VID
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University

Dissertation no. 58
Marianne Sund

Citizenship for persons with dementia living in nursing homes:

Becoming and co-ownership in the mundane

VID

Citizenship for persons with dementia living in nursing homes: *becoming* and co-ownership in the mundane

Marianne Sund

Dissertation Submitted
in Partial Fulfilment of the Requirements
for the Degree of Philosophiae Doctor (Ph.D)

VID Specialized University

2024

VID

ISBN: 978-82-8456-072-4 (e-versjon)
ISSN: 2535-3071

Dissertation Series for the Degree of Philosophiae Doctor (Ph.D.) at VID Specialized University No. 58

Cover: Dinamo

Printed in Norway: Totaltrykk, Oslo, 2024.

VID Specialized University
post@vid.no

www.vid.no

Acknowledgements

With a year and a half left of my thesis work I read an article stating that the PhD process takes students to the cutting edge of knowledge in their chosen discipline. I remember it so vividly: stopping, reading the sentence once more, and then asking myself 'does it feel like it?'. It certainly did not, but I crossed my fingers and thought that maybe in those final months everything would fall into place, both in the text and in my mind – that I would be on top of my topic, so to speak. However, this might not be the way it works. For everything I've learnt, I've realised how much more I don't know.

I have learnt a lot, there is no question about that. However, it would not have been possible without the vast number of people involved in this process. Most importantly, I need to offer my sincere appreciation to the nursing homes that invited me into their midst and allowed me to take part in their everyday lives. I truly enjoyed my days there, getting to know residents and the caring staff and leaders that worked there. The thesis would not have been possible without my supervisors Kirsten Jæger Fjetland and Halvor Hanisch. I could not have asked for a more empathetic and encouraging team to guide me and cheer me on through these years. Thanks to my co-workers at VID specialized University, my fellow PhD candidates, my research group "Citizenship and people in vulnerable life situations" and the Bachelor of Occupational Therapy programme in which I work. Your support and encouragement have meant a lot.

However, life is more than colleagues and work. I cannot emphasise enough how important the patience and support of my fiancé Knut Olav Meling has been. Thank you for still loving me, even though I know I have been a pain sometimes the last couple of years. Thanks to my wonderful friends. You know who you are and how special you are to me! And lastly, I want to thank my family! I dedicate this thesis to my mother and father, who both passed away far too young while I was working on this thesis. They always believed in me. Thank you for bringing me to the world and for teaching me that I can achieve whatever I want if I just do my best.

Crossing my fingers and can't wait for the future!

Best wishes from Marianne

Summary of the thesis

Background: In recent years, scholars of citizenship internationally have argued that current dominant medical and care-based understandings position people with dementia solely as in need of care while not sufficiently attending to the socio-political context influencing their lives. In Norway the last two dementia plans have promoted the participation and involvement of people living with dementia in a dementia-friendly society, as well as services built on theories of person-centred care. However, they scarcely address issues of citizenship or discrimination in the nursing home context. More than 30,000 people live long-term in nursing homes in Norway. International and national research suggests that people living with dementia in nursing homes may experience that their freedom, autonomy and agency are restricted and that they may be at risk of occupational deprivation.

Purpose of the study: This thesis explores what characterises citizenship practices for persons living with dementia in nursing homes. While many discussions of citizenship are of a theoretical or conceptual nature, this thesis explores the practices of citizenship in mundane aspects of life. The thesis aims to produce knowledge about how residents in nursing homes enact and express their citizenship in ordinary and everyday circumstances and explores the possible contributions of adding citizenship theories to the interpretive practices in nursing homes. To explore the concept and phenomenon of citizenship as mundane practices I use theories of occupation and narrativity to interpret the ways in which citizenship can be materialised in practice. In doing so, the thesis aims to provide knowledge of relevance for future developments in policy and professional practices addressing issues of citizenship in this context.

Methods: Citizenship is explored as a phenomenon emerging relationally and in an embodied way in ordinary life situations. Using an ethnographic design fieldwork was conducted in two nursing homes in the south-west region of Norway. The primary method of gathering data was participant observation. In addition, individual interviews and group interviews were conducted with staff and support staff. Participant observation focused on common areas in the nursing homes and provided a strategy for including residents' perspectives in a way that did not rely on coherent language or abstract thought, recognising that both actions and verbal expressions are narrative in nature. Narrative analysis was performed, which involved constructing stories of occupational and social engagement in the nursing homes that were then interpreted through theories of citizenship, occupation and narrativity. The study was assessed by the Norwegian Regional Ethics Committee and the Norwegian Centre for Research Data before commencing.

Results: The first article of the thesis is a literature review exploring how citizenship for persons with dementia living in nursing homes is conceptualised and described in the research literature. The article concludes that citizenship practices may be under pressure from certain nursing home structures and calls for more research exploring citizenship that encapsulates both residents' apparent needs and their abilities as citizens. The second article explores how people living with dementia in nursing homes express and enact their everyday citizenship. We suggest that residents can express their citizenship through the phenomenon of *becoming*, implying a continued opportunity for development and growth, in line with own occupational potential in ordinary life situations. However, a citizenship of *becoming* emerges in vulnerable moments and presupposes that institutional perceptions of activities as something offered need to be broadened to include supporting residents' natural desires to do within the mundane. The third article explores the potentially transformative characteristics of a citizenship lens. Constructed narratives of mundane social and occupational situations in the nursing homes are interpreted in terms of an activistic lens of citizenship, acknowledging that residents can communicate desires and resistance towards environments that constrain citizenship opportunities. The findings shed light on a phenomenon of co-ownership between residents and staff that requires a professional competence in actively interpreting residents as intentional.

Discussion and implications: The discussion sheds light on the social phenomena of *becoming* and co-ownership, as well as the inclusive and exclusive tensions inherent to a citizenship lens. It is argued that the characteristics of the occupational context mean going beyond the right for, or *provision* of, occupational engagement to support residents' opportunities to act in line with own occupational potential. This requires paying attention to residents' unique ways of expressing desires and capabilities and creating occupational contexts of familiarity supporting residents' opportunities to act. Further, it is discussed that interpretive practices in nursing homes can include or exclude residents from access to participation and thus opportunities to practice citizenship. It is argued that group-based interpretations of persons with dementia, based on a lens of pathology, may limit residents' opportunities for citizenship. Applying a lens of pathology can lead us to interpret behaviour as expressing dementia, e.g., viewing withdrawal or passivity as symptoms (apathy) and thus as normal or expected. A difference between recognising residents' rights as citizens to quality services and recognising their continuous role of responsibility towards their community is discussed, highlighting the recognition of their medical needs, their need for care and safety, and their rights and capabilities as citizens. The discussion points to three possible implications of citizenship for regulations in the field, suggesting increased attention towards issues of agency, interpretive practices and discrimination in future dementia policy.

Conclusion: This study contributes to knowledge of the practices and characteristics of citizenship in the more advanced stages of dementia in the long-term care context. It contributes to increased knowledge about the occupational context of citizenship, shedding light on citizenship as vulnerable practices enacted within mundane aspects of nursing home everyday life. Theories of citizenship were found to provide a perspective in which to question current understandings and practices, challenging pathologising views and logics underlining nursing home care. This thesis adds to our knowledge of citizenship by bringing forward the phenomena of *becoming* and co-ownership. Co-ownership is suggested as an active professional and institutional responsibility to ensure that nursing homes are communities where residents are interpreted as intentional and capable, as well as supported to share responsibilities and spaces and influence occupational opportunities. *Becoming* is seen as the personal dimension of development and growth, in which people with dementia act in line with own occupational potential. In the everyday lives of people living with dementia in the nursing homes, *becoming* was found to emerge in vulnerable and fleeting moments, thus needing continuous recognition and support to be upheld. Through the work on this thesis, citizenship emerges as something more than provision of rights or occupational opportunities, but as the recognition and support of inherent and naturally occurring expressions of agency in the mundane.

Oppsummering av avhandlingen

Bakgrunn: Medborgerskapsforskere internasjonalt har senere år argumentert for at dagens dominerende medisinske og omsorgsbaserte forståelser posisjonerer mennesker med demens primært som i behov for omsorg, samtidig som de ikke i tilstrekkelig grad tar hensyn til den sosiopolitiske konteksten som påvirker deres liv. De to siste norske demensplanene fremmer deltakelse og involvering av personer som lever med demens i et demensvennlig samfunn, og tjenester bygget på teorier om personsentrert omsorg. Imidlertid tar de i liten grad opp spørsmål om medborgerskap eller diskriminering i forhold til sykehjemskonteksten. Mer enn 30 000 personer har langtidsplass i sykehjem i Norge. Internasjonal og nasjonal forskning tyder på at personer som lever med demens i sykehjem kan oppleve begrensninger i frihet, autonomi og aktørskap, og står i fare for aktivitetsdeprivasjon.

Formålet med studien: Avhandlingen utforsker hva som kjennetegner medborgerskapspraksis for personer som lever med demens i sykehjem. Mens mange diskusjoner om medborgerskap er av teoretisk eller konseptuell karakter, søker denne avhandlingen å utforske hvordan medborgerskap praktiseres i helt ordinære sider av livet. Avhandlingen søker å produsere kunnskap om hvordan beboere utøver og uttrykker sitt medborgerskap i sykehjemshverdagen, og utforsker potensialet i å legge til medborgerskapsteorier til fortolkningspraksisene i sykehjem. For å utforske konseptet og fenomenet medborgerskap, anvendes aktivitetsteori og teori om narrativitet for å fortolke måter medborgerskap kan materialiseres i praksis. Avhandlingen tar sikte på å bidra til kunnskap om medborgerskap som har relevans for fremtidig politikk og profesjonell praksis på feltet.

