imaginary of dementia is related to cultural imagery, but it goes beyond specific images or depictions. The notion of cultural imaginary encompasses a broader cultural and collective understanding and perceptions of dementia. While my dissertation engages with visual archives or theatrical representations of people with dementia, this study is interested in how they influence and shape broader societal beliefs and attitudes toward dementia. Therefore, this dissertation employs the term 'cultural imaginary' as a more potent notion.

This dissertation addresses four categories of questions related to the primary research question. (1) Can theories and perspectives of Performance Studies offer new insights into 'performing dementia' and 'performing medicine,' distinct from dominant biomedical perspectives? (2) Can notions and theories in Performance Studies and Critical Disability Studies reframe alternative consciousnesses of persons with dementia, utilizing non-ableist language? Can they also challenge biomedical discourses that label altered perceptions of time and reality in individuals living with dementia as abnormal and deviant? (3) How does theatre and performance contribute to "enhanc[ing] imaginative understanding and creative engagement with the complexities of mind [while living with dementia] through embodied practice" (Shaughnessy and Barnard 205)? (4) How does contemporary theatre and performance engage with the ideas of normative ageing? Can theatre and performance, with an age-critical perspective, counter normative discourses related to ageing and expand cultural scripts of growing old and old age while reflecting various non-normative ageing stories? (5) How can theatre and performance industry be re-imagined and transformed by considering the participation of persons with dementia as creators, performers, and audience? What might dementia futurity in theatre and performance look like?

These research questions are informed by the recent scholarships in Performance Studies that examines "the potential of performance and theatre to intervene in, shape, inform, and extend vital debates around biomedical knowledge and practice in the contemporary moment" (Mermikides and Bouchard 2016). Most of the existing studies on the second question, *the performance of dementia*, have taken a more traditional approach within theatre studies, analysing how dementia is represented in plays and performance works (Batch 2019; Gibson 2020; Lee 2023). While my research also engages with the representation of altered consciousness of people living with dementia in Chapter Four, the original contribution of this dissertation lies in re-thinking conditions of mind affected by dementia from a perspective that bridges Critical Disability Studies and Performance Studies. In the editorial collection of essays *Performing Psychologies* (2019) edited by Nicola Shaughnessy and Philip Barnard, multiple scholars have discussed how conditions of mind or what they call "mind space" (4) are accessed through creative practices of drama, theatre, and performance. The overarching research task of this dissertation is to problematise the normative views that have framed the conditions of mind of people living with dementia and to suggest developing non-ableist perspective.

Chapter Two critically reflects on the dominant cultural imaginary of dementia, which associates persons with dementia with the living dead. This reflection engages with a historical subject—the medical practice of Dr. Alois Alzheimer and the medical gaze acted upon the first actual patient with Alzheimer's disease, Ms. Auguste Deter. From a Performance Studies perspective, my research investigates the *performativity* and *citationality* of the photographs of Ms. Auguste Deter by applying performance theories from Diana Taylor (2003), Rebecca Schneider (2011), and Ariella Azoulay (2008). In other words, this chapter asks what has changed in the last 100 years regarding the perception of persons living with dementia, and how the stigmatising and dehumanising image of persons with dementia, communicating the idea of "the zombie trope" that is exemplified in Ms. Deter's famous portrait, still predominates, and conjures up the social fear and shame regarding dementia. Goldman (2017) has taken a Humanities approach to access Ms. Deter's voice, emotions, and experiences of the asylum by looking through the medical records of her from a non-medical perspective. While Goldman has primarily engaged with written texts, my study offers an embodied and phenomenological reading of the visual archives of Ms. Deter and questions the ethical and civil responsibility of the contemporary observers who see her photos taken in the 20th century. The chapter discusses how contemporary portrayals of individuals living with dementia in online stock images still reinforce stigmatizing stereotypes, particularly those associating them to the living dead.

After critiquing stigmatising views on dementia in a more general sense, Chapter Three and Four investigate how Humanities perspectives, more specifically perspectives of Performance Studies and Critical Disability Studies, can challenge normative, ableist, and marginalising perspectives towards conditions of mind affected by dementia. My research hypothesises that notions and theories in Performance Studies and Critical Disability Studies can counter the negative framings used in biomedical discourses, which characterise the consciousness of people with dementia as abnormality and deviance. By connecting the theory on crip time in disability studies and time concepts in performance theories that embrace nonlinearity, temporal crossing and drag, and simultaneity, my research suggests fostering an inclusive approach in thinking and talking about the altered perception of time and reality.

Chapter Three begins by critically examining binary, ableist, and marginalising languages—disorientation, discontinuity, asynchrony, atemporality—that describe the time and reality perception of individuals living with dementia that are deviant from the normative consciousnesses. This dissertation problematises the ways in which normative framings used in clinical and cultural discourses enhance the process of othering people with dementia, by demarcating the boundaries of normal and abnormal. This is pioneering research that provides thorough overview of how temporality of dementia is studied and discussed across multiple disciplines including Health Sciences and Psychology, and critical reflections on the current discourses regarding its association with stigma and marginalisation of people living with dementia. After a critical review on existing discourses on the temporality of dementia, my dissertation explores how we can re-think and re-frame the alternate consciousnesses lived by individuals with dementia. Drawing on the theories of crip time, Chapter Three establishes my activist standpoint, which advocates for examining and re-envisioning taken-for-granted systems and conditions in which we are located, rather than imposing normative assumptions and expectations upon individuals affected by dementia.

Chapter Four turns its attention to the conversation around neurodivergent aesthetics in Performance Studies (Shaughnessy 2013; Hilton 2018; Shaughnessy and Barnard 2019) and explores how performance practices can counter ableist views towards various consciousnesses and enhance more inclusive views towards people living with dementia. By analysing creative, imaginative, affective, and embodied representation of dementia temporality in contemporary performances, this dissertation foregrounds how creative modalities of performance can foster more inclusive views towards altered consciousnesses and counter the predominant ableist framing that frame living with dementia from a normative perspective. The distinct contribution of Chapter Four is connecting the field of work on representation of dementia to broader theatrical engagements with diverse cognitions and sensory experiences of neurodivergent individuals or persons with mental disabilities. The analysed performances in the chapter suggest that theatre and performance have great strength in articulating the lived experiences of dementia and the so-called insider perspective while retaining affective, embodied, contextual aspects that can be easily lost in medical and neurological research.

While Chapter Four showcases several plays and performances that enhance affective and embodied understanding of the alternative consciousness of people with dementia, some of the theatrical works still portray the loss of memory and other cognitive abilities due to ageing and dementia through the prevailing tragic narrative. Such works typically connect the changes in cognitive abilities to the loss of self, relationships, and personhood. In this regard, Chapter

Five broadens the scope of discussion and explores how theatre and performance can overcome narrow, stereotypical, negative views on growing old and old age while portraying changes and challenges that can follow ageing. In this chapter, this thesis analyses three age-critical performances that successfully reflect the complexity of ageing—encompassing both the pleasures and the perils[10]—by inviting older citizens to share their lived experiences of ageing and diverse views on ageing. Rather than analysing more fictional plays on dementia, this chapter, by discussing performances that employ the technique of Theatre of Real People, highlights the need to explore ways for actual older adults living with dementia to share their heterogeneous experiences of living with dementia through theatre.

This discussion is connected to the concluding chapter's contemplation on what a 'dementia futurity' within theatre and performance might entail. In Chapter Six, before suggesting remaining questions to advance inclusivity of people with dementia in theatre and performance, I introduce my lived experience as a family member of a person with dementia. I discuss my own visual artwork *Across Time through Dementia* (2021), a college-style portrait created as an homage to my husband's grandfather who lived with dementia. I articulate how it captures him as a whole person and does not re-install the dominant tragic narrative that focuses on the loss and discontinuity of self. By highlighting the importance on focusing on the person, not the disease, and emphasising the enduring qualities of people affected by dementia, the concluding section suggests the possibility and necessity for persons with dementia to take part in theatre and performance as creators, performers, and audiences.

This dissertation contributes to the growing intersection of theatre and dementia by expanding discussions on the performance of dementia both in aesthetic and everyday contexts,

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[10] I borrowed this explanation from the book title, Lynne Regal, *Out of Time: The Pleasures and the Perils of Ageing*, 2013.

and this is the first in-depth study that focuses on the temporality of dementia and reality perception within Performance and Theatre Studies. In Arts and Humanities, the main research focus regarding dementia has been changes in memory. My research expands the broader potential of Arts and Humanities to critically engage with various aspects of mind affected by Alzheimer's disease and dementia. A few scholars in Arts and Humanities recently have paid attention to the orientation and temporality of people living with dementia. I have presented papers on this topic at a few conferences. My conference paper, "Disorder and Disorientation: Time and Place Experiences of Persons with Dementia" (2019),[11] reflects on the binary and normative implications of languages such as disorder and disorientation. My conference paper, "Dementia: Performing Discontinued and Incoherent Temporality and Personhood" (2020),[12] critiques how the emphasis on continuity, unity, linearity in accounts of identity and selfhood can foreground the dehumanisation of persons with dementia.

Hailee Yoshizaki-Gibbons's doctoral dissertation in Critical Disability Studies, *Time and Again: Old Women and Care Workers Navigating Time, Relationality, and Power in Dementia Units* (2020), has conducted ethnographic research exploring the time-making between residents living with dementia and care workers in a long-term care home. She investigates what she terms "dementia time" by drawing on the concept of crip time. Researcher-practitioner Nicky Hatton's monograph, *Performance and Dementia* (2021), also briefly discusses how temporality can be considered in art practices that engages with people with dementia. She points out that slowing down and reconfiguring a sense of pace is essential for artists and researchers so as to *be* in the

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[11] This referred conference paper was presented on June 5th, 2019, at the Between Performance & Social/Health Science Seminar, during the Canadian Association for Theatre Research (CATR) 2019 at the University of British Colombia in Canada.

[12] This referred conference paper was presented virtually on July 25, 2020, at the Narratives of Temporality: Continuities, Discontinuities, Ruptures International Conference, annually hosted by the London Centre for Interdisciplinary Research.

care home environment with residents living with dementia (12). Gerontologist Stephen Katz has recently presented a conference paper, “Time, Memory, and Dementia: An Becoming/Un-becoming Approach” (2022).[13] In this presentation, he touches on how phenomenological ideas from philosophers Henri Bergson and Gilles Deleuze on temporality, which emphasise the co-existence, intermingling, and ever-changing relationship of past, present, and future, and allow us to rethink the linear construction and understanding of memory. MaoHui Deng’s book, *Ageing, Dementia, and Time in Film* (2023), also engages with Deleuze’s philosophy on time and expands the scholarship on ageing and dementia through a temporal perspective.

While building on these existing conversations, my dissertation explores what it means to position living with dementia within a disability politics and how theatre and performance theories and practices can foster more inclusive perspectives, languages, and social changes in relation to the alternate conditions of mind affected by dementia. By rethinking what is defined as the “normate subject” (Garland-Thompson 8) and normal minds and by advocating alternative ways of engaging with time and reality through Performance Studies, my research will open up possibilities that contribute to ongoing attempts to 1) articulate altered reality experiences among persons living with dementia differently beyond normative and binary framings, 2) expand discourse on alternate temporality by revealing how mainstream society and politics “thinks of, produces, and administers the person, and how this is challenged by practices that insist on another notion of personhood” (Edkins 135), and 3) promote an understanding of persons living with dementia that could lead to enhanced individual, social, clinical support, which, in turn, may accommodate living with dementia as an alternative ways of being and living.

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[13] Katz has shared his conference paper with me, and it is not published.

1.3 Methodology

1.3.1 Theoretical Lens and Framings

(1) Performance of Age/ing, Dementia, and Medicine

The primary disciplinary approach of this dissertation follows research methodologies of Theatre and Performance Studies; however, it also engages with Age Studies and Critical Disability Studies and employs an interdisciplinary approach to analyse both aesthetic and socio-cultural performances of ageing and dementia. Using methods of performance analysis (Pavis 2003; Balme 2008), I conduct a critical analysis of plays and performances which engage with living with dementia, specifically focusing on works that represent altered perception of time, reality, and self. Performance Studies not only analyses dramatic texts but also performance texts (Schechner 2017: 25), in which various networks of semiotic units interact; as such, my analysis considers anything on stage that can be part of the network of signs and have potential to generate dynamic meanings (e.g., stage set, actors, costume/makeup, lighting, objects, etc.). However, the semiotic approach has limits in articulating the affective psychological, and kinaesthetic experience of theatre and performance, so this study also draws on the phenomenological approach in discussing the performative aspects of theatre and perceptual and embodied experience of theatre and performance.[14] The examined plays and productions were accessed through a combination of written scripts, videos, photos, reviews and interviews, and spectating notes from visiting live performances and watching videos of the performances.

This research not only engages with the aesthetic performance of ageing and dementia, but also the performance of medicine and dementia within a social context, employing the

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[14] For the genealogy of semiotics in theatre studies and its methodological problems, see Fischer-Lichte, "Sense and Sensation: Exploring the Interplay Between the Semiotic and Performative Dimensions of Theatre." *Journal of Dramatic Theory and Criticism*, Vol. 22, No. 2, 2008, pp. 69-81.

perspective of Performance Studies which defines a broad range of "embodied praxis" as performance (Taylor, *The Archive and The Repertoire* 16). For example, in Chapter Two, I draw on Performance Studies perspectives in analysing how Ms. Auguste Deter, the first patient with Alzheimer's disease, has been observed, treated, documented, and framed under the 19th century medical gaze when she lived in a German asylum. Drawing on theories of performance and photography developed by scholars such as Ariella Azoulay (2008), Rebecca Schneider (2011), and Diana Taylor (2003), I articulate the performative force of the photographs of Ms. Deter in an asylum and its ongoing performativity and citationality, which contribute to the cultural imaginary and understanding of a person living with dementia.

(2) Framing Dementia

There are various points of views in understanding and framing dementia; it is important to state how this project approaches and understands dementia. Dementia has been dominated by biomedical models and the term is used to describe "several diseases affecting memory, other cognitive abilities and behaviour that interfere significantly with a person's ability to maintain their activities of daily living."[15] In the biomedical world, dementia is chronic and progressive, distinguishing it from delirium, which is transient. Since the early twentieth century, neurological research on Alzheimer's disease has identified degenerating neurons with the amyloid plaques and neurofibrillary tangles as the hallmark signs of the disease, yet research has not been able to establish a clear causal pathway between these signs and cognitive symptoms. Neurological research is dedicated to find what causes 'abnormal' changes in the brain and how to stop them. According to the most recent International Statistical Classification of Diseases and

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[15] The World Health Organization, "Dementia." *The World Health Organization Webpage*, 2023. https://www.who.int/health-topics/dementia#tab=tab_1. Accessed August 30, 2023.

Related Health Problems 11th revision (ICD-11) published in 2018 by the World Health Organization (WHO), dementia is categorized under *Mental, Behavioural or Neurodevelopmental Disorders* and more specifically *Neurocognitive Disorders* along with delirium[16] and amnestic disorders.[17] The WHO's campaign emphasizes that "although age is the strongest known risk factor for dementia, it is not a normal part of ageing" (2023); however, as Stephen Katz (2013) critiques, it is debatable whether "the ensuing AD movement has lessened or heightened the stigma about dementia" (311).

Challenging the biomedical model of dementia, research of Critical Gerontology, Humanities, and Critical Dementia Studies have expanded the perspectives of socio-cultural construction of dementia and have suggested that dementia is not simply a disease but a cultural phenomenon. These perspectives encourage the "examination of cultural and historical influences and thus question how societies have constructed and defined dementia" (Zeilig 2014). As Swinnen and Schweda (2015) write, "the concept of dementia is no longer limited to expert biomedical discourses but gets integrated into public imagination and popular culture" (10). The perception and experience of dementia can be personal, subjective, and culturally divergent depending on their political, economic, and socio-cultural contexts of countries (10). Goldman (2017) warns, predominant biomedical perspective focusing on the brain reduces personhood to cognitive ability, and "we have stigmatized pathological memory loss to the extent that people feel as if a decline in cognitive function effects their humanity" (5).

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[16] "Delirium is characterized by disturbed attention (i.e., reduced ability to direct, focus, sustain, and shift attention) and awareness (i.e., reduced orientation to the environment) that develops over a short period of time and tends to fluctuate during the course of a day, accompanied by other cognitive impairment such as memory deficit, disorientation, or impairment in language, visuospatial ability, or perception" (ICD-11). https://icd.who.int/browse11/l-m/en#http%3a%2f%2fid.who.int%2ficd%2fentity%2f897917531. Accessed July 31, 2023.

[17] "Amnestic disorder is characterized by severe memory impairment relative to the individual's age and general level of intellectual functioning that is disproportionate to impairment in other cognitive domains" (ICD-11). https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/386330688. Accessed July 31, 2023.

This study recognizes that the experience of dementia can become radically different as the lived experience of dementia intersects with multiple identity and sociocultural factors such as gender, race, class, etc. I agree with the argument of Swinnen and Schweda (2015) that "[u]nderstanding the multiple ways by which dementia, while biologically influenced, is at the same time culturally constructed contributes to the fight against stigma and can improve the wellbeing of people with dementia and their caregivers," therefore "dementia studies has a normative dimension" (11). Furthermore, as an investigation of dementia within Theatre and Performance Studies, my study follows the view that the ideas and images of dementia are reflected, shaped, and negotiated in the range of cultural artefacts, including literature, arts, film, mass media, public health campaigns, social media, and so on (see Swinnen and Schweda 2015). As this research is concerned with cultural imaginaries of dementia in general, while I recognize the differences of multiple types of dementia, I mostly use the term 'dementia' throughout the dissertation rather than using specific clinical terms (e.g., Alzheimer's disease, vascular dementia, etc).

My study is also guided and informed by the personhood movement in Critical Gerontology, Dementia Studies, and Nursing, which has revisited and challenged the concept of personhood which the Enlightenment engendered based on "hypercognitivism" (Kitwood and Bredin 278) and "a cerebral 'brainhood' figure" (Katz 2013: 310). Arguing for an alternative conceptualization of personhood and subjectivity, scholars have produced an interpersonal model of personhood (Kitwood and Bredin 1992) and models of personhood that restore the centrality of the body and recognize embodied cognition, selfhood, and agency (Kontos 2005; Kontos and Nagile 2007; Twigg 2010; Katz 2013; Kontos and Martin 2013; Kontos et al. 2017). Because this dissertation is a critical reflection on the biomedical conceptualization of temporal perception and reality orientation of persons with dementia, it examines the existing literature on temporality of dementia across multiple disciplines (e.g., Medicine, Health Sciences, Psychology). While this examination does not entirely disregard the significance of studies that can advance our understanding of dementia, it takes a critical approach to biomedical perspectives. Biomedical perspectives often generate marginalising and stigmatising framings, viewing dementia as “exemplars of deficit and loss therefore as radical departures from the so-called normal functioning of the human body” (Gibson 2020: 38). By developing an alternative way of thinking and articulating the altered temporal orientation experienced by people living with dementia, this dissertation will contribute to expand our understanding of how dementia temporality is related to the maintenance of the personhood, selfhood, and identity of persons with dementia.

(3) Normativity and Crip Futurity

Dementia raises fundamental questions regarding what it means to be human because the conditions of dementia disrupt the conventional assumptions of personhood, selfhood, agency, and citizenship (Bartlett and O’Connor 2007; Coors 2013; Birt et al. 2023). The biomedical definition of dementia has been often associated with the boundaries of normal and abnormal mind. Hence, the concepts of (ab)normalcy, naturalness, and normativity are central in my critical engagements on ageing and dementia. In my critique of these binary discourses, I engage with existing discussions within Critical Gerontology and Health Sciences. For instance, I draw on the concepts of “the third age” and “the fourth age” and its marginalizing and othering implications (Higgs and Gilleard 2014). Hannah O’Rourke and Christine Ceci (2013) also informs my criticism on this issue as they critically examine common conceptualizations of normal and abnormal ageing, including those found in anti-ageing science, successful ageing, and healthy ageing policy discourses and in health education textbooks.

The established theories on the social construction of normalcy within Critical Disability Studies (Garland-Thompson 1997; Davis 1995; 2010; Michalko and Titchosky 2009) are particularly helpful in advancing my critique. In *Enforcing Normalcy* (1995), Davis argues "disability is not an object but a social process" (2) and illustrates how disability is not an individual problem but is created by the concept of the norm and the gaze of the non-disabled. Rosemarie Garland-Thompson, Disability Studies scholar, termed "the normate" in her book *Extraordinary Bodies* (1997) referring to Erving Goffman's discussion of stigmas. Garland-Thompson defines the normate as "the social figure through which people can represent themselves as definite human beings" and explains that the normate subject is a constructed identity "by way of the bodily configurations and cultural capital they assume" and those who "can step into a position of authority and wield the power it grants them" (8).

Just as "the concept of disability is a function of a concept of normalcy" (Davis 2), the concept of dementia has been created in contrast to the normal mind; I argue that we need a new approach in articulating different minds of people living with dementia beyond the idea of normal and abnormal. In this sense, I draw on Crip theories (McRuer 2006; Kafer 2013), and more specifically the notion of "crip time" (Kafer 2013; Kuppers 2014; Samuels 2017; McRuer 2018; Backhausen et al. 2023) in my conceptualization of dementia temporality and perception as an alternative way of being and living. My study's original contribution is that it connects the notion of crip time with performance theories that challenge and trouble linear time concepts. Interweaving Rebecca Schneider's theory on reenactment and her use of Elizabeth Freeman (2010)'s notion of "temporal drag," I offer a critique of the ableist assumptions in the notion of “disorientation” and suggest a new account for the altered temporality lived by persons with dementia. McRuer (2006) notes that able-bodiedness is articulated in negative terms in contrast to disability in the same way that heterosexuality is conversely dependent on homosexuality (385). He further asserts that people are socially compelled to prefer and desire within a binary matrix for only one choice, able-bodiedness or heterosexuality. As such, McRuer (2006) terms this as “compulsory able-bodiedness,” which is constantly (re)produced in and through a wide variety of cultural institutions and social dynamics. Similar to queering, *cripping* as a verb means revealing “able-bodied assumptions and exclusionary effects” (Sandahl 2003: 37). Applying a crip perspective to dementia means revealing able-bodied assumptions and its marginalizing effects, and re-imagining “conceptual boundaries, relationships, communities, cultural representations, and power structures” (Hutcheon and Wolbring 2013). In re-conceptualizing dementia as an alternative way of being and living, I draw on similar discussions that advocate for a rethinking of dementia drawing on queer and crip theories (Ward and Price 2016; Sandberg and Marshall 2017).

While disability is often understood as an expected facet of ageing process, it is still debatable whether dementia should be considered as a disability or neurodiversity, whether people with dementia might consider themselves as disabled people. However, a few recent studies have argued that rethinking dementia through disability or neurodiversity can advance collaborative partnerships between people with dementia and disability communities and promote human rights of people with dementia (Shakespeare et al. 2017; Örulv 2023). The socio-political implication of locating people with dementia within a disability politics is not the focus of my study. Nevertheless, this study follows the dominant perspectives of Critical Disability

Studies which imagine a radically inclusive and accessible social and cultural organization, in which people with the widest array of minds and bodies can participate and flourish.

Living with Dementia: Relations, Responses, and Agency in Everyday Life (2017*)*, a collection of research by mostly scholars from Sweden and the UK, explains that dementia has been primarily seen as a disease and persons with dementia are encountered and described in care settings (Hydén and Antelius 3). They argue for the significance of shifting focus towards the various everyday contexts among persons with dementia, shifting focus "from care to a life with dementia" (Hydén and Antelius 3). This point of view is reflected in current movements advocating for dementia-friendly or dementia-inclusive societies and communities (see Lin 2017; Phillipson et al. 2019). I argue this movement is closely related to realizing what is defined as "crip futurity" or "disability futurity" in Critical Disability Studies (see Kafer 2013; McRuer 2014; Rice et al. 2017). These scholars in disability studies have addressed the concept of the "curative imaginary," which pertains to the notion of a future that can only be envisioned through the resolution or cure of disability. Instead, they have advocated for "crip futurity" which is inclusive of different bodies and minds with "a newly imagined and newly configured public sphere where full participation is not contingent on an able body" (McRuer, *Crip Theory* 30) and mind. This perspective should be applied to the politics of dementia; the crip futurity would mean re-imagined and re-configured environments and social structures that allow people with dementia to fully participate in their society as equal citizens.

1.3.2 Scope and Delimitations

My study focuses on a very specific aspect of dementia: the temporality of dementia; confining this dissertation's search to a geographical region is not feasible because there are limited number of productions that engage with this subject. The productions mentioned or analysed in the dissertation originate in English-speaking countries, including Canada, the United Kingdom, the United States, and Australia. All performances analysed in this dissertation are twenty-first century productions (mostly in the period of 2010s-2020s), and they are produced professionally. In terms of the artistic forms, they include dramatic plays, verbatim theatre, physical theatre using movements and mime, as well as theatrical dance pieces integrating dance and spoken languages. Performance analysis is based on available materials, including written scripts, video recording, live performance, online video snippets, photographs, theatre reviews, and academic papers. As such, the performances under analysis are chosen based on their relevance to my inquiry and the accessibility of their materials.

In Chapter Four where I conduct performance analysis, I discuss specific criteria in the selection of case studies as well as the available materials of each production. Performance analysis is highly dependent on available materials, including written script, video recording, live performance, online video snippets, photographs, theatre reviews, audience response, and critical papers. As such, the eight productions analysed in Chapter Four are not an exhaustive list of contemporary performances on the subject, and it is recognised that some performances that are particularly pertinent to the topic cannot be analysed in the body of the thesis because of limited access to materials.

In addition, in the literature review of the temporality of dementia (Chapter Three), because of the specificity of the subject, my research does not limit its scope to a geographical region and includes one study that is not conducted in a Western country (Japan); however, its findings were published in English.

Because my work charts a new area of study that is underexplored and employs an interdisciplinary approach connecting Theatre and Performance Studies, Age Studies, and Critical Disability Studies, I recognize that there are areas that can be explored and developed further theoretically. For instance, this research only considers professionally staged productions that represent the lived experiences of dementia and does not engage with many other forms of theatrical practices engaging with the subject of dementia. It will be important to explore community-based theatre, applied theatre, senior theatre, intergenerational theatre, and arts-based theatre or interventions.[18] Theatre that is created for and with persons with dementia and performance projects that are taking place in care homes are increasing (see Hatton 2016; 2021; Basting et al. 2016; Chivers and Kriebernegg 2017), and I aim to engage with these various practices in my future research. Although I recognize the significance and unique contributions of these forms of theatrical practices when it comes to the subject of dementia and care, I chose to limit my investigation to staged productions because this research focuses on the cultural imaginary of ageing and dementia, and professional productions tend to reach larger audience and reflect the dominant cultural narrative. I aim to pick up on these remaining areas of studies in my own future research and suggest that the intersectional study of theatre and performance, age, and dementia/disability needs to expand.

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[18] I have engaged with both local and international community-based theatre companies that centralise community older adults as co-creators or participants. For instance, I engaged with Edmonton-based intergenerational/senior theatre group GeriActors (https://geriactors.ca/) through a university course and additional workshops. I have also visited and interviewed British theatre company Spare Tyre (https://www.sparetyre.org), which has produced participatory and immersive theatre productions for older adults with dementia in care homes. However, these investigations were not relevant to my current research scope on time and reality experience of dementia.

Chapter Two: Unpacking Cultural Imaginary and Stigma of Dementia

> The basic goal is encapsulated in the metaphor of "not shooting" old people. Grim circumstances demand appropriate metaphors. To whatever reduces our dignity and personhood, let us retort, en masse, *We are still human*.
>
> Margaret Morganroth Gullette, *Ending Ageism or How Not to Shoot Old People*, 2017, p. 7 (emphasis in original).

2.1 Introduction: Social and Cultural Constructions of Dementia

Alzheimer's disease and other dementia is one of the most feared and stigmatized diseases of the twenty first century, and it is tightly associated with ageing, old age, and ageism (Bruens 2014). In a paper, "Separate and Unequal: A Time to Reimagine Dementia" (2021), Pia Kontos, a renowned Canadian scholar of Critical Dementia Studies, and her research team write:

> Since communicating verbally often becomes difficult for people with cognitive challenges, many have been unable to speak up for their citizen rights to access equal standards of living, participate in decisions involving them, their community, culture, recreation, privacy, and other aspects of their well being, in ways other disability groups have historically done. Left unchallenged are societal assumptions that the neuropathology associated with dementia 'eradicates the essence of the person'. This is evident in the metaphors and images in policy and popular culture that represent dementia as "the funeral without end", "the loss of self", "the zombie", and "a living death", which

> perpetuate a deep and pernicious fear of, and disregard for, persons living with dementia. (1397).

Just as ageing and old age are cultural constructs, dementia is also a product of social and cultural constructs. Scholars in Arts and Humanities have discussed the rhetoric, metaphors, and imageries of dementia through investigations of its representations in various media, including literature, film, and theatre. Goldman (2017) asserts that narratives of age-related dementia have evolved into "narratives of gothic horror" and have constructed cultural interpretations of dementia. In an anthology, *Popularizing Dementia: Public Expressions and Representations of Forgetfulness* (2015), Aagje Swinnen and Mark Schweda also have investigated how dementia is constructed through literary texts, arts, and media discourse. More recently, in *Dementia, Narrative and Performance: Staging Reality, Reimagining Identities* (2020), Janet Gibson has explored how people with dementia represent themselves and are represented in Theatre of the Real productions in Australia and the United States of America. In her doctoral dissertation, *The Loss of Small White Clouds* (2019), Morgan Batch has thoroughly surveyed and covered diverse forms of representations of dementia in contemporary performance, mainly in the United Kingdom.

2.1.1 Research Questions and Purpose

Drawing on these studies that explored narratives and representations of dementia, this chapter discusses how early 20th-century medical practices related to Alzheimer's disease have contributed to producing a certain imagery of dementia. As this is a big question, this research focuses to a specific case—I closely examine the medical practices of Dr. Alois Alzheimer and how they treated and documented Ms. Auguste Deter, while she was in an asylum in Germany. Prior to delving into an in-depth analysis of Ms. Deter, this chapter introduces biomedical perspectives of the Alzheimer's disease and dementia. It also outlines how Alzheimer's disease and dementia have been medicalized since the 20th century, while critically reflecting on the intricate relationship between ageing and dementia.

This reflection on the history of pathologizing and medicalizing of dementia is followed by my analysis of Ms. Deter. From a Performance Studies perspective, this chapter employs a phenomenological approach to engage with the archival materials of Ms. Deter. By re-visiting the medical archives such as diagnostic records, brain slides, photographs of her in mental institutions and scientific studies on her, this chapter discusses the process of cultural and social pathologizing of Ms. Deter and how an image of a person with dementia is impacted by conceptions of deviation and abnormality. In this critique, I also revisit the neoliberal discourse dividing "the third age" and "the fourth age"; and the concept of abjection that has been applied to people with dementia.

This chapter ends by questioning the socio-cultural displacement, segregation, and concealment of people with dementia. Institutionalization of older people with dementia is not only a practical care choice, but also a social and political practice that is closely related to the stigma around older citizens living with dementia. The politics of displacement and concealment is a key to understand the social understanding and construction of dementia. I reflect on these issues by looking at a participatory performance art *Could You Watch My Mom for a Moment?* (2019), created and performed by a Finnish disability activist and artist Jenni-Juulia Wallinheimo-Heimonen. In the discussion of this production, I reflect on where are the bodies living with dementia in our societies.

2.1.2 Theoretical Frameworks: Performance of Illness and Medical Body

This investigation takes a similar approach as many disciplines such as Medical Sociology, Medical Anthropology, and Nursing, which perceive “health and illness as social as well as individual bodily processes” (Bradby 1). For instance, in Medical Anthropology, Annemarie Mol has investigated how illnesses such as atherosclerosis, asthma, or diabetes are done differently in multiple situated practises and how we do body differently by living with a chronic condition (Mol 2002; Mol and Law 2004). In Nursing, Barbara Paterson (2001) focuses on the perspective of the person with the disease and outlines illness as an ongoing constantly changing process and experience. Medical Sociology considers more macroscopic factors entangled with these medical practices, including government policies and healthcare system practices, as well as intercultural and ethnographic influences.

Recently, scholars in Performance Studies have engaged with the performance of medicine and the medical body, by focusing on the performance of the body—the actions, gaze, and rhetoric that are “acted upon” the medical body (Mermikides and Bouchard 24). The critical analysis of the first patient with Alzheimer’s disease, Ms. Auguste Deter, will showcase how Performance Studies can offer new insights into and critiques of the medical practices (e.g., acts of diagnosis, treatment, and documentation, the body of the patients and medical practitioners) and medical contexts (e.g., physical environment of the asylum). In this approach, Performance Studies considers both the narrow concept of theatre and performing arts and the widely defined concept of performance. The latter extends the scope of Drama and Theatre studies to consider “‘action’ or ‘what people do in their activity of doing it’” (Schneider 1), following the impetus of Performance Studies. Richard Schechner’s famous notion of “restored behaviour” (or “twicebehaved behaviour") (Schechner 1981) points to the quality of repetition that defines performance. By being replayed over generations, these strips of behaviour exist separate from those who are behaving in a sense that these behaviours have already happened and "have a life of their own"—"the original 'truth' or 'source' of the behaviour may be lost, ignored or contradicted" (Schechner, *Between Theater and Anthropology*, 35). While unable to locate where these behaviours belong, they become "symbolic and reflexive," meaning these behaviours are loaded with "multivocally broadcasting significances" (Schechner, *Between Theater and Anthropology*, 36). Echoing Schechner, Marvin Carlson (2013) writes "the recognition that our lives are structured according to repeated and socially sanctioned modes of behaviour raises the possibility that all human activity could potentially be considered as 'performance,' or at least all activity carried out with a consciousness of itself" (4). In this sense, both the staged artistic performance and "the display of culturally coded pattern of behaviour" (4-5) are located on a continuum of performance. Building upon these theorizations of performance, this research attends to the performance of Alzheimer's disease and dementia; the performance of medical practices and gazes acted upon persons with dementia.

More specifically, I examine the biomedical practices enacted upon Ms. Auguste Deter and discuss how the idea of a pathological-abnormal subject is produced. Through a performance lens, I will look at how Ms. Deter, as an individual with dementia, was observed, diagnosed, documented, and how her life and body have been viewed, framed, used, and remembered in medical discourse and practice. The performance theories regarding the performativity of archival materials guide my analysis of both visual and written documentation related to Ms. Deter. Diana Taylor (2003), for instance, defines "archive" as enduring materials (i.e., texts, documents, buildings, letters, archaeological remains, bones, videos, films) that supposedly resistant to change, in contrast to the so-called ephemeral “repertoire” of embodied practice and knowledge (i.e., spoken language, dance, sports, ritual) (16-19). Peggy Phelan s book *Unmarked: The Politics of Performance* (1993), which rethinks the visibility politics in photography, painting, film, and theatre, also informs my discussion of the medical gaze and the (in)visibility of individuals with dementia. The works of Ariella Azoulay (2008) and Rebecca Schneider (2011) on photography also provide theoretical groundwork for this analysis. Following the French philosopher Roland Barthes, who argued that the ontology of photography is linked to performance, performative analysis of photographs foregrounds the “‘doing’ aspects of photography, asking how images exceed their frames and directly affect their viewers” (Levin 329). Azoulay (2008) and Schneider (2011) have invited us to rethink the time frame of the photograph—they refuse the view which understands a photo as testimony or evidence of past events and recognize the power and encounter of the co-presence between the viewer and the photographed body or event. By challenging the prevailing perspective of photography as a fixed event in the past, both scholars encourage us to fundamentally alter our relationship to photography and to contemplate the human rights associated with the individuals depicted in photographs, as well as the responsibility of the viewers. Informed by this perspective, I highlight the performative impact of the photographs of Ms. Deter and their enduring citationality. I illustrate how the photographs of Ms. Deter from the 20th century are recycled and replicated in current media, further contributing to the cultural construction of the image of a person living with dementia.

This chapter unpacks how the image of a lesser being or the living dead is created in a clinical context through a close analysis of Ms. Auguste Deter’s case, and how such dehumanising and objectifying views on persons with dementia continue to be reflected in media and cultural artefacts. While the medical practices applied to Ms. Deter in the 20th century differ significantly from current clinical approaches, we cannot dismiss the symbolic significance and influence of her case. Along with her famous portrait, her case continues to be featured in public and educational lectures on Alzheimer's disease and in media reports on medical progress related to dementia. As such, she is not simply a matter of history, but holds a performative power in constructing "a voice, sound, and an image" (Barz and Cohen 4) of this particular disease, Alzheimer's disease.

Diseases such as HIV/AIDS, tuberculosis, Alzheimer's disease, and breast cancer have become associated with specific qualities and images over time through various means, including cultural artefacts, media coverage, medical descriptions and education, and public campaigns. Barbara Ehrenreich (2001), in her personal essay "Welcome to Cancerland" (2001) critiques how "breast cancer culture," featured with charity runs and pink ribbon kitsch, has been tainted with cult-like religious fervour and images of obedient little-girls (Nielsen 97). As Susan Sontag (2001) famously argued, illness has a metaphorical dimension whereby particular, and often unrealistic, attributes are imposed upon or expected of those affected: the romantic qualities ascribed to tuberculosis in the nineteenth century or the way in which AIDS is characterized as a biblical plague in the 1980s. Some diseases are ascribed with romantic qualities, and some are particularly shamed. Drawing on these observations, this dissertation asks: What are the dominant cultural images and rhetoric of persons with dementia? How are they constructed and transmitted? How do medical practices applied to patients living with dementia influence the cultural construction of dementia, and how do the archives of Ms. Deter relate to the current cultural perceptions of individuals living with dementia?

2.1.3 Definitions of Dementia; Intricate Relationship of Ageing and Dementia

Before we dive into the analysis of Ms. Deter, it is important to understand how dementia have been defined historically. Depending on the time period and cultural context, dementia has been understood differently, and shifting views of the link between dementia and ageing have been proposed over time. The dynamic perspectives of dementia affirm that dementia is a social and cultural construct and is prone to shift. In Chapter One, I have laid out both biomedical framings of dementia and socio-cultural framings of dementia. Here, let's take a closer look at how the biomedical perspective and understanding of dementia and how its association with ageing have changed over time as scientific and medical research has progressed in Western societies. Additionally, we will examine how the concepts of normal and abnormal/pathological ageing have perpetuated in shaping the definitions of Alzheimer's disease and dementia.

The historical origin of the term dementia remains unclear; nevertheless, researchers have discovered the term was used in reference to the mental impairment associated with old age as early as the 1st or 2nd century (see Berchtold and Cotman 1998). Like the etymology of the term dementia—Latin de (out of) + mens (mind) + ia (state of)—cognition and perceptions of persons with dementia are characterised as being "out of mind," in contrast to the perceived norm of a sound and rational mind. Researchers point out that a longstanding history exists of an unclear differentiation between "normal brain aging and late-life brain disease" (Weiner and Lipton 4-5). Starting in the 1970s, influenced by Robert Katzman, the prevailing biomedical discourse began to view "dementia of Alzheimer type (DAT) is a disease without age boundaries that is qualitatively and quantitatively different from 'normal aging'—except that age represents the single most important risk factor for its onset" (Holstein 159). Nonetheless, numerous scientists and physicians continue to raise doubts about the age-independency of dementia due to the lack of a conclusive answer regarding whether certain changes in brain cells and the nervous system are attributable to ageing or not (Weiner and Lipton 8-13). An increasing number of researchers are proposing an alternative viewpoint, considering Alzheimer's as a plausible manifestation of brain aging (Gaines and Whitehouse 2006). O'Rourke and Ceci (2013) also raise the issue of unclear distinctions between normal brain aging and Mild Cognitive Impairment (MCI), and the fact that "even the final diagnostic criteria for AD [Alzheimer's disease] remain problematic; on autopsy, the plaque characteristics of AD are actually present in many older adults without the symptoms of AD (Katz and Peters 2008)" (qtd. in O'Rourke and Ceci 56). They further highlight that the clear differentiation between normal ageing and Alzheimer's disease is significantly influenced by political factors, such as securing government funding (O'Rourke and Ceci 56-57).

In the early 20th century, the German psychiatrist and neuropathologist Alois Alzheimer (1864-1915) discovered abnormal changes in the cerebral cortex of the brain of a female patient named Ms. Auguste Deter, who was in her 50s. This discovery led to the emergence of the idea an age-independent form of dementia. Ms. Deter exhibited the main features of what was then called "senile dementia" (a term referring to age-related dementia in the past) although she was relatively young. This finding indicated the existence of an age-independent type of dementia (Toodayan 2016). Her symptoms included severe memory loss, disorientation, hallucination, and agitation. She was admitted to a large asylum, the Institution for the Mentally Ill and for Epileptics in Frankfurt, Germany in 1901. Dr. Alois Alzheimer examined her while he was in Frankfurt and continued his examination after moving to Heidelberg in 1903. His study of Ms. Deter's case marked a significant milestone in dementia research. In recognition of his contribution, Emil Kraepelin coined the term "Alzheimer's disease" in 1909 (Engstrom 407), like many other disease names such as Parkinson’s disease or Down syndrome that are named after physicians or scientists rather than patients.

Moreover, this late nineteenth to early twentieth century is the hallmark where Alzheimer’s disease was foregrounded as a “solely biomedical concept” (Goldman 79). As Goldman notes, “the development of Alzheimer’s disease as a clinico-pathologic entity” (48) is closely associated with distinguishing normal from abnormal. This biomedical development of dementia is a legitimate beginning of the pathologizing narratives “differentiating the normal from pathological, and aging from disease; and of sorting out the various roles that psychosocial, environmental, and genetic factors have been reputed to play in producing dementia” (Whitehouse et al. 48). However, early researchers including Alois Alzheimer and his colleagues such as Gaetano Perusini and Emil Kraepelin were inclined to identify the occurrence of dementia in middle-aged individuals as odd or unique cases of senile dementia, and “reluctant to view Alzheimer’s as distinct from normal aging” (Goldman 73). After tracing the complex origins of Alzheimer’s disease in Germany, Goldman writes: “Yet as we have seen it was extremely difficult for these early researchers, including Kraepelin, to draw firm boundaries between normal and pathological adulthood and old age, and between healthy and pathological aging” (76).

Because of its deep association with ageing, the biomedicalization of dementia is often led to distinguishing normal and abnormal ageing; it can further marginalization of older adults with dementia. O’Rourke and Ceci argue that present-day Western culture supports “a particular understanding of healthy aging as normal aging” (52). The healthy ageing or normal ageing defined and promoted by anti-ageing science, ageing policy discourse, and health education textbooks “is or should be devoid of disease and abnormal (i.e., pathological) functional or cognitive decline” (52).

The World Health Organization (WHO) defines dementia as “an umbrella term for several diseases affecting memory, other cognitive abilities and behaviour that interfere significantly with a person’s ability to maintain their activities of daily living” (WHO 2023). The most common type of dementia is Alzheimer’s disease (AD); there are multiple kinds of dementia such as Vascular dementia, Lewy body dementia, Frontotemporal dementia, mixed dementia, and so on (Alzheimer’s Association 2023). As mentioned before, the WHO’s public health campaign stating, “although age is the strongest known risk factor for dementia, it is not a normal part of ageing” (WHO 2023), itself attests the historically and culturally deeply associated relationship between ageing and dementia.

Challenging the biomedical perspectives of dementia, Critical Dementia Studies and particularly personhood theories have undertaken a re-evaluation of the traditional Western philosophy of personhood and the notion of being a person. This is due to the Cartesian notion of personhood, which views an individual lacking normative cognitive functions, especially memory, as diminished, a lesser being, or even a non-person (see Dewing 2008; Katz 2013; Higgs and Gilleard 2016). For example, Tom Kitwood (1997) criticises the reduction of personhood to “autonomy and rationality,” emphasising the moral responsibility of others in shaping personhood. He defines personhood as “a position or social relationship that is bestowed on one human being by ‘others,’ in the context of relationship and social being” (8-9). Furthermore, by shifting our focus towards corporeality, embodied personhood, and relational selfhood, alternative philosophical frameworks of personhood (e.g., Kontos 2005; Moser 2010) have asserted that “persons are more than their brains, that personal identity does not rest only on mental continuity, and that the story of dementia exceeds that of tragic loss and decline" (Swinnen and Schewda 11).

As these alternative models of personhood and selfhood are gradually integrated into nursing and caregiving practices for individuals living with dementia, how does this distinct perspective of personhood influence the broader societal perception of dementia and its impact on those who are affected by it? In recent times, we have witnessed a growing number of socio-cultural movements aimed at promoting inclusive perspectives and shifting discourse from perceiving dementia as "a social death" to embracing a discourse centred on "living well [with dementia] discourse" (Parland et al. 2016). Despite these efforts, the historical stigmatisation associated with dementia (see Urbańska et al. 2015) continues to influence public perception, leading to an enduring view of dementia as "the most terrifying of conditions" (Bruens 84). This perspective often results in individuals with the condition being treated as if "they are no longer people" (Bruens 84). Parland et al. (2016) argue that there is a tendency for the public to regard persons with dementia as 'other,' causing those without dementia to establish "a social and psychological distance between themselves and this terrifying prospect" of the condition (4).