Metoder: Medborgerskap utforskes som et relasjonelt og kroppslig fenomen i ordinære hverdagslige situasjoner. Studien bygger på et etnografisk design og feltarbeid ble gjennomført i to sykehjem i Sørvest-Norge. Den primære metoden for å samle data var deltakende observasjon. I tillegg ble det gjennomført individuelle intervjuer og gruppeintervjuer med ansatte og støttepersonell. Deltakende observasjon fokuserte på fellesarealer og ga mulighet for å inkludere beboernes perspektiver på en måte som ikke var avhengig av språk eller evne til abstrakt tenkning, gjennom å erkjenne at både handlinger og verbale utsagn er narrative av natur. Narrativ analyse ble utført gjennom å konstruere fortellinger om beboeres aktivitetsmessige og sosiale engasjement i sykehjemmene. Disse ble fortolket gjennom teorier om medborgerskap, aktivitet og narrativitet. Studien ble vurdert av Regionale komiteer for medisinsk og helsefaglig forskningsetikk og Norsk senter for forskningsdata før oppstart.

Resultater: Den første artikkelen i avhandlingen var en litteraturgjennomgang som utforsket hvordan medborgerskap for personer med demens som bor på sykehjem konseptualiseres og beskrives i forskningslitteraturen. Artikkelen konkluderte med at visse karakteristikker ved sykehjem kan sette medborgerskapspraksis under press og det etterlyses mer forskning om medborgerskap som inkluderer både beboernes behov og evnene deres som medborgere. Den andre artikkelen utforsket hvordan mennesker som lever med demens på sykehjem uttrykker og utøver sitt hverdagslige medborgerskap. Artikkelen argumenterer for at beboerne kan uttrykke sitt medborgerskap gjennom fenomenet *becoming*, noe som innebærer mulighet for fortsatt utvikling og handling i tråd med eget aktivitetspotensial i ordinære hverdagslige situasjoner. Det beskrives at hverdagsmedborgerskap knyttet til *becoming* skjer i sårbare øyeblikk, og forutsetter at institusjonelle oppfatninger av aktivitet som noe som *tilbys* må utvides til også å anerkjenne beboernes naturlige ønsker om å gjøre innenfor det daglige. Den tredje artikkelen utforsker de potensielt transformative egenskapene til medborgerskapslensen. Konstruerte fortellinger fokusert på hverdagslig aktivitet og sosiale situasjoner i sykehjemmene ble fortolket i lys av teorier om aktivistisk medborgerskap, noe som demonstrerte hvordan beboere kan kommunisere ønsker og motstand mot omgivelser som begrenser muligheter for medborgerskap. Funnene kaster lys over et fenomen vi kaller 'co-ownership', eller med-eierskap, mellom beboere og ansatte, noe som krever en faglig kompetanse i å aktivt fortolke beboere som intensjonelle.

Diskusjon og implikasjoner: Diskusjonen kaster lys over de sosiale fenomenene *becoming* og co-ownership (med-eierskap), i tillegg til inkluderende og ekskluderende spenninger som synes å være iboende karakteristikker ved en medborgerskapslense. I lys av den aktivitetsmessige konteksten argumenteres det for et behov for å gå utover retten til, eller tilbud om, aktivitet, mot å støtte beboernes muligheter og evner til å handle i tråd med eget aktivitetspotensial. Dette krever oppmerksomhet mot beboernes unike måter å uttrykke ønsker og evner på, og familiære aktivitetskontekster som støtter opp om beboernes mulighet til å handle. Videre diskuteres det at fortolkende praksiser i sykehjem kan inkludere eller ekskludere beboere fra tilgang til deltakelse og dermed muligheter for å praktisere medborgerskap. Det argumenteres for at gruppebasert fortolkning av personer med demens, basert på patologi, kan begrense beboernes muligheter for medborgerskap. En patologiserende forståelse kan bidra til at vi tolker atferd som uttrykk for demens, for eksempel ved at en ser tilbaketrekning eller passivitet som symptomer (apati) og dermed som normalt eller forventet. Forskjellen mellom å anerkjenne beboeres rettigheter til tjenester av høy kvalitet og å anerkjenne deres kontinuerlige muligheter til å bidra til deres nærmiljø diskuteres, noe som fremhever anerkjennelsen av både medisinske behov, behov for omsorg og trygghet, og beboernes rettigheter og evner som borgere. Diskusjonen peker på tre mulige implikasjoner av medborgerskap for politiske reguleringer på feltet, og foreslår økt fokus på aktørskap, fortolkende praksiser og diskriminering i fremtidig politiske føringer på demensfeltet.

Konklusjon: Denne studien har bidratt til kunnskap om praksiser og kjennetegn ved medborgerskap i mer fremskredne stadier av demens i sykehjem. Avhandlingen bidrar til økt kunnskap om den aktivitetsmessige konteksten for medborgerskap, og kaster lys over medborgerskap som sårbare praksiser i ordinære sider av hverdagslivet. Teorier om medborgerskap bidrar til nye perspektiver og spørsmål til gjeldende forståelser og praksis, og utfordrer patologiserende forståelser og logikker i sykehjem. Avhandlingen bidrar til økt kunnskap om medborgerskap ved å bringe frem fenomenene *becoming* og co-ownership. Co-ownership foreslås som et aktivt profesjonelt og institusjonelt ansvar for å sikre at personer som bor i sykehjem fortolkes som intensjonelle og som mennesker med kompetanse. *Becoming* sees som en personlig dimensjon for utvikling og vekst der personer med demens kan handle i tråd med egen aktivitetskompetanse. I hverdagslivet til personer med demens i sykehjem fremsto *becoming* som et sårbart og flyktig fenomen som trengte kontinuerlig anerkjennelse og støtte for å muliggjøres. Gjennom arbeidet med denne avhandlingen fremstår medborgerskap som noe mer enn å bli gitt rettigheter eller aktivitetstilbud, men som en anerkjennelse og støtte av beboernes iboende og spontane uttrykk for aktørskap i det daglige.

List of articles

Article 1 – published:
Sund, M., Hanisch, H., & Fjetland, K. J. (2022). Citizenship for persons with dementia in nursing homes: A literature review. In K. J. Fjetland, A. Gjermestad, & I. M. Lid (Eds.), *Lived citizenship for persons in vulnerable life situations: Theories and practices* (pp. 29–45). Scandinavian University Press. https://doi.org/10.18261/9788215053790-2022-02

Article 2 – published:
Sund, M., Jaeger Fjetland, K., & Hanisch, H. (2023). Within moments of *becoming* – Everyday citizenship in nursing homes. *Scandinavian Journal of Occupational Therapy*, *30*(2), 239–250. https://doi.org/10.1080/11038128.2022.2085621

Pre-published online June 2022.
Referenced in text as Sund et al. (2023a).

Article 3 – published:
Sund, M., Hanisch, H., & Fjetland, K. J. (2023). Activistic citizenship in nursing homes: Co-ownership in the mundane. *Dementia*, *22*(3), 594–609. https://doi.org/10.1177/14713012231155307

Pre-published online January 2023.
Referenced in text as Sund et al. (2023b).

Table of contents

ARTICLES OF THE THESIS

1.0 INTRODUCTION

She looks at me and smiles, says she hasn't seen me before. I confirm, this is my first day. I shake her hand and present myself as Marianne. May tells me she likes it here, they take care of her, and the food is very good! She asks if I have been well received, she seems concerned if I feel included. A moment later breakfast is ready. May takes my hand and tells me to follow her. She shows me where I can sit, while pointing out her place at the table.
(Meeting May at Sunny Hill Nursing home)

May is an older lady, living at one of the local nursing homes in her town. Her everyday story is not one of a kind, nor the stuff of headline news. Rather, it is quite ordinary and perhaps easily taken for granted. Still, such narratives of ordinary life may hold power: the power to impact societal stories of inability and loss in dementia and to acknowledge that being old or living in a nursing home does not mean you stop being or *doing* who you are. This thesis is about her, and other residents living at Sunny Hill and Sea-Crest nursing homes, and what they can teach us through their ordinary lives.

1.1 Aims and main purpose of the study

This doctoral thesis explores the research question; *What characterises citizenship practices for persons living with dementia in nursing homes*? Against the background of reports, stories and research problematising discriminatory living conditions in the nursing home context, an ethnographic field study was conducted to seek insight into mundane aspects of nursing home living. Through fieldwork in two nursing homes, Sea-Crest and Sunny Hill, I got to spend time with residents like May to try to understand how she and other residents enacted, and expressed their citizenship, within their everyday lives.

Through the articles of the thesis, a lens of citizenship (Bartlett et al., 2010; Nedlund et al., 2019a) turns our attention towards residents' capabilities and opportunities for participation and agency in mundane aspects of everyday life. Agency is understood as the ability to initiate social action (Boyle, 2014) and is viewed as key to ensuring equality for people living with dementia (Nedlund et al., 2019a, p. 5). The thesis builds on an understanding of humans as occupational (Wilcock & Hocking, 2015) and narrative (Baldwin, 2008) beings. Occupation is defined as all the things people do through their lives (Wilcock & Hocking, 2015) and can be a means for people to express who they are to themselves and others (Laliberte-Rudman, 2002). Constructing narratives centred on residents' everyday lives, this thesis questions and theorises on how citizenship can be practiced within mundane aspects of nursing home living.

The thesis connects and discusses empirical, theoretical and socio-political conditions influencing people's lives using a theoretical framework of citizenship, occupational theory and narrativity to ground theories of citizenship in nursing home everyday life. Through this I aim to increase our insights into how residents living with dementia in nursing homes enact and express their citizenship in ordinary aspects of the everyday. In doing so, I seek to produce knowledge of relevance for future developments in policy and for professional practices addressing the issues of citizenship in this particular context. The first part of the introductory chapter provides some background and a rationale for conducting this study, engaging with central theoretical, political and social conditions in an attempt to answer the following question: "*Why is a study of citizenship for persons in nursing homes necessary*?"

1.2 Why is a study of citizenship for persons in nursing homes necessary?

> *Alzheimer's disease and related disorders are one of the most disabling and burdensome health conditions worldwide, making it one of the most daunting and significant global health challenges of our day.*
> *(Gitlin & Hodgson, 2018, p xxi)*

This is how the preface of the book *Better Living with Dementia* begins. It depicts a master narrative of loss and, not least, of the costs, both economic and personal, for people living with dementia, their families and society. However, this narrative is not rare. Estimated demographic changes in the years to come predict increasing numbers of older people in the population, as well as increasing numbers of people who will be diagnosed with dementia. The World Health Organization (WHO, 2017) reported that in 2015 around 47 million people were living with dementia internationally, with an expected increase to 75 million by 2030. Recently published numbers on the prevalence of dementia estimated that 101,118 people were living with dementia in Norway in 2020, a number projected to increase to 236,789 by 2050 (Gjøra et al., 2021).

Dementia is an umbrella term for several diseases affecting memory, other cognitive abilities and behaviour and interfering with the ability to maintain activities of daily living as before (WHO, 2017). Most people with dementia will at some point require help, support, medical assistance and care from municipal health and care services. Rokstad (2014) writes that while people do experience dementia differently, many describe it as a great strain that causes insecurity, anxiety and fear in the face of their gradual deterioration (p. 11). Vossius et al. (2015) report that in Norway, half the people diagnosed with dementia move to a nursing home within three years. According to the Norwegian Central Statistical Office (2022) 39,054 people currently reside in nursing homes in Norway and 31,607 of these are long-term placements. Estimates suggest that around 80% of residents in Norwegian nursing homes may have dementia (Bergh et al., 2012), and their average stay in a nursing home is 2.1 years (Vossius et al., 2015).

The current Norwegian dementia strategy (Norwegian Ministry of Health and Care Services, 2020) aspires to create a dementia-friendly society wherein people with dementia have the opportunity to participate in the community, live active and meaningful lives and be involved in decisions that concern them. It states the importance of combating stigmatising perceptions of dementia in society and ensuring services built on person-centred theories and respect for individuals' identity and needs. However, as this thesis will demonstrate, such political aspirations in the dementia and nursing home field might face challenges, both in Norway and internationally. The following section will shed light on some of these challenges, turning attention towards three themes of relevance for the exploration of citizenship in this study. To begin, I position the thesis in an international conversation critiquing how our paradigms of understanding might uphold stigmatising perceptions of dementia in society, in turn reducing people's opportunities in everyday life. Next, I turn my attention towards aspects of the Norwegian context in which this study took place with a particular focus on some of the strategies and policies underpinning the Norwegian dementia and nursing home sector. Lastly, previous research and reports have brought forward some challenges and aspirations from the perspective of people living in nursing homes, shedding light on everyday structures, routines and perceptions that may create discriminatory living conditions in long-term care settings.

1.2.1 Paradigms of understanding – challenging the master narrative of loss

> *I was told 'to give up work, give up study, and to go home and live for the time I had left'.*
> *(Swaffer, 2015, p. 3)*

O'Connor and Nedlund (2016) describe that the focus on citizenship represents a fourth turn in the development of understandings around dementia, from first being recognised predominantly as a natural sign of aging (senility) to being constructed as primarily a biomedical condition. Understandings continued to shift towards a more relational perspective, in which people are seen beyond their medical condition, to now recognising the importance of seeing dementia within a broader socio-political context. Throughout work on this thesis an important reflection has centred on how developments in our theories and understandings in society, professional practice and research can influence master narratives and assumptions, in turn affecting the lives people are enabled to live.

In their book *Broadening the Dementia Debate*, Bartlett et al. (2010) promote the social citizenship of people living with dementia. They describe how the medical paradigm has provided, and continues to provide, vital knowledge to the field of dementia, for example that medicalisation has led to refined diagnostic procedures and treatments that can slow progression of some dementia disorders (pp. 17–18). In addition, advancements in understanding the pathology of cognitive impairment and the work towards a cure in the years to come is highly important. However, as several authors in the citizenship field (Baldwin, 2008; Bartlett et al., 2010; Hydén & Antelius, 2017) have pointed out, a challenge emerges when we view people solely through a medical lens as it leads us to focus on disease. According to Cahill (2018, p. 128), this may lead to care dominated by clinical management, drug-treatment and policies of control and restriction.

The emergence of a theory of person-centred dementia care (Kitwood, 1997) in the 1990s can be seen as a reaction to the dominance of a reductionist medical paradigm. Bartlett et al. (2010) describe how it provided a framework for recognising the person as intrinsically worthy of respect and helped shift understanding of dementia from a medical to a humanistic perspective. They continue, explaining that the personhood approach theorises that some of the deterioration that we see are not caused by the disease itself but by how people are treated, causing loss of personhood. This recognises that performance, behaviour, and quality of life are not only determined by neuropathology but also by personal history, interactions and how people are perceived (pp. 18–21).

However, the person-centred approach has been criticised for not sufficiently addressing how the socio-political context influences the lives of people with dementia. In 2007 Bartlett and O'Connor published an article shedding light on some of the less known limitations of the personhood understanding. They argued that since personhood is an apolitical concept concerned with psychosocial issues within the individuals' immediate care environment, it lacks a political dimension. This fails to capture how wider social forces influence the lived experience of dementia and does not promote the vision of people with dementia as holding agency. Similarly, Kaufman and Engel (2016) argue that Kitwood's conceptual framework of psychological needs and well-being in dementia needs to be extended by adding the domain of agency, while Harnett and Jönson (2017) demonstrate that the focus on person-centredness may play into an ageist dynamic that is difficult to detect and combat due to the comparisons used to establish what constitutes a normal life. They argue that there is a strong tendency to define normality and justice by comparing residents and explain limitations as caused by the aging body rather than the organisation of support.

A range of authors have contributed to the conversation on the rights, and opportunities, of people with dementia and argued in favour of a citizenship lens recognising their social and political rights (Baldwin, 2008; Baldwin & Greason, 2016; Bartlett & O'Connor, 2007; Bartlett et al., 2010; Nedlund et al., 2019ab). In a recent scoping review exploring how citizenship has been defined and applied in dementia research, O'Connor et al. (2022) revealed four core themes underpinning citizenship discourse. The relationality of citizenship was foundational in all the reviewed literature. Facilitated agency and autonomy was a major theme, while a clearly defining feature of citizenship was the emphasis on positioning stigma, discrimination and exclusion as critical aspects of the dementia experience. The last theme was the recognition of possibilities for identity and growth as an inherent right and being able to participate in life in meaningful ways. In their qualitative meta-study exploring what enables or hinders social citizenship within the everyday occupations of people living with dementia, Peoples et al. (2023) conclude that contextual factors relating to society, culture, justice and everyday life can promote and prevent a sense of social citizenship when living with dementia. They call for inclusive communities that provide occupational opportunities and view people with dementia as citizens with fundamental rights to participate and contribute as valuable members of society. However, people living with dementia may experience that reductionist perceptions of their abilities can limit such opportunities. This chapter starts with a quote from an editorial by Swaffer (2015) exemplifying how societal understandings may influence people's opportunities. She writes that, following a diagnosis of dementia, she was told to give up work, give up study and go home and live for the time she had left. She later termed this Prescribed Dis-engagement, arguing that it sets people with dementia up for a life without any sense of hope or future, positioning them as victims or sufferers and increasing experiences of stigma and discrimination.

Publications and reports in the field of citizenship and dementia highlight the way reductionist master narratives can constrain people's opportunities for participation, self-determination and fundamental freedoms within society. Andrews (2004) writes that the power of master narratives derives from their internalisation. As such, the main stories of our societies, established over time, may be taken for granted as *truth*. As underlined by this international conversation, a paradigm shift towards citizenship might provide an added perspective that could challenge some of these internalised master narratives and help us recognise that people's lives are influenced both by perceptions of dementia, factors in our immediate environments, as well as the socio-political contexts in which our lives are lived. While the primary empirical data of this thesis centres on lived everyday life in nursing homes, societal perceptions and government policy contextualises these lived experiences in a certain cultural and professional context. The following section therefore outlines some central aspects in relation to Norwegian dementia and nursing home policy.

1.2.2 Norwegian policy – dementia-friendly society and person-centred care

> *People with dementia should be able to live safe and active lives. This applies regardless of the progression of the disease, and regardless of them living in their own home, in a nursing home or in assisted housing. Life should still be enjoyed and lived as long as possible…*
> *(Norwegian Ministry of Health and Care Services, 2020, p. 35, my translation)*

Both national and international policy promote the participation and self-determination of people living with dementia. Through their global action plan on the public health response to dementia, the World Health Organization (WHO, 2017) promotes a vision of a world in which dementia is prevented and where people receive the care and support they need to live with meaning and dignity. In Norway, three dementia strategies have been published in the past fifteen years. The last two, Dementia Plan 2020 (Norwegian Ministry of Health and Care Services, 2015) and Dementia Plan 2025 (Norwegian Ministry of Health and Care Services, 2020), both promote an overarching goal of a dementia-friendly society where people can participate and experience as much self-determination and autonomy as possible. Societal stigma is described as a barrier that takes a toll on individuals and their families, leading to the development of information campaigns directed at Norwegian society. The policy promotes aging in place and receiving necessary services and support in one's own home for as long as possible.