In her article "Dementia as a Cultural Metaphor" (2014), Hannah Zeilig discusses how there is "a range of emotionally charged metaphors about dementia" that are prevalent in the popular imagination. She states that these metaphors can be observed in newspaper accounts, political speeches, and in both documentary and feature films (258). Zeilig further points out that these "metaphorical descriptions of dementia can also be discerned in medical and scientific texts" (258). In an agreement with this point of view, I delve into an examination of how the medical practices and biomedical perspectives employed by Dr. Alois Alzheimer and early scientists during the early 20th century have played a role in shaping the prevalent perspectives regarding individuals with dementia. Approaching this topic from a Humanities standpoint, I conduct a critical analysis of *the medical gaze* imposed upon Ms. Auguste Deter, the first patient with Alzheimer's, for the last 100 years. Through this analysis, my research explores the potential connections between the treatment of this notable patient and the contemporary cultural imagery and metaphors associated with individuals affected by dementia, which frequently characterise these individuals as 'lesser beings' or 'living dead.' In particular, my application of performance perspectives on the photographs of Ms. Deter emphasises the transmissive power of the visual archives and raises questions about the ethical responsibility of contemporary viewers who continue to cite and engage with them.

2.2 Ms. Auguste Deter: The Medical Gaze Acted Upon the First Patient with Alzheimer's Disease

As the first case of Alzheimer's disease, Ms. Deter's case has been frequently discussed in tracing the history of Alzheimer's disease and conceptualizing dementia (O'Brien 1996; Maurer et al. 1997; Whitehouse et al. 2000; Bondi et al. 2017). She has been mentioned in academic articles that remark the achievement of early scientists and physicians (Maurer and Maurer 2003; Toodayan 2016); her brain slide, her verbal and written answers during examinations, life backgrounds, family trees, and personal data continue to be revisited and re-examined by scientists searching for answers to genetic or demographic causality to develop Alzheimer's disease (Lage 2006; Müller et al. 2013; Vollmar and Thyrian 2017; Keohane and Grace 2019) [see Figure 1]. In these studies, we can easily locate the voyeuristic gaze over her deviance. In the process of documenting and referencing medical advancements, Ms. Deter, as "undoubtedly one of the most famous patients in medical history" (Müller and Graeber 129), became a biomedical object with a sort of belonging to Dr. Alzheimer.

Often referred to as Auguste D., while she was institutionalized in the asylum, her pathologically deviant behaviours—in the eyes of doctors—were observed and recorded in detail from 1901 to her death in 1906. Although her husband, Carl August Wilhelm Deter, requested for a transfer to a more affordable institution due to the high costs of the Frankfurt institution, Ms. Deter was kept there because Dr. Alzheimer "intervened to prevent the transfer—presumably in anticipation of her demise and the prospect of obtaining valuable pathological specimens" (Engstrom 409). As noted by Engstrom, such arrangements were common strategies that "psychiatric researchers used to secure control over cadavers and to facilitate anatomic research … [which was] part of a politics of the psychiatric cadaver" in Imperial Germany (Engstrom 408). Engstrom remarks that "patients with dementia usually passed silently through clinics on their way to custodial institutions, … for their didactic usefulness in training students or for the prospective pathological specimens they would deliver upon autopsy" (410). In the asylum, "her condition worsened to the point where she lost almost all cognitive ability" and "on April 8, 1906, at age 55, Ms. Deter passed away." ("The Story of Auguste Deter).[19]

By being *marked* as the first medical discovery of Alzheimer's, her original brain slides, the "specimens" are still preserved under the custodianship of professor Graeber in Sydney (Toodayan 53, see Figure 1). In 1995 December, Konrad Maurer and his colleagues found the long-lost original 1901 file Ms. Deter, that has been missing since 1910 (Lage 16). The report included an interview with her husband, four photographs of her, papers with her handwriting, which evidences her cognitive impairment, a one-page case report summarizing her biography

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[19] American Senior Communities, "The Story of Auguste Deter." *The Webpage of the American Senior Communities*, https://www.asccare.com/story-auguste-deter/. Accessed August 20, 2023.

and history and the development of the disease (O'Brien 1996; Maurer et al. 1997; Maurer 2006; Whitehouse et al. 2000). The full transcription of Alzheimer's questions and Ms. Deter's responses is published in German in 1998[20] and translated in English in 2003 (see Maurer and Maurer 2003). After the re-publication of her clinical records, numerous academic journals quote the so-called deviance evident in Ms. Deter's responses during interviews medical professionals.

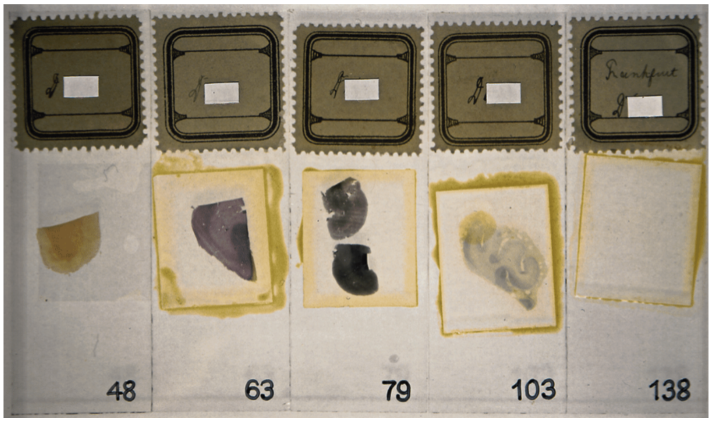

Figure 1. Auguste Deter's Original Neuropathology Slides. Photo Credit: Nadeem Toodayan. Image description:

Page and Fletcher's article "Auguste D: One Hundred Years On: 'the Person' not 'the Case'" (2006) is the first attempt that approaches her "as a person and as a fellow human being outside of the context of illness" (571). Goldman (2017) has also revisited her records and discussed how Ms. Deter has been "transformed almost into a clinical object" and "[h]er humanity and her experience in the asylum […] have been all but forgotten in light of contemporary society's obsession with her brain and its telltale stigmata of plaques and tangles" (52). By noting how "her photographic image and accounts of her experience, both prior to and

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[20] Maurer, Konrad, and Ulrike Maurer. "Alzheimer: das Leben eines Arztes und die Karriere einer Krankheit." *(No Title)*, 1998.

following her incarceration in the asylum, are entirely limited by and mediated through Alzheimer's and Perusini's case reports" (52), Goldman tries to access Ms. Deter's voice, emotions, and experiences by looking through the interview records from a non-medical perspective. She criticizes the lack of compassion and consideration for Ms. Deter's anxiety, fear, and her sense of isolation and loneliness (54-56). This is especially notable given that Ms. Deter has lost her home, connections with her family and others, as well as her social roles and responsibilities due to her confinement in the asylum (54). Recently, Rebecca Zaritsky[21]'s poem "To Alois Alzheimer, from Auguste Deter" (2021), which imaginatively speaks from Deter's point of view, critically highlights the power dynamic between patient and physician and the vulnerability of Ms. Deter.

Performance scholar Diana Taylor defines "archive" as enduring materials (i.e., texts, documents, buildings, letters, archaeological remains, bones, videos, films) that supposedly resist change, in contrast to the so-called ephemeral "repertoire" of embodied practice and knowledge (i.e., spoken language, dance, sports, ritual) (Taylor, *The Archive and the Repertoire*, 16-19). Ms. Deter's one body part, her brain became an "archive" in the form of a neuropathology slide because her brain holds significant value in medical history. The narrative of Dr. Alzheimer and Ms. Deter can be interpreted a medical version of what Taylor calls "the Scenarios of Discovery,"[22] where medical professionals and researchers become "the viewing subjects (we)" and patients are transformed into "the object (them)" (Taylor, *The Archive and the Repertoire*, 53-54). In this scenario, Ms. Deter is "marked" twice: as a monument of medical history in the

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[21] Rebecca Zaritsky is a student studying math at Georgetown University. She has been diagnosed with autism in her 20s; and she has talked about autism movements and stigma and shame surrounding mental conditions at TED talk and different podcasts. Her poem was published as a part of Bioethics Research Showcase at Georgetown University. The full poem can be found at the following link: https://www.acpjournals.org/doi/10.7326/M20-3816. Accessed August 20, 2023.

[22] Diana Taylor describes the story of colonization of Indigenous lands and people that are told from the conqueror as the scenarios of discovery.

past and as an ongoing land to be (un)discovered in the future. And what marks Ms. Deter is the unequal relationship between the doctors as self and the patient as other. Below is a quote from Rebeca Zaritsky's poem "To Alois Alzheimer, From Auguste Deter," which depicts Ms. Deter's powerless and vulnerable position during the five years she spent confined in the "castle" (Frankfurt asylum) until her death. While the question, "Did you love me?" is an imaginative element, it evokes indescribable emotions in me as a reader—perhaps because the poem restores the subjectivity and humanity of Ms. Deter that the biomedical narratives had erased.

> Where am I?
> You tell me I am
> In a castle, of sorts.
> But I have lost myself.
>
> Where might my bed be?
>
> Did you love me, sir?
> I cannot remember,
> So I will believe
> anything

Rebecca Zaritsky, "To Alois Alzheimer, From Auguste Deter" (2021).

Unlike other dementia patients, her case, as the first case of Alzheimer's disease, is continuously desired by the viewing subjects (Phelan 3). The examination of her brain did not end in 1906, but instead, her brain itself and "her life" have been re-visited, as does this chapter, and it will be re-examined in the future. For instance, just a few years ago in 2014, another report was published on the analysis of DNA extracted from a "106-year-old brain section from the cerebral cortex of Auguste Deter" (Müller and Graeber, Appendix 2). Keohane and Grace (2019) state this genetic research "leaves the case wide open" (5) and argue for the necessity to research Ms. Deter's family tree. For the sake of medical advancement, and in the same way explorers and conquerors claim their discovery of Indigenous land and people; the body (particularly the brain) and behaviours of Ms. Deter became an object which only the intellectual authorities can select, possess, interpret, record, and share as many times as they want, even long after her death (Taylor, *The Archive and the Repertoire*, 64).

In medical and scientific research and practices, the bodies of persons with dementia are "text" which "can be rationally and objectively observed, measured, tested and demonstrated" (Taylor, *The Archive and the Repertoire*, 23). Ms. Deter's body is just the beginning of the collection in the "Cabinets of Curiosities," which historically refers to small collections of extraordinary objects like today's museum and has been used as a metaphor to describe physical and intellectual exploration and discovery including medical discoveries (Mermikides and Bouchard 23-36). Following this first patient, other patients' cases are collected in the same cabinet and they "find their meaning only side by side with others" (qtd. in. Mermikides and Bouchard 13) and lose individuality and visibility. However, as Phelan points out, in the case of Ms. Deter, "visibility" does not confer any power upon her. Instead, it is "a trap" that "summons surveillance and the law; provokes voyeurism, fetishism, the colonialist/imperial appetite for possession" (6). Moreover, in the context of illness, patient bodies become objects under the "medical gaze," a concept articulated by Michel Foucault as "the doctor supported and justified by an institution, that of a doctor endowed with the power of decision and intervention" (qtd. in. Mermikides and Bouchard 4).

Even if we recognize the motives of the early researchers in the 20th century to find cures for the terminal disease, the medical history and practice of the early neurologists has contributed to setting up the long-lasting stigma and fear of the disease, as they can be treated like a "living dead" (Behuniak 2011), a "lesser being" (Patterson et al. 2018), "second-class citizen or non-citizens" (Bartlett and O'Connor, *Broadening*, 34). These discursive framings place individuals with dementia in a vulnerable position, making them susceptible to medical experiments, social isolations, and discrimination. A hundred years later, persons living with dementia and their families are still being asked to provide consent to autopsy and brain collection, allowing neurologists to study the biomarkers of Alzheimer's disease (Cairns et al. 2010). Even after more than a century of medical research, a cure or treatment of this terminal disease remains elusive. Then, shouldn't we be redirecting our attention elsewhere?

As Mermikides and Bouchard point out, there can be a discussion about the necessity of the medical gaze in the treatment of patients (4). However, the medical gaze has a potential to situate a patient's body in a single scenario—the Scenario of Patient—and overlooks the possibilities of multiple scenarios in which each patient was/is/will be part of. Page and Fletcher (2006) criticize that Ms. Deter "was offered little in the way of assistance to find her 'self' or to uphold her sense of selfhood and her unique personal identity" (581). Their conclusion is bleak: "her whole history before 1901 was disregarded as having no relevance, […] and there was no attempt made to hear her voice or to consider the person behind the illness" (581). Many patients with Alzheimer's disease and other dementias donate their brains for biomarker study, however, they are rarely recognized. In 2020, a Colombian woman Aliria Rosa Piedrahita de Villegas's "rare brain" received massive attention from the scientists and media. Dr. Lopera studied Aliria and her extended family for more than thirty years and describes her as "the Auguste D. of our time"; *The New York Times* article recognizes that we will learn a lot from her brain (Smith, "In Life, She Defied Alzheimer's"). In this news article, they include the famous portraits of Dr. Alzheimer and Ms. Deter that are often appear as a pair in media and academic journals. However, except for Page and Fletcher's research (2006), no one has critically examined the stigmatizing and negative narrative conveyed by the photography of Ms. Deter. In the following section, I delve into how the concepts of 'living dead' or 'lesser being' came to shape the cultural perception of individuals with dementia, conducting an analysis of the photographs of Ms. Deter.

2.3 Performative Force of the Photographs of Ms. Deter

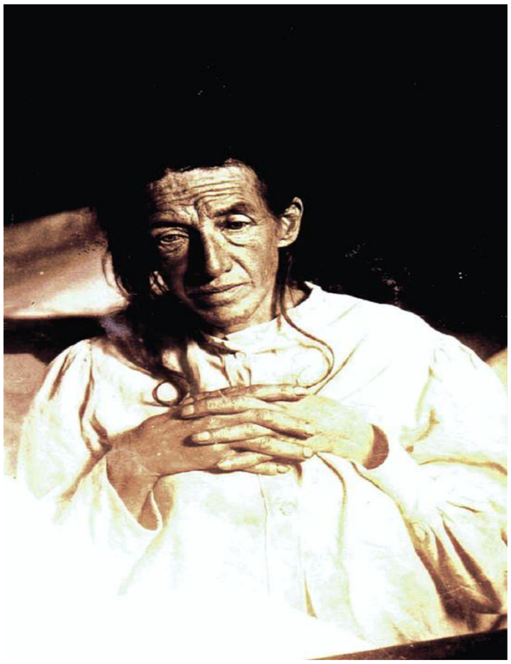

Figure 2. Ms. Auguste Deter's Famous Portrait Taken in the Institution for the Mentally Ill and Epileptics in Frankfurt, Germany, dated November 1902, taken by Rudolph, the Hospital

Photographer (Maurer et al. 1997: 1547). Image description: Ms. Deter with long hair and a wrinkled forehead wears white clothes. She has her hands together is looking slightly off from the direction of the camera.

The one photograph of Ms. Deter [see Figure 2], which wanders around on the internet[23] and reappears in many publications, clearly shows the century-long voyeurism imposed on her body by the medical and intellectual authorities. This one picture is chosen by various researchers for the sole reason that it is "the most impressive" among four photographs of her taken in the asylum (Maurer et al. 1997: 1546). In an academic article by Nadeem Toodayan, commemorating the legacy of Dr. Alzheimer, titled "Professor Alois Alzheimer (1864-1915): Lest we forget" (2016), an interpretive caption is placed beneath her photograph: "Touch with the slow finger of time, the nutrition of that thin layer, and backward by slow degrees creep the intellectual faculties, back to childish simplicity, back to infantile silliness, back to the oblivion of the womb" (52). Page and Fletcher (2006) write about her admission to the asylum:

> [Dr.] Nitsche notes that apart from being underweight, […], Auguste was otherwise in good physical health. Descriptions suggest that she was a tall woman with long brown hair, brown eyes and elegantly long fingers. However, the only known images of Auguste are a series of four asylum photographs taken around 1902, the most well-known being sepia stained which makes Auguste appear to be dirty and her features somewhat swarthy, with a sorrowful expression and dressed in the asylum nightshirt she is denied the more modest attire for a lady of the time (579).

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[23] For instance, see online posts such as American Senior Communities, "The Story of Auguste Deter." *The Webpage of the American Senior Communities*, https://www.asccare.com/story-auguste-deter/.; "History Module: Dr. Alois Alzheimer's Frist Cases." *The McGuill University—The Brain from Top to Bottom Blog*, https://thebrain.mcgill.ca/flash/capsules/histoire_jaune03.html. Accessed August 20, 2023.

Although the scientists found four photographs of her, we only get to see what they have selected. Performance Studies have revalued the performative power of photographs as “speech act, the intersubjective exchange between subject and viewer, and the use of photography as a form of participatory citizenship” (Levin 328). As Performance Studies scholar Laura Levin notes, “while earlier research on the relationship between performance and photography focused largely on the theatrical nature of the pose, [the analysis of] the performative encounter between spectator and image […] is becoming more prevalent in scholarship, and particularly in writings that take up issues of affective spectatorship in relation to photographs of violence, trauma, and loss” (328). This viewpoint acknowledges the dynamic interaction that takes place between the viewer and the photographed subject or event. In essence, this perspective of photography focuses on the performative power, ethics, and affective engagement of the viewer.

Similar to *The New York Times* news article mentioned earlier, the century-old portrait of Ms. Deter continue to be repeatedly used and viewed by the public. When we contemplate the performative force of photography, what does Ms. Deter’s famous portrait convey? What do we perceive from this particular image? In the photograph, with her gaze fixed somewhere indistinctly, Ms. Deter evokes the stereotypical images of the ‘living dead’ or ‘empty shell,’ which have become “a prevalent public paradigm” of Alzheimer’s disease (Aquilina and Hughes 143). The so-called “zombie trope” (Behuniak 70) has been associated with Alzheimer’s disease, as those who are affected are often perceived as losing their self, identity, and personhood. Because Ms. Deter’s portrait lacks contextual details or situational information, it holds an abstract quality. Indeed, through its repeated circulation over the last century, her portrait has transformed into a symbol of Alzheimer’s disease, devoid of any environmental context or individuality, or medical significance.

Furthermore, her portrait has often been paired with Dr. Alois Alzheimer's portrait in academic studies as well as media coverage [see Figure 3].[24] Interestingly, Auguste and Alzheimer's pose of hands are identical, but expresses a very different quality and narrative. Contrary to the authoritative and confident portrait of Dr. Alzheimer who stares at the camera, Ms. Deter is reduced "entirely into a clinical object […] [while erasing] her subjectivity […] and Auguste's experience in the Municipal Asylum" (Goldman 52). Her photo is used as if she is the signature of Dr. Alzheimer to show his great achievement. The more she appears deviant, abnormal, or blank, the more the public would find it more "impressive."

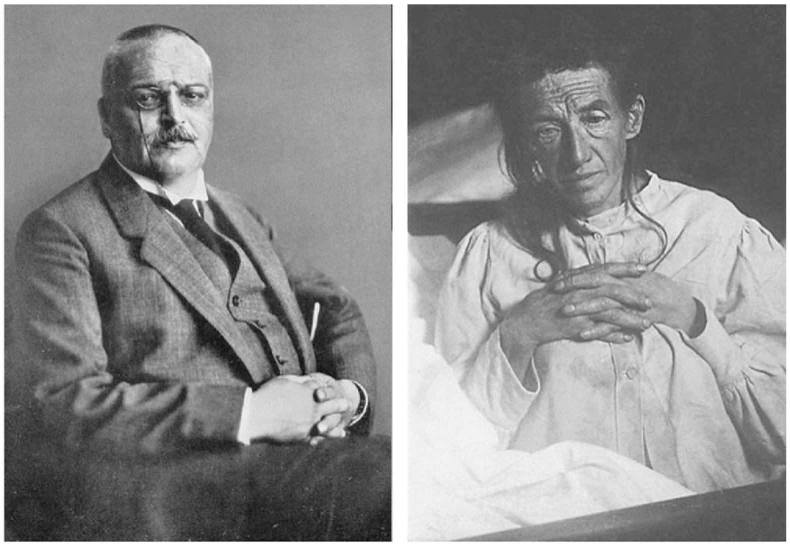

Figure 3. The Pair of the Portraits, Dr. Alois Alzheimer and Ms. Auguste Deter. Image description: Two photos side-by-side, on the left Dr. Alois Alzheimer with a moustache and short hair in a suit posing

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[24] See examples of online posts: Nicholas Chan, "Study: Mild Behavioral Impairment Can Help Predict Alzheimer's." *Being Patient*, 21 April 2020, https://www.beingpatient.com/mild-behavioral-impairment-predict-alzheimers/; Linda Marsa, "Are We Close to Curing Alzheimer's Disease?." *Discover Magazine*, 21 January 2015 https://www.discovermagazine.com/mind/cracking-the-alzheimers-code. American Senior Communities, "The Story of Auguste Deter." *American Senior Communities*, 11 September 2014, https://www.asccare.com/story-auguste-deter/. (Accessed August 25, 2023).

for the camera in a chair. On the right, Ms. Auguste Deter wearing white clothes with wrinkled forehead. Her hands are together, and her eyes are looking slightly off from direction of the camera.

For the contemporary viewers who see this photo, is there any ethical responsibility or "civic duty toward the photographed person" (Azoulay 16)? Let's discuss the performative power of Ms. Deter's portrait. Expanding Elizabeth Freeman's notion of temporal drag,[25] performance scholar Rebecca Schneider (2011) has challenged the naturalized and normative notion of time in her articulation of reenactments, theatre, visual arts, photographs, sculptures. By doing so, she blurs the ontological difference between the live performance in the present and archive which has been considered as completed in the past. Schneider borrows Fred Moten's term "inter(in)animation" to articulate the political and performative power of strategies like mimesis, archiving, documentation, and reenactment. All of these can inter-animate or be inter-animated with the past original—considered authentic and true. According to Schneider, inter(in)animation is a call, pull, conversation, tapping between "one time with another time" (*Performing Remains* 31), but what is remarkable and radical about Schneider's temporal crossing is the direction. Schneider's view suggests that the *pulling* between different events and bodies in different time, even between the dead and living, occur in multiple directions, and not just as past pulled into present, which is commonly conceived regarding reenactment. She discusses several concrete examples to demonstrate this kind of "cross-temporalized pull" and its effects (Barker et al. 93). For instance, Schneider asks us to think of the photographs of the Abu

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[25] Schneider expands the notion of Elizabeth Freeman's "temporal drag," used in queer theory to articulate the possibility of re-surfacing and co-existence of any events, bodies, feelings in different times. In *Time Binds* (2010), Freeman offers notions such as "temporal drag," "erotohistoriography" that articulate queer temporal enactments that interrupt "a vision of time as seamless, unified, and forward moving" and refuses the normative temporal organisation toward maximum productivity. Freeman pays attention to "excess" of the past and the affective, tactile, physical encounter of the past and present that is enacted in films, visual arts, and sculptures.

Ghraib scandal as presenting events that "*take place* in our hands, as we look at them" rather than "events that *took place*" (Barker et al. 94, emphasis in original). If we extend this perspective to the photograph of Ms. Deter, her image is *pulled* into the present moment when contemporary viewers look at it. In this perspective, the act of photographing her remains unfinished and incomplete until an encounter between the viewer and the photograph unfolds.

According to Schneider, the present encounter with photography is an activation of "syncopated time" allowing "then and now […] to punctuate each other" (2). Moreover, the force or threat of the photographs brought by a "temporal drag," generates possibilities to reconfigure, negotiate, disturb, co-constitute the past, present, and future (16). When we consider Ms. Deter's portrait through Schneider's perspective of time, we can say that there is an inter(in)animation between the time of viewing and the time when Ms. Deter was placed in front of the camera in the asylum in 1902. In this sense, her photographs become a hail or invitation (Schneider, *Performing Remains*, 141), a pulse from 1902 that; the viewers (including myself) in different times and places have the responsibility to this "civil contact" with the images (Azoulay 2008). Instead of situating Ms. Deter's photography into a single time frame of 1902, this perspective requests conversations with reference to multiple points in times since. By doing so, the photographic presence of the staged image of Ms. Deter "amplify or multiply the uncertainties" of the archive (Kaye 243). The performativity of an image remains and extends in relation to the viewer in multiple times and places.

Then, what is the pulse and invitation Ms. Deter's photographs sends to us? It is worth focusing on the context within which Ms. Deter's photographs appear. In comparison to this famous portrait, another photograph of her, found after a long search as it appears in only one article (Maurer et al. 2006), tells a much different story [see Figure 4]. This photograph was taken on June 18, 1902 (Maurer et al. 2006: 1620), just five months prior to the famous portrait. However, Ms. Deter appears considerably younger, and more importantly her facial expression and physicality convey a sense of unease and discomfort with the act of documentation. While the former image [see Figure 2] focuses solely on her upper body and emphasizes her facial features, the latter image [see Figure 4] captures her entire body along with a glimpse of the asylum environment. In the former, the emphasis lies in highlighting the wrinkles on her forehead, under the eyes, and around the mouth. In this photo, her emotionless or submissive facial expression robs her of voice, power, or subjectivity. In contrast, the latter image reveals her vulnerability and voice. The vulnerability is embodied through her huddled posture, furrowed brow, and eyes averted from the camera as if avoiding contact. Her body indicates that she was conscious of acts of photographing; she may have not consented to the photography and resisted either verbally or non-verbally.

Figure 4. A Photograph of Ms. Auguste Deter, in the Institution for the Mentally Ill and Epileptics in Frankfurt, Germany, Dated June 18, 1902. Photo Credit: Maurer et al. 2006, 1620. Image description: A black and white photo of Ms. Deter on a bed, with her arms holding her knees which are drawn close to her chest.

It is notable that, according to the records written by Dr. Alzheimer, she could have been completely isolated not long after her admission to the asylum. She was admitted on November 25, 1901, and Dr. Alzheimer has recorded his questions and Ms. Deter's answers from November 26 to 30 on four hand-written pages. On November 30, 1901, Dr. Alzheimer writes in his note: She frequently stays in the living room, touches the faces of other patients, and hits them. It is difficult to figure out what she wants. Therefore, she must be isolated. When we try to speak with her, she says, "I do not have either the will or the time. I don't want […]" (Maurer 26). Then he also notes that "she greets him in a friendly way," and says "Please have a seat. I did not have time" (27). However, Dr. Alzheimer's hand-written records end on this day, and we can see the changes of her level of anxiety described in the records published in 1909 by Alzheimer's disciple Gaetano Perusini. In this publication, Perusini transcribes an extract of the clinical records that "[Ms. Deter] becomes excited again and screams terribly (November 1901), she is in a state of fright, anxious and completely disoriented, violent towards everything (February 1902), completely rebellious, screams, and stamps her feet when someone goes near her. She refuses to be examined, screams spontaneously and often for hours (June 1902)" (Perusini 84). Analysing these written records and the starkly different narratives conveyed by the two photographs of Ms. Deter, we are compelled to contemplate the individuals behind the camera and the context in which these photographs were taken. Why was it deemed necessary to capture these images, particularly given Ms. Deter's clear and explicit aversion? Furthermore, considering how vocal and expressive she was as evident in the early records, what made her appear noticeably more resigned in the subsequent photo taken in November 1902? Could the famous portrait have been taken after administering more sedatives to her?[26]

As such, these archival photographs transcend to be a mere visual record of her appearance and transforms into a speech act (Levin 2009) about the living conditions, treatments, human rights, and suffering of people with dementia or other mental illness in mental institutions. Consequently, the latter photograph carries a stronger affective appeal to its viewers. On the other hand, the so-called "the most impressive" photo of Ms. Deter, chosen by scientists, has been withheld from the public, leaving the photographs which may "interpolat[e] their viewer as ethical citizens, inspiring political concern for the suffering of those photographed" (Levin 331) inaccessible. In summary, regardless of their intentions, scientists and historians have constructed a specific representation through a single iconic photograph. Just as Columbus created images of the natives in his journals and letters, even incorporating what is imagined rather than observed, the portrait of the first patient with Alzheimer's disease and the captions accompanying her photographs have cast an individual living with dementia as a "curious weird other" (Henderson 2019: 72), devoid of any medical significance.

2.4 Citationality of Ms. Deter's Image in Contemporary Representations of Persons Living with Dementia

Sociolinguists Kevin Harvey and Gavin Brookes (2019), in their analysis of the visual narrative from 100 commercial stock images on dementia, state that: "the people with dementia

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[26] For more details of her treatment in the asylum and critical readings of them, see Goldman, 55-56.

[…] are routinely subjected to the processes of objectification and disembodiment" (16). Harvey and Brookes go on to elaborate that these images frequently portray individuals with cognitive impairments in a passive and helpless manner, depicting them in a "listless state of suffering" or a "numb despondency" (17). As an illustrative example, they introduce the most common type of stock image of persons with dementia: a contrasting dyad featuring an individual living with dementia and a visiting caregiver or healthcare professional [see Figure 5]. In this image, reminiscent of Ms. Deter's iconic portrait, the portrayed figure with dementia conveys a sense of "being blank." They argue that representations of individuals living with dementia frequently portray them as "inactive, gazing vacantly towards an unspecified point outside the frame, without any apparent aim or purpose" (Harvey and Brookes 17).

Figure 5. A Typical Example of Stock Image Representing Persons Living with Dementia. Photo Credit: Harvey and Brookes (2019: 993). Image description: An illustration of a woman with light coloured hair stares forward as a second individual to the woman's right has her hand on the woman's shoulder.

The authors analyse these types of images—which portray the individual living with dementia in a way that diverts their gaze away from the viewer, leading to the creation of a negative sense of "distance," an "us and them" separation (18). They suggest that these images do not encourage viewers to relate or empathize with the person depicted (18), like the renowned portrait of Ms. Deter. In these images, the figure living with dementia come across as impersonal and somewhat objectified, disconnected, and distant, akin to a "specimen in a display case," as described by Kress and van Leeuwen (119). As a result, this manner of representation inhibits viewers from establishing an affective spectatorship and obstructs the potential for any civic responsibility towards the person being photographed.

Harvey and Brookes' analysis continue to surprise us because of the gruesome familiarity and citationality of Ms. Deter's image. They note that "the disembodied or truncated hand images" are often used to depict the individuals with dementia in objectifying terms—"the hands so depicted are invariably frail and immobile (even though they are the dominant focus of the camera they perform little action or productive function: they are at rest or else clasped together)" (19) [see Figure 6]. Like Ms. Deter's famous photograph, the hands are often resting on a woman's lap and the brightly lit light often makes it "easy to pick out granular details in the texture of the skin—features such as wrinkles and creases and even the bones and joints beneath it" (19). They read this imagery as "a potent index of fragility and decline that communicates […] the vulnerable materiality of the dementia body, a vulnerability which is further emphasized by the fact that we peer down at the hands as from a symbolic position of relative power and superiority" (19). They state these images subject individuals with dementia to "extreme levels of objectifications," and they "undermine—and perhaps even encourage us to question the 'essential humanity' of people with dementia so depicted" (20).

Figure 6. Visual Representation of Persons with Dementia through an Image Focusing Wrinkled and Immobile Hands. Photo Credit: Harvey and Brookes (2019: 994). Image description: An illustration of a pair of hands with visible wrinkles, resting on a lap.

The wrinkled hands themselves are natural physical changes of growing old; however, through continuous *citations* and *repetitions*, these images transform into symbolic representation of frailty of older adults. In her exploration of witnessing the events of 9/11 and the photographs associated with it, Diana Taylor (2003) discusses the control exerted by the media over the photographs of the tragic event, allowing only visuals and stories that conform to the established gendered narrative of heroes and victims that have long been a fixture in media (241-243). Likewise, we can witness the pervasive familiarity and continuous repetition of visual depictions portraying individuals with dementia. These recurring images, which accentuate the sense of otherness and the disengaged, disembodied nature, persistently connect persons with dementia to the idea of a living dead.

The othering and objectifying process of persons with dementia are connected to the social and cultural “abjection” (Julia Kristeva 1982) of the affected individuals. The notion of abject and the processes of abjection, inspired by Kristeva’s theory, are well established as a critical theory in Women’s Studies, Queer Studies, Disability Studies. Julia Kristeva writes “abject is not an ob-ject in front of me that I name or imagine”; and the abject “as fallen object, is what is radically excluded, drawing me towards the point where meaning collapses” (126). As the concept of abjection connotes a state of being cast off from norms and rules, recently scholars in Ageing Studies and Gerontology began to adopt this notion to the study of older adults (Gilleard and Higgs 2011; Gilleard and Higgs 2014; Bülow and Holm 2016). In Age Studies, the notion of abject is intricated with the social imaginary of frailty. Gilleard and Higgs (2014) argue that within the social imaginary, which demarcates the old-old age from the young-old through the idea of the fourth age, “old age is represented less than a status and more as a state of being, one that is typically envisioned through discourses about the costliness, the frailty and indignities of old age” (10). They continue to note that such othering “excludes the aged person from the everyday life of society and cast him or her into a position defined by its alienation and its vulnerability” (10). They distinguish “frailty as a potential state of personal vulnerability” and “frailty in its metaphorical representation of ‘event horizon’ beyond which lies the social death of the subject.” They further argue the latter operates “in a less tangible role attributing to deep or real old age a profound abjection and the collapse of agency and personal identity” (10). The latter sense of frailty lacks corporeal points of reference and rather it implies “the totalizing influence of high risk—not just of physical harm, but of becoming ‘lost’ from citizenship and the ‘civilized’ (15).

Drawing on theories of body articulated by Julia Kristeva, in an article titled “Dementia, discourse, difference and denial: ‘Who Did I Become?’” (1995), Jeannette Stirling also discusses how medico-legal systems erase individual differences and deny or silence the speaking subject in constructing the figure of the dementia body. She argues: “in mapping the dementia body, biomedicine is bound either to pathologize the social behaviour of the subject or dismiss it as irrelevant to the project of diagnosis” (153). For instance, the expressed irritation or anger of a person with dementia is reconfigured as an aggression rather than their voice and speech against “devastating physical and institutional odds” (153). She points out “the homogenizing process” of the medico-legal system and how aspects of a person that do not register within these system (e.g., cultural history, issue of sexuality) are denied or erased (155).

To counter the medical generalization and objectification of subjects living with dementia, I suggest employing Taylor’s notion of “scenario” as a frame to understand dementia as a social structure and behaviour (*The Archive and the Repertoire* 29) and include embodied and situated factors which often disappear from the mediated archive in the medical context. Going back to the medical documentation of Ms. Deter, there has been a lack of attention to the social context of Ms. Deter. Exceptionally, Page and Fletcher (2006)’s study has attempted to consider the social context of a working-class woman of Imperial Germany at the end of 19th century and included the physical environment in which Auguste Deter was situated (e.g., the grand Gothic architecture of the Municipal Asylum where she was admitted). By considering these elements, this study urges us to consider Ms. Deter as a whole person who must have been a part of many other scenarios (e.g., Scenario of Imperiality). We are therefore guided to transform her body from one fixed status—as an ill, deviant, abnormal body—to multifaceted and changing status—a social body, gendered body, domestic body, working body, healthy body, civilized body, accused body, etc.

2.5 Conclusion: Socio-Cultural Places for People with Dementia

This chapter has examined how persons with dementia continue to be medically, socially, culturally constructed, managed, and imagined. The frail, helpless, ugly image of people living with dementia is made through promoting the opposite—the normal, healthy, independent, productive aged bodies. Many areas of our social and cultural practices still enhance and exacerbate the fear of living with dementia. As imagined as the abject, persons with dementia are excluded from the everyday life of society instead of making our societies inclusive and liveable for those affected. The idea of a *dementia-free world* is promoted by the medical and pharmaceutical industry, but it does not serve any good purpose to the millions of people who currently live with dementia.

As the life-expectancy of human beings is extended longer and longer, the temporariness of able-bodied is becoming sharper. Lennard Davis reminds us in *Enforcing Normalcy* (1995) that only "15 percent of people with disabilities are born with their impairment" and most disabilities are "acquired by living in the world" by accidents, crimes, illnesses, and *aging*. The fact is: "The longer we live, the more likely we are to be disabled" (Davis 8). The pharmaceutical, cosmetic, and health industries promoting the idealized images of "the third age" continue to strengthen the division between normal and abnormal ageing. This logic of the third age endeavours to separate those healthy older bodies from those who age with or into disabilities, by enforcing the idea of the fourth age. The reverse ageism in the discourse of the third age is hidden while enhancing cultural fear through stigmatizing those who would fall in the category of the fourth age. Older subjects who acquired abnormality defined from an ableist perspective, such as older people with dementia or with severely impaired physical functions due to age, go through the process of becoming disabled citizens by being excluded, hidden, and erased from mainstream media which try to depict an idealized life of old age.

Disability Studies scholar Rosemarie Garland-Thompson argues, “The disabled body is the object of the stare. If the male gaze makes the normative female a sexual spectacle, then the stare sculpts the disabled subject into a grotesque spectacle” (26). I wonder if these statements are applied to those who are grouped under the fourth age which is associated with “frailty and death” (Shimoni 40). Do older bodies draw stares from young subjects and produce/perform a grotesque spectacle like disabled bodies? What do people imagine or picture when they hear terms like ‘dementia’ or ‘older adults with dementia’? Does the notion of dementia body produce what Lennard J. Davis called “a specular moment” to the normal bodies like those with visible disabilities? Do aged, ill, disabled bodies belong to “extraordinary bodies” (Garland-Thompson 1997) and make “commotions” (Sandahl and Auslander 2005)?

Goldman has surveyed the history in the literature which aligned dementia with the idea of “evil” and “the Gothic—a literary mode that typically features monsters and monstrous transformations” (4). She argues that the debate to differentiate the third and fourth age is fooling ourselves into thinking that “separating the normal from the pathological and labelling the latter as ‘disease’—we can ‘escape dread’” (31). She also draws on Julia Kristeva and argues that people living with age-related dementia and Alzheimer’s disease, are “inextricably connected to the abject and to [Canadian] society’s fear of death and the corpse” (32). Pia Kontos and Wendy Martin (2013) note that “the desired containment of the disruptive [dementia] body” reflects the sense of abject and grotesque signified by the “dementing bodies,” especially the late-stage dementia body (292). They underline how nursing practice in care homes is focused on policing and creating docile dementing bodies, marshalling bodies, and disguising and containing the negativities (292).

Finnish disability artist Jenni-Juulia Wallinheimo-Heimonen's street performance titled *Could You Watch My Mom for a Moment?* (2019)[27] raises questions about the care crisis in Finland. But it also provokes thoughts about the politics surrounding the cultural displacement, segregation, and concealment of the aged and disabled body, including the body affected by dementia. Through a street performance featuring a hospital bed and a soft textile sculpture of an older woman, Wallinheimo-Heimonen prompts questions about the whereabouts and rightful places of aged-disabled bodies. In this production, Mom (sometimes referred as Granny or Grandma) on a hospital bed, represented through the sculpture, is left with strangers for a few minutes while she goes to the bathroom, picks up a coffee or groceries. She defines this project as one of the "empathy object" series and a way to collect "ground level, subjective information" about ageing and what is currently happening in home care and nursing homes (Wallinheimo-Heimonen, *Jenni-Juulia Wallinheimo-Heimonen Website*). Here, the corporeality of Mom is again "ghosted" (Carlson 2003) by the familiar images of frail older adults with dementia—the image of Ms. Deter and the typical stock image representing persons living with dementia. The small body is curled up with the distorted skinny fingers on her chest and the wide-open blue eyes expresses a sense of fear and anxiety [see Figure 7].

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[27] The performance took place in the Punavuori area of Helsinki on September 13, and on Siltasaarenkatu street in Helsinki on September 20, 2019. Following these initial performances, a full-day live performance was held in the Viikki area of Helsinki on September 29, 2019, which was captured for a video installation lasting about 5 minutes. This video was subsequently exhibited in several galleries and museums, including the Equal Arts Festival at Mikkeli City Library (Finland, 2019), Galleria Toivo at Klaukkala Library (Finland, 2020), Festival 7 Dagen Sociale Film in Antwerp, Belgium (2020), and the Lappeenranta Art Museum (Finland, 2020). Two short clips of the production can be found on Jenni-Juulia Wallinheimo-Heimonen's website: Wallinheimo-Heimonen, Jenni-Juulia. "Could You Watch My Mom for a Moment? – Empathy Object #3." https://www.jenni-juulia.com/could-you-watch-my-mom-for-a-moment/index.html. Accessed August 28, 2023.

Figure 7. Screenshot of Scenes[28] from the Film Version of *Could You Watch My Mom for a Moment?* (2019). Filmed by Rasoul Khorram and Jaakko Pentikäinen, Photo Credit: Jenni-Juulia Wallinheimo-Heimonen. Image description: Top picture depicts the artist engaged in a conversation with two younger audience. There is a tree behind them. A soft textile sculpture named Mom is lying down on a hospital bed. The bottom picture depicts the artist engaged in a conversation with two children audience.

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[28] These are screenshot by the artist and shared on her webpage: https://www.jenni-juulia.com/could-you-watch-my-mom-for-a-moment/index.html. Accessed August 20, 2023.

Before the performance, the artist provided a narrative for this character through her social media, allowing the audience to understand that this older figure lives with Alzheimer's disease. For instance, on her Instagram page, she shared several photos of Mom. In one of the photos, Mom is seated in the passenger seat of a car [see Figure 8], Wallinheimo-Heimonen writes:

> A relaxing ride with #granny. She doesn't remember her name or where she lives due to #Alzheimers. But she enjoyed watching views and the scenery passing by. I sang some #lullabies and kept talking about her past. Helping her to remember. In any day soon we will go together to meet people who worry about the resources in #elderly care.

jennijuuliawallinheimoheimonen

891 likes

jennijuuliawallinheimoheimonen A relaxing ride with
#granny
She doesn't remember her name or where she lives
due to #alzheimers
But she enjoyd watching views and the scenery
passing by. I sang some #lullabies and kept talking
about her past. Helping her to remember. In any day
soon we will go together to meet people who worry
about the resources in #elderly care.

Figure 8. Screenshot of a Post on Jenni-Juulia Wallinheimo-Heimonen's Instagram.[29] **Posted on September 20, 2019. Photo Credit: Jenni-Juulia Wallinheimo-Heimonen.** Image description: A screenshot of a post on Instagram with the sculpture Mom in the passenger seat of a vehicle.

In this photo, we can observe that Mom not only has Alzheimer's disease but also has a physical disability, evident from her amputated leg. What does her body communicate? How does this differ from the narrative conveyed by Ms. Deter's portrait? While the wrinkles and the disabled body, presented through sewing lines and layered textures represent old age, signify the progression of age, they do not inherently portray a negative narrative. My contention is that this lack of negativity arises from the artist's contextualization of Mom as an individual—a mother who receives care and attention from her daughter.

Aged and disabled persons, including people with dementia, are often associated with ideas of loss, deviance, dysfunctions, powerlessness, or even "non-citizens and non-persons" (Gibson 341). They are often cared for in institutional settings for various reasons so the public may not get to see many older disabled people in their daily lives. By dragging a hospital bed around in the public space and asking the audience to make a (temporary) relationship with the figure as a caregiver, *Could You Watch My Mom for a Moment?* (2019) provokes thoughts as well as affects in the audience regarding older adults in society. By intentionally making a "commotion" (Sandahl and Auslander 2005), this production questions the current form of care and highlights "how physical and social segregation constitutes an obvious form of ableism" (Herron et al. 183). Although this production interrogates the care crisis in Finland, this question can be applied to other counties, including Canada. This performance prompts us to consider how

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[29] https://instagram.com/jennijuuliawallinheimoheimonen?igshid=MzRlODBiNWFlZA==. Accessed August 20, 2023.

society can become more inclusive of older disabled bodies. It emphasizes that these individuals are human beings who can derive enjoyment from observing the external world, engaging in conversations, and most importantly, are deserving of care, affection, and love [see Figure 9].

Figure 9. Disability Artist and Activist Jenni-Juulia Wallinheimo-Heimonen, Holding Her Textile Sculpture of Mom. Photo Credit: Jenni-Juulia Wallinheimo-Heimonen. Image description: The artist is seated on the ground, holding the sculpture named Mom in her arms. Both the artist and the sculpture are not wearing clothes.

Chapter Three: Exploring the Temporality of Dementia through Crip Time

> "You can maybe guess what's going to happen a little while from now—minutes from now, hours from now—we don't know what to expect. […] And if I think that somebody's been, that my wife had gone a while, I get very antsy. And it may be just a short time that she's been away—it feels like forever. I feel like it's time long before anybody else feels like it's time. It's just some kind of *time warp*"[30]
>
> Cary Smith Henderson, *Partial View: An Alzheimer's Journal*, 1998, 47, emphasis added.

3.1 Introduction: Experiencing Time and Reality Differently

In Arts and Humanities and popular culture, the affected memory has been the primary focus when engaging with the topic of dementia. However, there are numerous challenges and alternations that are experienced by people with dementia such as temporal and communicational difficulties. The World Health Organization (WHO) summarizes the biomedical definition of dementia as "a syndrome due to disease of the brain […] in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement" (*Dementia: A Public Health Priority*,

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[30] Cary Smith Henderson, a former history professor who was diagnosed with Alzheimer's disease, shares his experiences with shifted perceptions of time in *Partial View: An Alzheimer's Journal* (1998). He describes his experience of the sense of time as being separated, fractured, or circulating. I have included an excerpt from *Partial View* as it offers a first-hand perspective on dementia and its impacts on time perception. This work also demonstrates the ways in which persons with dementia can express their selfhood, agency, and voice in a unique and powerful way, without following the convention of an autobiography. This journal does not employ a typical chronological organization nor establish a coherent narrative. Anne Davis Basting (2003), in her reflection of autobiographies written by people with dementia, writes that "[*Partial View*] itself echoes Henderson's 'time warp;' in general, it gives no sense of beginning, middle, or end to its structure" (95). Basting points out how people with dementia often face the challenge to tell their story as the reflective 'I' in a chronological form by fighting "to gather up the fragments of self into a recognizable whole" (Basting, "Looking Back from Loss", 95).

2012). As this definition indicates, orientational and other temporal alterations are a big part of the lived experiences of persons with dementia and their caregivers.

Individuals with dementia can perceive time differently due to changes in their brain affected by Alzheimer's disease or other types of dementia. In Health Science and Medicine, this change in the perception of time and space is defined as time, place, and age disorientation; this condition refers to a set of orientational challenges experienced with the advancement of multiple types of dementia. It causes people to lose track of time and dates, have an altered perception of age, time, and place that can be different from the perception of those around them, and change their ability to read clocks or estimate the duration of time (Nygård and Johansson 2001; Rueda and Schmitter-Edgecombe 2009; El Haj and Kapogiannis 2016; El Haj 2017; Shiromaru-Sugimoto 2018). The shifts in temporal and spatial perception can also lead affected individuals to become lost and go missing; such incidents are reported almost daily.

Additionally, the sense of time and reality is intrinsic to one's sense of self and identity, and it also contributes to their engagements with the world and surrounding people. Under the dominant biomedical lens, these alterations are defined as temporal and perceptual deviance or disorder in contrast to what is deemed normal. Influenced by this biomedical perspective, the altered temporal awareness and perception can be interpreted as indicators of an 'abnormal' state to the surrounding people. Such alterations, exhibited by individuals with dementia, are often perceived as indicators of being 'out-of-mind,' 'senile,' or even 'insane' within socio-cultural contexts, and results in their marginalisation and dehumanisation. When people with dementia do not adhere to normative time and reality perception, their speech and behaviours are often nullified and ignored, and understood as an illusion or fake and, therefore, meaningless. Being and living with time/age disorientation is a fundamental and serious challenge, along with memory loss or language impairments, that put people with dementia in danger of losing their subject positions (St. Pierre, “Distending Straight-Masculine” 2015). In a clinical context, there are attempts to ‘re-orient’ persons with dementia by using supportive devices, or therapeutic practices that validate their perceived reality. However, both approaches imply a viewpoint which frames the minds living with dementia as an abnormal state to be corrected. Richard Ward and Linn J. Sandberg (2023) have pointed out how dementia narratives and practices have favoured continuity and order, whereby “fragmenting, disorderliness, gaps, and messiness are treated as an unwanted intrusion upon the person” (268).

3.1.1 Research Questions and Purpose

This research questions if Arts and Humanities can offer a different perspective on the altered consciousness of persons with dementia and counter the ableist and normative discourses that are pervasive in both medical and socio-cultural contexts. Theatre and performance practices engage with time and place in an imaginative and flexible manner. In Theatre and Performance Studies, temporal concepts such as nonlinearity, simultaneity, and porosity have played crucial roles in articulating the performance of age/ing (Basting 1998) and the performative force of an archive (Taylor 2003; Schneider 2011). My research questions if performance theory can offer a novel perspective on the varied ways in which persons with dementia perceive and inhabit time and reality.

In exploring the issue, I also draw on Critical Disability Studies perspectives because of the already established notions such as “crip time” (Kafer 2013), which troubles the normative relationships to time from a disability lens. The concept of “crip time,” allows us to challenge the normative and ableist standpoint that defines temporality among persons with dementia as abnormality, simply because they deviate from the normalised chronological relationship to time and reality. It also unpacks the underlying anxieties embedded in existing narratives that portray individuals with dementia as disoriented. This chapter builds upon Alison Kafer's proposal to "bend the clock to meet disabled bodies and minds" (27). In response to this call, this study suggests shifting the perspectives of the neurotypicals to meet persons with dementia, not the other way around.

The chapter starts with a summary review of existing literature on dementia and temporality within Health Sciences, Psychology, and Medicine. This literature review is essential to not only gather accurate knowledge on the topic, but also to understand how dementia crips time—how its profoundly altered relationship to time frustrates normative social expectations and reveals the ableist desires to re-orient and normalise persons living with distinct temporal perceptions. After conducting this review, the chapter delves into the exploration of the potential to redefine dementia temporality in a manner that is both non-judgmental and inclusive.

3.2 Literature Review on Dementia Temporality

Research on the temporality of dementia is typically situated in various disciplines in the Health Sciences, such as Medical Sciences, Nursing, Neuroscience and Psychology. I began my own research by examining existing studies and their findings before turning to a Humanities perspective. Although there are substantial clinical research projects assessing time knowledge and awareness among people with dementia, there is a lack of synthesis that allows us detailed knowledge regarding temporal aspects in living with dementia. To identify the changes in time experiences in dementia and its impacts, I reviewed literature on dementia and temporality across multiple disciplines by using six electronic databases.[31] Additionally, through hand-searching with more specific search words such as “disorientation,” “time orientation,” and “sundowning,” I found additional literatures that are relevant but did not come up in the selected databases to help our understanding of diverse alterations of temporality, enacted and lived by persons with dementia.

From these studies on dementia and temporality, the characteristics of temporality among people with dementia can be grouped into five main categories: (1) Changes in temporal knowledge and capacities, (2) Slower, extended, or flexible time, (3) Altered relationships with temporal chronology, continuity, and coherence, (4) Atemporality, (5) Inter-relational performance of time. Additionally, while my initial search on dementia and temporality did not yield results, it is important to note that diurnal rhythm disturbances including phenomena like sundowning[32] and day-night reversal, as well as associated sleep disorders, constitute further temporal changes experienced by a significant number of individuals with dementia. Below, I provide a succinct overview of the five categories I have identified. Following the summary, I present my critiques of the marginalising and ableist implications that are evident in the concepts and descriptions related to the temporality of dementia. I will re-visit these marginalising

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[31] Six electronic databases include PsycINFO, CINAHL (Cumulative Index to Nursing and Allied Health Literature), MEDLINE (Medical Literature Analysis and Retrieval System Online), MLA international bibliography, International Bibliography of Theatre and Performance, ProQuest Dissertations and Thesis. Search terms were constructed as follows in consultation with a librarian: (Dementia* or Alzheimer*).ti and Temporality.ab. The term “temporality” was used as the search with the term “time” yielded an excessive amount of study and a lot of them were irrelevant.

[32] Sundowning refers to the “restlessness, agitation, irrationality, or confusion that can begin or worsen as daylight begins to fade.” It is typically experienced by people with Alzheimer’s disease, and possible causes are affected biological clock, being overly tired, and unmet needs such as hunger or thirst, depression, pain, and boredom (National Institute on Aging, “Tips for Coping with Sundowning” 2017, https://www.nia.nih.gov/health/tips-coping-sundowning#:~:text=Late%20afternoon%20and%20early%20evening,tired%20caregivers%20need%20a%20break. Accessed June 27, 2023).

concepts (e.g., atemporality, distorted or destructed time) in subsequent sections, where I employ the perspectives of Critical Disability Studies and Performance Studies to further examine them.

3.2.1 Changes in Temporal Knowledge and Capacities

Persons with dementia can experience changes in temporal knowledge and capacities (e.g., having difficulty in remembering the past and planning the future), changes in semantic knowledge (e.g., reading hour/clock needle), and difficulty in estimation of duration of an activity by underestimating/overestimating time (Nygård and Johansson 2001; Jonveaux et al. 2013; 2015; 2017; Lee et al. 2007; Lesimple et al. 2016; El Haj et al. 2013). These challenges can impede individuals with dementia from adhering to the socially imposed clock time regarding pace, rhythm, and schedule. Temporal disorientation has been reported as a perceived burden to caregivers (Nygård and Johansson 2001). It is also reported that these social expectations related to temporal knowledge and abilities cause individuals with dementia to experience emotional distress and anxiety; for instance, people with dementia experience a sense of constant waiting, loneliness, and fear of embarrassment (Nygård and Johansson 2001). Jonveaux et al. (2017) point out that the altered sense of duration can be reasons for "inappropriate psychological behavioural actions"; for example, individuals with dementia might experience anxiety and agitation due to the prolonged absence of a caregiver, leading them to venture out in search of the caregiver, which puts them at risk of becoming lost (748).

As a care strategy, a number of studies (Sepctor et al. 2000; Nygård and Johansson 2001; Carrion et al. 2013; Camargo et al. 2015) have proposed the implementation of re-orientation tactics (e.g., rehabilitation cognitive training, maintaining daily routine) and technologies such as using various time aid interventions (e.g., reminders in the environment, electronic calendar) as well as Reality Orientation Therapy (ROT or RO).[33] However, it is noticeable that there is a lack of critiques concerning the imposition of temporal capabilities derived from the norms of able-minded individuals. In addition, there seems to be an absence of research or discourse addressing how society can foster greater inclusivity and adaptability toward the temporal changes experienced by individuals with dementia.

3.2.2 Slower, Extended, or Flexible Time

Both ageing bodies and altered cognitive capacities related to dementia are related to temporality, characterized by "slowing down" or "slowness" (Dörr-Zegers 2005; Gulde et al. 2018). The slowness is reported both in their daily activities as well as speech and conversations; people with dementia "are still able to produce speech, but their speech rate may be significantly slowed down due to word retrieval difficulty" (Meilán et al. 328). Louise Nygård and Marianne Johansson (2001) state people with dementia "experienced an increased need of extended time for doing daily chores, but some also difficulty in passing time (i.e., they had too much time)," or sudden "time shortage" (88-92). A participant in this study says "I need much more time now to get ready, if it gets messed up it does not work at all. In that case I just have to calm down and start all over again when it feels alright up here [in the head] again" (88).

James Rupert Fletcher (2019), exploring the emergence of dementia within interpersonal interactions, writes "temporal visibility" is observed when a person's action fails to satisfy such temporal expectations in an interpersonal situation (36). For instance, he observes communicative abilities of his study participant living with dementia are "noticeably lessened" when they talk about more recent events and the participant "appeared to experience something

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[33] It is a technique "aimed at reorienting people towards autobiographical data and the surrounding environment" (Galante et al. 2007, B27).

akin to aphasia, with increases in stuttering, pauses, and repetition" (36). Referencing an earlier study which characterises older people in contemporary society as temporal immigrants (Seltzer 1983), Fletcher finds the concepts of "temporal immigrants," or "temporal refugees" revealing when applied to people with dementia. The notions of temporal immigrants and refugees in Seltzer's study imply the difficulty of being acclimatised to a specific temporal context. Notably, Fletcher argues "if we engage with people with dementia on their own grounds, within their own temporal context, they are functional. If we attempt to force our own context upon them, without regard for their temporality, they are dysfunctional, and deviance is made visible" (37).

Some people living with dementia themselves perceive and describe time as more "elastic" (Fletcher 36) and "flexible" (Nygård and Johansson 88); and there is a difference between people who live alone and those with a spouse regarding their felt need for "external structures of time" (Nygård and Johansson 88). The findings in this category also raise the same question regarding normative, ageist, and ableist temporal expectations and how they can work against older adults living with dementia.

3.2.3 Time, Place, Age Disorientation

One of the most notable changes in temporality reported by number of studies (Shomaker 1989; Johnson and Johnson 2000; Nygard and Johansson 2001; Dörr-Zegers 2005; De Witt 2010; Herlant-Hémar and Caron 2012; Gjødsbøl and Svendsen 2019) is time, place, and age disorientation. The altered orientation of people living with dementia is also described as having nonlinear, complex, subjective relationships to the past, present, and future (Shiromaru-Sugimoto 2018). Many studies (Orona 1990; Glonek 2000; Edwards 2002; Gjødsbøl and Svendsen 2019) describe how the altered perception of the past, present, and future has impacts on the self and personhood of individuals with dementia.

For persons with Alzheimer's disease (AD), while the memory of the distant past is better preserved, the access to the recent past and their ability to project the future is typically disrupted. In contrast, people with Frontotemporal dementia (FTD) often experience retrograde autobiographical amnesia, which means the distant memories are not accessible and therefore experience "alterations of body expression, social disinhibition, changes in social and religious values" (Lebert 79).

In an earlier study, Johnson and Johnson (2000) describe the temporal experience of an individual with AD as a "trip back in time," and they problematically describe those affected individuals as "regress[ing] back and forth in time vertexing downward toward infancy[;] these variations in functioning make it extremely frustrating for caregivers" (91). They further explain age and time disorientation as the person with AD "making short time shifts reliving positive, negative, and sometimes traumatic experiences of their life again" (92).

Nygård and Johansson (2001) report that for their study participants, "the temporal relationships and coherence of past, present and future were often unclear and vague" (89). Herlant-Hémar and Caron (2012) report people with dementia experience discontinuity of time as they have difficulty in making connection between lived events (232); they even describe dementia as "an illness of the link (une maladie du lien)" (241) because the present is no longer related to other times, is not more than the juxtaposition of instants, of actuals, without continuity (233). Gjødsbøl and Svendsen (2019) also connect caregivers' experience of personal discontinuity in the persons with dementia by quoting terms such as "the experience of non-time" (Willerslev 3) and "not-dead-but-not-fully-alive" (Kaufman and Morgan 330) (53).

While many of these expressions found in describing temporality of AD have ableist and marginalising implications, there is a lack of critical reflection on these terms. Exceptionally, Tobias Haeusermann (2019) raises a question regarding the potential ethical risk of “forced continuity” practiced in dementia care, which promotes “a particular vision of personhood, based on past selves” and continuous and coherent self with their predementia, preadmission status (6). Agreeing with this point of critique, I will further discuss the issue of (dis)continuity later in the chapter by drawing on perspectives informed by crip theories.

3.2.4 Atemporality

One of the problematic and dehumanizing perspectives observed in the literature on the temporality of dementia is the ableist view that defines people living with dementia exist in atemporality. For instance, Glonek (2000) illustrates that people with dementia “exist in atemporality” (215) and suggests what he calls “directionless complex personal space-time model” to depict “the unsequenced, disorienting surreality a person with Alzheimer’s dementia probably experiences” (224). Parsons-Suhl et al. (2008) describe that people with AD experience “being-in-the-nothing” or “being a blank” (40). Herlant-Hémar and Caron (2012) similarly describe people with AD experience a “deconstruction of time,” as the change in the brain interferes with the normal chronological way of constructing time, dates and related events or people. As seen in the examples above, temporality of people with AD has been often framed through negative languages implying atemporality or directionless-ness; I will revisit and critique these framings by drawing on theories of crip time.

3.2.5 Inter-Relational Performance of Time

A few research projects have addressed the inter-relational aspects of time experience among persons with dementia. Johansson (2001) reports how people living alone experienced great flexibility in temporal rhythm and were more relaxed regarding the awareness of time or orientation, compared to those who lived with other family members. The research participants who lived with family expressed the need for external temporal structure or information to accommodate each other's rhythm (88). This study reveals how family caregivers and persons with dementia may perceive temporal challenges differently.

Gjødsbøl and Svendsen (2019) discuss how caregivers, clinicians, and relatives become the main performers of timework, a term borrowed from sociologist Michael G. Flaherty, on behalf of patients and they are occupied with restoring the patient's autobiography and personhood. For instance, a family caregiver enacts the person with dementia as "a person with a collective and biographical past and with a future," by making connections to moments and significant dates and imbuing their life with "a linear temporal structure" (52). While caregivers try to keep the continuity and linearity of one's life, many persons with dementia do not necessarily orient themselves toward the future of continued life (52). This research highlights how nursing home staff establish continuity when residents could not remember their life stories or what they enjoy (53). Similarly, Yoshizaki-Gibbons' (2020) research highlights the inter-relational characteristics of time experiences among persons with dementia and caregivers, by showing how older women with dementia and care workers resist the dominant temporalities in a care home—"the clock time, institutional time and bureaucratic time"—"by making time for and giving time to each other" (226-227). These studies exploring the ideas of inter-personal performance of time can be related to the ideas of relational personhood and citizenship (O'Connor 2010; Kontos et al. 2017). The findings on the inter-relational aspects of temporality suggest that persons with dementia can be inclusive in society when their different temporal needs are recognised and different strategies for inter-relational performance are developed.

3.3 Critiques of Terminologies and Languages Describing Temporality of Dementia

In this section, I critically reflect on the literature review on temporality of dementia, with special attention to the marginalising and stigmatising implications embedded in terminologies and languages used to describe the temporal perception and experiences of individuals with dementia. As shown in the literature review, the altered perceptions of time and reality experienced by individuals with dementia are often described as ‘disoriented’ in comparison to the normative, chronological, linear, and coherent concept of time. We should be reminded that not long ago, the medical terms ‘disorientation’ or ‘disorder’ were also used to define homosexuality. In the 1960s, the American Medical Association (AMA) defined homosexuality as a sexual disorder in *the Diagnostic and Statistical Manual II* (DSM,1968) (Horejes 9). By the time of *DSM III* (1980) “homosexuality was classified as Homosexual-Conflict Disorder, replacing an older label—Sexual Orientation Disturbance” (Horejes 9). In *Psychology of Orientation* (2002), Allen Jack Edwards explains that the term *dis*orientation implies not-intact, unhealthy, malfunction, disturbed or damaged in contrast to orientation. As such, if someone’s temporal orientation or sexual orientation is *out of sync* from what is defined as normative, it has been not only abnormalized, but also medicalized and serves as the ground to justify external interventions or, in some scenarios, societal discriminations. As such, the notion of disorientation is always only defined in contrast to the supposedly right, normal, orientation—whether it relates to temporal or sexual orientation.

This binary conceptualisation contrasting orientation and disorientation can be critically re-examined by applying a perspective of queer studies or disability studies. Disability Studies scholar Alison Kafer's theory on crip time (2013) indeed departs from the discourse on queer temporality, established by scholars such as Elizabeth Freeman, Lee Edelman, and Judith Halberstam (Kafer 27-29). Kafer argues that both crip time and queer time "can lead to feelings of asynchrony or temporal dissonance" as it is a kind of "departure[] from 'straight' time, whether straight time means a firm delineation between past/present/future or an expectation of a linear development from dependent childhood to independent reproductive adulthood" (34). Likewise, we can find the common connection between concepts such as disorientation and asynchrony and queer, ill, disabled subjects, while connecting orientation and straight temporality to heteronormative, abled subjects as a counterpart.

The phrase 'reverting back to being children,' which is a common cultural description of people with dementia, does not simply describe the observed age disorientation, but it implies negative connotations that enhance the stigma around dementia. Temporal rhetoric of infancy or childhood is often connected to old, ill, disabled subjects, implying dependence, decreased ability, and unproductivity. Kafer points out that the rhetoric of *remaining as a child* has been used to describe intellectual disabilities (54). From an ageist perspective, persons with dementia (or many other older adults) become highly dependent and require intense care; for instance, many of them need support in eating and toiletry *like a child,* instead of performing the so-called wise, guiding grandparents' roles. By adhering to the idealized normative life trajectories and blueprint of the normal ageing path, this idea of reverting back to childhood increases social stigma and fear around dementia.

Furthermore, the temporal perception and capacity of people living with dementia are frequently articulated using negative, binary, and ableist notions: dis/orientation, dis/order, de-construction of time, directionless-ness, a-temporality. These notions convey the perspective that the linear, forward-driven mode of perceiving, structuring, and experiencing time as the norm, while framing alternative ways of experiencing time as deviations and failure. Is it not possible to frame the unique and different temporality of persons with dementia without using these binary frameworks? In addition, expressions found in the literature, such as non-time, being-in-the-nothing, and atemporality are associated with a viewpoint that approaches living with dementia as meaningless. For instance, Glonek (2000) writes, "without a central point of reference, without the abstract unity of self in time, life assumes an unreal, meaningless character" (215). These expressions and descriptions repeat the ideas of living dead, zombie, empty shell, which are explored with the analysis of the photographs of Ms. Deter in Chapter Three.

On the other hand, some of the more recent research (e.g., Gjødsbøl and Svendsen 2019; Yoshizaki-Gibbons 2020) have pointed out that the care-partners, such as family members or nursing staff at care homes, become an important player in timework of people with dementia. There is a difference between the two studies just referred to: while the former (Gjødsbøl and Svendsen 2019) suggests the necessity to restore orientation and continuity by getting assistance from care-partners to maintain and perform personhood, the latter (Yoshizaki-Gibbons 2020) recognizes the difference and uniqueness of time experienced by people living with dementia. Instead of forcing the compulsory ableist time—linearity, chronology, continuity, coherence, punctuality, and speed of able-mindedness—Yoshizaki-Gibbons (2020)'s study suggests the importance to "focus on a particular moment in time and place and enter situated realities with one another" (228) by drawing on crip time and queer time. She frames "the time making" between female care workers and residents as a care practice as well as a political action against "bureaucratic and institutional time," which serve as "a nexus of power and a pervasive organizing principle of care structures and relations" (xi). She argues that female care workers and residents disrupt these normative, dominant, and linear approaches to temporality by "focusing on the moment in time and place, maintaining rhetoricity and affirming personhood, acknowledging and respecting situated realities, and engaging in a politics of flexibility, creativity, and collective care" (181). This perspective, acknowledging and joining situated realities of people living with dementia, has been advocated as a person-centred care strategy; it is the idea of what is called "Validation Therapy," advanced by Naomi Feil in 1993. Validation Therapy (VT) focuses on the unmet human needs and desires implied in the behaviours and verbal expressions of disoriented individuals, rather than correcting their perceptions and bringing them back to the present reality (Feil 2014). This approach recognizes exhibited behaviours as alternative expressions of the affected individuals, thus preserving their personhood, even if the expression may appear problematic in terms of social norms.

Understanding the altered temporal knowledge, capacity, and perception of people living with dementia and exploring how these can be supported are important for advancing the quality of life for people with dementia and their caregivers. At the same time, the languages that describe the temporality of dementia are also crucial in promoting human rights and justice for people with dementia. To realize a dementia-friendly and dementia-inclusive society, we need to recognize the possibilities of different time perceptions and explore the ways in which the people with a different temporality (both physical and mental) can perform as an equal social subject/citizen.

While I reviewed studies on dementia and temporality across multiple disciplines, it should be noted that the examined studies mainly focus on people with dementia living in North America, UK, and France. However, studies from Japan (Shiromaru-Sugimoto 2018) and Chile (Dörr-Zegers 2005) report similar findings regarding altered relationships between past, present, and future experienced by persons with dementia. Nevertheless, this literature review considers only studies with either abstract or full text available in English, thus it potentially ignores differences of time experiences among persons with dementia in diverse sociocultural contexts. For instance, the spatial disorientation experienced by immigrants with dementia can differ significantly from non-immigrant population, hence further research is required to discover cultural, socio-economical, racial, ethnic, and gender influences on temporality of dementia, as well as how other cultures have articulated the different temporality of people with dementia and whether normative notions are found in other cultures as well.

3.4 Dementia Temporality and Critical Disability Studies: Thinking through Crip Time

In this section, I explore the temporality of dementia by drawing on the perspectives of Critical Disability Studies, particularly focusing on theories of crip time. Alison Kafer's *Feminist, Queer, Crip* (2013) opened the gate to articulate and advocate the temporality of persons with disability and illness through her overarching notion of "crip time." Under this umbrella term, she illustrates the various aspects of crip time by analysing the temporality of people living with illnesses or disabilities such as static encephalopathy, HIV/AIDS, multiple chemical sensitivities (MCS), and post-traumatic stress disorder (PTSD). Furthermore, she suggests that more work needs to be done to understand the temporality of those living with depression, anxiety, or breast cancer. Following her, Robert McRuer has expanded further the notion of crip time in his monograph, *Crip Times: Disability, Globalization, and Resistance* (2018). By drawing on Jack Halberstam's work *In a Queer Time and Place* (2005), McRuer contemplates making a crip time and place to resist the hegemonic global political economy of neoliberal capitalism. Other researchers, including Petra Kuppers (2014), Ellen Samuels (2017), and Emma Sheppard (2020), have similarly contemplated the notion of crip time by examining temporal dimensions of disability across diverse contexts.

The notion of crip is crucial to offering an alternative approach to the biomedical perspective of dementia temporality. While *crip* as a noun has been a derogatory term (derived from the word *cripple* in English), crip has been reclaimed by disabled people and communities. McRuer writes, "more than disability itself [...] crip has functioned for many as a marker of an in-your-face, or out-and-proud, cultural model of disability" (19). He states "[c]rip's excessive, flamboyant defiance ties it to models of disability (and to uses of the term disability) that are more culturally generative (and politically radical) than a merely reformist social model" (19). McRuer describes the way crip has been used as a noun or adjective, but he claims that "the term's power when used as a verb in turn emanate from its uses as a noun or adjective" (21-23). Similar to the etymological politics of queering, *cripping* as a verb means uncovering "able-bodied assumptions and exclusionary effects" (Sandahl 37). By doing so, the lens of crip encourages the "re-imagin[ing] of conceptual boundaries, relationships, communities, cultural representations, and power structures" (Hutcheon and Wolbring, n.p.). Cripping entails "radically revisioning, from committed anti-ableist positions, the taken-for-granted systems in which we are located" (McRuer 22).

This critical concept of crip time, which emerges from a radical and activist perspective, forces us to revise "taken-for-granted systems" from the standpoint of individuals living with dementia, particularly older adults with dementia. Crip time is a highly promising concept in advancing our understanding of the lived experiences of getting diagnosed with dementia, socio-cultural framings of dementia, and the illness' varied impacts on time experiences. Theorizing dementia temporality through a crip lens echoes the recently recognized connection between dementia and disability (Shakespeare et al. 2019; Thomas and Milligan 2017). As the majority of persons with dementia are older adults, examining the temporality of dementia from a crip lens entails unveiling the ableist and ageist assumptions and expectations implied in the current discourses on dementia temporality.

Simultaneously, attending to the temporal rhetoric and the complex time experiences lived by those with dementia can expand the notion of crip time. I suggest that this undertaking serves as an entreaty for the concept of crip time to reflect on and incorporate the diverse perceptual relationships to time resulting from a range of brain diseases and mental health conditions. These perceptual and mental aspects of time have often received less attention in comparison to the prominently evident temporal experiences arising from physical disabilities. Given that altered perceptual and mental relationships to time experienced by individuals with mental disabilities are less visible, creative and imaginative possibilities in arts and popular culture (including theatre and performance) can play a crucial role in exploring and representing complex aspects of crip time lived by people with mental disabilities. The following chapter investigates how theatre and performance can offer an embodied representation of 'mental crip time' experienced by people living with dementia. Before this, in the next section, I will discuss how scholars in Critical Disability Studies have problematised ableist and normative temporal framings that are often applied to describe disability embodiment and experience.

3.4.1 Theories of Crip Time and the Notion of Asynchrony

While theorising the notion of crip time, several Critical Disability Studies scholars have critically engaged with the concept of asynchrony. This is because the temporal experiences of disabled individuals are frequently portrayed as deviations when compared to the temporalities of able-bodied subjects, both in terms of bodily time and life trajectories. These scholars have employed this concept of asynchrony to describe how disabled individuals perform time differently, but also to reveal the compulsory able-bodiedness (McRuer 2006) that is embedded in the dominant conceptualisation of time. Before advancing my critical discussion of dementia and temporal asynchrony, this section explores the underlying meanings and implications of the concept of asynchrony. I discuss this notion by examining a few studies which approach and re-claim the idea of asynchrony from a disability point of view.

Disability Studies scholars such as Alison Kafer (2013), Rachael Robertson (2015), Joshua St. Pierre ("Distending Straight-Masculine Time" 2015), and Ellen Samuels (2017) have disclosed how disabled subjects' bodily times, maternal times, or life courses are frequently framed as disruption, failure, and frustration by being contrasted to the times of the abled normal subjects. Connecting their discussions, I reflect on patterns that employ the prepositional phrase "out of" as a descriptive framework. Expressions such as "out of time" or "out of sync" are often used to characterize the atypical temporality enacted by disabled subjects. The descriptor *out of* typically implies a sense of failure, deviation, being left behind, or even exclusion from the presumed normal, expected, and desirable state—similar to the etymology of dementia, which derives from Latin, meaning: *out of mind*.

Kafer's examination of the case of pillow angel Ashley X, as well as her use of phrases like "out of sync" and "out of time" (47-68), provides a compelling example for highlighting and critiquing the underlying co-implicated ableist and heteronormative assumptions and anxiety towards disabled individuals. Kafer delineates the presence of ableist and misogynist anxiety that played a role in the emergence of the controversial Ashley Treatment, which was administered to a girl (Ashley) diagnosed with Static Encephalopathy a few months after her birth, and who experienced severe developmental disabilities (47-66). Kafer writes: “Ashley’s being ‘frozen in time’ is a casting out of time; the development of her female body has been arrested, removing from expected patterns of female development and aging” (66). She continues to write, “the Treatment itself was justified on the basis of Ashley’s being always already out of time: her mind and body were so asynchronous that medical intervention was necessary to prevent her from falling further out of time” (Kafer 66). As shown in here, she employs the notion of asynchrony to demonstrate how Ashley’s body and life are perceived and evaluated from the ableist standards.

Critical applications of these phrases—out of time and out of sync—are found in Robertson (2015)’s reflection on her maternal time raising her son with a developmental disability and St. Pierre (2015)’s paper on the male stutterers’ experience of asynchrony with the normative communicative time (“Distending Straight-Masculine Time”). Robertson writes that her son is always “either too ‘old’ chronologically or too ‘young’ cognitively, socially, and emotionally” (1). She also describes her maternal time as out of sync with the so-called normal maternal time: her lived time as a mother is quite different from the usual timeline that a mother experiences and can expect. The socially expected independence between a mother and a teenager child is not permitted to her due to her son’s different abilities and needs. While maintaining a critical stance toward the normative ideology of human development and standardized life trajectories, she acknowledges her susceptibility to this ideology. Being a mother, she too grapples with concerns about her son’s deviation from a heteronormative life course and anticipated future (such as marriage, parenthood, a conventional lifestyle, and more). Robertson’s reflection on her experience as a mother of a disabled son underscores the manifold psychological challenges induced by societal pressures to conform to normative temporal expectations.

Upon contemplating the speech experiences of male stutterers, St. Pierre defines the normative communicative time as “straight-masculine time” (“Distending Straight-Masculine Time” 56). He characterizes the experience of straight-masculine time as akin to “travelling at a consistent highway speed” (59). He argues that the attributes of the straight-masculine time are only brought to the forefront when a non-disabled speaker interacts with a disabled speaker, performing a temporality that is asynchronous with the efficient, objective, instrumental, and economic nature of straight-masculine time. He addresses how this non-normative communicative time performed by male stutterers threatens the socially perceived masculinity as well as the position as speaking subjects. St. Pierre asserts that “cripping queer (communicative) time” necessitates fostering choreographies that unveil a spectrum of communicative potentials that have been stifled or suppressed by straight time (55).

Observations and critiques by Kafer, Robertson, and St. Pierre underscore the ableist perspective that positions disabled individuals in relation to the spectrum of normal temporalities. From an ableist perspective, disabled individuals are perceived as out of sync with clock time, diverging from the norms of human developmental time, differing from conventional behavioural and communicative temporalities, deviating from expected life course timelines, not conforming to notions of productive and meaningful time, and not aligning with desired future temporalities. This ableist framework is evident in binary notions such as disorientation, asynchrony, and atemporality, frequently used to describe the temporality of dementia. In the subsequent section, I will delve deeper into a critique of asynchrony in the context of aging and living with dementia.

3.4.2 Interplay Between Ageing Bodies and Dementia: A Critical Examination of the 'Out of Time, Out of Sync' Framework

In this section, I employ the critical viewpoints of asynchrony to examine how the temporality of individuals with dementia is perceived and positioned as asynchronous when contrasted with normative temporal frameworks. I argue that there are primarily three dimensions in which the temporality of dementia is perceived as a deviation from the norm: (1) Behavioural and communicative time, (2) Perception of time and age, and (3) Life course.

First, the bodily and communicative temporalities of individuals with dementia are frequently labelled as 'frustrating' due to their divergence from the normative, able-bodied, and capitalist-driven tempo, pace, and rhythm of body and mind. According to this normative and ableist standpoint, their bodily and communicative time are considered out of sync with the norm.

Second, the altered perceptions of time and reality experienced by individuals with dementia are often described as 'disoriented' in comparison to the normative, chronological, linear, and coherent concept of time. As reported in the literature review, due to the change in brain and memory, people with dementia can experience altered age, place, and time orientation, and re-live past moments in the present. When individuals with dementia perceive their age younger than their biological age, their performance of age can be asynchronous to the socially accepted age norms.

Lastly, the discourse surrounding notions of third age and fourth age frame ageing with illnesses or disabilities (including dementia) as a failure and an asynchrony with normative, ideal, and desirable course of ageing and life course.

My critical reflection on each category follows below. It focuses on revealing and critiquing the ableist perspectives that judge the behavioural, communicative, and perceptual temporality of people living with dementia through the notion of asynchrony. There have been a limited number of studies offering critiques regarding normative temporal expectations and standards that oppress people living with dementia (Beard et al 2009; Yoshizaki-Gibbon 2020). In Yoshizaki-Gibbon's doctoral dissertation (2020), she defines dementia time as "an extension of crip time and queer time" and as a "temporal dis/orientation that challenges and disrupts normative and dominant forms of time" (214). She also identifies four tenets of "dementia time" [34]; each tenet describes the ways in which care staff or family members engage in dementia time to connect with people living with dementia. While Yoshizaki-Gibbon (2020) shares similar stance as my research as both studies draw on the notion of crip time to think about dementia temporality, her ethnographic study on dementia time focuses more on the aspect of care. Yoshizaki-Gibbon's research investigates how dementia time is put into practice to foster caring and meaningful relationships and interactions between older women with dementia and care workers in a care home.

While exploring applicable care strategies and social changes to support the various temporal changes of people living with dementia is an important task, it is not my primary focus. This study is primarily interested in disclosing ableist and normative perspectives and framings

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[34] She identifies four tenets of dementia time as (a) focusing on the moment; (b) maintaining rhetoricity to practice inclusion and affirm personhood; (c) acknowledging and respecting situated realities; and (d) emphasizing a politics of collectivity and care (191-202).

that are often applied to describe diverse behavioural and cognitive changes of people living with dementia. In this sense, like the work of Robertson, Kafer, and St. Pierre discussed earlier, the following reflection utilises the concept of asynchrony to illustrate how the behaviours and perceptions of people living with dementia are commonly understood and discussed through an ableist and normative lens. This critique of normativity serves as a preliminary step before delving into reframing the temporality of dementia without relying on such binary frameworks. Furthermore, the discussion highlights how the experience of dementia is frequently intertwined with the experience of ageing bodies, and how older adults living with dementia may face greater marginalisation compared to younger individuals with dementia or different mental disabilities.

(1) Asynchronous Behavioural and Communicative Time

As most persons with dementia are older adults with physical restraints or multiple chronic conditions, their bodily time (e.g., speed of an action or movement) is often slow or late in comparison to the speed, tempo, pace, rhythm of the younger bodies and minds. The ageing or aged subjects often require a "slow pace" and "extra time" in actions and communications, like many disabled subjects (Kafer 26-27). St. Pierre (2015) highlights how disabled speakers, specifically stutterers "experience a violent and persistent temporal decentring as [they are] folded into uncomfortable communicative rhythms and tempos woven around the bodily time of [their] interlocutors" ("Distending Straight-Masculine Time" 49-50). He continues to describe how "the normalized choreography of speech" (52), characterized with effortless flow and fluency without hesitation, fractures, ruptures, judges, and marginalizes disabled speakers and puts them in danger of losing their position as subjects and speaking participants in the world.

Likewise, many individuals with dementia often perform delays, repetitions, unpredictability, interruption, incoherence, and discontinuity in communication and action (Kindell 2015; Fletcher 2019). Using St. Pierre's term, an individual living with dementia can also be described as someone who cannot speak *straight* and thus disrupt the dominant temporality. Straight-masculine time is "rendered conspicuous only through disruption" by disabled speakers (St. Pierre, "Distending" 59). Similarly, persons with dementia, particularly those who develop communicative difficulties, frustrate the interlocutors by performing abnormal and unnatural communicative rhythms, logics, and directions of flow. Fletcher (2019) in one of the studies found in the literature review discusses how people with dementia stand out as "deviant" in their interactions with other people. Repetition performed by persons with dementia is one of the main reasons why fluent normalized rhythms are disrupted. Performance scholar Julie-Ann Scott (2018) discusses how the repetition of phrases is framed as a "product of an ill brain" under the dominant medical gaze, how it is ranked as the most common frustration experienced by caregivers, and how listening to individuals with Alzheimer's disease repeating phrases "without nuanced rewording was jarring, frustrating, and revealing" (117-118). Repetition (and boringness) is also culturally connected to the image of the old (Higashi et al. 477); for instance, it is easy to find a stereotypical and ageist cultural representation which depict older persons as repeating the same questions or stories.

The frustration towards the performed repetitions in dialogues and actions reveals an ableist and ageist temporality and requests the able-bodied (and able-minded) to bear with or join the slow, repetitive, fluctuating, and unpredictable rhythm. I would argue that individuals with dementia are not only revealing the ableist and ageist temporality inherent in normative speech and cognitive processes but also educate the neurotypicals about the importance of learning crip communicative time.

(2) Asynchronous Age Performance

By perceiving a younger age or past time as their present reality, individuals with dementia may exhibit age performances that deviate from age norms. For instance, as people with AD lose short-term memory, some of them can perceive their younger age as the present reality, which impairs them from remembering more recent relationships such as spouses and children, but instead, they may believe their parents (who died a long time ago) are alive and mistake their spouses or children as someone they knew in the past (Shomaker 96). When an alternate perception of age occurs, the identity and selfhood perceived by affected individuals can be asynchronous to the perspectives of the surrounding people. Furthermore, there can be a dissonance between their biological age and their behaviours (e.g., an 80-year-old man crying while looking for his mother). Such age performances that are out of the expected social norms are often perceived as jarring, uncomfortable, or even "grotesque," from the normative perspective. This is similar to how Ashley's parents and doctors perceived her disconnected body and mind; they perceived an asynchrony between the level of cognitive ability and her biological age and sexual maturity (Kafer 55).

Family caregivers and the surrounding community experience discomfort and anxiety regarding the performed asynchrony of biological age and perceived age of people with dementia. For instance, in a doll therapy, a person with dementia is provided with a teddy bear or a baby doll in order to reduce stress and agitation, by restoring care responsibility and structure in daily lives or to provide tactile and sensory stimuli. Although doll therapy is used carefully after evaluating the personal history and traumatic experiences, ethical aspects of doll therapy have become a controversial issue regarding whether it is demeaning or patronizing. Some researchers perceive this practice as treating people with dementia like children (Mitchell and Templeton 722). Some family caregivers report distress when they observe their family engaging with a doll and express their concerns about "their relatives being laughed at" (Gordon "Doll Therapy"). The discomfort or anxiety experienced by family caregivers stem from a normative and ageist perspective. For individuals with dementia, their perceived age and reality could be situated when they were young parents, and thus engaging with the baby doll can restore their sense of identity, responsibility, and purpose. However, older adults engaging with dolls stand out as abnormal deviance to the able-minded, because they are *too old* to play with dolls. This perspective and judgment evidenced here highlight the invincible clock time that always rises above the affected person's experienced time—the so-called normal subjects' resistance to "bend the clock to meet disabled bodies and minds" (Kafer 27).

(3) Ageing with Dementia as Asynchronous with the Normative Life Course

The notion of the so-called third age outlines ableist ideals and envisions futures centred around a healthy post-retirement phase. In contrast, the notion of the fourth age demarcates pathological ageing from healthy and successful ageing. This binary discourse reflects the prevailing viewpoint that stigmatizes and marginalizes alternative trajectories of ageing. In this view, ageing with dementia is positioned within the idea of the fourth age and is seen as an undesirable addition. In other words, the lives of older adults with dementia are perceived as out of sync (or asynchronous) with the normative life course, which conventionally concludes with the third age.

3.5 Conclusion: Bending and Reimagining the Clock to Meet People with Dementia

In Chapter Four, my research has contemplated the temporality of dementia through the concept of crip time. Alison Kafer writes that "crip time is flex time not just expanded but *exploded*" (27, emphasis added). Kafer employs the concept of explosion to communicate the necessity of reimagining concepts of time when viewed through a disability lens. In other words, crip time goes beyond mere adjustments or modifications to suit diverse minds and bodies. It challenges the conventional understanding of the typical connection with time and advocates for new possibilities concerning human developmental timeline, the pace and rhythm of behavioural and communicative time, as well as social rules and expectations related to temporality.

As such, the critical perspective informed by crip time provides a radical viewpoint for both medical and cultural perspectives regarding the altered consciousness of persons with dementia. Various examples of the so-called incorrect clock-drawings done by persons with dementia or cognitive impairments [see Figure 10] may visualize the completely different times perceived and experienced by people with dementia. The clock-drawing test is a widespread clinical tool used to screen multiple cognitive functions such as visuospatial cognition, information processing, memory, as well as time awareness and temporal knowledge. If the normative and ableist society changes its perspective, the drawings of the different clocks—a clock without hands, a clock with unconventional directions of hands, a clock without a closing circle, a clock omitting numbers or having too many numbers, a clock arranging numbers in cluster, a clock positioning parts of numbers outside of the circle—are not representing impaired or abnormal time perceptions. Instead, they can be thought of visualising exploded time(s), radically alternative time perceptions and experiences.

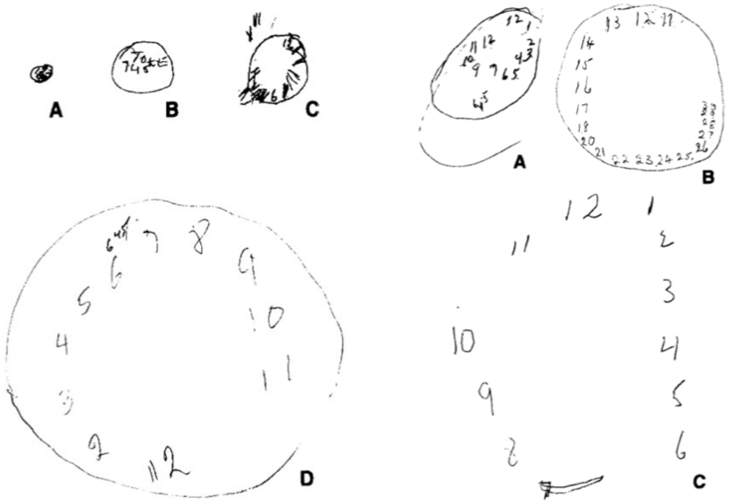

Figure 10. Clock Drawings by Persons with Dementia. Photo credit: Freedman et al (1994: 51-55).

Image description: Hand-drawn images of clocks. Some clocks do not have a complete circle or have more numbers than the so-called normal clocks.

While Kafer's concept of crip time did not encompass novel perceptions of time, considering the temporality of dementia through the lens of crip time would involve reimagining how we can perceive and encounter time within our minds differently, not just how our bodies experience time differently. Alison Kafer suggests areas for further research like the temporality of people with depression. Even though she does not clearly state as much, thinking time differently through disability (Kafer 34) also includes articulating the altered mental or perceptual relationships to time.

The reviewed studies on the temporality of dementia mostly discuss the cognitive temporal alterations experienced by individuals; they indicate the perceived and experienced time by people with dementia does not necessarily follow the normative chronology, linearity, continuity, or a forward or future-oriented sense of time. Building upon Kafer's concept of exploded time, I define the temporality of dementia as “the radically new times with alternate constructions, directions, and durations” (Lee 2021). With this definition, I broaden the concept of crip time to encompass the potential for diverse temporal perceptions as well as the varying potentialities of bodily and societal times.

Kafer writes: “Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds” (27). By bending the rigid expectations of temporal perception and its direction, people with dementia (and their caregivers) can be freed from the social and cultural pressure to conform to the normative time regime and continue to practice their personhood and citizenship. There are already examples that showcase how persons with dementia can express their thoughts and emotions in a creative way while embracing the changes in memory and temporal perceptions. For instance, this chapter has citied Cary Henderson’s nonchronological and fragmented journal in the introduction. It shows how the non-normative and non-chronological manner of autobiography allows him to engage with his complex and fluctuating emotions deeply, without tracing and reminiscing the past nor projecting hyper-positive hope for the future. TimeSlip, the famous and successful storytelling project developed by theatre scholar Anne Davis Basting for people with dementia, is another excellent example that does not impose normative temporality on the individuals with dementia (see Basting 2013). When people with dementia are not forced to tell their story in an ableist and normative way, they could act as the “speaking subject” (St. Pierre, “Distending”) and exert their creativity and agency. By bending our concept of time and moving away from the ableist approach that labels certain relationships with time as normal and others abnormal, we can discover distinct strengths in these unique ways of being and living. Disability Studies and Queer Studies have also re-claimed “disorientation,” a medical term that has marginalising implications, and explored how (dis)orientation can be both “discursive violence” and at the same time “productive exposure to multiple ways of knowing and being” (Parrey 2016). By cripping society from the perspective of dementia, we as a community can be exposed to disorientation and find new possibilities for systems, practices, and relationships in strangeness, the foreign, and unfamiliarity (Parrey 2016).

In the next chapter, I expand my conceptualisation of the altered time and reality perception of individuals with dementia by drawing on performance theories. Furthermore, through concrete examples of theatre that represent characters who embody and enact alternative temporal perceptions, I explore further what it means to be and live with the temporality of dementia. This includes investigating what it means to re-experience the potentially traumatic moments of the past, re-live the past without knowing what has happened after the perceived timeline, re-turn to the so-called objective reality, and re-peat all of this.