When developing the Norwegian dementia strategy (Norwegian Ministry of Health and Care Services, 2020), policymakers sought the experiences and perceptions of people living with dementia and their families. Many experienced loneliness and lack of self-determination, participation, and meaningful everyday content in their lives, both in nursing homes and in their own homes. While Norwegian policy has promoted the provision of activities and social engagement within services over time, Kjøs and Havig (2016) concluded that the policy of increasing activities in nursing homes has not succeeded. They suggest that this is a complex matter and may require a fundamental change in staff culture. As one of five main areas of attention, the Norwegian quality reform titled "A full life – all your life'" (Meld. St. 15 (2017–2018)) promotes activities and community for both people living in their own home and those living in nursing homes. Responding to the challenge of loneliness, inactivity and lack of individually tailored activities, services should support 'meaningful moments' by ensuring older people are offered at least one hour of activity per day, amongst other measures. As part of the knowledge foundation for the quality reform, a report by Sudmann (2017) stresses the importance of challenging myths of the old as passive and dependent, which in turn influences the way they are met and treated within services.

Norwegian municipalities are obligated by the Health and care services act (2012) to provide nursing home services that ensure necessary and justifiable standards of health and care. The current Norwegian dementia plan (Norwegian Ministry of Health and Care Services, 2020) recommends that nursing home units for people living with dementia should be small-scale and tailored for their particular needs, supporting social interaction, autonomy and homeliness. The dementia plan explicitly identifies person-centred care as the standard to be achieved, whereas methods and communication techniques from person-centred theories form the basis of the national guideline for dementia and are recurring themes in teaching materials in the field. The dementia strategy does not explicitly address the concepts of citizenship or agency, and while the national Dignity guarantee (2011) states that services should strive to facilitate a life that is as normal as possible, what constitutes such *normal* in nursing homes is scarcely addressed in recent government reports.

Another topic that emerges as relevant in the exploration of citizenship in nursing homes is the position of universal human rights principles in Norwegian dementia policy. According to WHO (2017), policies and actions should be sensitive to the needs, expectations and human rights of people with dementia, consistent with the United Nations Convention on the Rights of Persons with Disabilities, hereafter named the CRPD (UN, 2006). This convention aims to combat discrimination against people with disabilities in relation to their right to full and effective participation in society. Norway sent its first report on the implementation of the CRPD to the UN committee in 2015 (Department of children, equality and inclusion) with the aim of providing a general picture of Norwegian policy for persons with disabilities. It mentions dementia in terms of chapter 4A of the Patient and User Rights Act (1999), which allows compulsory medical treatment when a person is not competent to give consent and refuses treatment. In addition, they state the importance of protecting residents in residential care homes against abuse and violation of integrity through ensuring sufficient qualified personnel recourses. Above this they scarcely address the living conditions for people with dementia within residential care homes or nursing homes in terms of the articles of the CRPD. An alternative report was issued for the civil sector (CRPD Coalition, 2019). While institutionalisation for other citizens of Norwegian society, e.g., for people with developmental disability, are critiqued, it is not explicitly discussed in terms of older persons or persons living with dementia. In a supplemental report from the Representative for equality and discrimination (2015), Sunniva Ørstavik asks why we allow the human rights of people with disabilities to be so systematically breached, arguing that it is because the paradigm shift has only happened on paper:

> We allow breaches because we still see persons with disability as a production error. The paradigm shift, which we write much about in this report, has only happened on paper. The Government still thinks it is functional ability, not discrimination, that makes people disabled. They do not see that the fault is in society. In our prejudices and barriers. In us. (p. 5, my translation)

Sunniva Ørstavik acknowledges that we are in a paradigm shift but claims that this shift has only happened on paper. But does this shift (on paper or in practice) include the dementia and nursing home context? In their report on human rights in Norwegian nursing homes, Kjørholt et al. (2015) argue that human rights standards have received limited attention in discussions about care for the older population and have scarcely been used as part of the framework it builds on. Kjørholt et al. (2015) further question whether, or to what extent, the rights enumerated in the CRPD would apply to residents of nursing homes.

Although WHO (2017) promotes the recognition of dementia as a disability and people's entitlement to the rights put forward in the CRPD, the current dementia plan (Norwegian Ministry of Health and Care Services, 2020) engages neither the articles or the purpose of the CRPD or the term discrimination in relation to the nursing home. The political documents and policy of the dementia field in Norway do highlight the importance of quality medical services, person-centred care, self-determination, and participation in people's everyday lives. Meanwhile, discussions of *how* to ensure residents can be active participants in their own everyday life, as citizens with agency rather than patients with needs within the nursing home context, remain scarce.

1.2.3 Living in nursing homes – a call for agency

> *When you're at home you can talk and walk around just as you want. If you want a piece of bread or a glass of milk, you go . . . that's how I do it when I am at home.*
> *(From the article "Like a prison without bars" by Heggestad et al., 2013a, p. 887)*

In the last several decades, an increasing amount of research has been conducted from residents' perspectives, exploring their experiences of living in nursing homes. In the study by Heggestad et al. (2013a), Eli, one of the residents of the nursing home unit, told the researcher that being at home means you can talk and walk around as you like. The study reported that several residents expressed feeling like their freedom was restricted, experiencing feelings of captivity and homesickness, An article by Bradshaw et al. (2012) reports that residents expressed concerns about lack of autonomy, while Cook et al. (2015) describe that residents wanted a *full life* in addition to good quality care, including being allowed to determine what they valued and achieve the things that mattered to them. Milte et al. (2016) identified access to meaningful activities and opportunities to feel useful and valued as important ways to support personhood in residential care, as well as having as much independence, autonomy, and flexibility in daily routines as possible. However, while Kielsgaard et al. (2021) demonstrate how meaningful engagement might be a way for people to connect to self, others and place, their analysis reveals a thin line between engagement and occupational deprivation.

Research demonstrates that people living with dementia in nursing homes are at risk of occupational injustice (Du Toit et al., 2019; Morgan-Brown et al., 2019), may experience loneliness, isolation and a search for home (Cahill & Diaz-Ponce, 2011) or find nursing home life boring (Mjørud et al., 2017). Meanwhile, O'Rourke et al. (2015) report that one factor that influenced quality of life from the perspective of people with dementia was the theme agency in life today. This was defined as the ability to express oneself and to experience autonomy and independence in day-to-day living and being able to determine the structure of daily activities, have a direction in life or achieve one's goals. Dekker and Pols (2020) demonstrate how aspirations of creating home in the nursing home produces continuous negotiations between public and private space, between feeling at home and professional care, and between objects and routines feeling homely or institutional. They argue that one way of relating home and institution is the integration of everyday rhythms of familiarity and efficiency. Home-making required attention to social interactions and rhythms, with the activities of preparing meals and eating together in particular being valued.

Still, publications shed light on how institutional structures, routines and pathologising perceptions of dementia may lead to restrictions in nursing homes. Inflexible local routines can constrain residents' opportunities to influence their own everyday life (Harnett, 2010) and lead residents to change previous everyday habits to try and adapt to the routines of the care home (Eyers et al., 2012). Persson and Wästerfors (2009) report that all staff in their study described how, in theory, residents could make decisions for themselves and had the same rights as everyone else. However, their analysis showed that when the needs of the individual resident collided with the interests of the institution as a whole, institutional routines were prioritised. An international critique has also highlighted the challenges of a reductionist medical model, turning attention towards how pathologising perceptions can create discriminatory living conditions for people with dementia. Dupuis et al. (2012) demonstrated how staff filtered the behaviour of people with dementia through a lens of pathology, which in turn guided how they understood the behaviour and reacted to it. The behaviour of residents without dementia was almost always viewed as intentional, while only selected behaviours from residents living with dementia were viewed the same way.

Steele et al. (2020) argue that the cultural understanding of dementia informs the day-to-day choices made by care home staff and family and that: "If we envisage these compounding factors in terms of concentric circles, then at the very core sit profoundly troubling views about the ontology and epistemology of people living with dementia—who they are and can be, and what they can know and want" (p. 16). They further describe how respondents in their study expressed assumptions that people with dementia could not know or express their own views and needs, and that a pathologising lens positioned certain behaviours as symptoms of dementia, in turn legitimising restriction. However, as Capsticks and Chatwin (2016) suggest, we might be observing a shift from a biomedical perspective that views behaviour as symptoms, to recognising it as a form of cultural resistance:

> …the emergent socio-political model recognises that much of the verbal and non-verbal communication of people with dementia is agentic, and is either a protest against their situation or a way of keeping self-esteem and a sense of personal efficacy alive in unpropitious circumstances. (Capsticks & Chatwin, 2016, p. 171)

This thesis seeks to explore and produce knowledge about this shift by analysing narratives of ordinary nursing home living. An important part of this investigation was to explore the current state of research-based knowledge about citizenship for people living with dementia in nursing homes which the thesis could build from. A literature review seeking to reveal gaps in our current knowledge is therefore presented in the next chapter.

1.3 Literature review – citizenship in nursing homes

[T]he everyday citizenship of people living in care homes requires urgent scrutiny. In this living environment, everyday activities typically become either a "therapy" or a potential risk.
(Nedlund et al., 2019b, p. 93)

In the first part of the introduction, I have provided arguments for why a study on citizenship is called for. In this section, I present an overview of the identified research focused on citizenship for people living with dementia in nursing homes. In their book about everyday citizenship, Nedlund et al. (2019ab) explore citizenship for people living with dementia in their own home. In the closing chapter, they call for the urgent scrutiny of citizenship in care homes, arguing that residents have few opportunities to experience it. Similarly, through their scoping review, O'Connor et al. (2022) found that most of the identified articles were focused on citizenship in the early stages of dementia. Considering that certain nursing home characteristics might challenge citizenship practices, I wanted to investigate how citizenship has been explored in the research literature in terms of this particular context.

This chapter builds on the work of the first article of the thesis (Sund et al., 2022), in which 15 articles published through 2019 were reviewed. This article situates the identified publications on citizenship within a critique of reductionist paradigms of understanding in the field. It discusses how citizenship practices may be under pressure from certain nursing home characteristics, such as inflexible institutional regimes, or limited in accordance with perceptions of abilities. The article concludes that multiple perspectives are needed to understand everyday life in a way that encompasses both people's needs and their abilities. In addition to the articles included in that particular publication, a repeated search was conducted in April 2022, in which five new articles of relevance were identified. In the following chapter, I start by providing a brief overview of how these 20 articles conceptualise citizenship for people living with dementia in nursing homes. In the second half of the chapter, I identify certain gaps in the current knowledge within which the thesis is positioned.

1.3.1 Conceptualisations of citizenship

Eleven of the identified articles explicitly explore, build on or extend on the conceptualisation of social citizenship in dementia, defined by Bartlett et al. (2010) as

> [a] relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood rights and a fluid degree of responsibility for shaping events at a personal and societal level. (p. 37)

A Canadian research environment, through a series of articles, has introduced a relational model of citizenship that builds on social citizenship and explicitly recognises the long-term care context (Kontos et al., 2016; Kontos et al., 2017; Grigorovich & Kontos, 2018; Kontos & Grigorovich, 2018a; Kontos & Grigorovich, 2018b; Grigorovich et al., 2019; Kontos et al., 2020). Kontos and Grigorovich (2018b) and Kontos et al. (2017) write that their model extends social citizenship by drawing on insights from the theoretical subfield of embodiment and dementia. Kontos et al. (2016; 2018) outline the tenets of the model, the first of which is embodied selfhood, underlining the body's capacity to perceive and experience, recognising its creative and intentional capacity. The second tenet of the model, relationality, captures the interdependence and reciprocities that underpin caring relationships. Connecting relationality with embodied selfhood turns attention towards the ways we interact in the world through our bodies. This is exemplified in the article by Kontos et al. (2017), which shows how creativity registered no meaning for Joseph – one of the residents – until he was tactically involved through his body. Two additional articles identified in the review were found to explicitly draw on this work on relational citizenship (Robertson & McCall, 2020; Bradwell, 2021), both focused on the arts.

Canning and Blakeborough (2019) argue that arts-based programming, such as intergenerational dance, provides support for social citizenship through creating and facilitating opportunities for meaningful social engagement. Lee and Bartlett (2021) build on and extend social citizenship, arguing that, to date, it has lacked a material lens and practical application for successful implementation in a care context. They introduce the concept of "material citizenship", arguing that object relations are a critical but overlooked site for citizenship. They define material citizenship as "the right to be included in decision-making relating to personal possessions and the right to have opportunities to use functional objects to perform everyday tasks" (p. 11). Baldwin and Greason (2016) introduce micro-citizenship in the long-term care context for people living with dementia. They argue that micro-citizenship resonates with the concept of social citizenship, while explicitly acknowledging the institutional context. They describe micro-citizenship as "those actions and practices of individuals, in immediate relationships, which uphold the liberties and freedoms of those involved while generating or supporting a sense of identity and belonging" (p. 293).

Other conceptualisations of citizenship brought forward in the articles are cosmopolitan (or inclusive) citizenship, which Marsh et al. (2018), referring to Grenier (2017), describe as involving more than just treating people with care and compassion, but ensuring inclusion, agency and negotiation, even when agency is considered to be reduced due to cognitive impairments. Ward et al. (2016) build on an understanding of an emplaced, embodied and performative approach to citizenship, and focus particularly on spatial, temporal and embodied dimensions to resistance emerging in the everyday. Simpson et al. (2018) explore sexual citizenship, focused on attitudes and rights in regards to sexuality and intimacy for older persons living in care homes. The interview-based study highlights the citizenship rights of care home residents of having their sexuality and intimacy needs recognised and met. Gjødsbøl et al. (2017) connect citizenship to civil participation in society, describing how the severe mental and physical disability of residents in their study meant that they were incapable of cultivating the societal bonds central to the Danish notion of the citizen. However, the authors argue that residents' life worth was established when residents gained qualities of personhood and agency through substitution processes carried out by staff.

Ursin (2017) and Ursin and Lotherington (2018) promote a collective and distributed understanding of citizenship. In Ursin's (2017) article, she shows how citizenship can be realised as an effect between social (e.g., family, professionals, friends) and material actors (e.g., food lists, journals, taxi-cards). Citizenship is thus not merely created in social relations but as an effect of socio-material practices that the person with dementia is part of shaping. Ursin and Lotherington (2018) argue that, while many conceptualisations of citizenship apply a relational approach, they continue to conceive of citizenship as a capacity pertaining to the individual: “Our aim is to demonstrate a possible way to eradicate the individual as the holder of citizenship, and to promote a collectivist and distributed understanding” (p. 62).

Two studies identified in the overview connect citizenship with occupational justice and occupational engagement in the exploration of nursing homes. Morgan-Brown et al. (2019) promote residents’ rights to engagement and social interaction, arguing that the deprivation of choice or experience in valued occupation is seen as occupational injustice and thus a human rights and citizenship issue. Bergström et al. (2021) report that over half of individuals with dementia living in the nursing home included in their study had two or more occupational gaps. They argue that occupational therapists, with their unique theoretical knowledge, can facilitate participation in occupations, in turn supporting the citizenship of nursing home residents.

1.3.2 Identifying the knowledge gap and positioning the thesis

A thematic overview of the publications presented in this chapter reveals that three of the articles address citizenship in terms of sexuality (Kontos et al., 2016; Grigorovich & Kontos, 2018; Simpson et al., 2018): one in terms of the resident-to-resident aggression discourse (Grigorovich et al., 2019) and seven in terms of arts and creativity. The articles centred on arts and creativity, focuses on dance and dementia (Kontos & Grigorovich, 2018a), musicality (Kontos & Grigorovich, 2018a), interventions involving “elder clowns” (Kontos et al., 2017; Kontos et al., 2020), an arts-based group intervention using a creative activity toolkit (Robertson & McCall, 2020), intergenerational arts – focused on one moment in a drama-based exercise (Bradwell, 2021) and intergenerational dance (Canning & Blakeborough, 2019). The latter interpreted data from weekly ballet classes in which residents with dementia and children took part. In important ways, these studies shed light on how citizenship can be supported creatively, through co-construction and the competency and intentionality of the body. However, they neither encapsulate nor explore how residents can act as citizens with agency within mundane situations in the nursing home, which is the focus of this PhD study.

Other articles explicate, and demonstrate, how citizenship can be practiced in specific places, such as the community garden (Marsh et al., 2018) or the care-based hair salon (Ward et al., 2016). Marsh et al. (2018) report that residents participated in unexpected ways and appeared to feel freer in the community garden then inside the walls of the residential care setting. I interpret this to indicate that there might be characteristics about the institutional setting in itself that should be explored if we are to support residents’ opportunities and abilities to act in citizenship ways. Morgan-Brown et al. (2019) argue that common areas of residential care can provide valuable resources to support active citizenship, promoting the citizenship rights of residents for occupational and social engagement. However, the two articles that explore and connect citizenship to the occupational lens do so instrumentally, by measuring degree of social and occupational engagement (Morgan-Brown et al., 2019) and degree of occupational gaps between doing and wanting to do, as reported by proxies (Bergström et al., 2021). While these publications shed light on the occupational rights of people with dementia, they do not provide insights into how residents can practice their citizenship through mundane occupational practices or the characteristics of such practices.

Several studies do turn attention towards more mundane aspects of nursing home everyday life. Baldwin and Greason (2016), in promoting micro-citizenship, argue that it can be realised in both active and passive ways. Actively, residents might engage in and contribute to the everyday chores or be involved in the governance of the nursing home. In outlining the more passive realisations of citizenship, the authors describe how meaning and identity can be brought together through narrativisation. To illustrate micro-citizenship, Baldwin and Greason (2016) draw on data from focus groups with staff in nursing homes. This thesis, on the other hand, explores such mundane citizenship practices by turning attention towards the actions and expressions of residents within the everyday routines of nursing homes, aiming to produce knowledge on how they might characterise mundane forms of citizenship. Both Lee and Bartlett (2021) and Gjødsbøl et al. (2017) use ethnographic methods to explore nursing home everyday life. Lee and Bartlett (2021) centre their attention on materiality and the role of functional objects as a mechanism for citizenship, while Gjødsbøl et al. (2017) focus on how residents gain qualities of agency and personhood through the actions and interpretations of staff in care. These studies do not pay particular attention towards how residents themselves act, move and express themselves in the nursing home context.

The publications by Ursin (2017) and Ursin and Lotherington (2018) provide insights into how the social and material create opportunities for citizenship. In terms of this thesis, this relationship sheds light on occupation as a social, material and mundane phenomenon. However, the authors investigate citizenship through interviews with next-of-kin and professionals, not by turning attention towards the ways people with dementia act in the nursing homes. In addition, while their study privileges agency as collective and distributed through care collectives – focused on what it is that makes citizenship happen compared to studying what citizenship is – further exploration is needed around what characterises practices of citizenship in nursing homes, highlighting the abilities of, and opportunities for, citizenship in mundane aspects of life.

1.3.3 Brief summary and the way forward

This overview of studies exploring or conceptualising citizenship in the context of people living with dementia in nursing homes demonstrates that the lens of citizenship has been increasingly used to frame research since the first identified publication by Baldwin and Greason in 2016. Analysing the perspectives of citizenship, there is an overall recognition of the fundamental relational aspects of citizenship in the articles. Citizenship is recognised as influenced by the macro and micro contexts of nursing homes, in terms of both political, structural and immediate physical and social environments. Reviewing the articles, while many advocate attending to the private and ordinary aspects of citizenship for people living with dementia, few actually turn their methodological attention towards how residents themselves initiate or engage in agentic ways in natural situations in nursing homes. Consequently, this PhD study fills a gap in the current knowledge of citizenship by attending to how residents express and enact their citizenship within the nursing home context, as well as what characterises such practices.