Chapter Four: Theatrical Approaches to Represent Syncopated Time and Reality Experienced by Persons with Dementia

4.1 Introduction: Theatrical Representation of Altered States of Consciousness among Persons with Dementia

In the representation of people with dementia within popular culture, the primary indicator of dementia has been affected memory or memory loss. More recently, theatre and performance have paid closer attention to the clinical backgrounds of different types of dementia as well as the various symptoms of dementia beyond changes in memory: communicative challenges, perceptual and behavioural alterations, time and reality orientation, and mood and personality changes.[35]

Among these alterations, my dissertation surveys theatrical works that engage with altered perceptions and experiences of time and reality of persons living with dementia and inquires how theatre and performance have responded to cultural understanding and attitudes regarding these altered perceptions. As discussed in Chapter Three, the realities perceived and experienced by persons living with dementia have often been understood and articulated through binary frameworks that contrast the so-called ‘our’ reality of the neurotypical people and ‘their’ reality of people living with dementia. The reality of persons with dementia is contrasted to “a consensus of reality” (Batch 2019) and “objective reality” (Gibbons 2020) experienced by those without dementia. The reality perceived and experienced by individuals with dementia is

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[35] For instance, the lead actor Simon Russell Beale prepared to play Lear by researching Lewy Body dementia for the 2014 National Theatre production of King Lear.

described as “their own reality,”[36] “distorted reality,”[37] “different reality or a different idea of reality,”[38] “subjective reality” (Erdmann and Schnepp 2016), “alternate experience of reality” (Batch 2019), “situated reality” (Gibbons 2020), and “lived perspective of reality” (Gary 2021) —however, these terms are employed in their discussions without clear definitions.

In my analysis, I use two terms to describe the realities experienced by people with dementia: “experienced reality” and “syncopated reality.” First, by employing the term “experienced reality,” my research aims to highlight the embodied experience without implying a dichotomic counterpart of the reality of those without dementia. When individuals living with dementia perceive a reality different from the so-called objective reality, it is not merely a mental experience; their bodies act and respond within that reality. Persons with dementia engage with their environment and others on a corporeal and emotional level, making behavioural, communicative, and physical choices. As such, the term “experienced reality” emphasises the often-overlooked tangible, corporeal, and affective aspects of the alternate experience of reality. Second, I propose a new term “syncopated reality” by drawing on the notion of syncopated time. This term highlights the inter(in)animation between different periods, memories, and selves that are brought together. Syncopated reality counters the common misunderstanding that people with dementia simply live in the past. At the same time, it acknowledges the influence of human agents and environments in the present on the re-enacted past. This view highlights that the realities experienced by people with dementia are not entirely distinct from the so-called

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[36] Bursack, Carol Bradley. “Should You Play Along with Dementia Patients’ Realities?.” *Aging Care*, 2023. https://www.agingcare.com/articles/playing-along-with-dementia-realities-121365.htm. Accessed August 30, 2023.

[37] Melore, Chris. “What the World Looks Like to Someone Living with Dementia: Photos Show Distorted Reality, Even in Own Home.” *Study Finds*, March 24, 2021. https://studyfinds.org/what-world-looks-like-dementia/. Accessed August 30, 2023.

[38] Social Care Institute for Excellence, “When People with Dementia Experience a Different Reality.” *Social Care Institute for Excellence*, October 2020, https://www.scie.org.uk/dementia/living-with-dementia/difficult-situations/different-reality.asp. Accessed August 30, 2023.

objective reality, and thus discourages ableist approaches that may nullify and ignore what is experienced and expressed by people with dementia.

Some theatrical representations reflect dominant ableist, ageist, and normative assumptions about or reactions to people living with dementia whose temporal abilities or perceptions do not conform to normative standards or expectations. On the other hand, some theatrical works have demonstrated the ability to embrace the discontinuity and nonlinearity of time perceptions experienced by persons with dementia, providing the audience with an embodied understanding of what it means to live with a different temporality and perception of reality and self.

4.1.1 Research Questions and Purpose

This chapter questions how people with dementia experience fluctuating, porous, fluid perceptions of reality themselves and whether performance theories and practices can offer an insight into the so-called *insider experiences* by using its unique artistic properties and affordances. Regarding the difficulties and limitations for an outsider (who does not live with dementia) to grasp and articulate various individual experiences, I propose theatre and performance can enhance embodied understanding of the lived experiences with dementia as this genre of arts uses actual human bodies as the medium. In addition, I find the potential of Rebecca Schneider's theory of reenactment and non-normative approach to time discussed in Chapter Two can be further expanded in articulating the nonlinear and porous perceptions of persons with dementia. By re-visiting concepts such as temporal drag, syncopation, and inter(in)animation, this chapter explores how performance notions can illuminate the corporeal and affective experiences of living with nonlinear temporality and realities.

After defining syncopated time and inter(in)animation within the context of dementia, this research discusses several theatrical works that portray the altered temporality of people with dementia. Through diverse examples, this chapter will investigate the dramaturgical strategies and theatrical elements used to represent the unique and complex time and reality experiences of those people. In this analysis, this research explores the following questions: How do theatre and performance provide an embodied representation of the inter(in)animation of different periods, memories, age-selves, and realities experienced by individuals living with dementia? How do these theatrical works challenge the dominant, normative, and ableist perspective that have been defining the minds of persons with dementia?

I have categorized the identified productions into three groups based on the distinct aspects offered by these theatrical works in representing the alternate state of consciousness of persons with dementia: (1) materialising perception and experience of time, age, and reality, (2) offering insight into the insider experience of living with alternative temporal perception, and (3) suggesting new and positive perspectives on alternative perception of time and reality. However, each production belongs to multiple categories. Below, I will provide a brief explanation of the three categories and the analysed productions under each category.

First, the main significance of theatrical representation of dementia temporality and reality perception is that theatre and performance can materialise the syncopated time, memories, multiple age-selves, and environments perceived and experienced by persons with dementia. While this quality is applicable to all theatrical productions, my research explores the power and significance of materialising the inter(in)animation of time embodied by persons with dementia through the analysis of two performances, *Autobiographer* (2011) by Melanie Wilson and *Inside Out of Mind* (2013) by Tanya Myers.

Second, I discuss dramaturgical strategies that are used to represent nonlinear, porous, rapidly changing perceptions of time and reality among persons with dementia through three plays: *The Other Place* (2011) by Sharr White, *The Father* (*Le Père*) (2012/2015) by Florian Zeller, and *Plaques and Tangles* (2015) by Nicola Wilson. My analysis aims to investigate whether theatre can provide an insight into the so-called "insider" perspective of the lived experience of dementia. I examine whether the dramaturgical strategies employed in these productions create theatrical possibilities for more inclusive and empowering representations of syncopated reality experienced by persons with dementia, or if they inadvertently foster what Liam Jarvis (2020) describes as "disability tourism," satisfying the curious eyes of able-minded audiences. Petra Kuppers (2016) has critiqued what she calls "outsider-art"—art that exoticizes people with disabilities and different minds as "cultural Others" and "the new Eden of creativity" (93). Drawing on these critiques, my research explores whether these theatrical works offer the audience an opportunity to question and rethink the cultural constructions of the "normative mind," or if they merely serve as a form of voyeurism for neurotypical audiences.

Third, my research articulates how theatre and performance can provide new and positive outlooks on what is clinically referred to as the disorientation. I discuss three productions: a physical theatre, *The Nature of Forgetting* (2017) by Theatre Re; a full-mask performance, *Finding Joy* (2014) by Vamos Theatre; and a play *The Visiting Hour* (2021) by Frank McGuiness. Through the analysis of these three works, I investigate how theatre can propose alternative perspectives on the altered memory and time perception of individuals with dementia.

4.1.2 Research Methodology and Selection of Case Studies

The productions identified here are selective examples, gathered over the last few years. I surveyed them through academic journal articles, anthologies, and monographs on dementia and theatre. In particular, studies by Morgan Batch (2019) and Janet Gibson (2020) have been a great resource as both works survey and document extensive numbers of contemporary performances on dementia in English-speaking countries. Batch does not solely focus on the temporal experience of dementia, but her research provides basic information for more than 200 dementia-related contemporary plays and performances.[39] Batch has documented several examples of the contemporary theatre works that disrupt or disregard chronological linearity in representing the altered consciousness of people living with dementia (82). Although she does not provide a detailed discussion on each production, she has identified works such as *André & Dorine* (2010), *On the Concept of the Face, Regarding the Son of God* (2010), *Autobiographer* (2011), *Also a Mirror* (2011), *Daisy* (2011), *Sundowner* (2011), *The Other Place* (2011), *Memory Points* (2012), *RUFF* (2013), *Angeleta and Etelvina* (2014), *Plaques and Tangles* (2015), and *The Nature of Forgetting* (2017).[40] Janet Gibson's research specifically investigates verbatim theatre[41] on dementia to explore "the ethical provocations they would offer" (4) in contrast to what she calls (in a cynical and critical sense) the "right kind of dementia story, […] circulating accounts of loss, despair, failure, and tragedy" (3). Gibson argues that these types of stories have become a framework or, as performance scholar Jon McKenzie calls it, a "mode of power," which guides and determines "the ways in which, and the contexts where, people with dementia

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[39] See the appendix to her doctoral dissertation (pp. 266-300). Most works are contemporary pieces that were produced between 2000-2018, but she includes some cases from 1960-90s.

[40] Among these identified works, Batch offers an in-depth analysis of Melanie Wilson's *Autobiographer* (2011), an Australian dance theatre company KAGE's *Sundowner* (2011), a promenade performance by England theatre company Platform 4's *Memory Points*, American theatre duo Split Britches' *RUFF* (2014), and Italian theatre director Romeo Castellucci and his theatre company Socìetas Raffaello Sanzio's *On the Concept of the Face, Regarding the Son of God* (2010).

[41] In this context, it refers to theatrical works that use "the words and stories of people living with dementia" (Gibson 2020: 4) instead of fictional stories created by playwrights.

'perform' their stories and selves" (3). While Batch's work has explored staged theatre performances using multiple forms (e.g., traditional play, dance theatre, mime, puppetry, etc.), Gibson investigates both professionally staged works and socially engaged performance practices and interventions. One of the very first monographs to identify plays and theatrical works on dementia is Michael Mangan's *Staging Ageing* (2013). Theatre scholar Valerie Lipscomb's book chapter in the recently published anthology *The Bloomsbury Handbook to Ageing in Contemporary Literature and Film* (2023), identifies a few plays that explore the cognitive change in persons living with dementia; Lipscomb lists Sharr White's *The Other Place* (2011), Florian Zeller's *The Father* (French original in 2012, English translation in 2015), Stephen Karam's *The Humans* (2015), and Jordan Harrison's *Majorie Prime* (2015).

I also found some of the theatre works that engage with the subject of reality and time perception affected by dementia through major online theatre reviews such as *The New York Times*, *The Guardian*, *Playbill* in the period 2019 to 2023; and in academic journals that feature theatre reviews such as *Contemporary Theatre Review* and *Canadian Theatre Review*. Because of the specific focus and its rarity of my research topic, I have not imposed limits to one geographical region, though my research is limited to English-speaking countries. This chapter does not intend to cover an exhaustive list of available plays and theatre on time and reality experience of people with dementia. Instead, I analyse specific selected productions that illustrate my hypothesis concerning the distinct capabilities of theatre and performance in offering an embodied representation of the alternative state of consciousness among persons with dementia, and in countering ableist approach regarding the different perceptions affected by dementia.

Due to the limited space, my research does not offer an in-depth analysis of each case.[42] While many productions identified in this chapter deserve more detailed studies on their own, I leave them for the future research. This chapter, therefore, offers an overview of how selected contemporary Western theatre has evoked divergent consciousnesses of persons living with dementia by using dramaturgical and theatrical strategies. Furthermore, informed by perspectives of Critical Disability Studies, my research offers insight into how contemporary theatre and performance expand an embodied understanding of living with dementia. This results in a more inclusive perspective of minds that are different from the neurotypicals and counter ableist approaches that frame these conditions as disoriented and abnormal.

4.1.3 Theoretical Foundation: Neurodivergent Minds on the Contemporary Stage

In response to the neurodiversity movement, Theatre Studies scholars have explored how theatre and performance can uniquely and effectively stage distinct cognition and consciousness of people with autism or other spectrum disorders by using specific dramaturgies and techniques of live performance. Scholars Nicola Shaughnessy, Carrie Sandahl, Leon J. Hilton, and Megan Johnson, bridging Theatre Studies and Critical Disability Studies, have discussed how theatrical techniques are used to represent neurodivergent minds and perceptions. For instance, Leon J. Hilton (2018) analyse how the New York-based experimental theatre company Elevator Repair Service (ERS)'s *The Sound and the Fury* (2015) stages a neurodivergent character's distinct mode of cognition and temporally fragmented mental experience through its unique use of sets, lighting, and sound. Megan Johnson (2018) has highlighted how Vancouver-based theatre

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[42] For an example of an in-depth analysis, see my peer-reviewed journal article on Florian Zeller's *The Father* (*Le Père*): Lee, Heunjung. "Theatrical Affordances to Stage the Perceived-Experienced Reality of People with Dementia: Florian Zeller's Dramaturgy of Porosity in *The Father*." *Contemporary Theatre Review*, (Forthcoming 2023).

company Neworld Theatre’s *King Arthur’s Night* (2017) showcases how novel and powerful aesthetics can be generated by re-imagining and re-telling the Arthurian legend from the perspective of Canadian actor Niall McNeil, who lives with Down syndrome. For Nicola Shaughnessy (2013), dramatic intervention that foregrounds neurodivergent aesthetics can “de-mythologise the [autistic] condition by challenging stereotypes” and “the modalities of performance [can] offer an appropriate space for ‘encounters’ with autistic states of being while also questioning the dualisms which distinguish between the aesthetic and non-aesthetic” (321). Shaughnessy’s notion of “neurodivergent aesthetics” refers to “the phenomenology of the autistic experience with particular reference to the imagination in autism” (322). However, I suggest that this notion can be expanded to include the phenomenology of various neurodivergent minds, including dementia.

Individuals affected by dementia often live with altered perceptions and consciousness that differ from those of neurotypical people. However, the boundary of the neurodivergent group is “currently not transparent or well-defined” (Russel 293) and there are mixed opinions as to whether people with dementia should be included in the neurodivergent group or in the disability community generally. The linkage between disability and dementia “has been forged incrementally,” and “activists and researchers within disability studies in the Global North have been relatively slow to refer to people living with dementia as disabled people” (Thomas and Milligan 116). With the cultural stigma around dementia, only recently has there been increased discussion around how “seeing dementia as a disability could place people with dementia, as self-advocates, at the centre of their own stories, and help provide an enabling identity” (Shakespeare et al. 1076). While pointing out the risks and tensions that ensue by including dementia in neurodiversity, Linda Örulv (2023) has argued that a neurodiversity perspective or paradigm can be applied to dementia "insofar as it points to how [normative models of functioning] limit our possibilities to act and interact in society, thereby alienating and marginalising minorities that diverge from them" (248). I follow and suggest that contemporary performance has a unique power in that it can stage the altered minds and states of being and living with dementia; by doing so, it can offer critiques of the ableist perspective that validates only neurotypical models of the human sensorium and mind.

Hilton (2018) argues that "the emerging discourses of neurodiversity and neurodivergence offer powerful new methodological possibilities for theatre and performance studies" (166). Sandahl (2002) similarly asserts that alternative aesthetics and creative possibilities can be generated when the performance is created from the vantage point of one's phenomenological experience of disability, and furthermore, theatrical space can be revolutionized (17-32). While there are theatrical works that centralize neurodivergent perspectives, there have not been many contemporary performances that offer the perspectives of persons living with dementia. A few research-based plays such as *Cracked: New Light on Dementia* (2014, written and directed by Canadian playwright and scholar Julia Gray)[43] and *I'm Still Here* (2006, co-written by Canadian playwright Vrenia Ivonoffski and scholar Gail Mitchell)[44] are collaboratively written with persons with dementia and/or their family members. However, Michael Mangan (2013) points out the absence of attempts to portray dementia "from the inside" and the interests of plays on dementia lie with "those who have to cope with the loss of the person they once knew" (144-145). Julia Henderson (2019) similarly observes that many

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[43] For further information on the play and the creative team, see the website of *Cracked: New Light on Dementia*, https://crackedondementia.ca. Accessed August 27, 2023.

[44] For further information on the play and the creative team, see Gail J. Mitchell, Christine Jonas-Simpson, and Vrenia Ivonoffski, "Research-Based Theatre: The Making of *I'm Still Here!*" *Nursing Science Quarterly*, Vol. 19, No. 3, (2006), pp. 198-206.

contemporary plays on dementia “focus strongly on caregiver perspectives (most are structured as narrated by the caregiver), and therefore the lived experience of dementia from the inside remains unexplored” (73). Many plays and films portraying dementia mark the boundaries “that create a ‘them’ of dementia worlds and an ‘us’ of supposedly normal cognitive intact worlds” (Gibson 6). In this context, theatrical works that validate diverse minds of persons with dementia are noteworthy in that their dramaturgy raises some important questions for contemporary theatre regarding techniques for representing the alternative consciousness of those living with dementia. Although most productions discussed in this chapter are not created in collaboration with an individual living with dementia, they are important examples of experimentation with dramaturgical techniques that dramatize minds living with dementia. From a neurodiversity lens, I reflect on how different theatre and performance works recognize a different mode of perceiving and experiencing the world and how dramaturgical strategies or aesthetic choices repeat or challenge the binary perspective that contrasts normal versus abnormal.

4.2 Performance Theory and Dementia Temporality: Nonlinear and Syncopated Time

I introduced performance scholar Rebecca Schneider’s theory on reenactment in my analysis of Ms. Deter’s photographs in Chapter Two. To recap, Scheneider’s theory suggests a radically different view in thinking about the temporal ontology of theatre, visual arts, photographs, and sculptures. Borrowing Fred Moten’s term “inter(in)animation,” she claims that both political and performative reenactment can *inter-animate* (*be inter-animated by*) the past original, which is typically considered authentic and completed. In a reenactment, the past is questioned, interrogated, responded to; therefore, the past can be brought back to life anew (Schneider and Ruprecht 2017).

Even though Schneider's theory accounts for the ontology of performance itself, her theorization of a crossing, nonlinear, porous concept of time provides a radical viewpoint of time. Schneider's suggestion that "time may be touched, crossed, visited or revisited, that time is transitive and flexible, that time may recur in time, that time is not one" contests "the forward-driven linearity of temporality," which is deeply embedded in the "Enlightenment claims" as well as "Western anxiety over ideality and originality" (29-30). In other words, Schneider suggests "a new way of articulating the relationship between past and present, one that reworks the language of chronology and unidirectional transmission" (Barker et al. 93). She has also remarked the "cross-temporalized pull" (Barker et al. 93) between the past and the present.[45]

It is important to note that both Schneider and Kafer developed their theories on time by drawing from and expanding theories on queer temporality. In the case of Schneider, she extends Elizabeth Freeman's concept of "temporal drag," employed in queer theory to illuminate the potential for events, bodies, and feelings to resurface and coexist across different periods. In the following section, I adopt Schneider's notion of cross-temporalized pull and inter(in)animation to offer an original account for the temporal leaps, discontinuities, and oscillations experienced by individuals with dementia. I also expand Schneider's notions such as syncopation and transmission of affects to shed light on the embodied experience of persons with dementia when their temporal perception changes.

4.2.1 Inter(in)animation of Selves, Memories, Realities and Transmission of Affect

The fluctuation and changeability of cognitive ability of subjects with dementia are well-known, and the occurrence of time or age disorientation is often temporary and varies from day

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[45] Refer to page 132 of this dissertation for a more detailed explanation.

to day. Johnson (2000) describes this fluctuation in disorientation as the ability to “mak[e] brief quantum leaps in memory” (92). While introducing several clinical cases who exhibited fluctuating regression, Johnson writes that people who previously “travelled back to their childhood years, [and] do not recognize or even respond to any of their nuclear family” suddenly “can make tremendous cognitive shifts upward to the present” (92). In other words, persons living with dementia can “alternate between awareness of the past and present” (Shiromaru-Sugimoto 3189).

We might ponder: when this sort of reenactment occurs to individuals with dementia are they pulled back to the past or does their past get pulled into the present? When the two selves existing in different times are *pulled together and touch upon each other*, what happens? What remains to unfold? Does something completely new take place? Schneider views reenactment, redoing, and reperforming as an activation of the “syncopated time,” where the “then and now” intermingle, “punctuat[ing] each other” (2). The reenactment or temporal replay is “not merely citational”; the past possesses a “force” or “threat” to the present through “temporal drag” (14). Consequently, the interaction of these two temporal references creates possibilities to reconfigure, negotiate, disrupt, and co-constitute the past, present, and future. The question remains: Does this co-existence of selves, brought together by syncopating across several intervening decades, hold power and unveil new potential? How do the past self and the present self inter(in)animate each other?

By relying on this perspective, which does not conceive selfhood within a linear timeline, we can escape from the trap of (dis)continuity of self, the prevailing narrative that defines the (lack of) selfhood and personhood of persons with dementia. When the perception of time and reality shifts, individuals with dementia can simultaneously exist across and inhabit two distinct time periods. The self in the present moment coexists with their past self (or past selves) or a re-imagined version of their past selves. The encounter of these selves crossing different times can allow individuals with dementia to express unresolved desires, regrets, wishes, and emotions, much like what the theory of Validation Therapy suggests (see Feil 2014).

I argue that this *syncopated time* enacted by people with dementia exemplifies what Schneider refers to as the stickiness of time and emotion (36-37). Drawing on Sara Ahmed (2000)'s conceptualization of emotion's stickiness and Freeman's notion of dragging, Schneider explores how we can experience "the transmission of affect in the jumping and sticky viscosity of time," stemming from the "hauntingness of history" and "the queasy 'something living' of the pastness of the past" (60). This concept of the transmission of affect is pivotal in emphasizing the corporeal and affective engagement of individuals with dementia within a syncopated time, as discussed in the subsequent analysis of theatrical works. By highlighting the "mutually disruptive energy" between the past and the present (Schneider 15), I will delve into the corporeal and affective impacts that people with dementia experience when re-living or re-enacting past moments of their lives.

4.3 Materialising Experienced Time, Age, and Reality of Persons with Dementia

In a live performance, the experienced reality of a person with dementia is enacted by human performers, as well as various theatrical aesthetics using scenography, soundscape, and lighting. The productions identified below use different theatrical techniques to enact the minds of persons with dementia, such as having multiple performers embody one character at different ages or using video projections to portray the experienced syncopated reality of a character with dementia. I discuss two productions as examples in this category: Melanie Wilson's play

Autobiographer (2011), which represents what is clinically called age-disorientation; and Tanya Myers's research-based theatre, *Inside Out of Mind* (2013). Through these two productions, my research demonstrates how theatrical modalities and strategies can effectively give an embodied representation of the experienced reality of persons with dementia that are inaccessible to those without dementia. I also reflect on the significance, limits, and risks of embodied, staged representation of the minds of persons with dementia.

4.3.1 *Autobiographer* (2011) by Melanie Wilson

Autobiographer (2011) is a performance about the memory of a 76-year-old woman, Flora, who lives with dementia. It premiered at the 2011 Dublin Fringe Festival and subsequently toured the UK[46]; the play portrays the perceptions, inner thoughts, and emotions of its protagonist Flora. Melanie Wilson, a UK-based performance maker, wrote and directed the piece and starred as one of the multiple age-selves of Flora in the production. As research-based performance, it uses lyrical texts and an abstract soundscape, including elements like "piano phrases and vocal whispers, echoes and naturalistic weather sounds, synthesized sounds, notes and tones, silences and ambient noises" (Mangan 147). Mangan notes its contemporary theatre setting and design, exemplified by "hundreds of light bulbs of different sizes and brightness, switching on and off at varying speeds like the synapses in a brain" (146-147) [see Figure 11]. Flickering lightbulb was similarly used to represent the changing and fluctuating mind of a person with dementia in a concert theatre *STYX* (2020) by a UK-based theatre group The Second

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[46] The full text of the play was published in 2012 by Bloomsbury Publishing. Several theatre reviews, a short video of the production, and excerpts of the soundtrack are available online. For the video, see https://vimeo.com/29684361. Accessed August 27, 2023). For the soundtracks, see https://soundcloud.com/melanie-j-wilson/autobiographer-introduction; https://soundcloud.com/melanie-j-wilson/autobiographer-breakdown. Accessed August 27, 2023.

Body (see Gillespie et al.[47]). Representing the mind of the character living with dementia through an abstract set design is also used in the staging of Sharr White's play, *The Other Place* (2011); Nicola Wilson's play, *Plaques and Tangles* (2015); and an opera about dementia, *Sky on Swings* (2018) for which Canadian playwright Hannah Moscovitch wrote the libretto, employing traditional dramatic devices [see Figure 12].

Figure 11. Screenshot of the video recording of *Autobiographer* (2011, Melanie Wilson). [48] **Smock Alley Theatre, Dublin, Ireland. Photo Credit: Melanie Wilson.** Image description: Four female performers are looking up and many lightbulbs are drawn above them.

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[47] Gillespie, Benjamin, Julia Henderson, and Heunjung Lee. "Performing Dramaturgies of Care in Quarantine: Aging, Inclusivity, and Aesthetics in a Virtual World." *Pandemic Play: Community in Performance, Gaming, & the Arts*. edited by Catherine Quirk and Carolyn Ownbey, Palgrave Macmillan, *Forthcoming 2023*. This is a book chapter I co-authored, however, as it is currently in-press, there is no page number. Publication status can be found at the following page: https://research.edgehill.ac.uk/en/publications/pandemic-play-community-in-performance-gaming-and-the-arts. Accessed August 14, 2023.

[48] See https://vimeo.com/29224448. Accessed August 27, 2023.

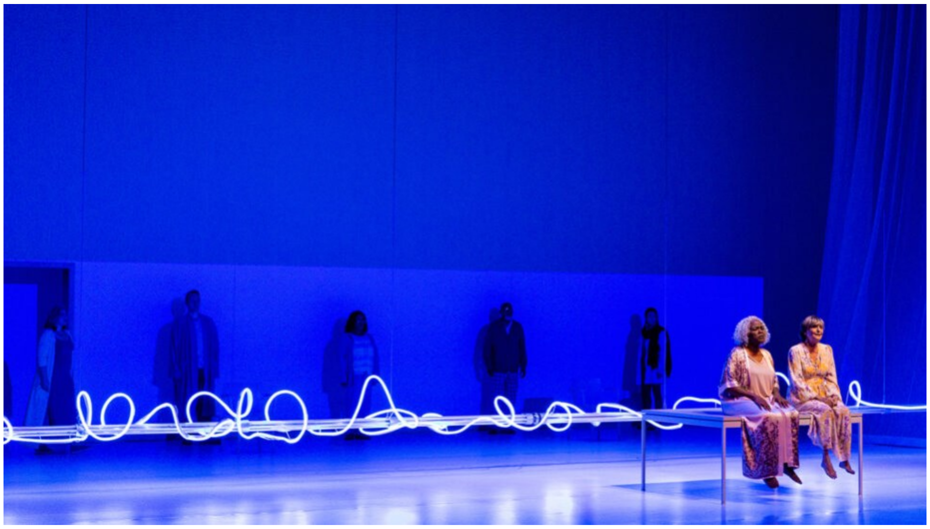

Figure 12. A Scene of *Sky on Swings* (2018, Opera Philadelphia). Perelman Theater, Philadelphia, United States. Photo Credit: Dominic M. Mercier. Image description: Two female actors are sitting at a bench and there is a wiggly neon light behind them which represents the minds of persons with dementia.

The most notable feature of *Autobiographer* (2011) is the ways in which it represents the multiple age-selves of Flora in attempt to portray physically and visually what is clinically called age-disorientation. Flora is performed by four performers of different ages who are costumed identically [see Figure 13],[49] and it also includes a short appearance of a child who plays Flora at the age of eight. Melanie Wilson explains "[Flora] is engaged in a constant attempt to remember; to keep hold of her own story and identity and relate that to the audience [and] to herself" (Douglass, "How Do You Make a Drama About Dementia?"). Multiple age-selves of Flora coexist, interact, and contradict one another. They engage in conversations about her memories, stories, thoughts, and feelings

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[49] The original 2011 and 2012 UK production starred Janet Henfrey, Alice Lamb, Penelope McGhie, and Melanie Wilson. Each of them represents Flora in her teens, 30s, 50s, and late 70s and a voiceover represents Flora around age eight. For more information about the production, see Melanie Wilson's webpage https://melaniewilson.org.uk/Autobiographer-2011. Accessed June 26, 2023.

related to various moments in her life and different individuals, including her children, from varying temporal standpoints. In Mangan's description, "as Flora talks both to herself and to the audience, her words are woven together into a shared monologue" (146). Comparing Wilson's play to Abi Morgan's play *Lovesong* (2011),[50] Mangan writes "whereas the double-casting of *Lovesong* represented integration, this in *Autobiographer* represents fragmentation" (146). However, considering the interactive, conversational, and even complimentary relationship between different age-selves of Flora, it will be more accurate to say that *Autobiographer* presents both fragmentation and integration between the multiple times, selves, and memories. I argue that this production showcases a visualization of "inter(in)animation" (Schneider 2011) between different age-selves. It also conjures Anne Davis Basting (1998)'s depth model of aging, which challenges "strict divisions between life stages"; it imagines the aged body as "embody[ing] past and potential changes across time" (141-142). Although Basting's theorization of the aged body applies to all subjects, not just those who live with dementia, dementia makes us see clearly how one's different age-selves are "pulled together" and "inter(in)animate" (Schneider 2011) each other.

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[50] *Lovesong* (2011) portrays an older couple's love and relationship, and they look back on their life as a newly married couple as the wife is ill with a late-stage cancer. By using double casting, the couple at different ages simultaneously exist, and the past and present collide; however, this play is not about dementia. For further information on this production, see Frantic Assembly, "Lovesong Resource Pack." https://www.franticassembly.co.uk/index.php/actions/tools/tools/download-file?id=1599. Accessed August 27, 2023.

Figure 13. A Scene of *Autobiographer* (2011, Melanie Wilson). Smock Alley Theatre, Dublin, Ireland. Photo Credit: Monika Chmielarz. Image description: In pairs, four performers playing the main character Flora are sitting back-to-back on chairs in pairs; all of them are wearing a navy dress.

Batch (2019) analyses *Autobiographer* as an example of a theatrical work that uses theatrical forms and technologies to stage alternate experiences of reality among people with dementia, along with analysis of *Really Old, Like Forty Five* (2010) by Tamsin Oglesby and *Inside Out of Mind* (2013) by Tanya Myers (see 92-137). Batch writes “the work is nonlinear and contains no naturalistic staging, so the experience of the play is one of a non-reality—without place and without time” (93). Through its breaking-down and fractured soundscape and abstract stage design, *Autobiographer* materializes the placeless-ness, timeless-ness, and unanchored existence, which often frames the temporality of people with dementia. As such, in a sense, it reflects or repeats the medical and cultural discourse of “atemporality” and “deconstruction of time” discussed in Chapter Three. However, because the play centralizes the character living with dementia as the narrator and allows her to speak from her point of view, it overcomes the ableist perspective towards persons with dementia. In this piece, atemporality does not function as a sign of deficit that sets the protagonist apart from the normative subjects. Instead, *Autobiographer* provides a space for a person with dementia to express themselves, showcasing an alternate way of constructing and performing a self that does not rely on chronology, coherence, or linearity. I agree with Batch (2019) that "th[is] play destabilises this notion of accumulative memory […] and dismisses the idea that linearity is key to selfhood" (95). Moreover, *Autobiographer*'s immersive and intimate staging[51]—in this production the audience are placed surrounding the performance space and asked to participate in filling lines when Flora struggles with her memory—partially embodies the idea of "relational citizenship" (Kontos et al. 2017) and allows the people watching the protagonist to ponder on their responsibility towards or relationship with persons affected by dementia.

Some theatre reviewers are critical of the extreme fragility of this production, arguing that it makes it challenging to fully grasp Flora's story. Consequently, they find it difficult to develop emotional sympathy or engage with the character (Gardner "*Autobiographer* – Review"; Orr, "Review: Autobiographer"). However, Mangan highlights its power to theatrically express the experience of a person living with dementia. He contends that the negative response of a reviewer, who felt that the performance left the audience "with a vague, wispy residue behind," mirrors "the attributes of the dementia sufferer's experience" (149)—we should exercise caution regarding the use of a term like sufferer since it accentuates the negative aspects of dementia. This production is particularly significant because the interchanges between different age-selves are not framed as abnormality but are embraced through theatrical imagination such as a

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[51] See Batch 97-98 for more detailed description of the staging and audience interaction.

character can be played by multiple performers. Batch (2019) argues that employing "a naturalistic set—designating spatial and temporal contexts—would render Flora unmoored from time and place" (104). She goes on to explain that Wilson's dramaturgy, which avoid "linearity and a recognisable chronology," allows "Flora's plurality to go unchallenged and similarly permit[s] the language to be a vessel for Flora's fragmented recollections" (104). She also interprets the fragmentation in the production as contributing to the "texture and rhythm in the performance" (104).

As Gibson (2020) notes, "dementia (and the theatre that could emerge from it) provides a provocation to many widely held beliefs in our present-day Western culture, especially certain foundational beliefs about testimony, and notions of authentic voice and agency" (118). *Autobiographer*, in this context, can be seen as raising a critical question about the conceptions of selfhood, personhood, and identity defined and promoted within a "hypercognitive culture" (Post 1995; 1998). Post (1998) has stated that a hypercognitive culture tends to exclude "the deeply forgetful by reducing their moral status or by neglecting the emotional, relational, aesthetic, and spiritual aspects of well-being that are open to them, even in the advanced stage of the disease" (2). Similarly, scholars such as Kontos (2005) and Leibing (2008) have expanded the embodiment approach in selfhood and personhood to recognize the power and agency of the body. In this performance, enacted through the interactive four age-selves of Flora, an experience of a syncopated time becomes a way to maintain and express the sense of selfhood and identity for people with dementia. The embodied representation of the interactions among the multiple age-selves of Flora allows the audience to ponder the positive potential of a syncopated temporal experience, enabling contact between different age-selves.

4.3.2 *Inside Out of Mind* (2013) by Tanya Myers

Inside Out of Mind[52] is a research-based theatre directed by Tanya Myers and produced by Meeting Ground Theatre Company with an educational purpose. It premiered at Nottingham Lakeside Arts in 2013 and toured the UK in 2015; it was shortlisted for a National Lottery Award. The script of the play was devised based on 600,000 words of ethnographic field notes about dementia care and care workers in a care home conducted by Professor Justine Schneider and colleagues at the Institute of Mental Health, University of Nottingham (Myers, "Inside Out of Mind"). While this piece employs a mimetic stage design representing a care home or dementia ward, it also materializes the perceived-experienced realities of a resident called Mr. P or Mr. Gabriel Proust through non-naturalistic theatre devices such as music, sound effects, voiceover, and video projection [see Figure 14 and Figure 15].

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[52] The script was published in 2017 by Russell Press Ltd., and the director provided me the script for the purpose of research. A live performance of *Inside Out of* Mind was filmed by We Are Caravan and the film was screened before audiences of NHS (National Health Service) professionals in England for a year after its creation, however, the video is only available as a hardcopy DVD, apart from a few short video snippets. See https://youtu.be/EO_R5AWv0ac; https://youtu.be/Kbir0cCQPYM. Accessed August 27, 2023. For an interview video with the director, see https://youtu.be/yY4WTdqOR6U. Accessed August 27, 2023. There are also academic reports and book chapters written by the creators (Schneider et al. 2014; Schneider and Myers 2015; Myers and Schneider 2016; Schneider 2017), and there are critical analyses of the piece (Batch 2019; 2020).

Figure 14. A Scene of *Inside Out of Mind* (2013, Tanya Myers). Lakeside public Arts Centre, Nottingham, United Kingdom. Photo Credit: Alan Fletcher. Image description: A scene of a Halloween party in the care home. Residents are wearing witch hats and sitting on chairs; two care home staff are assisting the residents.

Figure 15. A Scene of *Inside Out of Mind* (2013, Tanya Myers) and Its Use of Video Projection. Lakeside public Arts Centre, Nottingham, United Kingdom. Photo Credit: University of

Nottingham. Image description: Intense blue light and digital image of web-like tree branches are projected onto the wall of the stage set. Performers' silhouettes are visible, and they are frozen without moving.

The production team introduces the piece as a "fusion of love stories, crisscrossing time and space, where walls turn into forests; thunder to gunfire; books to birds; with untold stories kept under their wings" and it is "darkly comic, and offering glimpse of a mysterious world, this insightful play enters into the experience of dementia care" (Myers, "Inside Out of Mind"). They continue to describe the play as moving "between multiple realities where time and identity drift apart" (Myers, "Inside Out of Mind"). Instead of following the story of a protagonist, this play portrays the busy life of a dementia care ward and depicts the so-called 'non-normative' or 'abnormal' behaviours[53] of seven residents with different types of dementia as well as care practices of their family caregivers, 10 care staff and registered nurses, and an ethnographer.[54] As such, it portrays various types of dementias and symptoms, and touches on diverse subjects such as death, loss and the discontinuity of self, living conditions at an institutional care facility, cultural stigma and perceptions of dementia, care-related burdens and challenges, and connections and new relationships between residents and care staff.

Regarding the representation of time and reality perception and experience of people living with dementia, this production uses projection to portray the resident Mr. P.'s syncopated time experience that weaves together his memories of the French Resistance during the Second World War and his current life at the dementia ward. Mr. P's altered perception of reality and his

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[53] For instance, the play depicts typical dementia-related behaviours such as yelling, repeating same words, and carrying around a doll (see Batch 2019: 120-124).

[54] In the script, the playwright writes that this production can be performed with nine actors (doubling) or in community productions with as many performers as can appear on stage on the ward. There are specific directions about the doubling.

inner thoughts are delivered by his voice (sometimes via microphone and/or voice over). The audience hears him shouting, crying out, and whispering; however, the staff in the play describes him as “our silent soul,” which suggests that his voice is only audible to the audience (Myers 11). There is one scene where he slides to the floor and cries out while hearing the angry cry of another resident, Magda, from offstage—which triggers his memory of when his fiancé was shot by the Nazis. This is when nurses hear him for the first time, and they run to assist him.

To present his porous and syncopated realities, video projections are used in both small and large scales; at times these projections transform the entire set with the image of an abstract forest, and sometimes they are used to temporarily transform the hospital whiteboard into a French café window to depict Mr. P’s perceived-experienced reality in France. Batch (2019) describes a scene of Mr. P as “he projects his own reality onto the consensus of reality and […] others […] are cast in the layered reality” (127). Other scenes also depict how triggers, such as a particular sound or food, can “drag” or “pull” their memories and experiences of the past into the present. (Schneider 2011). While Batch acknowledges the risk of positioning these residents whose reality does not follow a consensus of reality as “anachronistic” (128) or “existing out of time and place” (127), she suggests that the production’s dramaturgical strategies afford the residents’ experience “credence” (128) as their perceived reality is materialized on stage. For instance, Mr. P is dressed in a 1940’s tailored suit to indicate the period in which he perceives he lives, and the sound of turning book pages turns into the flapping of butterfly wings, which provokes his memory in the forest although the perceived reality is not explicitly explained. Batch writes “the residents’ speech and behaviour—while it may appear incongruous—is compatible with their sense of reality, their inner world” (130). As such, *Inside Out of Mind* showcases how theatrical modalities such as video projection and sound effects become a way to materialise and give credence to the experienced reality of people living with dementia. The audience sees the inner world of a character with dementia as they are creatively and imaginatively enacted through embodied praxis.

In *Inside Out of Mind*, the use of non-naturalistic and abstract elements such as video projection demarcates the boundary between the perceived-experienced reality of persons living with dementia and the so-called objective reality. Making other performers stay frozen except the residents, who are perceiving an alternative reality, is also a way this performance demarcates two different realities—there are multiple instances where only Mr. P and Anna speak and move while other characters freeze momentarily. In contrast, performances such as Florian Zeller's *The Father* and Sharr White's *The Other Place* (2011) do not provide a clear indication of or hierarchy between the two realities—the perceived-experienced reality of a character with dementia and of surrounding characters who do not live with dementia. In the next section, I will discuss the implications and effects of such dramaturgical strategies used to represent altered time and the reality experience of persons living with dementia.

4.4 Feeling the Mind of Persons Living with Dementia through Dramaturgy of Porosity

White, Zeller, and Wilson share a similar approach in their plays on dementia. Each playwright creates a disorienting and confusing experience by putting the audience in the shoes of the person with dementia through dramaturgical techniques (e.g., writing nonlinear and repetitive scenes, or creating scenes where its location or situation is vague) as well as theatrical strategies such as using double casting. My analysis frames these dramaturgical tactics that create substantial porosity in time, space, and characters employed as a *dramaturgy of porosity,* which offers new approaches regarding embodied and affective representations of dementia on stage. These works, employing a dramaturgy of porosity, have been described as offering an immersive, disorienting experience akin to what persons with dementia may experience. In my analysis, I describe how an immersive experience of syncopated time is enacted through this dramaturgy of porosity. While three productions share a similar dramaturgy, each employs a range of different theatrical techniques; I will discuss what are distinct effects achieved in each production. Drawing on the concept of the neurodivergent aesthetic, my analysis explores the implications of these representations, questioning whether these productions can foster a new, meaningful encounter with different states of consciousness through theatre.

4.4.1 *The Other Place* (2011) by Sharr White

Written by American playwright Sharr White, *The Other Place*[55] is one of the rare Broadway productions on dementia and it portrays the porous and blurred perceptions of the past and present experienced by the play's protagonist and narrator, 52 years old female neurologist Juliana Smithton. Both the Off-Broadway production in 2011 and Broadway production in 2013 were directed by Joe Mantello; *The Other Place* received two Outer Critics Circle Award nominations, for Outstanding New Off-Broadway Play and Outstanding Actress in a Play (Laurie Metcalf). It features only four characters—Juliana (the protagonist living with dementia), Ian (her husband and an oncologist), and characters named The Woman and The Man who play multiple roles.

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[55] The full text of the play, short video excerpts of its productions, multiple online theatre reviews, and an online interview with the playwright are available. See video excerpts from https://www.youtube.com/watch?v=d_9K2HJCgww; https://www.nytimes.com/video/theater/100000001995429/excerpt-the-other-place.html; https://youtu.be/R8_ldAyOAYg. Accessed August 27, 2023. The playwright is also known for his other Broadway plays such as *The Snow Geese* (2013), and *Pictures from Home* (2023).

The play begins with an ambiguous scene. Juliana is meeting with Dr. Teller (played by The Woman), or she is at home talking to her husband—due to the absence of a realistic stage set,[56] the audience cannot know which for sure [see Figure 16].

Figure 16. The Opening Scene of *The Other Place* (2011, Sharr White). The Lucille Lortel Theater, New York City, United States. Image description: An older man in a suit stands to the left, a woman in a trench coat sits on a chair in the centre, a female doctor holding a chart stands to the right. Countless empty picture frames form a wall behind them.

Juliana talks about a young woman in yellow bikini whom she saw during her lecture among the doctors, and The Woman starts to write something down on her medical notepad as if she is

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[56] A theatre reviewer depicts the abstract set as "a tangle of dull grey picture frames that seems a representative of the inside of her brain, laced with lighting that bursts at times into a display that could symbolize her neuron misfiring" (Mandell, "The Other Place Broadway Review" 2013), and Morgan Batch (2019) similarly read the set as alluding to "the warped reality of the 'demented' character" (82).

diagnosing Juliana. As Juliana talks about it, the scene is transformed into a new situation, and The Man comes to the stage.

> Man: (*Into mic.*) Chekity checkity … checkcheckcheck! (*The Man gives a thumbs-up and exits.*)
>
> Juliana: … Thank you. (To us.) I begin the lecture, I say ladies and gentlemen (Into mic.) … pardon me, lady and gentleman—I see we have a guest with us today in a lovely string bikini—miss, are you a doctor or are you just here to show someone where it hurts. (To us.) Yes, this gets a bit of laugh and the girl seems embarrassed, I am satisfied. I continue. What, what are you writing. (*The Woman puts her pen down*).
>
> White, *The Other Place*, 7.

From what Juliana tells us, her husband has filed for divorce; her daughter has run away to marry an older man; and she is convinced that she is dying of brain cancer—after all, she was a renowned neurologist giving a speech about an anti-dementia drug. However, as the play unfolds, things get confusing and nothing seems certain. *The New York Times* reviewer Charles Isherwood writes “facts that seem firmly established in one scene melt into vapor a few scenes later, leaving you with a vague itch to press pause to sort things out, or maybe rewind. Or both” (Isherwood, “Who Do You Think You Are, Anyway?”).

The dramaturgical strategy of *The Other Place* is very similar to Florian Zeller’s Westend play *The Father* (*Le Père*, 2012; the English translation was published in 2015). Both plays make the audience share the disorienting experience through a specific writing strategy. Different scenes deliver conflicting information and confuses the audience. A porousness of characters is achieved by the characters named generally ‘Man’ and ‘Woman.’ They play multiple roles, and this effectively materializes how a person with dementia confuses the people around them. In *The Other Place*, one female actor in her late 20s or early 30s, casted as ‘The Woman,’ plays multiple characters such as Dr. Cindy Teller (a neurologist), Laurel (Juliana and Ian’s daughter), and a woman. Similarly, a male actor cast as ‘The Man’ plays three different characters. This strategy is also used in Zeller’s *The Father*, and the porosity of characters allow the audience to share the perception of the protagonist whose perception of surrounding people continuously shifts.