1.4 Main goal and research questions of the thesis

Everyday citizenship brings to the fore the idea that a person living with dementia has a voice and multiple interests and identities. It shifts the focus away from diagnostic and post-diagnostic support – all of which is important, of course – to the 'normal' everyday routines of a person's life.
(Nedlund et al., 2019a, p. 3)

The literature review reveals a need for further exploration of citizenship as everyday practices in nursing homes. This PhD thesis responds to this need by turning attention towards how the actions and expressions of residents in this context can be understood and interpreted as citizenship. The knowledge brough forward holds relevant insights that can inform future professional practices and policy in how to perceive, and support, residents' status and abilities as citizens. Consequently, it aims to contribute to the advancement of living conditions for people with dementia in nursing homes.

THE MAIN RESEARCH QUESTION OF THE THESIS IS: What characterises citizenship practices for persons living with dementia in nursing homes?

To answer this question, three sub-questions were developed, each corresponding to an article in the thesis (See table 1, Overview of articles):

1. How is citizenship for persons with dementia living in nursing homes conceptualised and described in the research literature?
2. How do people living with dementia in nursing homes express and enact their everyday citizenship?
3. How can mundane social and occupational situations in nursing homes shed light on citizenship for people with dementia, and what is the potential of adding an activistic lens of citizenship to our everyday interpretive practices?

Each article in the thesis utilises specific theoretical and analytical perspectives in its investigation. The first article is based on a literature review of published peer-reviewed research. The main criteria for inclusion were use of the term citizenship, a focus on people living with dementia in nursing homes and inclusion of both empirical primary research and theoretical articles. A narrative summary was conducted of the 15 articles that met the inclusion criteria, and the results were discussed in terms of Goffman's (1961) concept of the "total institution". The second article explores expressions and enactments of citizenship in nursing homes. After fieldwork in the nursing homes, narratives of three residents were constructed and interpreted through the occupational dimensions of *doing*, *being*, *becoming* and *belonging* and everyday citizenship. The third article investigates the transformative power of mundane and relational enactments of citizenship in nursing homes, exploring the potential of adding an activistic citizenship lens to our interpretive practices. Narratives were constructed and interpreted using narrative theory, occupational perspectives and theories of citizenship.

Table 1: Overview of articles

Title	Research-question	Theoretical perspectives
Citizenship for persons with dementia in nursing homes – A literature review	How is citizenship for persons with dementia living in nursing homes conceptualised and described in the research literature?	Discussed in terms of Goffman's (1961) concept of "total Institution"
Within moments of becoming – Everyday citizenship in nursing homes	How do people living with dementia in nursing homes express and enact their everyday citizenship?	Interpreted in terms of Wilcock & Hocking's (2015) occupational dimensions and everyday citizenship by Nedlund et al., (2019ab)
Activistic citizenship in nursing homes: co-ownership in the mundane	How can mundane social and occupational situations in nursing homes shed light on citizenship for people with dementia, and what is the potential of adding an activistic lens of citizenship to our everyday interpretive practices?	Interpreted in terms of both narrative, occupational and citizenship theories, in particular active and activistic citizenship (Boje, 2017, pp. 203–205) and Isin's (2008) "acts of citizenship".

1.4.1 Defining and delineating the thesis

This thesis explores citizenship as practices in nursing homes. Consequently, my definition of the term "practices" has implications for the methodological and analytical strategies employed throughout the study. According to the *Merriam-Webster Dictionary* (2023), the term "practice(s)" refers to typical ways of behaving or doing, to rehearsing or developing skills, and to being professionally engaged. The term thus emerges as connected to doing or being engaged in some way. While authors such as Baldwin and Greason (2016) appear to use the term to encapsulate both personal and professional practices that support citizenship, the analytical attention on practices in this thesis centres on the doings of residents.

To explore practices, attention was turned towards occupational doing. Occupational doing is understood as both embodied doing and verbal expressions, and encompasses all that people do throughout their lives (Wilcock & Hocking, 2015). Exploring citizenship in the everyday or mundane meant attending to what Scott (2009) describe as the routine, familiar and unremarkable. It entailed analysing occupational situations that happened in the common areas of the nursing homes where fieldwork took place, outside structured activities programmes or intimate/personal care.

While analytically exploring narratives of occupational doing in the nursing homes as practices of citizenship, some social phenomena emerged as particularly significant: specifically, agency, belonging and becoming. I will provide a brief definition of these phenomena before they receive further attention in the theoretical chapter (see also Figure 1).

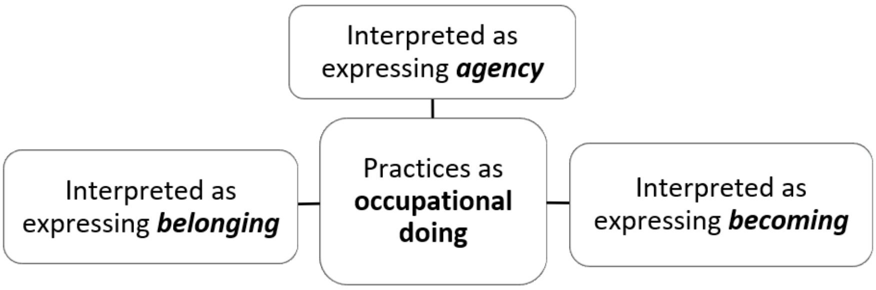

Figure 1: Main concept and phenomena

Agency is understood as "the ability to initiate social action or at least influence their [people with dementia] own personal circumstances" (Boyle, 2014, p. 1130). In this thesis, the understanding of agency is informed by both narrative (Baldwin, 2008) and embodied (Fuchs, 2020; Kontos, 2005) conceptions and is viewed as expressions that can be interpreted as possible resistance (acts of citizenship; Isin, 2008) and intentionality (Fjetland & Gjermestad, 2018). This means that residents' occupations throughout their everyday life are interpreted as intentionality and capacity and possible expressions of resistance.

Belonging is brought forward as a central dimension of everyday citizenship by Nedlund et al. (2019), as well as a dimension of occupation by Wilcock and Hocking (2015). In this thesis, residents' experience of belonging as citizens in the nursing homes is interpreted as a dynamic relationship that influences, and is influenced by, occupational doing.

Becoming as a term is brought forward as an occupational dimension by Wilcock and Hocking (2015), linked to the idea of undergoing change or developing through occupation. I connect it to the definition of social citizenship as outlined by Bartlett et al. (2010), highlighting that people with dementia have the right to grow and participate in life to the fullest extent possible. In this thesis, the social phenomenon of becoming is interpreted as closely intertwined with experiences of belonging and the recognition of mundane expressions of agency.

1.4.2 Outline of the thesis

The introduction has outlined different challenges and opportunities for the realisation of citizenship in the dementia and nursing home field, and now concludes with a reflection on researcher preconceptions and positioning of the thesis. I continue by presenting the theoretical framework, clarifying how I have utilised and combined central theoretical concepts in the thesis. Following this I outline the methodological choices and analytical procedures applied. The overall results and implications of findings from the articles are summarised and discussed in the second half of the thesis. The discussion brings the results of the three articles together, suggesting *becoming* and co-ownership as central characteristics of citizenship practices, and provides a critical reflection on both the perspective of citizenship and the knowledge production of the thesis. I end by offering some suggested implications for future policy and research, and a summary of the main contributions of the thesis.

1.5 Researcher preconceptions and positioning of the thesis

Given the subjective nature of qualitative research, the analysis of data is always going to be filtered through the researcher's lens.
(Stanley & Nayar, 2015, p. 12)

When planning this PhD study and commencing fieldwork, my perceptions of nursing homes and of dementia were informed by my previous experiences, my background as an occupational therapist and particular authors in the field. I began working in nursing homes when I was 17 years old. Even then, I was preoccupied with residents' opportunities for engagement in activities. I remember the frustration and deep injustice I felt when I was told, while working in my first nursing home, that there was no point in trying to engage a resident in an activity as she would not remember it. I continued working in nursing homes while studying to be an occupational therapist, a programme of education that provided theories and tools to support people to engage in meaningful occupations. After completing my degree, I worked in a hospital ward for geriatric psychiatry for a decade before pursuing my master's degree, for which I qualitatively explored meaningful activity in nursing homes. Although the nursing home figures in many texts as something dreaded and a place of lost identity (Stafford, 2003a), I believed that life can be good in nursing homes, largely due to the capacity for care and engagement of many of the professionals I have met in this field throughout the years. However, I have sometimes been struck by a societal – and professional – focus on people's "inability" and cognitive decline.

This PhD project responded to a call for research on citizenship, participation and meaning in everyday life and activities, particularly for people in vulnerable life situations. It is positioned within the PhD programme Diaconia, Values and Professional Practice at VID Specialized University. The PhD programme is situated in the study of professional practice in health and welfare services, with diaconia and values as its main perspectives. In the programme description, values are described as relating to the norms and ideals that guide or influence services, as well as the attitudes, preconceptions and notions that can be studied in practice (Centre of Diaconia and Professional Practice, n.d.). This call for research on citizenship in everyday life provided an opportunity for me to explore nursing home living through a slightly different angle than the person-centred lens that had previously informed much of my understanding of dementia and occupational engagement in the field. While I have been preoccupied with people's opportunities to engage in meaningful activities for my entire professional career, I did not have thorough insight into the realm of citizenship before I commenced work on this thesis. Throughout the process and knowledge production of this PhD, my perspectives have shifted from a slightly more institutional and therapeutic understanding of occupation and a normative, rights-based view of citizenship to a more existential, embodied and mundane understanding. Thus, this process has changed the way I personally view dementia and nursing home life, and I find the prospect of this new perspective promising for future research in the field.

I recognise that the choice of theories utilised as interpretive lenses in the thesis were influenced by my own preconceptions and something that emerged through a gradual dialogue with data from the nursing homes. Some of the main inspirations for designing the study were Ruth Bartlett and colleagues' publications promoting a broadening of the debate around dementia to include citizenship (Bartlett & O'Connor, 2007; Bartlett et al., 2010), as well as Baldwin and Greason's (2016) article on micro-citizenship in long-term care. The latter's argument that citizenship can be realised through ordinary everyday activities helped expand my understanding of how the highly normative perspective of citizenship could be translated into people's everyday lives. These arguments appeared to harmonize with my own professional understanding of humans as occupational beings and contributed to turn my attention towards how residents engaged and expressed themselves through mundane everyday occupations.

Consequently, less attention has been centred on residents' medical and care needs or citizenship at the level of rights and duties in society and policy. This thesis must be read with this in mind, considering that the emerging analytical focus turned my primary attention towards interpreting situated and contextualised narratives focused on residents' abilities. During this process, Nedlund et al.'s (2019ab) concept of everyday citizenship helped establish a focus on the ordinary lives of residents in the nursing homes. The occupational dimensions by Wilcock and Hocking (2015) provided a lens through which to attempt to interpret residents' verbal and embodied expressions; and later, activistic citizenship (Boje, 2017; Neveu, 2014; Isin, 2008) was found to be an interesting lens through which to shed light on residents' ability to communicate their desires and opposition in everyday life. These theories are further outlined in the next chapter.

2.0 THEORETICAL FRAMEWORK

In this chapter, I outline the theoretical framework used to interpret the empirical material in this thesis. This includes perspectives on citizenship and agency, as well as theories of occupation and narrativity. The chapter concludes with a reflection on some strengths and limitations regarding the theoretical framework and the way theories have been combined in the thesis.

2.1 Citizenship – status, rights and duties

> *Citizenship is a status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties with which the status is endowed. There is no universal principle that determines what those rights and duties shall be.*
> *(Marshall 1992, p. 18)*

Boje (2017) writes that citizenship is associated with the discourse outlined by Marshall after the Second World War, which defines citizenship as an individual's participation in society through their rights and duties (p. 158). Marshall (1992) conceived of citizenship as divided into three parts: civil rights (e.g., freedom of speech, thought, faith and the right to conclude contracts), political rights (the right to participate in the exercise of political power), and social rights (e.g., economic welfare, security and adequate standards of living) (p. 8). According to Boje (2017), Marshall's work laid the foundation for the development of the classic welfare society as we know it, the leading principle of which is to ensure citizens' economic and social living conditions through establishing social institutions: first and foremost including those with a status as citizen in the territorial state (p. 169). Describing citizenship as a "status bestowed" (Marshall, 1992, p. 18) implies that it is something given by others and can therefore be taken away by others. Such notions of citizenship, according to Boje (2017), are closely connected to the citizen's duty to contribute through work and active participation in society.

Boje (2017) argues that the conditions for *practicing* citizenship are central in relation to citizens' inclusion or exclusion, and that citizenship is constantly changing as actors fight for rights and equality through political struggles (p. 28). Isin (2017) writes that, historically, particular characteristics of some social groups (e.g., being propertied, male, heterosexual and able bodied) became the dominant universal characteristics of the state (p. 503). For example, Vollp (2017) describes how women were considered unfit candidates for full membership, and late into the 19th century many were not considered independent legal subjects and thus could not control property, make contracts or vote in political elections (pp. 154–155). However, Donaldson and Kymlicka (2017) argue that some members of society (e.g., children and people with cognitive disabilities) are still relegated to the status of passive subjects. These citizens are acknowledged in national law with formal citizenship status – and thus rights to protection and the provision of services – while being excluded from active citizenship.

In the dementia field, Nedlund and Bartlett (2017) highlight that, to elaborate on the elements of rights when studying citizenship, it is necessary to ask, "rights to what?" They argue that democracies build on reciprocity in relationships, underlining the importance of equal access to participation, influence and self-determination. As such – and of significance in this PhD project – the citizen is entitled to more than protection and services, but also to have access to participation. They further argue that access to participation is influenced by normative ideas about good governance and the good citizen in society, notions I find important because they shed light on how established ideas about dementia or the nursing home can shape people's opportunities. While people with dementia have increasingly advocated for their equal rights and inclusive understandings of their capabilities and social positions in society (Nedlund et al., 2019; Nedlund & Bartlett, 2017; Bartlett et al., 2010), as pointed out in chapter one, stories of how people living in nursing homes are recognised and supported as active agents remain scarce.

While historical developments and political aspects of citizenship situate the thesis in a broader socio-political context, the theories applied to interpret the empirical material have centred on human action within mundane arenas of nursing home life. The following sections outline the theories applied as such interpretive lenses.

2.2 Everyday citizenship – recognising agency in the everyday

In the context of everyday citizenship, recognition of agency is key to securing social equality.
(Nedlund et al., 2019a, p. 5)

This thesis explores citizenship as mundane, everyday practices. To this end, Nedlund et al.'s (2019a) conceptualisation of everyday citizenship was found to be particularly useful. According to Nedlund et al. (2019a), everyday citizenship recognises the unremarkable, routine and mundane of human lives, thereby expanding the canvas for examining citizenship. In this thesis I explore citizenship by turning attention towards the ways residents acted and expressed themselves throughout everyday life, recognising mundane forms of agency and the conditions in which such agency emerged.

2.2.1 Dimensions of everyday citizenship: rights, access and belonging

Referring to their chapter in the book *Living With Dementia: Relations, Responses and Agency in Everyday Life* (Nedlund & Bartlett, 2017, pp. 52–57), Nedlund et al. (2019a) outline a model of everyday citizenship to help us understand, explore and enable citizenship for persons living with dementia, comprised of three dimensions: rights, access and belonging. According to Nedlund and Bartlett (2017), the first dimension – rights – encompasses the formal dimensions related to the person's legal connection to society (p. 52); however, in reality, people can have equal rights while having different opportunities to enjoy those rights in practice (p. 57). The dimension of rights relates to issues of governance and democracy, a theme briefly touched upon in the previous chapter.

The second dimension – access – sheds light on the relationship between citizens and political and social communities, concerning the conditions for practicing citizenship. According to Nedlund and Bartlett (2017), to understand citizenship, we need to understand access to participation in society. Such access can be refused to people not in a position to practice their citizenship rights, and concerns both practical conditions for participation as well as deciding what citizenship is or entails (p. 54). The critiques directed at nursing homes in terms of limitations on agency and participation (as outlined in the introduction), illustrate the importance of exploring how people with dementia have access to opportunities to practice citizenship. In this thesis, access to participation is explored within the micro-community of the nursing home. In terms of this micro-community, I understand access to concern the unique immediate physical and social environment, the institutional routines of each nursing home and societal and political regulations and attitudes about dementia and nursing homes.

The third dimension of citizenship relates to the citizen's *belonging* to a political entity or community. Nedlund and Bartlett (2017, p. 56) describe how, traditionally, belonging is based on nationality and a legal relationship to a sovereign state. However, they outline that it also has a subjective side, feeling and experiencing that you belong as a citizen. As such, belonging is both regulated in the constitution and practiced and constructed by citizens. In this thesis, belonging is explored as an occupational dimension, recognising that belonging to a community influences, and is influenced by, the occupations of that specific community (this is further outlined in the chapter on occupation).

2.2.2 The concept of agency

In everyday citizenship, the practice of citizenship sheds light on agency as a key to ensuring equality (Nedlund et al., 2019a, p. 5), a phenomenon that also became central in the analytical work of this thesis. According to Boyle (2014), people with dementia has often been assumed to lack the capacity for agency, seen as ability to initiate social action or influence own circumstances. Boyle further notes that while work on agency has concentrated on rationality, language, intentional action and goal orientation, research on dementia has shown that even though people with dementia may lack these abilities, they can demonstrate a creative capacity for agency in habituated, embodied, and emotional forms. Nedlund et al. (2019a) write that the point is to recognize each person's potential for agency and to see every social relation and practice, however mundane, as a potential opportunity for agency. As outlined in the introduction, agency in this thesis is perceived as enacted and expressed in both narrative (Baldwin, 2008) and embodied (Fuchs, 2020; Kontos, 2005) ways. Nedlund et al. (2019a) write that narrative agency depends on the ability and opportunity to express oneself in a way recognisable as a narrative (p. 6). While I will return to the concept of narrative agency in the chapter about narrativity, I conclude this chapter by reflecting on what I mean by an embodied understanding of agency, which highlights the inherent competency of the body.

In 2005 Kontos published a paper problematising how the body is often treated as passive rather than active and intentional. In it, she argues for an understanding of dementia that embraces the idea of the body as a fundamental source of selfhood that does not derive its agency from cognitive forms of knowledge. Kontos (2005) further argues that if selfhood is essentially conceptualised only in relation to others, we neglect the existential expressiveness of the body and its relation to the world. Fuchs (2020) similarly argues that if the ability to think, remember and make rational choices is the basic criterion for personhood, the status of persons living with severe dementia is threatened. He argues that all our experiences sediment as sensorimotor habits and capabilities and are brought together in bodily memory. This bodily memory becomes accessible to us through the practical movements of everyday life, built up through repetition and practice.