The Playbill introduces *The Other Place* as a mystery that “unfolds as fact blurs with fiction, past collides with present and the elusive truth about Juliana boils to the surface” (The Playbill, “The Other Place”). According to Isherwood’s review of the production, “the disorientation is not accidental. Mr. White’s aim is to keep us wondering about everything we are told by the play’s protagonist and narrator” (Isherwood, “Who Do You Think You Are, Anyway?” 2013). Similarly, in theatre reviews of Florian Zeller’s *The Father*, the most frequently used description of the play is that it puts the audience in the shoes of a person with dementia (Clapp, “The Father Review”; Ritman, “How the Father Crafted an ‘Immersive Experience’”). However, there is a major difference between *The Other Place* and *The Father*; not everything becomes clear in *The Father* while everything gets resolved in *The Other Place* at the end of the play. I will discuss the implications of this choice in my analysis of *The Father*.

4.4.2 *The Father* (*Le Père*, 2012; the English Translation in 2015) by Florian Zeller

The Father represents the world perceived and experienced by André, an 80-year-old man living with dementia; it has been performed by older actors (Kenneth Cranham was 71 years old when he played André in the 2015 Wyndham Production in the West End, UK,[57] and Anthony Hopkins was 83 years old when he played Anthony in the 2020 film adaptation[58]—the character's name was changed for the American production and happened to be the same as that of the actor). Many critics praised both the play and film's insights into the physical and emotional experiences of persons with dementia (Williams, "The Father, Tricycle Theatre"; Billington, "The Father Review"; Bradshaw "The Father Review"). *The Father*'s story centres around a series of familial conflicts between André and his daughter Anne and her partner. The play starts in a modern Parisian flat: André frustrates Anne as he accuses his newly hired caregiver of stealing his watch; then, he eventually finds his watch in a kitchen cupboard where he had hidden it. Anne struggles to balance her life with caring for her father; her partner suggests moving him to a nursing home. While the plot is quite simple and even somewhat typical, the play confuses the audience through repeated, fractured scenes that move back and forth in time and space, enacting the experienced reality from André's perspective. Because of the conflicting information given by repeated scenes, the audience cannot be certain about what André's job was (engineer or tap dancer), whether he drinks coffee or not, and whether Anne ever divorced or not.

While this confusion created through writing strategies is similar to Sharr White's *The Other Place* discussed above, the stage and setting of *The Father* employs a realistic design, representing an apartment. In addition, while the abstract and minimalistic set stays unchanged throughout the production in *The Other Place*, the transformative set and props of *The Father*

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[57] The Wyndham's 2015 production was directed by James MacDonald. Claire Skinner played André's daughter Anne; Nicholas Gleaves played Pierre; Jim Sturgeon and Rebecca Charles played the characters named Man and Woman; and Kirsty Oswald played Laura.

[58] Its screen adaptation, *The Father* (2020) was an Oscar-nominated film starring Anthony Hopkins and Olivia Colman; co-written with Christopher Hampton and directed by Florian Zeller where the character of André is renamed Anthony.

create substantial porosity in time and space and enhance the disorienting effects. The play's stage direction state:

> *Simultaneously, the same room and a different room. Some furniture has disappeared; as the scenes proceed; the set sheds certain elements, until it becomes an empty, neutral space.*
>
> Zeller, *The Father*, 180.

In the 2015 Wyndham Theatre's production, the audience sees a living room with a dining table on the side and a small opening to the supposed kitchen area at the back. Whenever a scene is interrupted, the audience is "plunged into darkness only to be jolted again by grating musical interludes and glaring lights that surround the stage" (Das 1813). When the light returns to the stage, the audience sees the same scene replayed with slight changes in actors and stage props. Unlike the screen adaptation of *The Father*, which was directed by Zeller himself, the live theatre production clearly foregrounds the interruptions and fragmentations; the bright, white set designed by Miriam Buether also makes the transformation of the set hyper-visible [see Figure 17 and Figure 18].

Figure 17. The 2015 Wyndham's Theatre Production of *The Father* (2015, Florian Zeller). Wyndham's Theatre, London, United Kingdom. Photo Credit: Alastair Muir. Image description: André with white hair and beard sits with a woman with dark brown hair sit in a room. The woman has her right hand stretched out to hold the man's left hand.

Figure 18. The Protagonist of *The Father* (2015) and the Empty Set. Wyndham's Theatre, London, United Kingdom. Photo Credit: Alastair Muir. Image description: André wearing white pyjama with strips stands pressed against a white wall. There are doorways to either side of the man.

Just like Sharr White's strategy in *The Other Place*, Zeller achieves a porosity of character by creating characters named 'Man' and 'Woman' who play multiple roles in his script. In the 2015 Wyndham production, Claire Skinner appears as Anne in the Act One, then Rebecca Charles plays Anne in Act Two. The character of Pierre, who has or had a romantic relationship with Anne, is also played by both Nicholas Gleaves and Jim Sturgeon. Also, Rebecca Charles and Jim

Surgeon play healthcare staff at a nursing home at the end of production. In this way, *The Father* represents the protagonist's confused and porous perceptions of the people around him in an embodied and corporeal manner.

According to Leon J. Hilton (2018)'s analysis of Elevator Repair Service's production of *The Sound and the Fury*,[59] a similar dramaturgy of porosity is used to stage the neurodivergent character Benjy Compson and "[his] distinct and vivid mode of processing sensory-perceptual experience" (165). Hilton writes that the production of *The Sound and the Fury* is difficult to follow as "separate narratives and chronological events intertwine with one another and break off midstream" (165). To enact Benjy's perception of the world, 12 performers interchangeably play many characters with constant costume changes and at times different members of the ensemble work together to portray a single figure through synchronized movements[60] (Brantley, "Review: 'The Sound and the Fury'"). These unique theatrical modalities evoke the sensory-perceptual contours of neurodivergent characters (Hilton 180). Sharr White and Florian Zeller have shown that such theatrical modalities can also be applied to the characters living with dementia.

One last aspect to note is the distinct endings of *The Other Place* and *The Father.* In the live theatre production of *The Father*, the final scene depicts André who is left alone in an empty white space—another common theatrical device to manifest the state of being and living with dementia. This type of ending perpetuates the dominant tragic narrative of dementia, depicting the journey as a gradual progression of decline and loss. Such a narrative is problematic and deeply stigmatising. Nevertheless, it is worth analysing the distinctive approaches taken by the theatrical production of *The Father* and the film adaptation in how they handle the puzzles and

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[59] For more information on the production, see the website of theatre company, Elevator Repair Service (ERS): https://www.elevator.org/shows/the-sound-and-the-fury-april-seventh-1928/. Accessed July 21, 2023.

[60] The trailer video of the production shows how different members of ensemble collaboratively embody a single figure. See https://vimeo.com/102772438. Accessed August 27, 2023.

mysteries at the end. As the theatre audience observes the empty stage which represents a care home, questions arise: How long has André lived in the nursing home? Did he ever actually live in a flat? Does the play suggest it was all mere illusion? By contrast, the puzzles and mysteries are resolved in *The Other Place*, and the film version of *The Father* also restores a sense of linearity and chronology by inserting Anne's car-ride from one place to another (presumably London to Paris). As a result, when viewers see the nursing home at the end of the film, they can conclude that what happened in the apartment is only in André's mind and not real. While the film's ending somewhat resolves this riddle, the play makes us feel like we have been pulled back to the very beginning of the story and the puzzle begins again. In a live performance, the audience members also remain seated in the same place and are told that what they saw an hour ago never existed, that the stage was the white, empty room in the nursing home all along. It is hard for the audience to deny what they saw on stage, and at the very least it makes them feel what the protagonist must have felt. Therefore, I argue that this theatrical strategy creates what Nicola Shaughnessy (2013) calls "neuroaesthetics or neurodivergent aesthetics" (321), which offer a more embodied and corporeal encounter with the neurodivergent modes of engaging with the self, others, and the world.

4.4.3. *Plaques and Tangles* (2015) by Nicola Wilson

Nicola Wilson's *Plaques and Tangles* (2015)[61] premiered at the Royal Court Theatre in London, UK, in October 2015, under the direction of Lucy Morrison with Monica Dolan starring as Megan. Megan knows that she has a 50 percent chance to develop Alzheimer's disease with

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[61] A full play text, photos, and theatre reviews of the production are available, however, there are no available online video excerpts of the production, except an abstract trailer of the Royal Court Theatre production (https://youtu.be/S9wamDeM9HM?si=ohMIdO7yLYWuY8dx. Accessed August 30, 2023).

her genetic condition, and Sophie Leggett (whose family developed Alzheimer's in their early 40s) has given advice to the production about Familial Alzheimer's disease (Brimelow, "First Trial to Stop Alzheimer's"). Regarding its theatrical tactics, Jules Morgan (2016) describes that "realism dominates, and theatre intervenes using impressive gimmicks to replicate time shifts, and fragmented and confused mind—memory loss" (671). Marco De Ambrogi (2015) notes "the play's non-linear structure helps the audience to enter the maelstrom of Megan's mind—the story moves backwards and forwards across time, with some scenes played in reverse" (e42).

Similar to White's and Zeller's, multiple actors play one character to represent a porous and syncopated reality perception of the female protagonist Megan, who is a lexicographer and has early onset of Alzheimer's disease. For instance, Megan's genetic counsellor Barbara is played by the same actor who plays her mother Eva. The audience also sees Megan at different ages between 21 to 48, in a non-linear way. Younger Megan and Old Megan play different ages, along with her husband Younger Jez and Old Jez. However, as noted by a few reviewers (Hemming "Plaques and Tangles"; Pringle, "Plaques and Tangles; Treneman "Plaques and Tangles"), Wilson's play was not as successful as Zeller's or White's in creating the disorienting experience of a protagonist living with dementia. It could be that the audiences had already been exposed to similar techniques, and it was less fresh. But it also seems that *Plaques and Tangles* was not effectively written for a live theatre. The action takes place over 26 years. In contrast, from scene five to scene nine of *The Father* depicts a single day and focuses on creating the disorienting effects rather than a complex narrative. Zeller's play enacts the disorienting effects by abruptly closing scenes and replaying moments of the earlier scene. In a review of *Plaques and Tangles*, Sarah Hemming writes "[i]n places it feels overly elaborate and deliberate: you notice the style rather than the situation (the backwards scenes [are] jarringly awkward to perform)" (Hemming "Plaques and Tangles"). She also notes, "some huge plot developments feel contrived and heavy-handed, overloading an already emotive issue" (Hemming "Plaques and Tangles"). One possible explanation for the play's shortcomings is that Wilson primarily writes for television. Therefore, she may not be accustomed to crafting scripts for live performances, which have more compact timeframe than TV series.

On the other hand, many reviewers appraised its power in depicting the emotional struggles of Megan's children who experience both "anger and rejection towards their mother with their desire to help and protect her" as she becomes violent and does not recognize her family (De Ambrogi e42). Jules Morgan (2016) writes that "Megan, clinging on to the present, is thrown back into her past by her disease"; she further describes Megan as "disappear[ing] and at times almost demonic and uninhibited" while some of her traces remain (671). Billington also says the play was "moving when it confronts the impact of Megan's condition on her family […] [as they] learn of the secret she [Megan] has hidden for many years and of the even chance that one of them maybe genetically affected" (Billington, "Plaques and Tangles Review").

While this production's theatrical engagement with a rare topic, the genetic inheritance of Alzheimer's and its impacts on family, is notable, the representation of Megan's mother Eva (who also lived with early-onset Alzheimer's in her forties) seems problematic as it repeats the stigmatized image of a person living with dementia—the dishevelled white hair of Eva and her clothes reminding of an asylum and shockingly close to the recycled image of Ms. August Deter discussed in Chapter Three [see Figure 19 and Figure 20]. In the play, Eva, who appears in dream sequences and hallucinations, serves as a source of comic relief. I am sceptical about what the performed abnormality and deviance of Eva brings to the play, besides reinforcing the common stereotype of people with dementia as lesser beings.

Figure 19. Old Megan and Her Mother Eva Taking MMSE (Mini Mental State Examination) in *Plaques and Tangles* (2015, Nicola Wilson). Royal Court Theatre, London, United Kingdom. Photo Credit: Alastair Muir. Image Description: Two performers are seated on a staircase. Megan is dressed in dark clothing and her mom Eva is dressed in white attire and has white hair. Both performers are looking in the same direction to the right of the picture.

Figure 20. Old Megan and Her Mother in *Plaques and Tangles* (2015, Nicola Wilson). Royal Court Theatre, London, United Kingdom. Photo Credit: Tristram Kenton. Image Description: Two performers are seated on a staircase. Eva with white hair wearing a white shirt, has hand in front of her face and her tongue sticking out. Megan turns her head, while closing her eyes and displaying annoyance.

4.5 Remembering and Reconnecting; New Perspectives on Disorientation

While many productions portray the challenges and struggles related to the altered time and reality perception, a few theatrical works offer a novel perspective on this change. Analysing *The Nature of Forgetting* (2017) by Theatre Re, *Finding Joy* (2014) by Vamos Theatre, and *The Visiting Hour* (2021) by Frank McGuinness, this section demonstrates how these theatrical productions suggest a fresh and positive outlook on what is medically labelled temporal deviance or a mental abnormality. These works' narratives shed light on how the experience of syncopated time, reality, and memory can enable individuals with dementia to resolve their sorrows or regrets and to re-connect with both lost loved ones and those around them.

4.5.1 *The Nature of Forgetting* (2017) by Theatre Re

The Nature of Forgetting (2017) is a physical theatre created by the London-based theatre company Theatre Re. It prioritizes visual performance, using movements, live music, and lighting, complemented with a limited use of verbal language to portray the altered time and reality perception of Tom, a 55-year-old man with early onset dementia. Since its premiere at the London International Mime Festival at Shoreditch Town Hall in 2017, it has toured worldwide from 2017 to 2023.[62] Theatre Re consulted neuroscientist Kate Jeffery and conducted workshops and interviews with people living with dementia and their caregivers to create this piece.

There are four performers and two musicians[63] on stage of *The Nature of Forgetting* (one of the musicians play as a teacher later in the piece), and the stage set is minimal—there are two

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[62] This analysis is based on my viewing of a dress rehearsal of the production in 2022 in London at the invitation of the theatre company. For further information about the production history, see Theatre Re's website. https://www.theatrere.co.uk/the-nature-of-forgetting.html. Accessed August 27, 2023. There are also online video snippets, photos, and many online reviews.

[63] Theatre Re's director Guillaume Pigé as Tom, Louise Wilcox as his daughter Sophie and wife Isabella, and Eygló Belafonte and Calum Littley in a variety of subsidiary roles (Guerreio, "Theatre Re, The Nature of Forgetting

clothes racks on the side of main platform, where most of the actions happen and performers bring in and out props such as desks, bicycle, etc. [see Figure 21]. The performance begins with Tom getting dressed for his 55th birthday party, while his daughter Sophie repeats slowly that his blue jacket is ready for him, and his red tie is in his pocket—which indicates his difficulty with memory. As Sophie leaves, Tom's memory of his deceased wife Isabella is pulled into the present and he cries after Sophie: 'Isabella!'—both Sophie and Isabella are played by the same actor Louise Wilcox. In a non-linear way, Tom enacts his multiple age-selves and portrays his experience of syncopated realities that are neither exact re-enactment of past events nor of present situations. Teresa Guerreio, an online theatre reviewer, describes "this vivid, fast-moving piece of physical theatre jumps from Tom's present fog of perplexity to his past, through a rush of his life-long memories" ("Theatre Re, The Nature of Forgetting review").

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review"). There are also percussionist Nathan Gregory and composer and multi-instrumentalist Alex Judd (Guerreio, "Theatre Re, The Nature of Forgetting review").

Figure 21. A Scene of the 2023 Production of *The Nature of Forgetting* (2017, Theatre Re) at Shoreditch Town Hall, the London International Mime Festival, United Kingdom. Photo Credit: Danilo Moroni. Image Description: A brightly lit stage within a dark room. On the centre elevated platform, Tom appears to move actively. Two other performers on either side of the centre platform are handling clothes hanging on a clothes rack.

The audience observes significant moments and memories from his life, including his childhood, the birth of his daughter, his wedding night, and his first kiss. Most importantly, they discover how he lost his wife Isabella, as certain sounds (e.g., a knocking sound or the sound of a chime) and familiar environments (e.g., a noisy bar) constantly make him re-live his deep memories, both happy and tragic, related to his youth and his wife. Triggered by the sound of a car horn, he repeatedly experiences the moment when he and his wife were driving and had a car crash—Tom was distracted, and the car crash led to the death of Isabella. These narratives are expressed through swift, virtuosic, expressive, and dynamic movements. Performers around Tom constantly change outfits to portray different moments of the past and different people in his life.

This theatre piece has toured internationally with more than 150 performances; while some critics have praised the energy and physicality of the performance, the captivating music of the piece, and its emotive charges (Guerreio, "Theatre Re, The Nature of Forgetting review"; Sommers, "The Nature of Forgetting"), others have critiqued the young age of the performers and the loud music. Online reviewer Peter Mortimer writes, "the actors are pretty young, and their fierce energy sometimes sits uneasily with the realities of the subject matter" (Mortimer, "Review: The Nature of Forgetting"). The director of the show states in an interview that "[they] wanted to show that he [Tom] is not growing old, but in fact, dealing with a very specific condition" and he even argues that this piece "is not about dementia but about the fragility of life and that eternal ‘something’ we all share that is left when memory is gone” (Sanchez, “Preview: ‘The Nature of Forgetting’”). While there are younger people who live with early-onset Alzheimer’s disease, Mortimer’s critique is valid because the majority of the population affected by Alzheimer’s disease comprises older adults. In a review for *The Times*, Donald Hutera notes that “although the music is overbearing, the use of sound effectively indicates the ‘noise’ in Tom’s brain” (“The Nature of Forgetting Review”). He finds that the scenes, which “unfold in a fractured yet fluid style,” offer a compelling glimpse into Tom’s mind (“The Nature of Forgetting Review”).

What is also intriguing and powerful about this piece is the way it portrays the inter(in)animation between the past and the present. Whenever Tom experiences a syncopated time, he tries to control his memories and environments, and his feelings and regrets in the present influence the reenactment of the memories. Elizabeth Hayward, an online blogger, writes, “[f]or 75 minutes, Pigé hurtles himself around in a mania of desperation to seize memories as they come close to the surface before lingering and fading” and “Tom seems to begin searching for a particular moment with his loved one to re-live” (Hayward, “Review: The Nature of Forgetting”). Whenever his memory of the car accident is re-accessed or re-enacted, it is slightly different. At the end of the performance, Tom manages to stop the car before the accident occurs, so he resolves his deepest regret that haunts and hurts him. As such, this work gives a different view of the altered time and reality experienced by people with dementia. It suggests these lapses of memory and time are a chance to re-connect with loved ones and resolve lingering emotions and feelings.

4.5.2 *Finding Joy* (2014) by Vamos Theatre

Finding Joy[64] is a silent mime performance created by Vamos Theatre, a leading full mask theatre company in the UK; it premiered at the Brighton Fringe in 2014 under the direction of Rachael Savage and has toured internationally including Germany, Spain, Norway, and China.[65] *Finding Joy* uses masks designed for this production by Kent-based mask and puppetry specialists Strangeface, and different masks represent Joy at key moments of her life. This show focuses on the intergenerational relationship between the 83-year-old woman Joy (played by Bidi Iredale), who lives with dementia and experiences nocturnal wanderings, and her teenage grandson Danny (played by James Greaves), who decides to look after Joy. Danny is described as "a dabbler in drugs and petty crime" (Gardner, "Finding Joy–Review") and "hangs around the streets with his friends, listening to jungle music" (Jauregui, "Finding Joy–Vamos Theatre"). As Danny's mother is too busy to care for Joy, Danny cares for Joy and they begin to grow close.

Through seventeen episodic scenes, *Finding Joy* illuminates Joy's important moments of life, including her work experience in a sewing shop, her marriage, and going on a picnic with their little baby. The production also portrays the current everyday life of Joy, such as Danny assisting Joy at bedtime [see Figure 22], their hospital visits, and an incident where Joy finds herself on a street in the middle of night.

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[64] There are short online video snippets, photos, and theatre reviews are available. See trailers of the show: https://www.vamostheatre.co.uk/media/finding-joy-showtrailer; https://youtu.be/6Sm5Zk_lPwo. There is also a BSL show trailer which gives more information about the narrative https://www.vamostheatre.co.uk/media/finding-joy-bsl-show-trailer. Accessed August 27, 2023. On the website of Vamos Theatre, there is also an education package and materials visually describing its story, designed for enhanced accessibility. See https://www.vamostheatre.co.uk/user_resources/downloads/Finding-Joy-visual-story-Vamos-Theatre.pdf. This visual story board briefly describes each scene of *Finding Joy*. Accessed August 27, 2023.

[65] Following the creation of *Finding Joy*, Vamos Theatre has developed a dementia-friendly interactive performance called *Sharing Joy* which can tour to various venues and engages with people with dementia through music, dance, and puppetry. For further information on *Sharing Joy*, see https://www.vamostheatre.co.uk/shows/show/sharing-joy. Accessed August 27, 2023.

Figure 22. Joy and Danny in *Finding Joy* (2014, Vamos Theatre). The Courtyard, Hereford, United Kingdom. Image description: Two performers are on stage wearing masks covering their faces. Joy is dressed in pyjamas and holds a purse. Danny in the background wears dark casual clothes while making a bed for Joy.

Similar to *The Nature of Forgetting*, *Finding Joy* also depicts how certain sounds and situations trigger memories, causing individuals with dementia to experience a syncopated reality. For instance, when Danny leaves her at bedtime, Joy searches for her handbag and accidentally falls, injuring herself. She hears an ambulance siren, and the sound of siren “morphs into the war sirens[s]” (Hayward, “Review: Vamos Theatre’s Finding Joy). As the memory of her childhood is triggered, a young Joy runs on stage [see Figure 23].

Figure 23. Younger Joy and Older Joy in *Finding Joy* (2014, Vamos Theatre). The Courtyard, Hereford, United Kingdom. Photo Credit: Elizabeth Hayward. Image description: Two individuals are on a stage lit by bluish stage lighting. The individuals are both wearing masks. The foremost figure is younger Joy; she displays a worried or concerned expression. In the background, older Joy gazes at the younger Joy with a furrowed brow and a hand touching her head.

The syncopated time between the present and the wartime resurfaces as Joy undergoes on X-ray on her hip at the hospital and when she becomes lost at a busy street at night. During these moments, Joy re-experiences the sadness of parting with her mother at the train station during the war. These scenes allow the audience to witness simultaneous parallels between a younger Joy and her older self, presenting Joy as a "body in depth" (Basting 1998) traversing different times and spaces. While her grandson Danny might not perceive Younger Joy in the same way the audience does, over time, it suggests that Danny comes to better understand his grandmother and finds ways to comfort her. A reviewer describes it as Danny "learn[ing] how to make her feel secure and how to bring her out of her memories," and further notes that Danny "brings out her playfulness and makes her laugh despite the situation" (Hayward, "Review: Vamos Theatre's Finding Joy").

However, there is also criticism. In his review, Darren East critiques the somewhat reduced and romanticized portrayals of dementia in *Finding Joy*, noting that "apart from one climactic anxious moment, the dementia symptoms kept pretty much within the spectrum of charming minor frustrations, which is not, I am sure, the full experience" ("Vamos Theatre: Finding Joy"). This critique is valid, yet it also reflects the prevailing tendency in popular culture, described by Janet Gibson as "the right kind of dementia story," which often focuses solely on the tragedies of dementia (see Gibson 38-41). While the dominant narrative of dementia-related plays tends to be tragic, emphasising the burdens and struggles of the family caregivers, *Finding Joy* offers a more positive perspective on individuals affected by dementia and the role of dementia in strengthening family relationships. Observing the relationship between Joy and Danny, the audience can reflect on various enduring qualities of persons with dementia such as their humour and ability to love. Furthermore, the play illustrates how Danny learns about his grandmother, finding a different way to connect with her and share his love, and also becoming a caring person himself. As such, the narrative of *Finding Joy* suggests that dementia can offer family caregivers a new opportunity to discover and learn about their relatives living with dementia, offering a chance to build a deeper family bond and understanding. This perspective challenges the prevailing discourse of dementia that views caregiving as solely burdensome without recognising the positive aspects it can bring.

4.5.3 *The Visiting Hour* (2021) by Frank McGuinness

One of the most recent plays on dementia, *The Visiting Hour* (2021)[66] is created by Frank McGuinness, a playwright based in Dublin. In fact, this is Frank McGuinness's second play about dementia; he also wrote *The Hanging Gardens* (2013), which depicts a novelist who has three children and lives with dementia. *The Visiting Hour* (2021) reflects the context of the COVID-19 pandemic and was virtually aired during that time. The minimalist set design represents a weekly visit of a daughter (played by Judith Roddy) to her father (played by Stephen Rea) in a care home; due to the COVID restriction, they are separated by a pane of glass that represents a window [see Figure 24]. Strangely, the father is dressed in a tuxedo with a white frilled shirt, a bow tie, and pyjama trousers, all while on barefoot. There are no other performers except for them. Periodically, a voiceover reminds them that visits can last only 60 minutes.

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[66] This production was filmed at TheGate Theatre, Dublin, and had its world premiere streamed on 22 April 2021. It was directed by Caitríona McLaughlin. I watched the live virtual performance in 2021. The full play text is published by Faber & Faber in 2021. There is a short interview video with the cast members, Stephen Rea and Judith Roddy. See https://youtu.be/JaunGyf2guQ?si=6_ORSo5AdNCBC6F2. Accessed August 27, 2023.

Figure 24. A Scene of *The Visiting Hour* (2021, Frank McGuiness), Virtual Performance. Photo Credit: Ros Kavanagh/*The Guardian*. Image description: The Father sits in a chair in his bare feet on the left. His daughter sits on a park bench with her legs crossed on the right. The two are facing each other and there is a clear glass partition between the two.

As a digital performance, there was no live audience in Dublin's Gate Theatre's auditorium, where the production was both performed and filmed; however, the production cleverly utilises the empty theatre auditorium to evoke a music hall as perceived by the father. As the camera turns, the video shows what is behind his daughter; viewers of the online performance can see a large, luxurious auditorium with its lowered chandeliers [see Figure 25].

Figure 25. A Scene of *The Visiting Hour* (2021, Frank McGuiness) Shown from A Different Angle, Virtual Performance. Photo Credit: Rich Gilligan. Image description: Two individuals sit facing each other in a dark space with green lit walls in the background.

Their conversation is at times playful and engaging, but also fragmented and confusing as the father's perception changes. In the middle of the conversation, he slips away as his memory intrudes into his present and he is immersed in the perceived-experienced reality. It seems like he might have been a professional singer—although we cannot be sure. Helen Meany, a reviewer for *The Guardian*, describes their interaction as "a performance in which both know their lines, as she feeds him cues for verbal riffs and familiar routines." What the father says contradicts his daughter's memory about their family, it upsets her, and they argue; he also gets upset and frustrated. They "dance round topics such as lemon drizzle cake and the Eurovision Song Contest, like people whose lives are forever on repeat" (Charleton, "The Visiting Hour Review"). Because of the highly fragmented and circular nature of the dialogue, the audience cannot get a comprehensive understanding of the characters nor their family stories. Nevertheless, what this production highlights is the selfhood expressed by the father living with dementia through his speeches and singing. Moreover, the alternative and momentary connections made between the father and daughter stand out, despite the so-called non-normative conversation they engage in. For instance, the scene where the father and daughter connect through singing an Irish folk song, The Waxie's Dargle, offers a compelling and powerful portrayal of an alternative form of connection and communication between an individual with dementia and their caregiver. Music is commonly used for caregivers in their attempt to connect with their loved ones living with dementia. Although these moments of connection do not last long, *The Visiting Hour* realistically depicts both the struggles and enduring affections between family members—the visiting hour might refer to both the disconnection and connection.

4.6 Conclusion: Theatre and Embodied Representation of Lived Experiences of Dementia Temporality

In this chapter, I explored how the alternate time and reality perceptions of persons living with dementia are represented using dramaturgical and theatrical strategies. By analysing multiple examples, this research questioned whether theatrical representation of the different consciousness of people with dementia can counter ableist approaches and promote a more inclusive perspective of dementia. As demonstrated in the discussed productions, some theatrical works on dementia adopt a more inclusive approach that acknowledges and validates the perceptions and experiences of individuals with dementia. While some productions risk re-inscribing the decline narrative, they also offer an embodied and sensual understanding of what it feels like to live with an altered temporal perception. Furthermore, these works provide a critical space for reflecting on the attitudes and approaches of able-minded individuals interacting with those with dementia. Regarding the so-called deviant behaviours and perceptions exhibited by characters living with dementia, some plays shed light on ableist and discriminatory attitudes, while others showcase more empathetic and compassionate approaches.

The analysed works have demonstrated how theatre and performance can provide an embodied representation of the modified perception experienced by individuals living with dementia. However, these works have employed two distinct modes. Some productions, such as *Autobiographer* and *Inside Out of Mind*, employ a non-realistic approach to represent the altered consciousness of people with dementia. This is achieved through an enacted "dreamscape," using video projection, cartoon-like, surreal, or poetic elements (Batch 84). On the other hand, plays like *The Other Place*, *The Father*, and *Plaques and Tangles* portray the nonlinear and porous experience of time and reality as perceived by individuals with dementia while upholding a realist dramaturgy. What are the effects and implications of these distinct dramaturgical and aesthetic approaches?

As noted by Batch, a dreamlike and imaginative portrayal of the alternative experiences of reality of persons with dementia can "re-contextualize the experience of dementia—namely the associated memory loss and disorientation"—through the lens of "an adventure narrative" (Batch 165). However, concurrently, when non-realistic elements are utilised to illustrate the cognitive states of those with dementia, while depicting others in a realistic manner, this staging inherently demarcates those affected by dementia from those who are not. This approach establishes a hierarchy between the so-called objective reality of neurotypical individuals and the perceived-experienced reality of those with dementia. The use of fantasy-like representations can also lead to dehumanisation and infantilisation by attributing an otherness to people living with dementia (Batch 236). In these representations, the use of illusionary visual portrayal of characters with dementia can have unintended effect of distancing the audience from them as subjects and mythologizing the condition (236). I argue that this kind of representation carries the risk of establishing a voyeuristic space, allowing able-minded individuals to glimpse into the mental state of the disabled 'Others.'

Plays like *The Father*, *The Other Place*, and *Plaques and Tangles*, which do not employ imaginative elements to evoke the consciousness of character with dementia, still showcase a dramatic world marked by a distinct division between insiders and outsiders (i.e., characters with dementia and those without). However, by situating the audience within the perspective of the protagonist living with dementia, rather than within the viewpoint of the surrounding neurotypical characters, these works mitigate the potential for voyeuristic inclinations that the audience might project onto the protagonist, to some extent (see Lee 2023). For instance, in *The*

Father, viewing the world through André's eyes allows the audience to experience similar affects felt by the protagonist, such as bewilderment and frustration. In this way, while spectators may not fully grasp the same level and complexity of emotions experienced by the character with dementia, it offers an opportunity to empathetically imagine what it means to live with such a state of not-knowing and uncertainty.

In summary, contemporary theatre and performance utilise both realistic and non-realistic staging strategies to portray the alternative state of consciousness of individuals living with dementia. While I have reflected on the potential implications and effects of each approach, we need more examples to assess whether a particular dramaturgical approach is more effective in creating a space for encounters with the states of living with dementia through a "neuroaesthetics" (Shaughnessy 2013). In addition, further investigation is necessary to identify if theatrical works about dementia establish a unique neurodivergent aesthetics that differentiates them from theatrical works exploring other forms of mental and cognitive diversity.

In this analysis, I have also demonstrated how theatrical works like *The Nature of Forgetting*, *Finding Joy*, and *The Visiting Hour* offer a positive and critical perspective on the alternative perception of time and reality experienced by persons with dementia. The narratives presented in these works shed light on how the experience of syncopated time, reality, and memory can enable individuals with dementia to resolve lingering emotions (*The Nature of Forgetting*) and express their selfhood and identity (*The Visiting Hour*). This also applies to Sharr White's *The Other Place*. The protagonist, Juliana, re-connects with her lost daughter, Laurel, even though the people around her do not believe or recognise what Juliana is experiencing. These productions show how the altered temporal orientation of characters with dementia not only let the characters re-encounter traumatic memories, but also allow them to remember and re-live significant and precious moments and people in their lives, thereby finding comfort and love.

Furthermore, theatrical representations on the altered time and reality perception of individuals living with dementia provide a critical space to reflect on the experience for caregivers when their relatives living with dementia engage with a different perception of reality from their own. The reactions and attitudes of these surrounding characters are as important as the representation of the character living with dementia because that representation reflects the social and cultural stigma and attitude towards persons with dementia. The represented actions, languages, and responses of surrounding people can either reflect the contemporary cultural attitudes, or they can critique, challenge, and suggest more inclusive and supportive behaviours when engaging with persons with dementia. In works such as *The Father*, *The Other Place*, and *Plaques and Tangles*, the family caregivers and surrounding people demonstrate a variety of reactions towards the supposed cognitive "deviance" of the protagonist living with dementia. For example, in *The Father*, the daughter of the protagonist is upset about his confusion but tries to comfort him; her partner becomes frustrated and even angry with him; the care assistant finds his behaviour surprising but also adorable, sometimes treating him like a child, which upsets him. Meanwhile, the healthcare staff in the nursing home respond to him without any sign of surprise as his disorientation has become a mundane phenomenon for them. The reactions we see in *The Other Place* are similar: frustrated by his wife's behaviour (who has dementia) and by the things she says, the protagonist's husband screams and curses into the air. Until the very end of the play, his attitude does not change. He dismisses his wife's expressed concerns and beliefs, and asks the doctor to "stop" her disease. On the other hand, in *Finding Joy* and *The Visiting Hour*, the audience gets to see alternate ways that family caregivers connect and communicate with their relative who is living with dementia and how they embrace the different state of being and living. Although the father in *The Visiting Hour* often says things that can be offensive or hard to comprehend, the daughter tries to have a conversation with him, even if that may not make sense to others or the audience. It seems that she is hurt that her father does not recognize his only daughter and only family member, but she responds to whatever topic her dad suddenly brings up and joins whatever activity he initiates, including playing along when he tells knock-knock jokes. *Inside Out of Mind* also shows a variety of reactions family caregivers and healthcare staff display when they interact with residents with dementia in a care home.

Theatre and performance not only reflect but also construct social imaginary about what it means to live with dementia and what it means to have a family member with dementia. The stigmatizing and negative representations can create what Janet Gibson (2020) called "normative age-and-dementia-effects" (93), a term she borrowed from the phrase "normative age-effects" conceived by Bridie Moore (2014: 2). The limited, tragic stories of ageing with dementia are not only used to inscribe or re-install the fear of ageing and old age but also suggest what constitutes desirable and ideal ageing, equating them with ageing without illnesses or disabilities. In the following chapter, my dissertation expands its discussion beyond dementia and explores how contemporary theatre and performance can challenge normative ideas of ageing. This research contends that the stories of older adults living with dementia should be diversified and included in the heterogeneous cultural scripts of ageing, as a part of the myriad possibilities of ageing paths.

Chapter Five: Troubling Normative Ageing through Age-Critical Performance

5.1 Introduction: What Constitutes Normative Ageing and Non-Normative Ageing?

When the majority of people affected by dementia are older adults, one of the core problems with the established tragic narratives of dementia is that they depict losing memory and cognitive abilities due to ageing and dementia as instances of abnormal or unsuccessful ageing. While ageing with illnesses or disabilities (including dementia) are stigmatised, certain pathways of ageing are idealised and celebrated; non-pathological ageing is one of them. In this section, I will discuss the problem with the normative discourse that defines what ageing should look like and what constitutes desirable ageing versus what does not. Then, I will reflect on how theatre and performance can counter normative ideas related to ageing, which define what is considered a standard or regular ageing process and distinguish deviations from typical ageing paths. In this chapter, I problematise the ways in which normative discourse on ageing does not acknowledge heterogenicity of ageing and old age. I aim to showcase how theatre and performance can contribute to illuminating both the pleasures and perils of diverse ageing paths and scenarios, challenging stereotypes and myths of ageing.

Mass media and public health campaigns continue to prescribe what constitutes normal and natural ageing. For instance, the World Health Organization (WHO) repeatedly emphasizes that dementia “is not a normal part of ageing,”—rather it is a disease in the brain—to raise awareness of the need for medical diagnosis and help-seeking (*Dementia: A Public Health Priority*, 2012). Despite its intention, when the binary discourse dividing successful/normal/healthy ageing versus unsuccessful/abnormal/unhealthy ageing is prominent in the cultural narratives of ageing, the phrase "dementia is not a normal part of ageing" can make people associate dementia with failure and abnormality, contrasting it with the idea of normal or normative ageing. Alzheimer's disease and other types of dementia often go hand in hand with the ageing-as-decline narrative, ageism(s), and age-related fear, stigma, shame, and discriminations. Growing old should not be synonymous with dementia; at the same time, older people living with dementia should not be cast out from the ageing narratives and ageing futures.

The concept of normativity in relation to ageing is complex. When "the master narrative of decline" (Gullette 2004) predominates Western views of growing old, what constitutes normative ageing and non-normative ageing? Both the discourse equating ageing with decline and loss and the idea promoting successful and healthy ageing are equally problematic. The former makes people, including older adults, perceive ageing in one way, mostly in the negative terms of decline, loss, deterioration, and erosion. The myth of old age not only generates cultural fear and anxiety over growing old, but it also serves as the basis for *ageism*,[67] which refers to prejudice and discrimination directed toward a certain population based on their chronological age (Butler 1980: 8).

The latter, the paradigm of 'successful ageing,' has been explored as a response to the narrative of ageing as decline (Rowe and Kahn 1997). Yet, the idea of positive and successful ageing is saturated with ableism. Rowe and Kahn (1997)'s research first stimulated the field of ageing research to investigate the criteria and determinants of successful ageing and the ways to achieve that. It is interesting that normal, natural, or usual ageing is equated with the ideas of

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[67] The term "ageism" was first coined in 1969 by Robert Butler, the first director of the US National Institute on Aging; initially, it was understood as a concept that applies only to the elderly, but now ageism is understood as a discriminatory attitude and practice that applies to all ages (Loretto et al. 288). For a history of the term ageism, see Achenbaum, W. Andrew. "A History of Ageism Since 1969." *Journal of the American Society of Aging*, Vol. 39, No. 3, 2015, pp. 10-16.

ageing with pathology, disease, or dysfunctions and is contrasted to the successful ageing in Rowe and Kahn's research (433). By proposing the distinction between "usual and successful aging as nonpathologic states," they define successful ageing with three main components: "low probability of disease and disease-related disability, high cognitive and physical functional capacity, and active engagement with life" (433). Since this MacArthur model of successful ageing,[68] the idea of successful ageing has been explored within various contexts to promote the well-being and quality of life for older adults and related concepts, such as active and productive ageing, have emerged (see Katz and Calasanti 2015). It has also been critiqued by many scholars both in Humanities (e.g., Katz and Calasanti 2015; Gibbons 2016) and Health Sciences (e.g., Angus and Reeve 2006; Topaz et al. 2014). For instance, Angus and Reeve (2006) state ageist attitudes are entrenched in the value patterns in Western society with its emphasis on productivity and independence (138) and criticise the paradigm of healthy aging "where the problem of dependency is displaced with the normalizing view that older people should be responsible for their own health and well-being" (145). Such rhetoric, promoting the idea of independency as the core of successful ageing, ignores many physiological realities of older adults, as well as socioeconomic and other equity factors that seriously influence whether such a definition of 'success' is possible for the majority of older adults.

Despite critiques of the reverse-ageism implied in the notion of successful, healthy, productive ageing, disability-free and illness-free ageing are still considered successful in current

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[68] The MacArthur model of successful aging is a theoretical framework developed by a group of researchers at the MacArthur Network on Successful Aging in the United States. Concerned with the field of gerontology had become preoccupied with disease and disability in late life, the researchers conducted a series of studies on high-performing older adults and formulated this model of successful aging by identifying factors that influence the well-being of individuals in late life. For further information, see Rowe, John W., and Dawn C. Carr. "Successful Aging: History and Prospects." *Oxford Research Encyclopedia of Psychology*, 2018.

literature and are promoted with the concept of “the third age.”[69] On the other hand, older adults with disabilities or illnesses are demarcated through the notion of “the fourth age,” and their vulnerability, frailty, or dependency continue to be stigmatized (see Higgs and Gilleard 2014). Sociologist Silke van Dyk (2016) highlights the “growing polarization within later life” and states that a dual process of othering applies to the two groups: the third agers are othered through “glorification,” while the fourth agers are othered through “abjection” (110). She writes, “even though third agers are frequently redefined as capable adults, these capabilities are generally more closely associated with the nature pole of the binary, thereby generating a clear distinction from competitive, rational, and hard-working adults” (113). She claims the third agers are labelled as “the age-afflicted other,” which, in turn, serves to confirm the apparent agelessness and superiority of midlife (115). The neoliberal idea of successful ageing drives society to be ageless. Older adults are either compelled to resist the ageing process or are shamed and devalued when they become dependent, unable to ‘contribute’ to the social, cultural, and economic life in the same way young people do.

5.2 Disrupting Normative Scripts of Ageing and Old Age through Theatre and Performance

Along with popular media and other literary genres, theatre and performance are also cultural apparatuses that construct understanding of growing old and elders, and a growing number of scholars have investigated the relationship between the performing arts and cultural consciousness of ageing and old age. Anne Davis Basting first connected Age Studies with Theatre Studies and wrote a monograph titled *The Stages of Ages* (1998), which investigates the

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[69] Historian Peter Laslett (1994) coined distinction between the third age and the fourth age, and he also established a similar differentiation between ‘young-old’ and ‘old-old’ (Laslett 1988).

ways in which different theatrical performances construct their own meanings of old age in America. Basting's observation of the representation of ageing also echoes the decline narrative:

> For almost two centuries to become 'old' in the United States has been largely regarded in terms of loss. To become old is to lose beauty. To become old is to lose power, both financial and physical. It is to lose one's independence and to lose one's flexibility and potential for growth. And now, with the specter of Alzheimer's haunting those over eighty, to become old is to risk losing one's very self. These are the myths that feed the reality of the house of old age that America built (Basting 1).

Kathleen Woodward's significant monograph *Figuring Age: Women, Bodies, Generations* (1999) expanded the scholarships on ageing in Performance Studies as she reflects on age/ing as a performative identity like gender and race.

Since these two pioneering works, for the last two decades, scholarship focusing on ageing within Theatre and Dance Studies has grown and expanded. Various scholars have explored how plays illuminate, construct, and transform the meanings of growing old.[70] A few studies have theorized how age/ing as social difference is performed in everyday life, performance art, and contemporary theatre (Woodward 1999 and 2006; Swinnen and Port 2013). Scholars have also discussed what Age Studies can offer to Theatre and Performance Studies, and vice versa (Lipscomb 2012; Fuchs 2014; 2018). More recently, scholars have articulated the ways in which mature dancers and performers address and embrace and/or navigate the ageing reality of body and mind through their radical and critical works (Nakajima and Brandstetter 2017; Martin 2017; Hansen and Kenny 2019; McLeod 2021; 2022; Gillespie 2022). The launch of the interdisciplinary journal *Age, Culture, Humanities* by Cynthia Port and Aagje Swinnen in

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[70] These studies include Basting (1998), Lipscomb and Marshall (2010), Mangan (2013), Moore (2014), Casado-Gual (2015), Lipscomb (2016), Henderson (2018), and so on.

2014 is also a remarkable milestone in the field because it invites "cross-disciplinary, critical investigations of the age, aging, and older age, as seen through the lens of the humanities and arts" (Age, Culture, Humanities 2023)[71]. Furthermore, the prominent journals in the field such as *Performance Research*, *Modern Drama*, and *Theatre Research in Canada* have published special issues on ageing featuring a wide range of research (Switzsky 2016; Gough and Nanako 2019; Henderson et al. 2019). The diagram below visually summarizes crucial studies that have reflected on age/ing and expanded this intersectional and interdisciplinary area of research within Theatre, Performance, and Dance Studies [see Figure 26].

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[71] Age, Culture, Humanities. "About." *Age, Culture, Humanities Webpage*, 2023, https://tidsskrift.dk/ageculturehumanities/about. Accessed August 30, 2023.

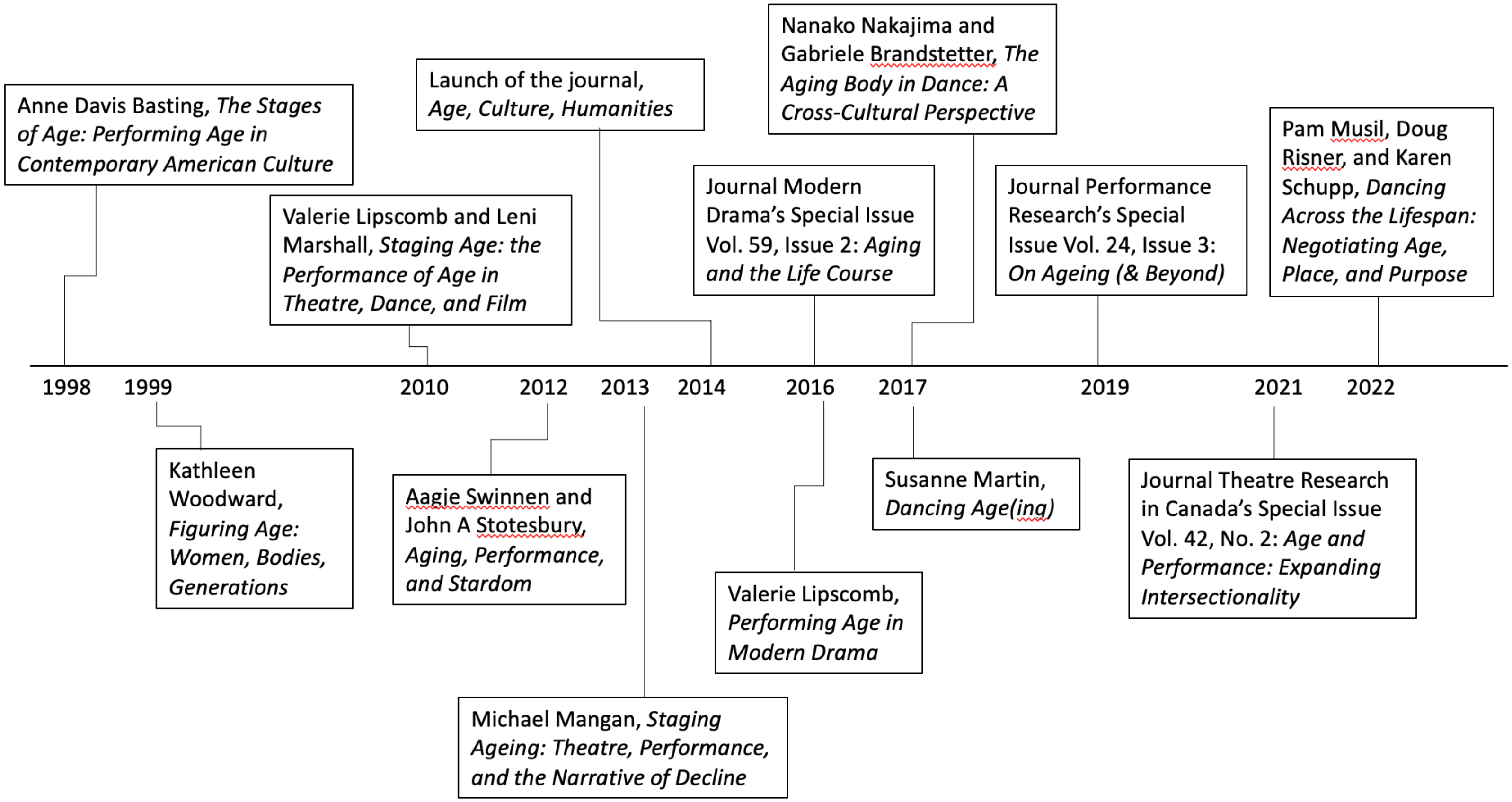

Figure 26. Selective List of Studies on Ageing within Theatre, Dance, and Performance Studies. Image Credit: Heunjung Lee.

The performativity of age enacted on stage is particularly promising in disrupting or subverting normative scripts of age and ageing. By drawing on Judith Butler's theorization of gender as an effect that is generated by cultural apparatus, scholars in Theatre and Performance Studies have examined the performativity of age (e.g., Basting 1998; Lipscomb 2012; Swinnen and Port 2012; Moore 2014; Henderson 2018). The notion of performativity "defines age not only as a state of *being* but through acts of *doing*"—meaning "age identities are formed and perpetuated through the repetition of behavioural scripts connected to chronological ages and life stages" (emphasis in original, Swinnen and Port 12). The key point in this approach is that its "possibility of subversion and change" as "a repetition can never be identical to its original script" (Swinnen and Port 12). Because actors "both enact age upon the stage and negotiate behavioural norms associated with their own chronological age" (Swinnen and Port 12), theatre and performance can be a site to confirm or disrupt the normative scripts of age.

When a disruption is generated by theatre and performance, "accepted enactments of age and aging" can be displaced and we can find "new ways to (continually) re-script old age and aging" (Moore 164). By summarizing such disruptive effects of theatre and performance, Bridie Moore (2014) states "the performative characteristics of theatre might be profitably mobilised to displace the production of normative age-effects" (164). Such disruptions and re-constructions of scripts of age/ing can be achieved by troubling normative images, stories, imaginations associated with age and ageing. Through an analysis of three age-critical performances, this chapter interrogates how performance may interfere with normative narratives of growing old and create new narratives and images of old age.

5.2.1 Research Questions and Purpose

In this chapter, I will explore the following questions: How does contemporary theatre and performance engage with the ideas of normative ageing? Can theatre and performance, with an age-critical perspective, counter normative discourses related to ageing and expand cultural scripts of growing old and old age while reflecting various non-normative ageing stories? Through critical analysis of contemporary performance works, this chapter explores how theatre and performance with an age-critical approach can offer intricate and culturally rich scripts of older age, which have the potential to challenge and counteract stereotypical images and narratives of aging. To combat both ageism and reverse ageism, theatre and performance need to create space to observe heterogeneity of ageing.

I find the possibility to showcasing the heterogeneity of ageing in theatre works that stage older citizens (not actors portraying old characters) and incorporate their lived experiences of ageing. This chapter conducts case studies of three age-critical performances that reflect what Gullette (2011) terms "aging-as-experienced" by highlighting both pleasures and perils of ageing. The three case studies are Canadian theatre production *All the Sex I've Ever Had* (2010-; shortened as *All the Sex*) by Mammalian Diving Reflex,[72] Belgian theatrical dance piece *Gardenia* (2010) and *Gardenia-10 Years Later* (2021) by laGeste (previously les ballets C de la B),[73] and a few works of aged-disabled Finnish dancer Tuuli Helkky Helle (1933-2018). The in-depth analysis of these cases highlights how these productions challenge and question the normative ideas of ageing, aged body, and aged mind.

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[72] Mammalian Diving Reflex is also shortened as MDR in other academic journals. However, Mammalian staff refer to themselves as Mammalians, and this dissertation uses Mammalian.

[73] *Gardenia* and *Gardenia-10 Years Later* was originally produced by les ballet C de la B, but they joined their forces with another dance company kabinet K in 2022 and they will continue their work under a new name laGeste. https://www.lageste.be/en. Accessed August 15, 2023.

By discussing theatrical works that trouble the normativity of ageing, this chapter aims to demonstrate that we need more diversified narratives of ageing, including stories of older adults living with dementia, that do not repeat either “the right kind of dementia story” (Gibson 38) nor narrative that romanticizes living with dementia. In short, this chapter is an advocacy for more diversified representations of older adults with dementia, other cognitive and/or physical disabilities, illnesses, gender and racial diversity, that can reflect the “complex open-endedness of living and interpreting the life course” (Gullette 2018: 257).

5.2.2 Theoretical Lens and Framings

(1) Age-Critical Performance

One of the primary tasks undertaken by scholars who adopt an age-studies approach to dramatic texts and contemporary performance practices is to examine how theatre and performance can disrupt the Western culture’s master narrative of decline and counter ageism (Lipscomb 2023). Susanne Martin (2017) first used the term “age-critical performance” (127) in her research on dance and ageing, and I apply her term to describe dramatic theatre and other forms of performance that critically engage with ageing and old age. Martin argues that age-critical works are produced by performance-makers and ageing artists who “explicitly and critically address their own age(ing) realities and fantasies on stage and use their own bodies as performance material” (126). She states that these age-critical works further illustrate a critical representation of age/ing by colliding with age norms (127-137). In *Staging Ageing* (2013), although he does not use the term age-critical, Michael Mangan similarly distinguishes age-critical works from plays that simply feature prominent older characters. He discusses selective works "which afford a significant degree of illumination to questions of ageing, and a range of responses to 'the master narrative of decline'" (6-7).

The intersection of Theatre and Performance Studies with Age Studies (and Dementia Studies) has witnessed substantial growth. Scholars in the field continue to investigate and theorise the meanings and power of age-critical performance and "anti-ageist drama" (Lipscomb 2023: 27). Building upon prior research that has analysed examples of age-critical performances and explored the discursive power of theatre and performance on ageing, I define age-critical performance as follows: Age-critical performance refers to discursive practice that (1) broadens the heterogeneity of ageing narratives and images of old age, challenging oversimplified and stereotypical portrayals of growing old; (2) illuminates the complexity of ageing—encompassing both the pleasures and the perils; (3) engages in critical conversations concerning biomedical and cultural knowledge, perceptions, and practices related to ageing and old age; and (4) serves as a platform for reimagining and experimenting with the accessibility and inclusivity of older performance creators and performers.

(2) Experts of Age/ing

As a critical framework to honour the actual aged bodies and the staging of their lived experiences in contemporary theatre, I draw on the concept of "experts of everyday life," which is coined by German theatre company Rimini Protokoll in the 1990s. This concept refers to their non-professional performers who shared their lived experiences, knowledge, jobs, skills, or physicality in the work of Rimini Protokoll (Malzacher 23-26). In their works, the "experts of everyday" are often marginalized people in our society whose lives are often unseen and whose voices are often unheard. Rimini Protokoll have invited diverse experts of everyday, such as truck drivers, trash collectors, call centre workers, air traffic controllers, and migrant workers (see Garde and Mumford 62-63), to present their lived experiences and let the audience peek into their everyday life, as well as various social disparities, conflicts, and contradictions that are deeply woven into their lived experiences. Since Rimini Protokoll, the term was employed by other theatre practitioners and theorists to refer to non-professional performers of Theatre of Real People (Mumford 2013; Garde and Mumford 2016). Theatre of Real People is also referred to as Reality Theatre and refers to a German theatre form that centralises the lived experiences of community performers, especially marginalized subjects. This form of theatre "develops or diverges from documentary theatre through its foregrounding of non-professional theatre performers who present aspects of themselves or of their lives" (Garde and Mumford 4).

Meg Mumford (2013) explains the mode of Reality Theatre as characterized by "an interest in extending public understanding of contemporary individuals and society; a focus on representing and/or putting living people on stage; and an aesthetics of 'authenticity effects,' artistic strategies designed to generate (and then, in some cases, destabilize) an impression of close contact with social reality and 'real' people." (153). Jürs-Munby et al. (2013) identify theatre that makes an encounter with 'real people' are a strategy of "postdramatic theatre" (Lehmann and Jürs-Munby 2006) and they observe that the real people "bring aspects of their real-world identity into the theatre, unadorned with fiction or character: disabled performers, as well as untrained actors who stand as witness and whose testimony evades and challenges 'imposed, official history'" (3).

The selected case studies of this research stage 'real' ageing subjects and their lived experiences of ageing rather than actors playing older characters or fictional stories of ageing. To a certain degree, these performances adopt the strategy of Theatre of Real People (Garde and

Mumford 2016) and share traits of autobiographical performance (Heddon 2008). While acknowledging that most creative works are often "informed by who we are, as subjects embodied in time and space, with our own cultures and histories," Deirdre Heddon defines autobiographical performance as "work which foregrounds some aspect of a life-story, a *bio*" (7-8; emphasis in original). Heddon states that 'auto' indicates "the sameness of the subjects and object of that story: that is, the 'author' and 'performer' collapse into each other as the performing 'I' is also the represented 'I' (8).

I propose to frame the older performers/authors in the case studies as *experts of age/ing*. Similar to Rimini Protokoll's approach in their famous production *100% City Series*,[74] Mammalian has produced more than 30 city editions of *All the Sex* since 2010 by inviting community participants from a chosen city. Mammalian typically recruit five to seven older adults with various backgrounds in terms of their gender, race, class, ability, and they develop the performance script by employing a verbatim technique. As such, ordinary older citizens from different cultures become the performers and storytellers who share their lived experiences related to ageing, sex and romantic relationships, and their ageing bodies.

In *Gardenia*, seven queer and trans adults in their 60s to 80s, who used to engage with drag performance in their youth, reflect on their so-called non-normative ageing experiences and ageing bodies. The majority of the older performers have no professional background in theatre or dance, and they present diverse old bodies that would typically be considered 'ugly' according to the conventional standards of beauty (Dreysse 2020). While *All the Sex* is more strictly autobiographical—nothing in the production is fictional—*Gardenia* loosely draws on the life

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[74] Rimini Protokoll has produced 100% City Series by presenting 100 inhabitants of the city in which it is being staged. "The cast is chosen using socio-demographic statistics, so the performers represent the population, and hence, on stage, can claim that they are performing as their entire city." Protokoll, Rimini. "100%[City]." *Making with Data*. Huron, Samuel, Till Nagel, Lora Oehlberg, Wesley Willett (Eds), AK Peters/CRC Press, 2023, p. 148.

experiences of each performer and portrays the shared memory, pain, and joy among older queer and trans subjects through interweaving spoken text, songs, and dance. The dance pieces in which Tuuli Helkky Helle participated as a dancer incorporate her identity as an older artist and activist with cerebral palsy, along with autobiographical elements from her life. Additionally, the activist performances and short films that feature her address the physical and social environment Helle had to navigate with her ageing-disabled body in Finland, as well as the political and policy changes she encountered.

In all three case studies, the performed identities, culturally situated ageing experiences and its intersections with other identity markers (e.g., gender and disability), and the materiality of the ageing body itself become the centre of the productions' dramaturgy and aesthetics. By using the term experts of age/ing, this dissertation highlights that the body of an age (or the body in ageing) is socially and culturally constructed in a specific time and place, and therefore, theatre which offers a close encounter with experts of age/ing allows the audience to see the heterogeneity of ageing stories, as well as rich culture, history, and time embodied through their bodies. Through an in-depth analysis of these contemporary performances featuring actual older community performers and their lived experiences of ageing, my research demonstrates how theatre and performance can disrupt normative cultural scripts of ageing and old age.

5.2.3 Selection of Case Studies

I have picked the three case studies by handsearching academic monographs, peer-reviewed journals, online news articles about theatre and dance companies that have worked with older adults or engaged with the topic of ageing, and by surfing websites of theatre and dance companies. The case studies are selected according to three main criteria. First, this research narrows its focus on performances that are devised based on the lived experiences of older people and present a space where the performed identity, presence, and materiality of ageing itself become the centre of the productions' dramaturgy and aesthetics. This criterion was important to this analysis because a hypothesis of my research is that the lived experiences of older citizens and the physicality of older bodies have a different performative power than fictional ageing narratives (often performed by younger performers acting old). The analysed productions engage with aged subjects as an archive and exhibit of culture, society, and time, highlighting what theatre and age scholar Anne Davis Basting calls the "temporal depth" (*The Stages of Age* 22) of ageing. As the selected productions foreground the various lived experiences of ageing and being older adults and its intersections with other identity markers, they support the central viewpoint of age studies that "people are aged by culture" and age-related norms, images, narratives, beliefs, attitudes are "systematically taught" (Gullette 2017, xiii).

Second, this research purposely discusses the works that are made as full professional productions and presented to a large audience. All three works have toured multiple countries, have been invited to international festivals, and been nominated for major theatre and dance awards. This criterion was important to this analysis because, as Black and Lipscomb (2017) point out, many theatre and performance works focusing on ageing, dementia, and caregiving "tend to be separated from professional arts organisations and even from professional performance space, taking place instead in institutional settings such as assisted living facilities" (33). Research-based theatre projects on ageing also often tend not to be full professional productions (34). They continue to warn that the isolation of age-related theatre from the professional performance realm can further marginalise the older community and ageing-related concerns within the broader community (34). Rosalind Fielding (2019) also writes that "the amateur/professional discourse is particularly of note when compared to critical studies on performance and the older generation, which has often been dominated by discussions of amateur and not-for-profit ventures," and points out that older people's works are poorly understood and researched in both profit and non-profit contexts (133). The performances analysed here successfully demonstrate the power and unique aesthetics that older performers can bring to the contemporary theatre and challenge the youth-oriented mainstream theatre as well as the dominant trend of excluding ageing-focused works from the aesthetic discussions and research in Theatre and Performance Studies. They are not only significant in terms of raising important questions in regard to ageing and ageism, but they also showcase inclusive dramaturgies and explore new aesthetics of ageing that are generated by aged bodies.

Lastly, the selected productions question and trouble the idea of normative ageing and/or the idealized ageing life course which rule out many non-normative ageing scenarios. This criterion was important to this analysis because my research questions whether theatre and performance have potential in challenging ageism and expanding cultural scripts of growing old and old age. Instead of reflecting or repeating the dominant binary narratives of ageing—whether it is a declining narrative or successful ageing narrative—these selected performances go against the idealization of a singular ageing narrative and portray how diverse ageing process and experiences can be depending on their race, ethnicity, gender, abilities, etc. While the case studies are mainly productions of Western theatre company, *All the Sex* was produced in more than ten countries including Southeast Asian countries such as Taiwan, Japan, and South Korea, and they typically include a cast consisting of mixed genders, sexual orientations, races, abilities, and classes. The analysis of both the Canadian and South Korean version of *All the Sex* highlights the need to situate ageing experience within a diverse perspective of different cultures.

There are multiple productions that could fit my research criteria. Toronto-based dance theatre company Moonhorse Dance Theatre[75] has produced experimental and critical works of mature artists and allowed them to explore their aged bodies and its relationship to dance practices. A South Korean choreographer Eun-Mi Ahn's contemporary dance piece, *Dancing Grandmothers* (2011-),[76] explores cultural characteristics of older Korean women's aged bodies (in their 60s to 90s) and the collective memories and knowledge embodied and expressed through specific gestures and movement vocabularies (see Park 2023). However, this dissertation chose examples that explore most under-represented ageing narratives such as queer and trans ageing (*Gardenia*) and ageing with disability (several works of Tuuli Helkky Helle). Because this dissertation approaches dementia as a disability, and despite language barriers and geographical distance, the case study of the Finnish aged-disabled dancer Tuuli Helkky Helle occupies a crucial place. In the following sections, three case studies are discussed in depth.

5.3 *All the Sex I've Ever Had* (Mammalian Diving Reflex): "Fear Ageism, Not Ageing"

I explore the age-critical power of the works by Toronto-based theatre company Mammalian Diving Reflex, specifically its community-based performance *All the Sex I've Ever Had*, developed in 2010. The show has been touring around the world with adaptable editions, featuring local older adults from diverse countries and cities. Through developing the notion of

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[75] See the company's website for further information. https://www.moonhorsedance.com. Accessed August 15, 2023.

[76] The Korean title of the production is 조상님께 바치는 댄스, meaning 'Dance, a Tribute to the Ancestors.' After its premiere in 2010, this production has been invited to multiple performing arts festivals and toured in Europe. For further information, see https://www.festival-automne.com/en/edition-2015/eun-me-ahn-dancing-grandmothers. Accessed August 20, 2023.

"experts of age/ing," my analysis emphasizes the generosity and power of the older community performers who share their aged bodies and their lived experiences of aging. I also analyse the theatrical devices adopted in *All the Sex* to ensure a safer space for the older participants who share their most private and vulnerable life stories in front of the public. Although the recitation of culture and history intermixed with personal stories is a significant aspect of this transnational work, *All the Sex*'s city-specific versions share a common dramaturgy and aesthetics. I draw on multiple productions and reviews of *All the Sex* including a Canadian production *All the Sex-the International Edition* (2014) in Toronto.[77] However, I mainly focus on the 2021 Gwangmyeong edition (near Seoul) in South Korea,[78] the most recent production at the time of writing, and a production I had access to in both languages (Korean and English) used in the performance. While my argument is primarily based on the viewing of the live performance of *All the Sex-Gwangmyeong* (2021), I also draw on various archival materials of other productions such as the script of *All the Sex-the International Edition* (2014) shared by the theatre company, theatre reviews of multiple *All the Sex* editions, and publicly available short videos of multiple editions of *All the Sex* on Mammalian's YouTube page,[79] to better understand the relational aesthetics and dramaturgy *All the Sex* installs among older community performers, younger creative team members, and the audience.

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[77] *All the Sex-the International Edition* (2014) was performed from June 12 to 15, 2014 as part of the Luminato Festival 2014, at the Isabel Bader Theatre in Toronto. Mammalian does not have the video recording of this production; therefore, I draw on its written script and photographs for my analysis.

[78] *All the Sex-Gwangmyeong* (2021) was performed from December 17 to 18, at the Gywongmyeong Civic Center in Gwangmyeong, South Korea. It was co-produced with a local theatre company, Elephants Laugh. I attended the live performance of *All the Sex-Gwangmyeong* (2021) on December 17 and 18, 2021. In the following year, the production with the same cast was invited to Seoul Performing Arts Festival (SPAF) and staged in Seoul from October 8 to 9, 2022.

[79] There are a few short films of All the Sex on Mammalian Diving Reflex's YouTube page, including *All the Sex-Singapore* (2013), *All the Sex-Prague* (2013), *All the Sex-Helsinki* (2018), *All the Sex-Ghent* (2019), *All the Sex-Bochum* (2021), and *All the Sex-Gwangmyeong* (2021). https://www.youtube.com/@MammalianDivingReflex/videos. Accessed August 15, 2023.

Mammalian Diving Reflex's Community-Engaged Works: Disrupting the (Ageist) Social Body

"Fear Ageism, Not Ageing," is a slogan age critic Margaret Gullette promotes (2014; 2018) that superbly captures what this somewhat radical and ecstatic production *All the Sex I've Ever Had* tries to convey. The production engages with the under-represented subject or even tabooed subject, the sexuality and sexual life of older adults through theatre, and consequently challenges us to confront our internalised age-biases, stereotypes, and assumptions. By creating a space for older adults to share their lived experiences, voices, and views, the production shows how older bodies on stage can reveal and critique the ageist past and present, and how they may impact present and future imaginings of ageing. In other words, *All the Sex* makes both performers and audiences face ageism carried within us and asks us to fight against it together.

Since 1993, Toronto-based Mammalian Diving Reflex has been creating multiple intergenerational community-engaged works to safely explore, question, and disrupt expectations based around sexuality, gender, and age, while using theatrical distancing techniques like those of other community-based works (Tidey and Haupt 227). Mammalian's interests in the social constructions of age norms are not limited to old age, and they have worked with different age groups using multiple forms of theatre, including Theatre of Real People, promenade theatre, site-specific works, participatory performance, video installation and podcast, talk shows, etc. Mammalian's works often recruit local citizens, and Mammalian's artists collaboratively work with the local participants to create community-engaged works. The ordinary people, such as children, teenagers, and older people who share similar age demographic, or a group of people with a shared background (e.g., immigrants, teachers, etc.) become creators and performers in Mammalian's works.

By bringing people together, Mammalian's community-engaged works aim to create space for people to share their lived experiences, to have fresh conversations, to connect with each other in a new way, and to dismantle social barriers. In their expression, Mammalian's theatrical works are a place for a "creative collision" between people to occur (Mammalian, "About-Methods"). One of the ways to create these creative collisions is to subvert normative social roles and dynamics between people and to situate people in a different context that can generate a new relationship, different from ones in usual social spheres. For instance, one of their long-running productions *Haircuts by Children* (2006-ongoing), invites local children aged 8 to 12 from a selected city, and professional hairstylists train the children to be a hairstylist and run a local hair salon for a week. The hair salons offer a "theatrical experience of reality" (Edinborough 2016), in which children and adults interact as hairstylists and clients. As such, a new relationship is tested out—one that is different from the dominant care-giver and care-receiver relationships between a parent and children, a teacher and students, a governing body and body in danger and need. The children get to exert their agency and ownership as partners, collaborators, and artists who make creative and responsible decisions, and the adult participants can reflect on their attitudes towards children and question the normalized relationship between children and adults in our society.

Mammalian has produced many works with children and teenagers. In works such as *Naptime* (2006), *The Children's Choice of Awards* (2007-2017), *Eat the Street* (2009-2018), and *These are the People in your Neighbourhood* (2012-ongoing), they invite local children to be the designers, playwrights, directors, performer, public speakers, and collaborators of performances and theatrical events, and enable the audience to see the world from the perspectives of the children. Furthermore, the so-called “Young Mammals”—young collaborators and members of Mammalian in their 10-20s—have been the central subjects in creating and leading many of their productions. Their teenager-focused or teenager-led productions include *Nightwalks with Teenagers* (2011-ongoing), *Teentalitarianism* (2016-2019), and *The Last Minutes Before Mars* (2020-2021). These works investigate and explore diverse social topics and concerns, such as climate change, drugs and criminality, migration, and the refugee crisis, from the perspectives of Canadian teenagers or teenagers from a selected city. Mammalian has also engaged with older adults in their works such as *Wisdoms in Toronto* (2015) and *Strange & Familiar* (2018), which are artistic interview projects between older adults living in a care facility and teenagers. Keren Zaiontz (2020) writes that Mammalian aims to show that minors are more than “grossly inadequate or ‘immature’ versions of adults,” and to open an intergenerational dialogue through scenarios in which a different type of lateral sociality between adults and kids might emerge” (23). Mammalian’s productions with children and young adults—the difference between the works with young children and older adults are the span of time lived by these subjects—can also be described as works that centralize experts of age/ing.

Through community-engaged performances that are based on certain views, experiences, and concerns of group of people that play with age norms, Mammalian’s works allow the participants and audiences to ponder what children and teenagers can do, are allowed to do, and who determines these rules and expectations related to certain ages; their performance practices validate the viewpoints, concerns, and desires of younger generations that are often ignored in ageist societies. According to Darren O’Donnell (2008), the founder and artistic director of Mammalian, the theatrical productions of Mammalian are a form of “social acupuncture”

(O'Donnell 2008) that "playfully and creatively poke" (Mammalian, "About – Methods") at energetic stagnations and blockages in our societies. "Social acupuncture" is a concept developed by O'Donnell, and it metaphorically draws on the East Asian medical practice of acupuncture, which aims to correct the energy imbalances in a body through pinpricks. To put it simply, the idea of "social acupuncture" imagines community-engaged theatre as a needle which pokes a social body instead of a human body. In an interview, O'Donnell also mentions that creating socially engaged works was a very personal response as he often felt he was "living on the surface of the city (Toronto)" and "wanted to have a deeper connection with the people in [his] immediate surroundings" (Jarvis 72-74). The concept of "social acupuncture" communicates his desire to directly engage and affect the world and social sphere through arts, even if it generates discomfort and pain, or awkwardness, tension, confusion, embarrassment, failure, etc. between the participants (O'Donnell 50).

"The blockages in the social body" (O'Donnell 47) that Mammalian tries to disrupt are different for each production. Mammalian states that our society is full of abundance and "almost all people are generous and willing to share when provided the right context" (Mammalian, "About – Methods"). However, the abundance is "locked in social structures, institutions, and dynamics creates holding patterns of energetic stagnation" (Mammalian, "About – Methods"). Mammalian's community-engaged works aim to disrupt current patterns of energetic stagnations and "dissipate and distribute energy, yielding new and unexpected ways of relating to—and being with—one another" (Mammalian, "About – Methods"). In this sense, they have defined their works as "relational aesthetics" (Whyte "Mammalian Diving Reflex Turns 20"), generating new relationships and encounters between different ages, neighbourhoods, races, and classes in a theatrical context, which triggers "a temporary situation characterised by social generosity" (Mammalian, "About – Methods").

Some of their earlier works such as *Home Tours* (2005) and *Diplomatic Immunities: The End* (2007) have been criticized because of their ethical risk for the participants (e.g., objectifying and exoticizing interviewee such as sex workers in the creation of *Diplomatic Immunities*) (Levin and Solga 2009; Zaiontz 2012). In the case of *All the Sex*, I argue that several theatrical devices ensure a safer space for the older participants to speak about their lived experiences related to ageing and sexuality. I elaborate on these strategies used to create safer spaces in a later section where I discuss the relational aesthetics and dramaturgy of this piece.

More than 10 Years of *All the Sex I've Ever Had*: A Production History and Overview

Like other performances by Mammalian, *All the Sex* employs a mode of Reality Theatre by finding and staging 'real' elders in our everyday life and their autobiographical stories related to ageing and sex. Relational aesthetics are enacted on stage between performers and expanded to the audiences to contribute to challenging ageism in theatre and our society. The idea for the production was conceived when the founder O'Donnell observed active seniors vigorously riding bicycles in Germany in 2009. This observation inspired him to "needle" a bit into the social sphere in which seniors are rarely shown as sexual beings (Bent, "How Senior Theatre Is Forging Ahead"). O'Donnell first tested out the idea of the show with a focus group and interviews with older Torontonians in 2010, and the output of the focus group interview was presented as the theatrical event *You Can Have It All*[80] at the Justina M. Barnicke Gallery, Hart House, at the University of Toronto [see Figure 27]. An online brochure of the performance states that

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[80] *You Can Have It All* was performed from February 12 to 13, 2010. https://artmuseum.utoronto.ca/program/mammalian-diving-reflex-can/. Accessed August 15, 2023.

Mammalian learned from the Torontonian seniors that "aging can yield a way of being in the world that is open, generous, and fearless" (Art Museum University of Toronto, "Mammalian Diving Reflex: *You Can Have It All*").

Figure 27. Presentation of *You Can Have It All* (2010), the Justina M. Barnicke Gallery, Hart House, the University of Toronto, Toronto, Canada, 2010. Photo Credit: Mammalian Diving Reflex. Image description: The performers are seated on the far side of a long table covered by a white tablecloth facing the audience. The table is elevated slightly on a small stage situated in the corner of the room. The audience are seated in chairs facing the performance.

Then, it was developed as a full production called *The Best Sex I've Ever Had* with two members from the Toronto focus group and German older adults in Oldenburg, when they were invited to the Pazz International Performing Arts Festival in 2010 (Stage Door News, "Toronto: Mammalian Driving Reflex Looks Back at 2011 and Forward to 2012"). Later, the production was expanded to touch on all kinds of sex, not just the best; as such, a more complex version, *All the Sex I've Ever Had*, premiered at the Pazz Festival in 2012.[81] Since then, Mammalian has toured making different city editions: *All the Sex-Bern* (2012), *All the Sex-Singapore* (2012), *All the Sex-Glasgow* (2013), *All the Sex-Philadelphia* (2013), and *All the Sex-Prague* (2013). In 2014, it returned to its home, Toronto, with a production called the *All the Sex-the International Edition*, which stages one performer from each previous production. Perhaps, with an international edition, Mammalian intended to reflect the multiculturality and diversity of Toronto or they simply wanted to celebrate the success of its international tour from 2010 to 2013. As such, unlike other city editions, the 2014 production was highly multilingual, featuring English, German, Mandarin, and Czech (with English surtitles).[82] After the 2014 Toronto production, *All the Sex* continued to create different city editions with local casts in over ten countries, including Australia, Austria, England, Slovenia, Finland, Taiwan, Belgium, Japan, South Korea, and Switzerland. So far, *All the Sex* has been touring more than 30 cities and 10 countries since 2012. Surprisingly, there has been no English-Canadian city version of *All the Sex* yet; *All the Sex-Quebec City* was produced in February 2023.[83]

The creation process of *All the Sex* can be described as finding experts of age/ing in a chosen city, learning about their lived experiences, and helping them find their unique voices (Mumford 258). The scripts of different *All the Sex* editions are based on the autobiographical stories told by local community participants, non-actors aged 65 plus—so far, the oldest participant was 100 years old and took part in the 2021 and 2022 South Korean production. In

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[81] *All the Sex I've Ever Had* (2012) was performed in Oldenburg, Germany from April 20 to 29, 2012.

[82] A reviewer pointed out that this approach limited the engagement of Canadian audiences, as they were "forced to read surtitles half the time" (Taylor, "Luminato 2014"). This perspective reflects a White-centered attitude, especially considering the diverse population of Toronto, where the ethnic and racial backgrounds of the audience may align with the multi-lingual nature of the international edition.

[83] Details of the tour dates and venues can be found on Mammalian's website: https://mammalian.ca/projects/all-the-sex-ive-ever-had/. Accessed August 16, 2023.

each version of *All the Sex*, five to seven older adults, sitting at a conference-style long table with microphones, share their memories and experiences related to sex—both memories of the past and of their current sex life—in detailed, unfiltered, raw language. Typically, a cast consisting of mixed genders, sexual orientations, races, abilities, and classes share their life stories—particularly those memories related to sexual intimacy, pleasure, surprises, desires, and various forms of love. Although some versions of *All the Sex* feature more homogeneity among cast members in terms of their racial and gender backgrounds, many *All the Sex* editions have staged diverse older populations. Older adults with disabilities performed in *All the Sex-Ghent* (2019) and *All the Sex-Tokyo* (2021); five out of six cast members in *All the Sex-Chicago* (2022) were African Americans, and Mammalian recently announced on their social media that *All the Sex-Sydney* (2023) is going to be all LGBTQIA+ version and will be performed at the Sydney World Pride 2023. Although they are a Canadian theatre company, they have created many Asian country editions such as *All the Sex-Singapore* (2012), *All the Sex-Taipei* (2019), *All the Sex-Kyoto* (2021), *All the Sex-Tokyo* (2021), and *All the Sex-Gwangmyeong* (2021), and have explored the diverse paths of ageing and ageism in different social and cultural contexts.[84]

Let me provide an overview of the stage setting and how the performance of *All the Sex* typically unfolds. The stage setup for *All the Sex* is simple and consistent across different editions. It features a long table with microphones, glasses of water, and wine, along with copies of the script [see Figure 28]. Both younger production crew members and older performers enter the stage together, greet the audience, and collective pledge not to share or gossip about the performer's private stories when they leave the show. The creators, cast, and audience are not

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[84] Despite the production's long-run and positive public reception, it has somehow not attracted academic attention from Theatre Studies or Age Studies–although there are several theatre reviews in media and online blogs. My research offers the first in-depth academic discussion of its dramaturgy, aesthetics, and cultural impacts on ageism.

allowed to share what they heard in this production. A blog reviewer who watched *All the Sex-Melbourne* (2017) in Australia writes, “I could tell you about how this mercurial wander down memory lane, guided by six inspiring, open-hearted, and wonderfully unguarded seniors, all aged over 65, will make you smile, laugh, guffaw, sigh, and maybe even cry a little. I could share how touching, funny, sometimes shocking, sometimes heart-breaking their stories are […] I could tell you all this, but I just can’t. I promised, after all” (Boon, “Melbourne Festival”). A similar response is found in an online review on *All the Sex-the International Edition* (2014) in Toronto. Reviewer, Mike Crisolago, writes “I, like all the others in attendance, swore that whatever happens in the Isabel Bader Theatre stays in the Isabel Bader Theatre” (“Luminato 2014 Review”). This collective pledge puts me in a tricky position as a critic. Nonetheless, this research addresses its dramaturgy and aesthetics without breaking this promise, recounting the power of the audiences’ pledge, which plays an important role in breaking ageist barriers between participants and in creating a safer community for making and performing *All the Sex*. With the respect to the oath, when it is necessary, I only quote parts of the scripts by replacing the names and details to maintain the confidentiality of performers in different *All the Sex* editions when they indirectly—yet, inevitably—reveal varied cultural experiences, generational memories, and historical traumas.

In chronological order, from the year when the oldest performer was born (typically between 1920-1940) to the present, each performer reads short verbatim lines that are selected and edited based on the hours of interviews. The shared stories touch on a wide range of life experiences related to sex, sexuality, romance, and love: first crushes, kisses, sex, the best or worst sex they’d ever had, the birth of siblings, watching pornography, pregnancies, miscarriages, masturbation, purchasing of sex toys or lubricant, honeymoons, affairs, one-night stands, impotence, menopause, and so on. The verbatim scripts are intentionally delivered in the present tense. For instance, when the year 2003 is announced in the *All the Sex-the International Edition* (2014), a cast member says, “I am sixty-five. I am on a bike tour with [her] and for the first time, I can’t get it up. I hear that too much bike riding is not good for that” (White, “Luminato: Seniors Talk About All the Sex They’ve Had”). While some of the stories that emerge as they talk about their sexual fantasies, obsessions, failing sexual functions, and finding new ways of enjoying sex in their later lives are hilarious and explicit, some stories are heavy and heart-breaking and include stories about unplanned pregnancies, miscarriages, abortions, the death of loved ones, coming out as gay in their later life, and losing sexual interests or abilities due to physical or mental illnesses.

Figure 28. The Stage of *All the Sex-the International Edition* (2014), Luminato Festival, Toronto, Canada, 2014. Image description: The performers are sitting on one side of a long table. The

closest performer is dressed in a suit and tie with glasses and holds a champagne glass in his right hand while looking down at the script resting on the table.

Depending on the country-specific and city-specific editions, culturally well-known music punctuates each decade, and those songs evoke the sentiments of the era. The older performers may sing along and dance to it, sometimes with the younger production crew, and celebrate the arrival of millennium by counting down and popping confetti [see Figure 29]. The performance also has several interludes in which older adults and younger crew members dance together, as well as a few Q&A interludes in which they invite audience members to share their own stories. Each production concludes with a future scene, approximately 20-25 years from the year of the performance, in which older performers talk about their sexual and romantic life. For instance, *All the Sex-the International Edition* (2014) starts in 1937, when the oldest Torontonian participant was born, and everyone shares their stories over the course of the decades up to 2014. Then, skipping two decades, the participants are asked to speak from 2037 and they chose subjects such as their bodies and health, sexual life, fantasy, and dreams, imagining that they have reached their late 80s or 90s.

Figure 29. The Scene of Millennium Celebration in *All the Sex-the International Edition* (2014), Luminato Festival, Toronto, Canada, 2014. Image description: The older performers and younger production crew gather closely while raising champagne glasses and smiling for a photo. In the background, the number 2000 is displayed on the screen.

In the Q&A interludes, different questions are posed to the participants; they are related to the stories of the older performers in each edition. In the 2014 Toronto production, after one of the older performers shares a story about having sex in a park, a production staff member asks the audience to raise their hands if they have had sex in public and invites some audience members to share their stories. By contrast, in the 2021 Gwangmyeong edition, an older cast member's story revealed the complexity around affairs, cheating, and love; and questions asked to the Korean audience included: "Have you ever cheated or been cheated on?" and "Have you comforted or healed someone with sex?" These were followed up with improvised questions if the audience was willing to share their stories. These Q&A sessions allow audience members to experience and witness the challenge to speak about their intimate stories in front of the public, and to realize the vulnerability, courage, honesty, trust, and generosity exemplified by the older performers.

Power, Vulnerability, and Generosity of the Experts of Age/ing

By participating in a version of *All the Sex*, older performers display power, vulnerability, and generosity. The older adults on stage embody all the complexities intertwined with ageism in our society—concern, shame, guilt, embarrassment, courage, awakening, and liberation. Through their vulnerability, the older adults in *All the Sex* exert a powerful presence that cannot be achieved by actors playing fictional roles. Their bodies—voice, tone, and facial expressions that display both nerves and excitement—testify to the deeply-rooted ageism against older adults. At the same time, they speak to the necessity to free themselves from shaming discourses and practices. When they freeze and stare at the audience during the performance, their silence questions us and our assumptions, expectations, and imaginations. Their bodies say so much more than what words can capture and express. The vulnerability expressed by amateur, everyday bodies displays a great degree of generosity. Instead of interrogating or shaming the potential ageist perceptions and attitudes of those watching and listening, they invite the audience to witness how older subjects view sex, practice sex in their own terms, and long for continued or stronger intimacy and love as all humans do.

While the experts in Rimini Protokoll's works are often selected for their professions, the experts of age/ing in *All the Sex* are chosen because their lives share a similar span of time and history. By sharing diverse ageing narratives and lived experiences in a specific city, culture, and era, these experts of age/ing in *All the Sex* editions reveal cultural and historical events and collective memories intertwined with their personal lives. For instance, in the *All the Sex-the International Edition* (2014), performer's stories mention the bombing during the Second World War and the Stonewall uprising in 1969; these moments allow the audience to realize the vast duration of time lived by these citizens and see the powerful presence that comes from their depth of experiences. In other words, these experts of age/ing in *All the Sex* allow the audience to peek into the memories, political changes, and social environment spanning multiple decades. As such, although the term experts of age/ing may be considered as a sub-category of "the experts of everyday," it highlights a duration of time (memory, history, and changes) lived by ordinary subjects. On the contrary, the emphasis is on the now in the notion of "experts of everyday"—the contemporary, pressing issues and the current cultural contexts. Experts of age/ing are experts of change and experts of becoming.

Furthermore, this notion of "experts of age/ing" speak to the marginalised position of older adults in ageist societies. Older performers in *All the Sex* and the older adult's stories related to sex share the quality of what Rimini Protokoll calls "the foreign, the unknown, the different, the strange" (Mumford 155). Although the cultural sensitivity surrounding older people talking about their sexuality varies across countries, ageism is shared by many cultures, particularly when it comes to the sexuality of older adults. Older people are often depicted as nonsexual subjects in popular cultures and media, so little is known and discussed when it comes to the sexual desires, behaviours, and functions of older people. By assuming the natural decline in sexual interest and ability, sexuality in later life is mainly discussed from a biomedical perspective, which only explores or suggests medical treatment or support (Gewirtz-Meydan et al. 150). While sexuality in older men is tolerated more, older women face an even greater ageism, one which inhibits them from expressing their sexuality and enjoying a healthy sex life (Chepngeno-Langat and Hosegood 93). Older LGBTQ+ individuals are rendered even more invisible in the discourse of ageing and sexuality, and a deep-seated stigma disables them from coming out or expressing their sexuality (Hafford-Letchfield 2008). Considering these ageist social contexts, through various editions of *All the Sex*, it is remarkable that Mammalian has created spaces for older adults with different gender, race, ethnicity, sexual orientation, and physical ability to share and express their experiences and views on ageing and sexuality, and to do so in a semi-public space.

Some people may be more open to sharing their intimate stories and may even have a sort of activist intention when they join the production; and some cultures may be more accepting than others. However, talking about their sexual experiences in public can be a burden on older adults due to the ageism present in many cultures, including Canada. An interview article with a Canadian performer of the 2014 Toronto production shares the fears and burdens she felt. She says, “When the idea was presented to me, I was absolutely horrified and couldn’t imagine that I could possibly do it” (Crisolago, “Luminato 2014 Interview”). However, after the performance, she states that “I found it very liberating and very easy […] People [at] my age are uneasy because we see that the young people are horrified with the idea of older people having [sex] (Crisolago, “Luminato 2014 Interview”). Online reviews also highlight that *All the Sex* offers a rare space for older adults to share their sexual lives and that challenges ageist perspectives and assumptions. An online review of the Toronto production writes, “in our youth-obsessed culture, this performance lets people come face-to-face with a reality we, more often than not, choose to ignore: our older friends and relatives have sex. […] [it] offers a frank and provocative style of storytelling, engaging the audience with true accounts and authentic stories" (Castello, "Toronto Premiere"). In a theatre review (written in Korean) published in a Korean academic journal, Ji-Su Nam (2022) also addresses similar ageist views and taboo regarding sexuality of older adults in Korean context. She writes that the older adults' honest confessions about their memories and ongoing sex life offer an exhilarating pleasure in a social and cultural atmosphere in which older adults are usually perceived as asexual beings or beings who must abstain, and which assumes sex is exclusive to young people (91). She notes that *All the Sex-Gwangmyeong* foregrounds Korea's modern history, from the Japanese colonial period to the contemporary day, and interprets the dancing scenes as a liberation from the cultural climate that has tabooed sexual desires and the neoliberal system in which people are tired out with constant competitions and even sexual desire becomes a luxury (91-93). Both the reaction from the cast and reviews indicates the strong, continued presence of ageism and stigmatization of sex among older adults. In other words, *All the Sex* becomes a place for both the older participants and the audience members to (en)counter ageism. *All the Sex* allows older participants to learn, challenge themselves, find meaningful connections with other cast members and younger people, and experience a sort of transformation and liberation through performance. Younger audiences gain new understanding of ageing and sexual lives of older adults; because the performance allows a mutual conversation, it also overcomes a simple voyeurism and instead builds connections between people of all ages.

A Dramaturgy of Accessibility and Relationality

People of all ages also connect with each other on stage through *All the Sex*'s relational dramaturgy, which weaves intergenerational and intercultural relationships with younger production crew members, and broader audience members. Each version of *All the Sex* has multiple workshop sessions, team introductions, and interludes that invite younger crew members to appear on stage and the audience to participate. The collaborative moments between the older cast, younger production crew, and the audience of varied ages are the key to understanding *All the Sex*'s relational dramaturgy and aesthetics, which is pursued by all of Mammalian's works. Mammalian's crew members are mostly young Westerners, although they often include local production teams from the chosen city; thus, the encounters occurring between the production team and the local performers are intercultural and intergenerational. While this intercultural and intergenerational composition of the production team can lead to complications and inefficiency in communication, it creates the necessary theatrical *distance* for performers to feel safe and to speak comfortably.

For instance, the interactions and communications between the local younger crew members and the older performers are still bound by cultural scripts, which can hinder the formation of new relationships between young and old folks from the same culture. However, the intercultural composition of *All the Sex* situates the participants outside of a normalised context and relationships, which is crucial to overcoming the socially accepted behaviours and relationships that support ageism and perpetuate the separation between generations.

According to a reviewer of *All the Sex-Tokyo* (2021), productions start with workshop sessions that allow the younger production staff and older performers to build trust and a sense of community; for instance, everyone involved in the production (not just older performers) share their first, last, best, and worst sexual experiences (Sumiyoshi, "True Colors Festival"). A short video of the development of *All the Sex-Singapore* (2013) also indicates that the Mammalian team employs a variety of games and activities that allow the older participants to relax, have fun, and open up.[85] The theatrical setting allows people to have uneasy and uncommon conversations and to join the "galvanising interface through which to view the uneasy disconnects between [...] different ages" (Whyte 2013). In honest, awkward, uneasy, and uncommon conversations, both younger and older participants discover and challenge their own prejudices and ageist thinking and begin to see each other anew. The interdependence, collaboration, and friendship among different generations are also enacted on stage throughout the performance, and the enacted relationality creates a safer atmosphere for the audience and a sense of community.

This form of relational dramaturgy also serves as a device to ensure accessibility for older non-professional performers. At the beginning of each production, older performers and the younger production crew enter the stage together; one of the staff introduces not only the performers but also the production team and each member waves to the audience. The following is the introductory scene of the *All the Sex-the International Edition* (2014) in Toronto:

> We've got a panel of seven seniors: four women and three men. The women are from Toronto, Glasgow, Singapore, and Oldenburg, and the men are from Bern, Prague, and Philadelphia. The production team is comprised of six women and five men. The women

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[85] The video is available on Mammalian's YouTube channel. https://www.youtube.com/watch?v=TF_f3OJsPcc. Accessed August 15, 2023.

> are from Toronto, Prague, and Berlin and the men are from Toronto, Berlin, Amsterdam, and Hamburg. Two of the Torontonians are middle-aged, while the rest are under the age of 36.
>
> Script of *All the Sex-the International Edition* (2014), p. 2.

By sharing the ages and backgrounds of the production team, this introduction highlights the intergenerational composition of the team; at the same time, it invites the audience members with various ages to reflect on their own age, reminding everyone that age is “the one difference we are all likely to live into” (Woodward x).

Mammalian provides various forms of assistance for the older community participants to successfully perform in *All the Sex*, offering both physical and emotional supports. For instance, they enable older performers to share their experiences with their own voices by employing multiple devices of assistance such as printed script, microphones, glasses of water, surtitles, and even the stage setting that allows older performers to sit throughout the performance. During the performance, it was evident that *All the Sex* productions do not require older performers to memorize their lines. Some older performers often looked down to find their lines, were slow in finding their lines, or forgot it was their turn to read; sometimes, the surtitle above the performers did not match what the older performers were saying. However, it was clear that these mistakes were expected and accepted. For instance, a “younger” performer helped when another performer was late to read their lines.

Furthermore, through a joint entrance and multiple interludes, *All the Sex* enables a constant interaction between the younger production crew and older performers and enhances the safety for the aged performers. The dark backstage and strong stage lights can be difficult to navigate for people who have no experience on stage and especially for many older adults who may experience vision and/or hearing challenges and difficulty in walking. Therefore, the joint entrance is not only a theatrical device to highlight the intergenerational and intercultural composition of the team, but also becomes a strategy for younger crew members to guide and assist older performers. Moreover, by joining the dance interludes, the younger crew can check in with the older adults, create an atmosphere for the non-professional performers to be at ease and relax, and assist in handing out champagne glasses or cleaning up the confetti on stage [see Figure 30]. These can be seen as an expanded version of what Julia Henderson (2019) defines as a "dramaturgy of assistance, […] a dramaturgical approach to include and support performers with varying degrees of age-related memory loss" (76). Although experts of age/ing in *All the Sex* do not have obvious memory problems, the approach taken in *All the Sex* showcases the ways in which they include older community performers without theatrical experience and with various barriers related to old age. Through a dramaturgical approach that assists the participation of experts of age/ing, Mammalian realizes a theatre in which anyone can participate.

Figure 30. A Collaborative Dance Interlude in *All the Sex-Gwangmyeong* (2021), Gwnagmyeong Civic Centre, Gwangmyeong, South Korea, 2021. Photo Credit: Gwangmyeong Cultural Foundation. Image description: Both older performers and younger production crew of the performance are standing up and dancing. Confetti are scattered on the table.

Finally, dance interludes, in-performance Q&A sessions, and lobby interactions also build a sense of community among the people who occupy the same space each night of the performance. The intergenerational encounter between the older performers and audience members extends to post-performance interaction around archive tables that exhibit the personal belongings of the cast [see Figure 31]. The older performers bring diverse items that highlight their lived experiences and memories, such as photos of themselves or loved ones, old clothes, baby shoes, their favourite books, items related to their professions. For example, some cast members share multiple stories related to their deceased spouses during the performance; at the post-performance engagement, the audiences get to see the photos of the figures that appeared in the stories and share their own experiences and thoughts with the performers. Because of the Covid-19 pandemic, food and alcohol were limited in the Gwangmyeong version; however, other *All the Sex* versions usually involve food and more time for the performers and audiences to engage in conversation. Through these interactions, *All the Sex* brings people together in new and unusual ways, even if it is temporary. These in-performance Q&A and post-performance interaction sessions often highlight the shared humanity across generations, rather than the generational differences, and create moments of connections that can shake negative stereotypes and perceptions about different generations.

Figure 31. An Archive Table at the Lobby of *All the Sex-Gwangmyeong* (2021), Gwnagmyeong Civic Centre, South Korea, 2021. Photo Credit: Gwangmyeong Cultural Foundation. Image description: Performers and audience members are gathered around an archive table. The table displays photos and personal items brought by an older cast member of the production.

Conclusion: Staging Diverse Ageing Stories and Bodies

Mammalian's *All the Sex* stages a condensed version of the lived experiences of older bodies, aged 65 to 100 years old, in two hours. Even though what the audience get to hear in *All the Sex* is still only a fraction of their lives, the audience already witness the great depth of emotions and memories carried by these experts of age/ing. At the end of the production, after the chronological recollection of the times lived by these performers, the audience sees the aged bodies as embodying all the ages they have lived and their extensive life moments. Each performer's body on stage is *abundant* and *generous*, allowing mostly younger members of the crew and audience witness the resilience and strength of human beings. With many counter-ageist narratives that communicate power and joy, the aged bodies on stage tell the younger audience members not to fear growing old but to look forward to the days ahead even if they include difficult days. As an age studies scholar, I want to emphasise that I am not describing *All the Sex* through another ageist rhetoric of "sageism"—the older the wiser (Minichiello et al. 268). Ageing and old age are depicted through heterogeneity because *All the Sex* stages each individual's diverse life course, lived experiences, and different challenges and struggles depending on their gender, class, ability, etc. By creating a cultural space for experts of age/ing in different cultures to share their new joys and findings in old age without excluding the life stories of hardships and challenges related to old age, *All the Sex* shows that the generalized ageist narrative of decline is a culturally produced myth and apparatus.

Although *All the Sex* shares some similarities with Rimini Protokoll's *100% City* Series, Mammalian' s city-specific versions are more interested in giving spaces to marginalised voices than having statistically accurate representation. As discussed earlier, Mammalian always seeks a diverse representation of older adults in their recruitments and many versions of *All the Sex* have succeeded in including disabled older adults, elder queers or transgender persons, and racialized older adults in Western countries. *All the Sex-Tokyo* (2020) in Japan included older casts with various sexual orientations, one performer who lives with cerebral palsy, and another who was diagnosed with bladder cancer and has artificial parts in their body that hinder their sexual activities. An older cast who is blind also successfully participated in *All the Sex-Ghent* (2019) in Belgium [see Figure 32], and many productions included casts who require wheelchairs because of their mobility challenges.

Figure 32. A Performer with Visual Impairment in *All the Sex-Ghent* (2019), Vooruit, Ghent, Belgium, 2019. Photo Credit: Mammalian Diving Reflex. Image description: The older performers, a woman in the centre who is blind and a man on either side of her, are smiling and seated at a table. Purple light is shone behind them.

In this approach, some productions have, in a sense, an imbalanced representation. For instance, the majority of *All the Sex-Chicago* (2022) performers was African American, and the majority of *All the Sex-Tokyo* (2020) was queer older adults. However, this deliberate and political recruitment approach of Mammalian allows us to witness a wide spectrum of aged bodies, refusing the normalised stereotypical representation of old people on stage. As the production's content draws on the actual lived experiences of these diverse casts, it not only creates visual diversity, but also enables the audience to hear dissimilar experiences and views on sexuality among older adults that absolutely cannot be generalised in an ageist narrative. Rather than reflecting each city's dominant ageing voice, *All the Sex* tries to bring the most marginalised, underrepresented voices to the mainstream stage and challenges whatever bias and assumptions we previously had. The cast of *All the Sex-Gwangmyeong* was quite homogeneous (they were all straight, Korean national), despite the production team trying to recruit a more diverse cast. Although they were able to interview some of the queer seniors, the production team was unable to convince them to partake in the show; these incidences of failures may well reflect the cultural stigma around older adults with different sexual orientations in South Korea. Even so, the 100 years old participant in *All the Sex-Gwangmyeong* had difficulty with mobility, vision, and hearing, which was superbly accommodated by other older casts and younger crew throughout the performance; these age-related challenges are shared across different countries. The various conditions of ageing bodies not only guide the production's aesthetics, but also are integrated in the stories they share about the sexuality of older adults. With these diverse older casts, *All the Sex* does not simply repeat the so-called successful ageing stories of those who have little issue in enjoying sexual lives, nor does it repeat the declining narratives of ageing, which suggest that older people lose sexual abilities, desires, and charms.

By allowing spectators to have a close contact with the diverse, aged subjects and their expertise—comprising their life stories and various opinions related to sexuality—Mammalian's *All the Sex* provides an opportunity to observe the particulars of being and of growing old in different times and cultures. For instance, by making close contact with the experts of age/ing in Toronto whose life span from the 1940s to the 2010s, the production addresses the meaning of ageing and living as an older person in Canada. Therefore, the thirty different versions of *All the Sex* themselves become a compelling statement that expresses how different each older adult's ability, attitude, opinion, and expectations can be; and how diverse, generative, beautiful, powerful (and also challenging) ageing can be. Both vulnerable and powerful, older performers of *All the Sex* force compel the audience to confront the depth of ageism in our societies. At the same time, *All the Sex* counters ageism by giving space for older adults to share the unspoken and unknown stories, views, and desires. Through making a theatrical encounter with the experts of age/ing, Mammalian stirs up the ageism, which is one of the blockages in our social sphere as it limits relationships between people to certain patterns, regulate who can be seen and unseen in certain social spheres, and hinder people from reimagining new connections between generations.

5.4 *Gardenia* and *Gardenia-10 Years Later* (laGeste): Nonlinear Queer and Trans Ageing

Introduction of the Case Study

Next, I analyse the second case study, which engages with another under-represented topic in theatre and performance: queer and trans ageing. Drawing on Both Age Studies and Performance Studies, I investigate the performativity of age in *Gardenia* and questions what this performance adds to the critical illuminations of age ideologies afforded by contemporary theatre and dance. By analysing the narrative, aesthetic choices, and dramaturgical strategies of the piece, I discuss how *Gardenia* offers a unique viewpoint on aging from a queer and trans perspective, challenging various heteronormative and chronological conceptualization and assumptions of ageing and old age.

The ageing experience and life course of queer and trans people frequently depart from the heteronormative and (re)productive model of ageing which lay out certain life events and anticipations along with one's chronological ages and life stages. However, it is rare to see ageing trans and queer subjects on the contemporary stage and the dominant narrative of a linear ageing life course fails to reflect the ageing experiences and concerns of the older queer and trans community. The Belgian dance theatre company laGeste's *Tanztheater* (theatrical dance) piece *Gardenia* (2010) and its restaging with the original casts *Gardenia - 10 Years Later* (2021) engage with the complexity and attributes of queer and trans ageing.

While previous articles and reviews on this piece have briefly discussed the aging bodies and narratives of aging (Dreysse 2020; Hutera 2021), the central inquiry of these papers has focused on gender and sexual identity. My analysis contributes to articulating this piece's value in offering a new meaning of ageing from queer and trans perspectives. Drawing on the existing discussion on non-linear ageing of older trans adults (Ruth Pearce 2018), I argue that *Gardenia* offers a nuanced demonstration of trans and queer ageing as a continuous and painful conversation between multiple selves across one's life-course. In addition, I demonstrate how

Gardenia challenges the dominant view and narrative that idealise youth over old age, by representing the complicated relationships and responses to the past and youth among older Belgian queer and trans adults.

My analysis of *Gardenia* is grounded in an examination of the live performance of the 2022 laGeste production in Ghent, Belgium[86]; the video archives of both 2010 and 2021 productions; and the performance script in English (translated and provided by laGeste). I also draw on Thomas Wallner's documentary film *Before the Last Curtain Falls* (2014), which captures the autobiographical stories and personal lives of the older performers in *Gardenia*.

Production Information of *Gardenia* (2010) and *Gardenia-10 Years Later* (2021)

The Belgian dance theatre company laGeste's *Tanztheater* (theatrical dance) piece *Gardenia* (2010) and its restaging with the original casts *Gardenia - 10 Years Later* (2021)[87] engage with an under-represented topic in theatre and performance: the complexity and attributes of queer and trans aging. Co-created by a Belgian team with choreographer Alain Platel, theatre director Frank Van Laeck, and composer Steven Prengels, the production portrays nine performers who are at different stages of aging. It was the aged trans actress Vanessa Van Durme (b. 1948), who came up with the idea of the production and brought together her former drag artist colleagues who performed in cabaret theatres in their youth. The 2010 production premiered in Ghent, Belgium, and toured worldwide for two years with great success, totalling

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[86] With the support of the University of Alberta FGSR (Faculty of Graduate Studies and Research) research travel funding for doctoral students, I attended the live performance of *Gardenia – 10 Years Later* at the NTGent Theatre in Ghent, Belguim on September 25, 2022. The NTGent Theatre provided video recordings of both 2010 and 2021 NTGent productions of Gardenia.

[87] *Gardenia* and *Gardenia-10 Years Later* was originally produced by les ballet C de la B, but they joined their forces with another dance company kabinet K in 2022 and produce their work under a new name laGeste. https://www.lageste.be/en. Accessed October 15, 2023.

over 200 performances.[88] A decade later, *Gardenia - 10 years later* (2021) reunites the original cast, except Andrea de Laet (1952-2016), who passed away. However, de Laet's absence is very present throughout the 2021 production—with her dress that is draped over her chair and performers engaging with her dress in their dance [see Figure 33].

Figure 33. A Scene of *Gardenia – 10 Years Later* (2021), the NTGent Theatre, Ghent, Belgium, 2021. Photo Credit: Luk Monsaert (laGeste). Image description: Two chairs are placed at the front of the stage. The chair on the left has a pink glitter dressed, worn by Andrea de Laet during the original production of *Gardenia* (2010), draped over it. A performer is seated on the chair on the right, dressed in black boots and a white dress shirt. Behind the chairs are the remaining four performers in various states of dress and undress spread throughout the rest of the performance space. Pieces of clothing are scattered on the floor in the performance space.

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[88] Since its premiere in Ghent, *Gardenia* toured around the world for about two years and it was staged in Avignon, Paris, Vienna, Berlin, London, Amsterdam, Belgrade, Barcelona, Lisbon, Oslo, Quebec and Montreal, Taipei, and a tour of Russia. In 2012 *Gardenia* was nominated for the prestigious British Olivier Award. In 2014, the life of older cast members and the tour of *Gardenia* was captured in the documentary film, *Before the Last Curtain Falls*, and the film received many awards at international film festivals. laGeste, "Creation: Gardenia - 10 years later." *laGeste Website*, 2023. https://www.lageste.be/en/creations/gardenia-10-years-later.Accessed August 15, 2023.

In *Gardenia*, there are seven older performers who are in their 60s to 80s and self-identify as transgender woman, gay man, or gender non-conforming,[89] and two younger professional dancers (a young man in his 30s and a woman in her 50s) who are described as Young Guy and Real Woman in their program.[90] While some cast members like Dirk Van Vaerenbergh (b. 1954) and Griet Debacker (b. 1964) have performed in theatre and TV shows, most older cast are amateur performers engaged in drag performances at night while continuing in their professions as nurse, public servant, clerk, etc. Inspired by the documentary film *Yo Soy Así* (*This is Me*, 2000, by Sonia Herman Dolz) which portrays the closing of a cabaret in Barcelona and the lives of older trans artists, *Gardenia* suggests a fictional setting: the opening scene implies that this performance is the grand finale for a long-lasting cabaret theatre.

Although *Gardenia* does not explicitly portray personal stories, this performance draws on the memories and affects shared among seven experts of age/ing with the lived experiences in Belgium as LGBTQ individuals born in between 1940s and 1960s. As such, similar to *All the Sex*, this performance presents a space where the performed identity, presence, and materiality of aging itself become the centre of the productions' dramaturgy and aesthetics. However, unlike *All the Sex*, *Gardenia* explores themes of violence, loneliness, and the search for love through the interweaving of spoken text, song, and dance, rather than retelling real-life stories and memories.

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[89] In most theatre reviews and interviews, the older performers in *Gardenia* are introduced as "transvestite" or "transsexual" (Jennings 2011; La Rocco 2012) however, these are outmoded terms as they imply pathologizing views and histories which have defined non-heterosexual gender identity and non-typical gender behaviours as psychiatric disorders (see Davies and Davies 2020). The trans community has claimed that these terms can be offensive to many trans individuals. It also fails to capture the various and fluid gender identities of the cast in *Gardenia*. Some of the members self-identify as a trans woman and chose to undertake sex reassignment surgery and hormone therapy, while some are gender non-conforming or identify as a queer man who performs drag. Also, while some have come out in their youth, one of the performers had not officially come out and did not want people to know that he is gay until the performance of *Gardenia* and its documentary film (Barnard 2014).

[90] laGeste, "Creation: Gardenia - 10 years later." *laGeste Website*, 2023. https://www.lageste.be/en/creations/gardenia-10-years-later. Accessed October 15, 2023.

Nonlinear Queer and Trans Ageing

First, let me attend to the opening scene of *Gardenia* and discuss how older queer and trans performers simultaneously embody both their younger and older selves. The performance begins with Van Durme singing Judy Garland's "Over the Rainbow" with all other performers stand behind her, clad in grey suits and looking directly at the audience [see Figure 34 and Figure 35]. Judy Garland is a renowned gay icon, and this song holds particular significance within the queer community, as it conveys themes of escape and dreams. In this scene, the low-pitched voice of Van Durme with the quality of a bass and her older, tall, charismatic body overlaps with the more familiar cultural image of a young girl from *The Wizard of Oz* (1939). Xavia A. Publius, a transgender scholar and activist, says Van Durme sings "it a full octave lower than one would normally sing it," which "set[s] up a trans space by valuing trans vocality" (Lee and Publius 146). She further states that "[t]he way she performs it," the audience can feel that "there is a lot of life lived by the time of that performance, and a trans life at that" (146). I argue that this effect is achieved by the temporal depth created by the overlap and the contrast between the ages of original singer and the 75-years-old trans woman Van Durme. I read this scene as Van Durme speaking from a dual perspective, channelling both her present self and her younger self. The lyrics of the song are well-known and include the following lines:

> Somewhere over the rainbow
>
> Way up high
>
> There's a land that I heard of
>
> Once in a lullaby
>
> Somewhere over the rainbow

Skies are blue

And the dreams that you dare to dream

Really do come true

Figure 34. Screenshot of the Video Recording of *Gardenia – 10 Years Later* (2021), 00:01:39, Recorded at the NTGent Theatre, Ghent, Belgium, July 25, 2021, by les ballets C de la B. Image description: Vanessa Van Durme wears a wine-colour pants suit in front of a standing microphone. The stage is square with chairs along the edge of the performance space facing inwards. There are seven other performers throughout the performance space who stands firmly in grey suits, facing and looking directly into the audience.

Figure 35. Opening Scene of *Gardenia – 10 Years Later* (2021), the NTGent Theatre, Ghent, Belgium, 2021, Photo Credit: Luk Monsaert (laGeste). Image description: A close-up shot of Vanessa Van Durme's upper body. Other performers stand behind her in grey suits.

Arguably, "Over the Rainbow" sung by Van Durme in her 70s can prompt the audience to question or imagine her childhood and younger self—a younger Van Durme who was trapped in the wrong body or wrongly judged by a heteronormative society, yearning for a place where she can be accepted as she is. The other performers behind her remain silent while looking directly into the audience; this image may prompt the audience to contemplate the past and life journeys of each performer and how they remember or relate to their own pasts. In this sense, the opening scene is an invitation to see Anne Davis Basting's depth model of ageing, which views older subjects as embodying "the layers of selves created throughout one's life" (*Stages of Ages* 141). The depth model of aging challenges the binary divisions of young and old and chronological conceptualization of ageing. Instead, this model suggests that "any social act of aging is always done in concert with the past, present, and future, no single representation of age can be a stable identity" (Basting, "Performance Studies and Age" 268

What does embodying layers of selves mean for older trans adults? What does "keep[ing] in touch with one's different ages or different age-selves (Basting, *Stages of Ages* 141) mean for them? The documentary film *Before the Last Curtain Falls* (2014) shows how *Gardenia*'s older performers have varied reactions and relationships to their past. In the film, some of the cast members share their childhood photos and talk about how they remember the past. While Van Durme expresses her anger and frustrations with people who want to know about her pre-surgery life, De Laet, in the film, says she still cherishes her 44 years of life before surgery as she has many beautiful moments. But De Laet also remarks that she did not smile when her parents had put her in a boy suit when she wanted to wear a dress. When we read the performance text alongside with the autobiographical stories told in the documentary film, we get to see how remembering and enacting past can be painful and traumatic.

In the performance, the act of dressing and undressing is the very core of this dance piece. The act of donning various garments, such as suits, floral dresses, and the drag costumes they wore in their youth, not only constructs narratives of the piece, but also offers a temporal experience for the performers. In the documentary film, Van Durme says:

> On the first day, they are going to put men's clothing. During the rehearsal, I was like 'oh my gosh' It's so long time ago. I had flashbacks. When I was still a boy, when I was 16. […] Crazy feeling. I did not like that at all because I was thinking about the time when I was still struggling with my identity.

As indicated in Van Durme's statement, it is evident that youth is not necessarily viewed or remembered positively from a queer and trans perspective. Knowing the autobiographical accounts of the performers regarding their pasts in the film, the opening scene of "Over the Rainbow," can be read as foregrounding queer and trans bodies as embodying temporal depth across a long lifespan; by doing so, highlighting the sense of resilience, survivor, and courage of these older subjects.

Constructedness, Performativity, and Physical Realities of Age and Aging

After the opening song, Van Durme gives an introductory speech and asks the audience to stand up and join her in paying respect to the deceased queer and trans colleagues and friends—those who did not have a chance to age.[91] While this practice was part of the 2010 production, in the 2021 production, Van Durme performs the scene by looking at De Laet's chair. The loss of their own highlights the early deaths of queer and trans people, making them feel more tangible and visible. Following this, Van Durme introduces each of the older cast members. They walk out and stand next to Van Durme as they are introduced, except for Young Guy—he remains at the back of the stage. The rest all hold each other's hands and raise their hands, implying a celebration.

A series of tableaux vivant portrays different ages and genders: from images of stereotypical old men to middle aged men, to younger women, and to drag queens, the performers not only change their garments but also their physicality, movement, and facial expressions, as the music changes. First of all, as the sound of castanets plays, resembling the ticking of a clock, Young Guy gradually bends forward to enact a stereotypical old man's body.

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[91] This gesture portrays the higher risk of mortality among trans individuals. Numerous studies have addressed the significant health disparities older LGBTQ adults face: this population often experience a lack of family and community support, increased risk of social isolation, discrimination and abuse in care systems compared to heterosexual peers. Also, these health disparities are connected with higher morbidity, premature deaths, and higher mortality among LGBTQ seniors (see Witten 2009; Fredriksen-Goldsen 2014; Hughto and Reisner 2016).

He exaggerates the trembling of his hands and legs. Other older performers also join him, enacting physicality of a typical old body: they look down at the floor and walk slowly with their hands behind their backs. The celebratory and joyful mood of the opening scene is over, and they all express lethargy, melancholy, and sadness [see Figure 36]. As such, the performance of 'old-old' can be seen as a re-inscription of ageist view of aging into old age, associating old age with decline and negativity. However, considering the emphasized constructedness and performativity of ages and genders in the following tableaux, I argue that the performance of stereotypical old body functions as questioning the culturally constructed images of old, rather than reinforcing the ageist view of old age.

Figure 36. Screenshot of a Tableaux Scene from the Video Recording of *Gardenia – 10 Years Later* (2021), 00:13:18, Recorded at the NTGent Theatre, Ghent, Belgium, July 25, 2021, by les ballets C de la B. Image description: Six performers spread out in the performance space facing either towards or away from the audience look at the floor with shoulders slumped. The performers display a helpless and lethargic facial expression.

In the following scene, they transition from old-age men to middle-aged men, commenting further on the performativity of ages and genders. Performers walk more confidently in a faster tempo, gather at the centre of the stage, and strike a series of poses and make tableaux-images that are typically associated with masculinity and middle-aged men such as carrying a suit jacket over one shoulder, and untying the tie and unbuttoning the shirt. By freezing intentionally between the actions during the act of dressing and undressing, they make the audience focus on the stereotypical gestures and expressions associated with certain genders and ages.

As the tune changes again to Giuseppe Verdi's "La Traviata" (1853), they again transition to the zone of femininity, stripping off their drab suits one by one, revealing colourful floral dresses and underwear, and freezing in mid-movements of undressing; the dancers express refined and gentle femininity. With another change of music to Jay-Z and Mr. Hudson's "Forever Young" (2009), the dancers' movement vocabularies become freer, more expressive, and playful, and the energy of the stage is more liberating, chaotic, and euphoric. Also, while they were more isolated in the previous segments, there are more contacts between the performers—holding hands, hugs, and kisses [see Figure 37].[92] Like this, using tableaux to highlight the notions of in-between-ness and constructedness, *Gardenia* comments on the fluidity and performativity of age and gender, while exposing and questioning the "culturally sanctioned" scripts of age and gender (Gravagne 2013: 16).

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[92] In the 2021 re-staging, the performers touch the dress of De Laet implying physical contacts with her.

Figure 37. A Tableaux Scene of *Gardenia* (2010), the NTGent Theatre, Ghent, Belgium, 2010. Photo Credit: les ballets C de la B. Image description: Six older performers wearing dresses in bright, vibrant colours strike poses t typically associated with femininity, sitting with legs crossed at the knees or standing in exaggerated poses with hips pushed to one side. On their right, two younger performers are kissing; Real Woman seated with her feet in the air and grabbing Young Guy's hair, who is standing.

What is intriguing is that the series of tableaux vivants do not suggest a linear and chronological narrative of ageing, nor unidirectional transition from masculinity to femininity. When Verdi's prelude from "La Traviata" starts playing, the performers resume wearing their suits. Using *re-plays*, *Gardenia* represents ages and genders as a fluid spectrum, rather than rigid categories or stages. The audience encounters familiar clichés and illusions of bodies, that get dispelled minutes later (laGeste, "The Cast Look Back"). Through a series of tableaux that constantly contradict and challenge the former, the performers portray multiple age-selves and genders across one's life in a non-linear way. Furthermore, the re-staging of the production itself functions similarly, troubling what was suggested earlier. For instance, in the 2021 production, the middle-aged female dancer reaches her 50s—an age shared by some of the older performers in the 2010 production. This challenges the binary distinction between the younger and older performers that was clearer in the original production.

As the performance unfolds, the older performers gradually apply makeup, jewellery, wigs, and drag costumes at varying rates, ultimately becoming all drag queens. Through asynchronous tempos and speeds in their movements and actions, such as (un)dressing, walking, and returning to chairs, they express each individual's unique aging paths and trans times (Pearce 2018). From the film *Before the Last Curtain Falls*, we can know that some members like Van Durme have reclaimed her gender identity in her twenties, while some of the members began to experiment with their gender identities in later life. The life-course of trans individuals is often marked with the time of coming out or undertaking hormone therapy or medical procedures. The notions of trans temporality such as "trans years" or "hormone time" (Horak 2014) acknowledge the time in which they lived with their felt gender (not the gender they were assigned at birth) and allow trans individuals to "employ an alternative chronology to make sense of their lives" (Pearce 3). From this point of view, some older adults' experience and age as a trans individual might be 'young,' while performers like Van Durme may be considered 'older' in terms of trans years. Thus, even though chronologically and physically, the aged performers may appear to be equally old, they have a significant age gap in the so-called trans age. When we consider the intersection of the age and queer/trans identity, various heteronormative and chronological conceptualization and assumptions of age are being questioned. In short, *Gardenia* shows that for older adults who experiment with their gender, coming out after retirement, changing their appearance and/or transitioning in their later life, chronological old age can be re-imagined as a chance, liberation, new beginning, and agency rather than a loss and decline.

While *Gardenia* addresses how both age and gender identity are culturally and socially constructed and performed, it also recognizes the physical realities of aging through re-staging of the production. In *Gardenia–10 Years Later*, all performers are literally ten years older than the original production; the actual consequences of the time are visible to the audience. In the 2021 production, slanted stage prominently foregrounds the aged bodies of the performers, as navigating the stage in high heels becomes more challenging. As Kathleen Woodward (1999) notes, unlike other markers of social difference, age cannot be solely understood as a social construction because we “must confront the physical dimensions, if not the very real limits of the body” (xxii). The markers of age on the bodies of the performers and De Laet’s attire serve as constant reminder of the physical realities of aging throughout the performance, prompting us to reflect on the finite nature of human beings. Therefore, the production makes us ponder both the constructedness and realities of ageing.

Challenging the Idealized Youth from Queer and Trans Perspectives

Lastly, it is worth questioning the aesthetic and dramaturgical choices of intermingling younger professional dancers among older queer and trans performers. In this section, I will discuss what this performance achieves by paralleling the older performers and younger performers through both harmony and contrast. Like the title of the documentary film *Before the Last Curtain Falls* implies, *Gardenia* suggests a narrative that implies ending is a new beginning: their website states it “starts from the end to the beginning” (Daluwein, “The Cast Looks Back”). The images, music, and narratives in *Gardenia* often portray a nostalgic and retrospective gaze towards the past and the turbulent life journeys of the performers. I argue that the retrospective gaze in *Gardenia* is highlighted through younger performers.

Throughout the performance, two younger cisgender performers—Griet Debacker and Hendrik Lebon—continuously move around the older performers, adding further complexity to the performance narrative by consistently introducing breaks within the overarching images and stories. The younger figures in *Gardenia* are depicted as those who are in the deepest agony, and they are constantly suffering, crying, and failing throughout the performance. Each younger performer has a prolonged solo of lip-sync with exaggerated facial expressions and movements. Two of them also have a frenetic and combative duet dance which involves lots of violent movements such as intensive hugging, pulling, pushing, and throwing [see Figure 38]. This long duet scene has been criticized as a symbolic battle between a cisgender female and male: a reviewer states that "as a metaphor for the transvestite condition it's too obvious and overwrought" (Jennings, "Gardenia - Review"), and another reviewer writes the solo and duet dance of younger dancers "reduces the other performers to the last place they should be: the margins" (La Rocco, "Upending Notions of Gender Identity").

Figure 38. The Scene of Fight Duet Dance between The Real Woman and Young Guy in *Gardenia – 10 Years Later* (2021), the NTGent Theatre, Ghent, Belguim, 2021. Photo Credit: Luk Monsaert (laGeste). Image description: The Real Woman (Griet Debacker) has her right hand on Young Guy's (Hendrink Lebon) chin and is pushing him away. Young guy's face is forced to look up but still holds onto Real Woman's body with his arms. Dirk Van Vaerenbergh, wearing a red dress, is out of focus and is seated towards the back of the stage.

However, this scene is open to more nuanced readings. I argue that this scene addresses the subject of 'violence' in a broader sense rather than depicting a specific story. It is important to note where the trans performers are and how they respond to this scene. Vanessa Van Durme sits on the left side of the stage, facing the audience; she avoids looking at what is happening at the centre stage. We also need to pay attention to Van Durme's facial expressions and body language; there is certainly a disgust expressed through her body regarding the violence that happens right next to her. [see Figure 39]. All the while, Dirk Van Vaerenbergh sits at the back of the stage, watching them silently. Considering these older trans performers watching or ignoring the fight and violence that happens around them, it is possible to read this sequence as re-enacted memories related to any kinds of violence experienced by the older performers, or their retrospective engagement with their youth.

Figure 39. Vanessa Van Durme and the Fight Duet Dance in *Gardenia – 10 Years Later* (2021), the NTGent Theatre, Ghent, Belguim, 2021. Photo Credit: Luk Monsaert (laGeste). Image description: Van Durme is sitting on a chair at the left side of the stage, wearing an outfit that is a clear reference to the 1950s film Sunset Boulevard. On the right, Young Guy lifts up The Real Woman. The younger performers are in blue suits.

If this scene is viewed as re-enacted memory of Van Durme or Van Vaerenbergh, the younger bodies may represent their younger selves. Right before this battle dance, there is a scene in which the Young Guy constantly sobs and asks questions to Van Durme, “Am I beautiful? Is my life beautiful?” Van Durme gives a blunt response to him saying, “Yes, you are beautiful.” I interpret this as her talking to her younger self in the past, who perhaps could not see the beauty around them, as indicated by her remarks in the documentary film. The old songs they lip-sync to—Young Guy lip-syncs to Charles Aznaour’s famous song “Comme Ils Disent”

(What Makes a Man) (1972)[93] and Real Woman lip-syncs to Caetano Veloso's version[94] of "Cucurrucucú Paloma," (1954) written by Tomás Méndez—also imply that these younger figures might be mirroring the past selves of the older performers. These songs, lip synced by younger dancers, express subjects of confusion, loneliness, search for their identity and love, etc. As such, I argue that, without suggesting a more direct autobiographical narrative, Young Guy and Real Woman embody the shared memory and pain among older queer and trans subjects: the absence of home, place, family; loneliness and sadness; lack of confidence; ongoing struggles and battles against violence and abuse; a sense of struggle of survival.

The two younger figures lingering among older adults also portray "the psychological and emotional backwardness" that has been characterized as queer temporality by many scholars (Crookston 878). The younger figures in *Gardenia* can be read as embodiment of what Elizabeth Freeman (2010) describes as "[the] stubborn lingering of pastness" (8) that characterises much queer experience and queer affect. Put differently, the younger figures act out the remembered emotions and memories of the older performers. While remembering the past through the younger bodies, the older performers present themselves in a place of grace and power, as they are portrayed as those who found a way to accept and live with their insecurities and variations. The retrospective gaze towards younger figures depicts unresolved griefs and angers; however, the recollection becomes a tool of resistance that validates their current selves despite their biological changes in their appearance and loss of their youthful bodies. As such, the retrospective gaze towards the past and youth become more of resistant affirmation for the aged selves who are portrayed through charisma and power as they have found a way to embrace and

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[93] It is a French song about gay man, his crossdressing at Paris clubs, and his close relationship to his mother.
[94] Caetano Veloso sang Cucurrucucú Paloma in the Spanish movie, *Talk to Her* (2002). This song is about the painful and destructive love of a man who misses a woman until he dies.

live with their vulnerability and instability. In this way, *Gardenia* re-imagines old age as a liberation and possibility rather than a loss.

But the audience are also reminded of the lonely lives of these older performers depicted in the documentary film and their concerns of getting old without family or partner—a broadly shared concern among queer and trans elders. Therefore, the presence of past selves portrays the complicated relationships to the past among queer and trans elders and present old age as "complex amalgam of multiple selves" (Basting, *The Stages of Age*, 136), who are still exploring their new selves in the later stages while remembering their turbulent yet glamorous life of youth. By making the younger bodies embody pain and struggle, *Gardenia* allows the older performers to embody figures of power and resilience, without erasing the painful history, the sadness they carry beneath, and the ongoing struggles as marginalised citizens. In short, the performance makes its spectators ponder the complexity of queer and trans ageing—both "the pleasures and the perils of ageing" (Regal 2013).

Conclusion: Old Age as a Prestige and Achievement, Rather Than a Tragedy

Throughout the performance, the older performers slowly transform into drag queens, putting on old drag dresses, wigs, and accessories [see Figure 40]; and at the end, they sing 'Over the Rainbow' one more time, which can be seen as a sort of a climax of the performance. However, this repeated song poses the same questions as the beginning: where is the land where their dreams come true? Have they arrived there yet? I argue that *Gardenia* aesthetically demonstrates "the older body in-depth," that "keep[s] in touch with one's different ages or different age-selves" (Basting, *The Stages of Age*, 141). In my analysis, I demonstrate that Basting's depth model of aging can offer a new way to acknowledge and empower the nonlinear course of queer and trans ageing. Van Durme's statement in her interview reflects this ongoing journey of older queer and trans performers as they find their places in society, saying, "I say to myself always, It's not where you start. It's where you finish. And I am going to finish on top, honey!" (Myles, "Ruth Myles"). By fully embracing the pain and beauty of both their past and old age through non-linear images, *Gardenia* enables the older queer and trans subjects to tell their unique stories and views of ageing. In this piece, the ageing trans and queer performers in their 60s to 70s embody both vulnerability and strength as survivors, enabling the audience to witness their charisma, power, and resilience. The presence of older trans and queer subjects itself and their strong will to perform suggests a new perspective on old age as prestige and achievement, rather than a tragedy.

Figure 40. Finale Scene of *Gardenia – 10 Years Later* (2021), the NTGent Theatre, Ghent, Belgium, 2021, Photo Credit: Luk Monsaert (laGeste). Image description: Older performers and The Real Woman are wearing their drag outfits. One of them stands in front with a microphone on the left while the

rest are slightly behind and to the right. Young Guy is wearing a grey suit pants without a top. Everyone has their arms stretched out in front of them as if greeting the audience. There is a red carpet drawn from the front to the back of stage.

5.5 Tuuli Helkky Helle (1933-2018): Radical Arts and Life of Older-Disabled Dancer

Introduction of the Case Study

The two previous case studies are a powerful testimony of the disruptive effect of performance to normative ideas of ageing. Rhetoric such as 'successful, healthy, productive aging' and 'ageless life' promote aging without illness and disability as the ideal and exclude those who age *with and into* disability from a desirable future. The third case study analyses the artistic practices of Tuuli Helkky Helle (1933-2018), an older disabled Finnish dancer. It investigates how she challenges the negative connotations associated with 'dependency,' which often leads to stigmatization and devaluation of older adults and disabled individuals. In this case study, I examine how Helle reclaims dependency as a positive concept through her dance, which highlights relationality and interconnectedness. This chapter also uncovers her extraordinary ageing path and explores how her vigorous engagements in visual arts, performance, and activism in her later life offer counter-images and counter-narratives to the cultural assumptions that link "feebleness and helplessness" to people with disabilities and older people (Tarvainen 296).

In this case study, I trace and document her artistic works by examining multiple archival materials such as video recordings of her dances, photographs, and copies of her poetry collections. In particular, the photobook, *Tuuli Helkky Helle 80 Years* (2013), which Sirppa Kinos (Helle's niece) created to celebrate Helle's 80th birthday and her life, is an invaluable source as it contains Helle's paintings, photos of her dances, conversations she had with Helle in the summer of 2012, and include excerpts of studies discussing disability policies and justice in Finland. My analysis of Helle's dance and body are based on the full video recording of the 2009 Hong Kong production of *Olotila* (*State of Being*),[95] a professional integrated dance-theatre piece of Rajat'on (Limitless) ensemble,[96] choreographed and directed by Tomi Paasonen.[97] I draw on this production because it was performed in English, while other productions were performed in Finnish. To discuss the performance of her aged-disabled body, I also draw on Helle's nude photographs in *Gala Dress* (2002),[98] a photo exhibition collaboratively created by Tomi Paasonen and Helle. Only short video clips were available for more recent works such as *Kaleidoscope - the Unbearable Beauty of Difference* (2010) and *Aurora Borealis* (2012) by DanceAbility; so, this dissertation only briefly discusses Helle's performance in these later productions. The short artistic activist film about Helle, *Muuten menee katu-uskottavuus* (*Otherwise, You Lose the Street-Credibility*, 2016),[99] and the film *Method for Better Service*

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[95] The premiere of *Olotila* was performed at the Zodiak Centre for New Dance, in Helsinki, Finland, September 13, 2000. Following its premiere, it was also invited to the Full Moon Dancer Festival (Pyhäjärvi, Finland), Theatre Festival (Tampere, Finland), Kulturhuset (Stockholm, Sweden), Dansstationen (Malmö, Sweden), Hebbel-am-Ufer HAUS (Berlin, Germany), Bergen International Festival (Bergen, Norway), Théâtre de l'Aquarium (Paris, France), and Hong Kong Mime Festival (HongKong) (https://www.yumpu.com/en/document/read/25102143/zustand-state-of-being-tomi-paasonen). Accessed August 18, 2023.

[96] Rajat'on ensemble is a Finnish dance collective, consisting of both disabled and non-disabled performers (Karhunen 2014: 11).

[97] Tomi Paasonen is a Berlin-based director, choreographer, and visual artist. After an accident that caused spine injury, he began working under the name Public Artistic Affairs (PAA) in Berlin and started to work with dancers with diverse backgrounds and abilities.

[98] This collection was invited and exhibited at multiple galleries, including Fort Mason Center in San Francisco, Lasipalatsi Galleria in Helsinki, City Gallery of Forssa, Full moon Dance Festival in Pyhäjärvi, Finland, and Rise Berlin in Germany.

[99] It was filmed collaboratively by Titta Aaltonen and Jenni Jenni-Juulia Wallinheimo-Heimonen. The information on this film can be found on the creator/director Jenni-Juulia Wallinheimo-Heimonen's website: https://www.jenni-juulia.com/muuten-menee-katu-uskottavuus-or-you-loose-the-street-credibility/index.html. Accessed August 25, 2023. The full video of the film is available on YouTube: https://youtube.com/watch?v=ah2yAx_1Miw&feature=shares. Accessed August 18, 2023.

(2016),[100] created by disabled artist Jenni-Juulia Wallinheimo-Heimonen,[101] are also important research materials to explore Helle's views and devotion to fighting for the rights and justice of older adults with disabilities. The video recordings and films used for this analysis were provided by creators of each piece: Jenni-Juulia Wallinheimo-Heimonen, Tomi Paasonen, and Sally Davison.

While the biographical materials offer important insight into Helle's approach to her life and arts,[102] my analysis of her dance and body focuses on the phenomenological and aesthetic aspects that are evident in these archives. From a Performance Studies perspective, I draw on phenomenological approaches to analyse her aged-disabled body performed in multiple dance pieces and photography, and discuss her body's corporeality, physicality, presence, movements, costumes, and relationships to the other bodies and beings. While I continue to expand the notion of experts of age/ing, this analysis is also guided by the theoretical perspectives of Ann Cooper Albright (2017; 2019) about gravity, interconnectedness, and disabled and aged bodies. Drawing on discussions on the "alternative danceability" (Nakajima and Brandstetter 2017: 61) offered by ageing and disability, this case study examines Helle's dancing body and how her body pushes back against the typical meanings of dance, beauty, mastery, and virtuosity, as well as the idealised notion of a successful and healthy aged body.

Furthermore, to articulate the ways in which Helle's dancing body reconfigures the ableist notion of dance(r) and dependency, I bridge theoretical discussions on disabled dance

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[100] Full video of the film is available on YouTube https://youtube.com/watch?v=uLyMzTbygm0&feature=shares Further information on the film can be found on Jenni-Juuli's website: https://www.jenni-juulia.com/method-for-better-service/index.html. Accessed August 18, 2023.

[101] For information of her works, see this interview with Jenni-Juulia Wallinheimo-Heimonen https://no-niin.com/issue-12/accessibility-is-not-static-a-conversation-with-jenni-juulia-wallinheimo-heimonen/ One of her artistic films on disability, *Squirrel* (2017) is featured as the cover image of *Routledge Handbook of Disability Studies 2nd Edition*(2019).

[102] Most materials are only available in Finnish, I have employed translation tools such as DeepL and Google Translate to access these.

with the theory of "relational citizenship" advanced by Pia Kontos in her research about persons living with dementia (Kontos et al. 2017). By conceptualising her aged-disabled body as a possibility of *relational bodyhood*, I contemplate how her artistic engagements at the last stage of her life challenge both ableism and ageism, and how her activism disrupts the stereotypical narratives of older persons with disability, making them a burden of society and invisible through the politics of concealment.

Extraordinary Ageing Path

Tuuli Helkky Helle (1933-2018) was a rare older woman who had performed in contemporary performances while living with a severe disability; her various art practices attest that she perceived her double-marginalized subjectivity—old and disabled—as the site for research and activism against ageist and ableist social gazes and perspectives. She was born with cerebral palsy, which seriously impacted her mobility and verbal communication. In *Muuten menee katu-uskottavuus* (*Otherwise, You Lose the Street-Credibility*, 2016), Helle says she lived with her parents until she was 40 years old, and in her own expression, she was extremely protected despite her desires for social life and adventure. She was self-educated—in her words, she was "mercifully released from compulsory education" (Helle 3), and she could communicate with people mostly through emails and written formats by using a communication assistive device.

However, after her father's passing, she decided to live on her own after living in a care home for a year. Although she struggled for a few years to be on her own, she states that her life became "wild" at this time (*Otherwise, You Lose the Street-Credibility*, 2016). She began to connect with other women living with severe disabilities and engage with dance, painting, writing, and photography. Freed from the normative life course, she began her artistic career at the age of 60. According to the neoliberal idea of the life course, this period is often referred to as the "third age," when someone retires from their profession and begins to enjoy a new leisure lifestyle until they enter the "fourth age." The "fourth age" is accentuated with the ideas of decline, frailty, and what is often described as "unbecoming" (Higgs and Gilleard 2014: 13). Her life course and ageing story, as well as her view of life, radically reject the stigmatized narratives of ageing with disability.

Helle performed in multiple dance pieces until she was 83 years old when she passed away. However, her life does not suggest the ableist narrative of "the triumph over disability" or "overcoming rhetoric" (see Linton 1998) nor the ageist narrative of "ageless self" (see McHugh 2000). I argue that she allows us to envision "disabled and aging futures as liveable and even desirable" (Changefoot and Rice 174), without conforming to the idealised, normalised life course constructed through chronological age and institutions such as school, family, work, and retirement (Hockey and James 91). It may be considered 'late' according to the standards of the normalised life course; however, she had engaged with diverse forms of arts for more than twenty years in her later life. From 2000 to 2009, between ages 67-77, she toured multiple countries as the central dancer in *Olotila (State of Being)*. After its premiere in Helsinki in 2000, *Olotila (State of Being)* was awarded with the "Theatre Event of the Year 2000," which is annually given by the Theatre Centre in Finland (Paasonen, "Olotila – State of Being"). According to Tomi Paasonen,[103] Helle once mentioned that she had an idea about creating a nude photo series with a disabled body; she had long thought of finding a beautiful 'model' for it, but through conversation and discussion with Paasonen, she became the model herself at the age of

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[103] T. Paasonen. Personal communication. December 21, 2022.

70. Over multiple years of collaboration, the radical and experimental work called *Gala Dress* (2002), featuring collections of nude photographs of Helle's aged and disabled body, was created.[104] She was also one of the founders of DanceAbility Finland, and in her 70s, she danced in Kaaos Company, one of the most significant integrated dance companies in Finland. Notable dance pieces she participated in are *Kaleidoscope - the Unbearable Beauty of Difference* (2010) and *Aurora Borealis* (2012), both choreographed by Sally Davison.

In addition, Helle painted and produced numerous paintings from the late 1980s to 2000s; and the subjects of her paintings range from her childhood memories, portraits of people around her, and self-portraits. In her 60s, she self-published two books of poetry: *Elämä on oivaltamista* (*Life is Understanding*, 1996) and *Palvelukseen halutaan* (*Looking for an Assistant*, 1996) which address her lived experiences with disability, her dreams, desires, and the ableist gaze imposed on her body.[105] Helle was not only an artist, but also an activist who passionately fought for disability justice and against ageism and ableism. Most remarkably, two years before her passing, Helle made a short activist film, *Muuten menee katu-uskottavuus* (*Otherwise, You Lose the Street-Credibility*, 2016) with Jenni-Juulia Wallinheimo-Heimonen. This film, which captures Helle writing a petition letter to the minister of Family Affairs and Social Services in Finland and her rap song called "Granny Rap." This film had a huge political impact against the disability service legislation reformation which suggested removing personal assistance for older people with age-related disabilities (see Era 2021). Shortly after this film, Helle participated in another activist performance that was documented as a short film *Method for Better Service*

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[104] Some of the photos of the exhibition can be found on Tomi Paasonen's webpage: https://www.paasonen.com/Gala-Dress. Accessed August 15, 2023.

[105] The English titles of these books were included in the short film, *Or, You Lose Street Credibility* (2016), made by Tuuli Helle Helkky and Jenni-Juulia Wallinheimo-Heimonen. Further information about the books can be found here: https://www.lounakirjailijat.net/lounakirjailijat/kirjailijat/?authorid=41&newstitle=Helle+Tuuli+Helkky. Accessed August 15, 2023.

(2016). This performance gathered five ageing female activists including Helle who live with long-term disabilities. In this activist performance, they go around the small streets of Finland on wheelchairs, naked, aiming to raise awareness of accessibility and celebrate diverse bodies. While other activists were middle-aged, Helle, at 83 years old during this performance, wore absorbent pad to deal with incontinence, yet nothing deterred her. She led the radical march from the centre of the group.

Tuuli Helkky Helle's *extraordinary* life-course, arts, and activism counter "the accepted notions of physical disability" and aging as "an absolute, inferior state and a personal misfortune" (Garland-Thompson 1997: 6). Her unique life story and bold acts reconfigure the old and the disabled as figures of desire, power, and subjectivity, and counter "the normate's frequent assumption that a disability cancels out other qualities, reducing the complex person to a single attribute" (Garland-Thompson 12). Tuuli's extraordinary life course and body of works give us an insight into the inclusive model of crip futurity which does not project the idea that disability-free or age-less life is ideal and successful. Helle uses her aged-disabled body as a political and artistic site to expose and challenge the ableist and ageist gaze, expectations, and prejudices. Despite her artworks which urges us to rethink the definition of body's capacity and beauty that are based on ageism and ableism, Helle did not receive much academic attention from either Age Studies or Disability Studies in her lifetime. In the following section, through an in-depth analysis of the dance pieces and photo exhibition in which Helle participated, this research discusses how she explores and foregrounds her own experience and views of ageing and disability. Additionally, it delves into how her arts fervently unsettle various norms and ableist assumptions applied to old-disabled individuals. The analysis also explores how her dance challenges ableist conceptualisations of dance and the dancer.

Reconfiguration of Dancer’s Body: Relational Bodyhood

Including Helle, there are seven dancers in *Olotila* (*State of Being*, 2000-2009)—five of them are disabled (four dancers are wheelchair users and one dancer is blind) and two of them are non-disabled. More precisely, there are nine performers including a dog and a robot who appear onstage in *Olotila.*[106] In this piece, the central figure is Helle even though one might say she has the ‘least’ movements. The performance starts with Helle’s voice, and her poems are woven through the performance. In the first scene, the audience sees her small body—approximately three to four feet in height, bent and curled up both due to her disability and old age—laid against an able-bodied younger male dancer, Stephane Hisler. Looking directly at the audience with a subtle smile, she speaks, but her words are indecipherable. Therefore, Hisler translates her words sentence by sentence:

> Today begins an adventure. A huge, exciting, and fascinating adventure.
> It is beyond comparison, and it will make me a great free person.
> Oh, my wonderful adventure.
> You who could release me from the change of my everyday life.
> But I am so small – too small to live up to you, today.
> So, today, I will make you a doll and trivial incident.
> Change to my habits. I cannot see the wonder of moments, today.
> I can only expect the great adventure to occur tomorrow.
> Not today.

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[106] The performers are Tuuli Helkky Helle, Stephane Hisler, Riikka Kekäläinen, Tom Leidenius, Dog: Ninnu, Riita Pasanen, Kalle-Antti Raunu, Sari Salovaara, and Eeva Simons. (Original order listed by Public Artistic Affairs, https://www.yumpu.com/en/document/read/25102143/zustand-state-of-being-tomi-paasonen).

This integration of her poem positions her as the main speaking subject, not a deviant object of the ableist and voyeuristic gaze. Instead of asking the disabled bodies to overcome their physical limits, this piece brings down the able-bodied to her height and her eye-line. The two dancers on the left side of the stage are lit from above with a pin light; there is a red rope hanging from the ceiling—the rope invokes the image of a noose and idea of suicide. When Stephane points to the rope, Helle shakes her head with a gentle smile. Behind them, the backdrop is a projection resembling a close-up X-ray image of a beating heart—in contrast to the rope and Helle's old body, it signifies both birth and death. While lying on the ground, Stephane gently lifts her off the floor and raises her body up with his arms; Helle's small body floats in the air while he continues to move with his back on the floor. Mirroring the idea of *pas de deux* of a classical ballet, he supports Helle's body, lifts her up, turns her body, drags, and assists her to walk little by little. Resting comfortably in his arms, Helle's arms are curled toward her torso and stiff legs are lifted upwards. Through these movements, her disabled body, which has always been "smaller," crips the normative idea of physical ageing which assumes that a person's body becomes curled up and gets smaller as they grow old. In *Olotila*, her small body invites the audience to reflect on the common ageist linkage between infancy and old age. The juxtaposition is also evident in the photos of *Gala Dress*. However, these representations are not in function of infantilizing her. I argue that her old, disabled, dependent body becomes the site to question and critique the rhetoric and politics of (in)dependency that haunt many older adults and disabled individuals.

This slow intro without many typical dance movements takes about ten minutes—which is a significant length for a dance piece. As the sound of the heartbeat gets faster and mixes with the beeping sound of a heart rate monitor from a hospital, other dancers join the stage. The blind dancer Tom Leidenius and Sari Salovaara with a stiff spine from rheumatism navigate the stage while maintaining physical contact with each other; another duet dance of Eva Simons in wheelchair and able-bodied dancer Riikka Kekäläinen follows the next. Because all the dancers in this piece are wearing the same costume—white top and white tights—the bodies of dancers seem intertwined and expanded; sometimes they make one big amalgam.

During the remaining first half of the 100-minute-long performance, Helle remains seated on a giant white bean bag, in a white Tutu, holding a female doll also wearing a white Tutu. While she does not have movement for a long period, she never recedes to the background. There is a scene where Helle dances a variation of classical ballet of *Don Quixote*; her dance is characterized with micro-scale movements [see Figure 41]. The movements of her foot and hand are so subtle and delicate, yet they are moving at her best and exert tremendous energy and powerful presence. The micro-scale movements are barely visible in the video recording, and there is a high chance it could have been challenging to notice from a far distance during a live performance. Yet, as the prima ballerina, she is dancing her version of this classical ballet with other dancers sitting around her—these more able bodies do not override her and give her space while maintaining still. Holding a fan in one hand, her face is enlightened and gracefully expresses elegance and joy.

Figure 41. Tuuli Helkky Helle's Solo Dance of *Don Quixote* in *Olotila* (2009), Hong Kong, 2009. Photo Credit: Tomi Paasonen. Image description: Helle is seated on a giant white bean bag wearing a white Tutu and holding a fan.

Tuuli's reflection on her body and her dream to be a dancer, documented in the photobook made by her niece, is worth quoting at length:

> When I told my parents at the age of 5-6 that I was going to be a dancer, I didn't understand at all why they were confused. My dearest dream above all has been to be able to dance. So, in the early 1990s, I applied to wheelchair dance, and got to know the Rajat'on dance ensemble. I participated in the Unlimited Dance 2000 project, the goal of which was to create new cooperation between dance professionals and disabled dance enthusiasts. *Olotila* premiered in September 2000, and it was performed for the last time in Hong Kong in 2009. I was selected as the 'prima ballerina' of *Olotila*. And indeed, I danced—although sometimes I borrowed moves from other dancers. I performed my solo number lying on the floor on pillows. This is how the little girl's wish was finally fulfilled, after decades of waiting!

Sirppa Kinos, *Tuuli Helkky Helle 80 vuotta: Juhlakirja*
(Tuuli Helkky Helle 80 Years: Celebration Book), 2013, no pagination.

Her dream, reflection, and actions disclose and confront the normative and ableist assumptions about dancing bodies—emphasizing "a traditionally virtuosic body," which not only present rigorous skills and technical mastery but also "sexual desirability" (Albright 2017: 64-65). For instance, in a traditional sense, dancing bodies are imagined as those who have excellent control over their bodies and transcend the limits of our material body and present "a perfect body—one completely unhampered by sweat, pain, or the evidence of any physical negotiation with gravity" (ibid: 65). Many postmodern dancers have challenged the narrow vision of dance. However, as Anne Cooper Albright (2017) points out, "this does not mean that we have sufficiently deconstructed the paradigm of the virtuosic dancer" (65).

Olotila enables Helle to dance on her own terms and celebrates her different bodily presence, without disguising her age and disability. This piece also does not suggest the common "triumph over disability" narrative that is commonly found in disability dance (see Albright 64-68 for her critique of these examples that focus on the capacity of disabled bodies to overcome their physical limits and in turn, paradoxically reinforce the exclusionary practices that it was meant to dissemble). Helle's expression, "borrowing moves from other dancers" (Kinos, n.p.) is striking because she suggests a new idea of dance and the dancing body. Her idea of dance suggests something greater than simply dancing with an assistant or help. I argue that her statement counters the fundamental idea that a dancer's body or anyone's body should stand alone—the individualistic, autonomous, and independent understanding of the body. Throughout the performance of *Olotila*, the ideas of relational, interdependent, and interconnected bodies are explored and foregrounded. The dancers continue to support each other's body, move others' bodies, and even *become* each other's bodies. Not only that, but Helle's body, rooted on the ground, highlights our profound relationship to gravity. Her body, always supported by something else (a pillow, other bodies, stage, wheelchair), underscores how our physical body is supported by nature, the environment, and other beings, including both humans and animals.

In the first half of the production, the projected image of heart in the background implies a life; a frontal image of a fully-grown foetus appears in the last ten minutes of the performance [see Figure 42]. When Helle's old, disabled, and dependent body is paralleled with this image, it risks infantilizing her—which often occurs in the narratives of elders and disabled persons; but instead, this image functions as a testimony about the inherent dependency all human beings and living creatures experience But most people, who do not experience an illness or disability, forget this, and assume that they been autonomous and independent.

Figure 42. An Image of Foetus at the Background of *Olotila* (2009), Hong Kong, 2009. Photo Credit: Tomi Paasonen. Image description: The image of a foetus is projected onto a screen at the back of stage and is stretched to be a storey tall. Green stage lights are projected width wise across the stage.

There are two dancers lying on the ground, along with a wheelchair. One dancer is standing and is looking at the image of a foetus.

From an ableist and ageist perspective, both the old and disabled become a problem against what Elizabeth Freeman (2010) calls “chrononormativity” that normalizes the notion of time for maximum productivity. Instead of revealing the problems within social and physical environments that are based on able-bodied values and standards, this perspective configures the older people and disabled people as an economic and social burden. Being contrasted to the idea of disability-free aging as positive and successful aging, ill, impaired, older, and frail bodies are configured as those who are dependent (physically, socially, economically) and cannot participate fully in the process of production. Fine and Glendinning (2005) write:

> Sociologists have scrutinized the social construction of dependency; politicians have ascribed negative connotations of passivity; while medical and social policy discourse employs the term in a positivist sense as a measure of physical need for professional intervention. Autonomy and independence, in contrast, are promoted as universal and largely unproblematic goals (601).

Refuting the traditional understanding that equates autonomy with independence, many philosophers and scholars across multiple disciplines (Kittay 1999; Fineman 2004; Sherwin and Minsby 2011; Kontos et al. 2017) have expanded more relational views of human ontology and reconfigured that “the inevitable primary dependency on others” as “a condition of embodied human existence” (Dodds 181). Relational perspectives consider the ways familial, community, institutional connections and interdependence enable one’s agency and autonomy. These perspectives also acknowledge dependency as “an indissoluble part of autonomy” (Scully 212-213). Negative attitudes and assumptions towards dependence have particularly marginalized and devalued people with serious disabilities and older adults. Scholars in Critical Disability Studies have already tackled the modernist idea that creates an illusion of autonomous, independent, and individualised self, as well as the illusion of a clear distinction between self and other (see Goodley 2013; Goodley and Runswick-Cole 2016; Shildrick 2019). They highlight the need to shift the fundamental and ontological understanding of subjectivity to align with "the postmodernist contention that the self is always embodied, dependent on its others, unsettled, and always in progress" (Shildrick 2019: 37). Gibson et al. (2012) similarly discusses how the "self-as-individual" has been called into question by postmodern theorists, and proposes "viewing persons [with disability], their caregivers, and their assistive technologies as assemblages of bodies/technologies/subjectivities that together achieve a set of practices" while refusing the view of the contained and sufficient self and negative assumptions of dependency (10). Scholars in Theatre and Performance Studies also have revisited the concept of care, interrelational mode of being, dependency recently; Fisher (2020) argues that relational perspective can open up new ways of reading disability theatre by "acknowledging the hidden mutual dependencies and attitudes of care" (86).

Throughout the performance of *Olotila*, images of assemblages, dependency, and interconnectedness are pervasive. The dancers' bodies frequently overlap and interconnect. The beeping soundscape serves as a reminder of our dependency on medical machines (e.g., ventilator, heart monitor). The visible relationship of our bodies to gravity is evident in the repeated actions of disabled bodies falling from the wheelchair to the ground, climbing back up, as well as other dancers moving by hanging onto the rope suspended from the ceiling. There is also a scene in which all disabled dancers are laid down in a confined space (outlined by light), able-bodied dancers, representing either carers or parents, mechanically cut food, while a surgical procedure description is typed onto the screen behind the performers. It is followed by the scene in which an able-bodied dancer feeds food to Helle, sitting on the beanbag; a voice-over, representing Helle's voice, says: "I had grilled meat and ice cream all at the same time. I had to because one was getting cold, and one was melting. […] Grilled meat and ice cream all at the same time. Boy, interesting life." This is brought from Helle's poem. While *Olotila* comments on the interconnectivity and dependency that are essential for our beings, in this scene, it reveals and critiques the reality of dependency and care in an ableist society, a reality that subjects many disabled and older people to bear inhumane treatments. Later, a dog and a robot also appear as performers; dogs are also cast as models who pose together with Helle in *Gala Dress* [see Figure 43]. I interpret the inclusion of animals or robots in these representations as a statement about the interconnectivity between disabled bodies with different living creatures and non-living things such as assistive devices and technologies (e.g., prosthetic limb, wheelchair). The interconnected relationship with other humans, animals, and technologies highlights the "embodied state of connected identity" (Whitburn and Michalko 230) of many disabled individuals. By including an image of a foetus living in the womb and another poem by Helle, about how dandelion gets its colours from the brightness of the sun, *Olotila* reveals the inherent interconnectivity and relationality among any living organism; therefore, it disrupts the narrative which frames only disabled and old people as dependent.

Figure 43. Tuuli Helkky Helle and Two Dogs in *Gala Dress* (2002), Photo Credit: Tomi Paasonen.

Image description: Helle is sitting on a wooden chair in the centre, naked. Two dogs are on either side of her; to her right a black dog lying down and to her left a brown dog lying on its side.

In *Olotila*, Helle reclaims dependency on her own terms, achieving her dream to be a dancer and to be freed. At the end of the piece, she comes out to the stage, once again carried by Hisler. With his support, she takes small steps, creating a visual echo of the opening scene. He lays her down to the ground and lifts Helle to the air by supporting her from below, and Helle reaches her hands towards the sky, making it appear as if she was floating. As the stage gets darker, we do not see Helle, but instead see a blurry image of a body in the same position as Helle flying and swinging while hanging on to the rope—I think Tuuli is borrowing another body to achieve the movement/dance she imagines and desires. In this image, the initial implication of the red rope that was drawn above Helle changes its meaning—from death or tragedy to freedom and dreaming.

I argue that Helle as an old and disabled dancer exemplifies a mode of alternative danceability. Just like Joshua St. Pierre (2015)'s discussion on how the disabled speaker offers new modes of posthuman communication (331), Helle's dancing body eschews the autonomy and self-mastery of body and offers a new way to dance through relationality, reciprocity, and interconnectedness. Helle says in the opening: "I am too small to live up to you;" she does not try to overcome her disabled and aged body to perform the normative idea of dance. Instead, she focuses on the movements she can make, her intention, physical and emotional feelings, facial expressions, energy, and perhaps breathing. The changing scenography in *Olotila* illustrates the dynamic movements of various organs such as the heart, brain cells, and muscles. In front of these images, the audience is invited to see the *inside* of bodies. Dreaming of being a dancer for more than 60 years, on this stage, as prima ballerina, we can envision her inner dance: the fast pumping of hearts, dancing muscles and bones, flows of air and heat, and tingling sensations at her fingertips and toes.

Furthermore, she shows her excellence in surrendering to the others' bodies, to the environment, and to the gravity—it is a special somatic skill to feel how the other body is and to completely entrust and to let go of one's control over their own body. I am using the word 'surrender' in a positive meaning, implying being able to entrust others including both other beings and environment. Helle's dance and her dancing body remind me of Anne Cooper Albright's investigation and theorization of the act of falling, which teaches us to be responsiveness, resistance, and resilience to falls and failures literally, emotionally, and financially (Albright 2018). Throughout the performance Helle never loses her agency and personality; and maintains her unique calmness, grace, and warmth without any signs of anxiety, tension, or fear. Her powerful presence, positive and playful energy, and calmness breaking through her small body are evident signs of the strong resilience that she had developed over seventy years of living with severe disabilities.

Anyone who has been onstage would understand how difficult it is to be present without many visible actions for the extended duration of time. Albright writes, “instead of nervously trying to avoid falling (metaphorically and literally) in a world in which so many aspects of our social, political, and economic environment are being turned upside down, I believe we need to learn how to fall with grace, connecting with gravity to find a place to ground our impact” (Albright 2017: 70). In the Western world that foregrounds “the cultural hegemony of the vertical” (71) and in the Western dance which “focuses on the virtuosity of the up,” Helle showcases how one can “celebrate the down” and teaches us “to dwell on the floor, revel in the process of rolling, sinking, crawling, and pushing” (71-72). Her dance, grounded in connectivity and relationality, “radically refigure the very category dance[r]” (66).

Similarly, in the intimate photo collaboration *Gala Dress* (2002), Helle brilliantly demonstrates the ways in which her body navigates the world in deeper connectivity, interdependency, and kinship with other beings. In this photo series, she poses her naked, disabled, and old body in relation to animals and nature such as a forest, a stream, ice, and sand. In the photo book created by her niece, Helle says:

> “I have been dependent on the help of others since I was born. I haven’t been able to choose who I’ve been naked in front of. But this nudity was my own choice.”
>
> Sirppa Kinos, *Tuuli Helkky Helle 80 vuotta: Juhlakirja*
> *(Tuuli Helkky Helle 80 Years: Celebration Book)*, 2013, no pagination.

By exposing her aged and disabled body through performative photography, Helle “reclaims her right to be seen naked” (Millett-Gallant 39); at the same time, she questions the social practices and values that render disability and aging both invisible and hypervisible. Helle's artistic self-exhibition was used by many disabled artists such as Mary Duffy, Susan Harbage Page, and Sandie Yi, who "confront[ed] stigma, manipulate[d] the gaze, and cleanse[d] shame" by performatively posing their disabled female bodies in nude (Millett-Gallant 40). While Helle shares this approach, her old age adds an extra layer to her photographs of naked bodies. Her exposed body—with saggy breasts and skin, winkles, white pubic hair, distorted legs—confront "the artistic and social traditions that have deemed [old and disabled female bodies] shameful and unacceptable" (Millett-Gallant 27). In addition, similarly to *Olotila*, the softness and vulnerability of her body, which simultaneously layer images of a young child and an old woman, create irony and unsettle the stigma around the dependency older or disabled bodies require. In most of these photographs, her body is laid on the ground; there are a few photos where her laid-down body is tilted via photoshop which makes her look like she is standing and dancing in water [see Figure 44]. In these photos, she as the speaking subject and active performer makes her aesthetic choices, shapes her bodies while laying down, and creates images full of dynamism and a wide range of affects.

Figure 44. Tuuli Helkky Helle in *Gala Dress* (2002), Photo Credit: Tomi Paasonen. Image description: A top-down image of Helle's naked body lying down on her side. Her legs are slightly bent, and her hands are near her face. She is lit up with a light from the left and her body is contrasted with the black background.

While making intentional and creative choices, Helle's body in this series of photography again display her mastery of relational engagement with other beings and environment. She comfortably surrenders or sinks into the surroundings, and therefore exemplifies *relational bodyhood* that relinquishes control over one's body and exists in reciprocal trust, relationship, and engagement with others. In this way, I argue that this project not only challenges the ableist perception which frames disabled bodies and old bodies as non-desirable and asexual, but also remarks disabled bodies as the critique of an autonomous, arrogant idea of the self. Her performances in both cases show her life-long lived experience of disability and dependent relationship with others gave her a gift that most able-bodied persons have lost. In both cases, Tuuli Helkky Helle's *relational bodyhood* shows a tactile and corporeal touch and contact with other beings and surroundings and offers critical insight into the possibility for human bodies to overcome the border of the self and exist more porously.

Conclusion: Living Relationally and Activism

I would like to conclude this case study by talking about Helle's incredible resilience that is exemplified throughout her artistic works and involvement in activism, which continued until the very last stage of her life. Helle's last artistic works are two activist short films, *Otherwise, You Lose the Street Credibility* (2016) and *Method for Better Service* (2016) that were collaboratively created with Finnish multidisciplinary artist Jenni-Juulia Wallinheimo-Heimonen. *Otherwise, You Lose the Street Credibility* (2016)[107] is an activist work about the rights of older adults who age *with/into* disability but also is an autobiographical documentary of Helle. This work was a response to the Finnish government's announcement that from 2018 they will remove the rights to personal assistance for people older than 75 years old. In 2016 when this was announced, Helle was 83 years old, and she wrote a rap song called "Granny Rap" to fight against the governmental disability service legislation reform. Although the policies of disabilities and older adults vary in different countries, this is an obvious example that reveals

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[107] This film was invited to multiple film festivals such as Serbia Film Festival: Seize the Film in 2017, Grand Rapids Feminist Film Festival (GRFFF) in Michigan in 2017, Bluenose Ability Arts and Film Festival (BAAFF) in Canada in 2018, Art Color Digital Cinema International Film Festival in Montreal in 2018.

the complexity surrounding ageing and disability and indicates the socio-political frame that tries to demarcate and contrast *ageing into disability* from *ageing with disability.*

In the film, she says: “I would like to ask Mr. Rehula (Minister of Family Affairs and Social Services in Finland), ten years from now, are you going to sit in a rocking chair and just stay at home? We all should come up with something to do, otherwise we will lose the street-credibility.” Then, clips of Helle follow with her rap song (sung by a younger volunteer performer): Helle on her electric wheelchair with a personal assistant taking the elevator, crossing the road, sending mails, doing grocery shopping. It is followed by the video where Helle writes a petition to the minister by using a communication device that translates her spoken words and types in written languages. The film mixes Helle going around the neighbourhood; her talk on her life journey and artistic works; young person singing the rap song, and the process of growing beans which is an artistic installation by Jenni-Juulia. This 83-year-old woman not only subverts the ageist assumptions about older persons by choosing ‘rap,’ but also the lyric humorously and critically reveals the ageism, elder abuse, and generational conflicts by talking about old women from an ageist perspective. The lyrics go like this: “Grandmas slosh around on the road […] [with] care services–paid by my tax money! Why don’t they stay home? […] Grannies don’t need supportive services. Such don’t delight old bones. So, let’s pack the grannies nicely into paper envelopes!” (Wallinheimo-Heimonen, *Otherwise, You Lose the Street Credibility* 2016). At the end of the film, she says: “I am privileged. […] I’m probably just a slowly growing individual. There is always something fun waiting to be found.” It is evident in her works that Helle was open to new and radical ideas and appreciated and cared about people around her.

Method for Better Service (2016) is a similar short film about a middle-aged disabled woman who acquired dystonia later in her life; the film questions if disabled people would get better service from carers if they could see one's personality and their life history. This film includes a clip of street performance-protest about accessibility in Finland. According to Jenni-Juulia,[108] when she asked her friends and activists who live with disabilities to join this sort of radical performance, only five people came along and Helle was one of them. Covering their faces with a thin fabric mask, five ageing women with disabilities on wheelchairs go through a busy street of Helsinki behind Finnish National Gallery Ateneum; they pass through the crowd until they encounter the stairs at the end of the street, turn back to where they started, and put their clothes back on and take off their masks [see Figure 45]. Like the strategy of *Gala Dress* (2002), the nudity/nakedness of older and disabled bodies in public addresses the double state of old-disabled bodies, which are simultaneously invisible and hypervisible.

Figure 45. A Scene of the Street Performance Captured in the film, *Method for Better Service* (2016). Photo Credit: Jenni-Juulia Wallinheimo-Heimonen. Image description: Four women in

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[108] Wallinheimo-Heimonen, personal communication, December 27, 2022.

wheelchairs moving through a busy street in Helsinki, Finland. They are naked and only wear a mask made of a thin white fabric. Tuuli Helkky Helle is at the centre; she is wearing an adult pad and white knee socks. A number of able-bodied pedestrians are walking past them.

Her artistic and activist works are motivated and informed by her lived experience as an expert of age/ing with disability. These radical works allow us to have a critical perspective and engagement about the ableist and ageist ideas within dance industry, dominant discourses of ageing and disability, and health care systems and disability politics. Perhaps, her life-long embodied experience of falling in everyday life and in dance practices has trained her to be resilient (Albright, *How to Land*, 20). Helle raised her voice for others until the last stage of her life and her works communicate her extraordinary mind which is characterized with extensive creativity, wonder, passion, openness, and compassion for others. In 2017, she was awarded "the Kunnia-Vimma (the honor-Vimma)" by Kynnys ry (The Threshold Association)[109] for her "versatile, irreplaceable life-long works where her contribution to the development of integrated dance in Finland is central" which is given to people who has been promoting disability arts in Finland (Purhonen 4). Her life journey and ageing story reconfigure ageing as an ongoing process of becoming and living with disability as a chance to exist more relationally to others, and therefore, exemplify an alternative crip ageing future that are enabled through enhanced embodied connections and relationships. Even though I do not know Tuuli personally nor have I met her in person, I feel honoured to learn about her unique and daring life journey and arts that underscore relationality, dependency, and care between beings and environment.

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[109] The Threshold Association (or Kynnys ry in Finnish) is a cross-disability organization, which focuses on the basic and human rights of persons with disabilities. https://enil.eu/meet-kynnys-ry-the-threshold-association-our-members-from-finland/.

5.6 Conclusion: Towards Heterogenous Cultural Scripts of Ageing and Old Age

In this chapter, I explored age-critical works that address various ageing realities, which encompass age-related changes in the body and mind. Through three case studies, this research has demonstrated how theatre and performance can reflect heterogenous cultural scripts of ageing and old age. Three performances—*All the Sex*, *Gardenia*, and *Olotil*—envision theatre, performance, and dance as places to observe and showcase a range of ageing stories and bodies, both similar and diverse. These spaces are intended to be provocative and subversive, aiming to expose and disrupt ageist cultural attitudes and perceptions. As such, these contemporary works offer an opportunity to expand and reshape our consciousness and imaginations of old age. These cases have also demonstrated how theatre and performance can create a platform for marginalised subjects to raise their voices and "reveal otherwise invisible lives" (Heddon 3). While I did not include a case study that specifically engages with memory changes or living with dementia, these age-critical performances speak to the need to reflect the diverse and complex narratives of ageing and living with dementia.

The analysed performances are devised based on the lived experiences of individuals ageing within their communities. As a result, they offer intricate and culturally rich scripts of older age, which have the potential to challenge and counteract stereotypical images and narratives of ageing. The represented ageing narratives by these experts of age/ing showcase what Gullette (2011) terms "aging-as-experienced," illustrating myriad possibilities of ageing scenarios (Gullette 2018: 257). While analysing three age-critical performances and developing a theoretical framework to honour the actual aged bodies and their lived experiences staged in contemporary theatre, I proposed a new term: *experts of age/ing*. The phrase experts of age/ing recognizes the actual “consequences of time on the body” (Henderson 2016: 49); at the same time, it also centralises older people as the subjects while drawing attention to the context of contemporary theatre which often marginalises or excludes older people from its main stage practices and studies thereof. I argue that the term, experts of age/ing, allows us to recognize the heterogeneity of ageing experiences and reframe each one’s age/ing as an access point to cultural memory, political history, and social changes. Framing non-professional older performers, especially marginalised subjects, like older adults living with disabilities and divergent sexual orientations, as experts of age/ing can highlight the beauty and power of aged subjects who are willing to share their lived experiences. In these case studies, the experts of age/ing embrace vulnerability, confront ageism, counter ageist stereotypes and prejudices, challenge ageist gazes, and advocate for their rights.

I argue that more heterogenous dementia narratives can be achieved when theatre and performance draw on the actual lived experiences of older adults living with dementia, which can reflect how diverse and complex the experience of dementia can be. In *Dementia, Narrative and Performance: Staging Reality, Reimagining Identities* (2020), Janet Gibson has explored how people with dementia represent themselves and are represented in Theatre of the Real productions in Australia and the United States of America. She argues that autobiographical verbatim theatre and applied performance practices, which use “words and stories about, with, and by people living with dementia can open up discursive spaces where the ethical, political, and aesthetic ramifications of the telling of these stories can be made apparent, and perhaps altered, for the benefit of those who live with age-related dementia” (19). While it was not the focus of my research to examine how older adults living with dementia can participate in theatrical productions as creators or participants, this chapter underscores the need to further explore the ways in which theatre can provide a space for experts of age/ing with dementia to share the complexity of their lived experiences of dementia. Like these three age-critical performances that draw on lived experiences of ageing, I envision theatre and performance created in collaboration with older adults living with dementia to offer an opportunity to examine, re-shape, and transform the ideas and images of dementia. In the concluding chapter, especially in the section where I explore dementia futurity, I propose future research questions concerning a more radical inclusion of people living with dementia in theatre and performance.

Chapter Six: Conclusion

6.1 Dementia Futurity in Theatre and Performance

The intersection of arts and dementia, more specifically, the intersection of theatre and dementia, has grown a lot. Theatrical and creative practices engaging with the subject of dementia are growing, and theoretical research on these practices are also flourishing. Then, what are remaining questions? In this concluding section, my dissertation ponders about "dementia futurity," drawing on the concept and discourse on crip futurity. The notion of crip futurity counters the ableist rhetoric of future which is based on curative or reproductive terms (Kafer 2013). I call for the need to expand the notion of crip futurity to reflect on the future of persons living with dementia. Dementia is framed as a disease, which mostly occurs at the end of life, and people with dementia lack the sense of community and activist supports in comparison to other disability community or neurodiversity community (Bartlett 2014). Due to these unique positions of dementia, the future among persons with dementia is rarely discussed. We need further exploration of the intricacy, challenges, and advantages in conceptualizing future/activism for persons with dementia within the frame of a community. However, "what the dementia futurity means" is a big and complex question; so, I will narrow it down to questions that can be relevant in thinking of dementia futurity within theatre and performance—both in practices and academia.

In her article "Infrequently Asked Questions, or How to Kickstart Conversation Around Inclusion and Accessibility in Canadian Theatre and Why It Might Be Good for Everyone" (2016), Jan Derbyshire, a Canadian theatre artist who experienced a series of brain injuries midway through her career, asserts that making theatre inclusive and accessible can benefit everyone, not only people with disabilities. While she did not address dementia per se, she speaks for the necessity for theatre to enhance “disabled people’s participation as creators, participants, and patrons” (268). Although the inclusivity and accessibility of persons with dementia in theatre practices was not the research focus of this dissertation, I argue that this question should be applied to artists, staff, and audiences with dementia. Despite the abundance of contemporary work representing characters living with dementia, attempts to revolutionize and re-imagine professional theatre to include individuals with dementia have been very limited. Participation in theatre for people with dementia has been mainly in the form of therapeutic works or community-based theatre.

Analysing two Vancouver-based professional Canadian theatre productions, *The Waiting Room* (by John Mann and Morris Panych, 2015) and *Sonic Elder* (by Vancouver’s The Chop Theatre, 2016), Canadian theatre studies scholar Julia Henderson (2019) discusses how “dramaturgy of assistance” can be utilized to include performers with dementia or age-related memory loss in a way that can “foreground [their] relational and embodied selfhood, thus highlighting the performers’ musicality and relationships” (72). In my paper on the theatre-concert *STYX* (2020), presented by the UK-based theatre group The Second Body, I discuss how this production “showcases a dramaturgy that centres around acts of care (in this case intergenerational)” and centrali[s]es an older woman with dementia “as the main performer by playing her interview excerpts through voiceover” (Gillespie et al. n.p). While these studies provide some guidance, I argue that further studies are required to question what the dementia futurity in theatre should look like in consult with partners with lived experiences of dementia, and to analyse the production and presentation of creative works on dementia regarding inclusivity of people living with dementia. I would like to leave some questions for future research: What hinders participations of persons with dementia in theatre? How can the creation and performance process in theatre be re-imagined in a way with the participation of the widest spectrum of creators possible? How can theatre dramaturgy and aesthetics be renewed and innovated by including artists with dementia in the creation and performance? How can academic research of theatre and performance studies be accessible for scholars with age-related memory challenges or dementia?

In Tokyo, Japan, the Restaurant of Mistaken Orders began its business in 2017. All the servers at this restaurant live with dementia [see Figure 46]. They ask their customers to come to their restaurant with an open, accepting, and caring mindset, while anticipating potential order mistakes, with the assurance that all dishes will be delicious. This unique restaurant was founded by Shiro Oguni, a Japanese TV director, with the intention of raising dementia awareness and addressing the widespread misunderstandings surrounding dementia, as well as combating the social isolation faced by individuals with dementia ("Restaurant of Mistaken Orders").[110] Apart from adding scarce employment opportunities for people living with dementia, the initiative is an example for other businesses and communities to follow, including the Arts. Could the theatre and performance industry adopt a similar approach in creating an accessible space for both audiences and creators/performers with dementia?

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[110] See their website for further information: http://www.mistakenorders.com/en/home.html, and an article about the restaurant, Peter Georgescu, "The Restaurant of Mistaken Orders." Forbes, August 18, 2023. https://www.forbes.com/sites/justcapital/2023/08/18/the-restaurant-of-mistaken-orders/?sh=44a3fd973d5c. Accessed August 27, 2023. Shiro Oguni also created a film on this restaurant (see: https://youtu.be/su34Gx-STQk?si=8qDcsW258mJkD9Vq. Accessed August 27, 2023).

Figure 46. The Restaurant of Mistaken Orders. Tokyo, Japan. Photo Credit: Shiro Oguni.

Image description: Six photographs capture the Restaurant of Mistaken Orders and its older servers who live with dementia. Some images depict their interactions and conversations with customers.

Furthermore, revolutionising and re-imagining theatre and performance industry from perspectives of dementia means more than simply making it accessible for people living with dementia. We need more critical arts that can prompt radical shifts of perspectives regarding dementia and generate new discourses related to the future of people living with dementia other than curing and ending dementia. Alison Kafer (2013) asks, “How might we imagine futures that hold space and possibility for those who communicate in ways we do not yet recognize as communication, let alone understand? Or futures that make room for diverse, unpredictable, and fundamentally unknowable experiences of pleasure?” In an article, “Imagining a Future without Dementia” (2017), British scholar Lucy Burke, specializing in the areas of critical medical humanities, argues that “contemporary debates about ageing and dementia [in the global north] are increasingly bound up with the promissory discourses of bio-gerontology and neuroscientific epistemologies that facilitate an imaginative investment in the idea that ageing and age-related conditions such as dementia might be ‘defeated’” (7). By exploring a few contemporary novels and sci-fi films on dementia such as *Rise of the Planet of the Apes* (2011), she discusses “the potential of these texts to express utopian or socially transformative impulses" and argues that through these media, "we can perhaps begin to acknowledge the ideological limitations of the neoliberal discourses that circumscribe the ways in which we currently understand dementia and our imaginative investments in the promise of its cure" (7). Taking a cue from this statement, I argue that the contemporary theatre and performance can and should scrutinize the ideological, political, and cultural conceptualizations of dementia future that only focuses on the world 'without' dementia by curing it and, instead, expresses multiple visions of dementia futurity by using the embodied, imaginative, thought-provoking quality and potential of theatre and performance.

6.2 The Story of My Family Who Lived with Dementia: Across Time through Dementia

I would like to conclude my dissertation by sharing my artwork, *Across Time through Dementia* (2021),[111] serves as an homage to my husband's grandfather, who was a driving force behind my research on temporality of persons living with dementia [see Figure 47]. During the period of my doctoral study (2016 to 2023), my husband's grandfather, until he passed away in 2020, made me wonder about how persons with dementia experience time and reality differently, and how it has been understood by those able-minded. This artwork encapsulates my perspective and activist point of view regarding persons living with dementia, urging us to radically change the perception of dementia and to rethink different consciousness of persons with dementia as brain variation rather than disorder and deviance.

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[111] The artwork won 2nd place in the "Images of Research" Competition at the University of Alberta in 2021 and was exhibited in *Connections: Bringing Neuroscience and Art Together* (Neuroscience and Mental Health Institute, U of A). Afterwards, it was featured at the public event *Hope for Tomorrow: Research Insights into Alzheimer's Disease* at the U of A, hosted by the Alzheimer's Society of Alberta and Northwest Territories in 2023.

Figure 47. ***Across Time Through Dementia*****. Photo Credit: Heunjung Lee.** Image description: Multiple layered photos depict a man. The composite figure portrays an older man gazing forward with a faint smile, coexisting with a younger man looking upwards into the distance. The individual is dressed in a suit, featuring a coloured city image on the left and a black-and-white depiction of Canada Place in Edmonton on the right.

My husband's grandfather, Woo Tse (1922-2020), immigrated from Hong Kong to Canada. Since 1990s, he travelled back and forth between Hong Kong/Macao and Canada with his wife to maintain their permanent residency as their grandson, Andy Lam, my husband, was growing up. I met Andy's grandfather in 2016 when I immigrated to Canada—we were engaged in 2016 and got married in 2017. We had family dinner every Sunday at his parents' place where his grandfather and grandmother were living too. In the beginning, we all had dinner at a dining room on the first floor, but as both grandparents began to have difficulty with walking, Andy and I delivered their dinner to their rooms upstairs and stayed with them or helped them eating their meals. According to my mother-in-law, Andy's grandfather showed a few signs of memory changes since 2009, but the symptoms of dementia including altered time and reality perception began in 2018.

He intermittently perceived that he was in Hong Kong or that he was younger, which led him not walking with his walker and falling and even going out to the street. We had to put up a poster, saying "This is Canada, Not Hong Kong" in Chinese on the door so he would not go out to the street by himself. After my husband's grandmother passed away in November 2016 and caring for him at home was not feasible, he was moved to a care home in Edmonton in 2018. My husband and I, along with my parents-in-law, were the only family members for him in Edmonton, so we made it priority to visit him as much as possible. In particular, my mother-in-law, who is the youngest daughter of Woo Tse, devoted herself to daily visits, sometimes going twice a day for two years.

This collage-style media artwork represents the porous realities that crossed from his earlier life in Hong Kong and Macao, the period during the Second World War, and his late life in Canada. In this artwork, multiple images of him at different ages are layered together, without implying any hierarchy between younger and older selves, or between pre-dementia and post-dementia selves. Through the layered and intertwined image, I emphasise the encounter and inter(in)animation between multiple age-selves, his memories, and perceived times and places. When I layered the photos taken at multiple moments of his life, the image naturally became more empowering by reflecting his complex personalities and identities: a strict but caring, intelligent, humorous man who endured through tough times of war and immigration and was also an ambitious and successful businessman, a founding member of an oil company in Hong Kong. He had difficult times and many challenges because of his vascular dementia, but he continued to enjoy reading letters and books written in Chinese and listening to Chinese opera in the nursing home. He was a caring grandfather towards us, but still a strict father for my mother-in-law. I created this image hoping it would capture him as a whole person and not repeat the dominant tragic narrative that focuses on the loss and discontinuity of the self. From our experience, while living with dementia, he had shown his unique personalities and identities in multiple ways, and also was a becoming and changing person—he learned my name and often would remember who I am and would tell me of his trip to Korea, my home country, in the 1980s.

The orange colour in the collage highlights his perceived present—the photo of his face is taken by me in the nursing home in Edmonton in 2020, a few months before he passed away, at age 98, and the bottom part is a photo of his home country Hong Kong, taken by him in 1998. His perceived reality did not seem to be anchored on a single period; rather it was based on *syncopated time* between the past and the present. He recognised me, a relatively recently introduced family member, but at the same time, he worried about me and my husband missing the ferry connecting Macao and Hong Kong. While his reality orientation may be different from us, his affection towards me and my husband was persistent. I imagine the orange light may move at any moment and create a different version of reality. At other times, he seemed to be reliving more traumatic moments of his past, such as the period of the Second World War or the time when he suffered from poverty right after the war. When he engaged with a syncopated time, different moments were pulled together and made them punctuate each other (Schneider 2). His perception of and reaction to the environment or situation (living in a care home) seemed to be affected by his emotions of the past. For instance, it made him worry about the cost of his food and room at the care home. Moreover, when he was engaged in a syncopated time, he often misjudged his physical ability—for instance, as he perceived his age as younger than his biological age, he tried to walk without his walker which led him to fall.

Each individual's experience of dementia and temporality can be drastically different; however, what we learned from grandfather is that dementia made his different age-selves, memories, times, and surrounding people and environment *pull together* and *inter(in)animate* each other. Embodiment of a syncopated time is therefore associated with physical and psychological re/actions of persons with dementia. When our grandfather worried about us missing the ferry, we could not know for sure who he believed we were; whether his love and care are pulled back to the past or his memory and emotions from the past are pulled into the present. When a close family member's reality perception is different from our own, it can be difficult and frustrating for family members; however, similar to the portrayals of *Finding Joy* and *The Visiting Hour*, our family also learned about him and his life in a new way. In the beginning of my research, I thought he was neither here nor there; but I think it is more correct to say that he was simultaneously here and there. No matter where his perceived-experienced reality was, we could meet him if we bend our own clock and judgment.

At the public exhibition in 2023, I had the opportunity to meet with many family caregivers of persons with dementia, and a significant number of them appeared to strongly resonate with my artwork. Some shared their own stories, teared up, and expressed gratitude for the research. I believe they responded in this way because arts and humanities, including theatre and performance, possess a unique power to represent and engage with complex physical and psychological experiences of persons with dementia in a creative, affective, and embodied manner. This artwork captures my doctoral research, which critically examines and confronts mainstream knowledge and cultural understandings and attitudes that marginalise, stigmatise, and suppress alternative ways of being and living. By challenging the binary discourse that divides normal versus abnormal minds, as well as, normal versus abnormal ageing courses, this research suggests the needs to dismantle ageist and ableist assumptions and narratives regarding people living with dementia, particularly older adults. It asserts that theatre and performance can serve as a critical and provocative site to promote a more radically inclusive approach to alternative perceptions and experiences of persons living with dementia.

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