In his article, Fuchs (2020) criticises a cognitivist concept of the self, as well as social-constructivist and narrativistic views of the person, which bind personhood to social relations. For example, he discusses that Kitwood's (1997) definition of personhood as a standing or status *bestowed* means that identity is upheld solely through the recognition of others. As I understand Fuchs (2020), he does not reject autobiographic or narratively conveyed identity, but argues that "bodily and autobiographical memory contribute equally to personal identity" (p. 673). This means that interpersonal and relational forms of personhood and recognition remain bound to the body. This thesis is positioned within an understanding of identity as simultaneously bound to the body and supported through relationships, recognising both verbal and non-verbal narrativity. However, in exploring practices of citizenship, I found it useful to combine such notions with the concept of occupation, where occupational doing can be a means to express oneself, underlining a dialectical relationship between occupation and identity (Laliberte-Rudman, 2002). In the next chapter, I present the occupational dimensions, as outlined by Wilcock and Hocking (2015), that became an important analytical lens in this thesis.

2.3 Occupational theory

> *[F]or people to achieve physical, mental, and social well-being, they need to have the opportunity to use their particular capacities and to aim at becoming what each person, family, community group, or nation has the potential to be.*
> *(Wilcock & Hocking, 2015, p. 265).*

To explore practices of citizenship, I chose to utilise theory that enabled attention to be turned towards how people acted and expressed themselves within the nursing home context. An occupational lens was found useful in this regard. At the basis of an occupational perspective lies an understanding of humans as occupational beings with an innate need to engage in simple to complex and multiple occupations (Wilcock & Hocking, 2015, p. 89). In this thesis, occupation is understood in line with Wilcock and Hocking (2015) as related to everything people do throughout their lives, both individually and collectively (p. xi). It is perceived, interpreted, and conceptualised in terms of a dynamic relationship between the things we *do* and our *being*, *belonging* and *becoming*.

Wilcock and Hocking (2015) write that *doing* is linked with words such as action, getting something done, carrying out, making, executing, and performing. It encompasses mental, physical, social, communal, spiritual, restful, active, obligatory, self-chosen and paid or unpaid occupations. *Being* is linked with words such as self, mind, essence, true being, core, soul, personality, and existence. It can be seen as a time for stillness and reflection and is a personal rather than social aspect of occupation (pp. 134–135). *Being* both expresses a state of existence and the needs and interests that drive individuals and calls for consideration of how people as occupational beings plan, think and feel about what they do (Wilcock & Hocking, p. 180). In other words, *being* is the sense of who someone is as an occupational and human being (Hitch et al., 2014a), and both *doing* and *being* usually change together after injury or illness (Hitch et al., 2014b). Establishing new ways of *being* alongside new ways of *doing* is essential to identity as occupational beings, building links between who we were, who we are and what we *do*.

Wilcock and Hocking (2015) use *belonging* to describe the social aspects of occupation related to people as social beings. They argue that the human need to *belong* is strongly felt, experienced through the ease and familiarity of *doing* things with people you care for or share a sense of place with. As such, *doing* with, alongside, and for other people fosters relationships and *belonging*; even many occupations done alone are often done in relation to others, providing a feeling of connection, being cared for or wanted. They argue that *belonging* is enacted through everyday practices, social conventions, behavioural norms, and rituals, and that participating in the occupations of a place gives one a sense of being in the right place, being recognised by others, and understanding the parameters and meanings of things that are done. *Belonging* is central to well-being because it is intertwined with identity and having a place in the social world (pp. 211–213).

Lastly, Wilcock and Hocking (2015) describe *becoming* as connected to the idea of change, transformation, or development, using words such as coming to be, coming into being, changing to, or emerging as (p. 137). They further note that as humans we develop and *become* different through what we do on a daily basis, and that *becoming* adds a sense of future to the notions of *doing*, *being* and *belonging*. Throughout their lives, people have the potential to grow or diminish, and their *becoming* can be strengthened, stagnant or sick. Positive *becoming* is described as a way of communicating what people think they are about, demonstrating what they can do and what they can contribute to their own growth and to the community. As such, it is the personal outcome aspect of occupation, its potential meaning and purpose. It is further argued that through *becoming,* people can change their place in the social structure, and negative *becoming* can lead to lack of social acceptance, self-consciousness, inhibition, depression and anger. Not being able to *do*, or lack of balance between *doing* and *being*, can lead to a feeling of not *belonging* and a negative experience of *becoming* (pp. 239–265). This underlines that *becoming* has to do with having the opportunity to use our particular capacities, as the quote at the start of the chapter underlines, *becoming* who we have the potential to be, and that it can be negative if *doing*, *being* or *belonging* though occupation is restricted or compromised.

2.4 "Acts" and activistic aspects of citizenship

> *[A]cts of citizenship can be performed in very discreet ways, through daily experiences, and under less visible guise than is usually considered, through experiences often qualified as "ordinary".*
> *(Neveu, 2014, p. 89)*

Interpreting narratives of occupational *doing* from the nursing homes shed light on *becoming* and *belonging* as social phenomena that can inform our understanding of citizenship as practices. These social phenomena centre on individual expressions of meaning, purpose and capacity, underlining the human need for influence and social engagement. However, occupational theories did not provide the concepts needed to more critically interpret how such *doing* might express mundane forms of resistance within nursing home life. In the third article of the thesis (Sund et al., 2023b), we aimed to analytically explore the potential of interpreting narratives through an activistic lens of citizenship. This meant that mundane occupational *doing* was interpreted as possible expressions of resistance. In this regard, Boje (2017) writes that to influence social, political and cultural rights, the citizen can actively claim citizenship through activistic practices. He defines enacting one's citizenship as those actions through which citizens interfere in the political decision process for their own or others' benefit (pp. 28–29).

Referring to Neveu (2014), Boje (2017) writes that literature on citizenship has traditionally attended to citizens' positions as political agents, neglecting how citizenship can be enacted within the ordinary. Neveu (2014) brings three different types of citizens into her discussion – the ordinary, the active and the activistic. She writes that common representations of the active citizens are those who vote and actively participate in public life and politics, while the activistic citizens challenge established roles and invent new sites and types of citizenship. She argues that, in the literature, the ordinary is often thought of as moments when nothing happens in political terms, and thus that we risk overlooking what we can learn from "the silent 'ordinary' ones" (p. 87). According to Boje (2017), in ordinary citizenship, people practice their citizenship through daily routines and lived life in contexts that do not have the character of political practice in the traditional sense. He describes active citizenship as a more involved form wherein people participate in the public sphere within the democratic system and its given structures and rules of engagement. Lastly, he writes that activistic citizenship is where citizens contribute to formulating and re-forming economic, social and political conditions. It can therefore be characterised by the enacting of civil disobedience that breaks with preconditioned rules and regulations (pp. 203–205).

Bringing these different types of citizens into our interpretations was useful in an attempt to bridge activistic notions of citizenship (traditionally centred on the public and political), with ordinary, repetitive and mundane practices within the nursing home community. In the third article of this thesis (Sund et al., 2023b) we do so by engaging with the concept of acts of citizenship as outlined by Isin (2008). Isin (2008) writes that acts of citizenship as an object of investigation is distinct from, but related to, the status and habitus of citizenship. He argues that the shift to understanding citizenship as practices has led to research exploring routines and habits of the everyday while neglecting the question of how people become claimants when they are least expected to. He argues that investigating acts of citizenship requires a focus on those moments when, regardless of status and substance, subjects constitute themselves as citizens. This draws attention to acts that may not be considered political, and "that the essence of an act, as distinct from conduct, practice, behaviour, and habit, is that an act is a rupture in the given" (p. 25).

While the embodied competencies of people with dementia emerged clearly through the analytical processes of this thesis, attention towards acts of citizenship (Isin, 2008) enabled an exploration of how residents in the nursing homes acted in ways that could be interpreted as a break with habitus, established practices and normative perceptions in nursing homes. Such interpretations were combined with inclusive understandings of narrativity and narrative resistance, which are outlined in the next section.

2.5 Narrativity and narrative resistance

If we are entrusted to be co-authors of a person's story, as I believe we are in the care of people with severe mental illness, then it follows that we should endeavour to author the story in the best way possible.
(Baldwin, 2005, p. 1024)

This thesis uses the concept of narrativity as a theoretical framework and ontological understanding of human nature, as well as a methodological approach towards analysis. In this section, the theoretical framework of narrative and narrativity is briefly outlined while its methodological implications and approaches are presented in the methods section.

Several authors in the field of citizenship and dementia connect citizenship and agency to the concept of narrativity (Baldwin, 2008; Baldwin & Greason, 2016; Nedlund et al., 2019a). According to Fjetland and Gjermestad (2018), the role and status of active citizenship can be interpreted as a relational, expressive, and narrative phenomenon. This interpretation relies on the concept of narrative co-authorship, building on the premise that all citizens have the potential for agency. They argue that interpreting such agency implies an expectation that all expressions are meaningful and intentional. As such, narrativity can be seen as a way of materialising citizenship through attention to a wide range of expressions taking both verbal and non-verbal forms. In a series of articles, Baldwin (2005, 2006, 2008) argues that our experiences, lives and Selves are storied. Humans are narrative beings, and we find our Selves in the stories we tell about ourselves and the stories others tell about us. Baldwin (2006) explains that narrative agency depends on being able, and having the opportunity, to express oneself in a form recognisable as a narrative. He contends that narrative and the process of narration (narrativity), as they are currently conceived and operationalised, exclude certain individuals and groups, which he calls the "narratively dispossessed":

> [A] person (or group of people) is narratively dispossessed when it is not possible to construct a recognisable narrative because of the way recognisable narratives are conceived and the means of constructing such recognisable narratives are denied to that person (or group). (pp.104–105)

He problematises how the current conceptualisation of narrativity as fundamentally chronological and reliant on language for its articulation can restrict the possibility of narrative agency. Thus, to challenge the narrative dispossession of people living with dementia, we must reconceptualise our understanding of narrativity (Baldwin, 2006). In this thesis, in line with Baldwin (2005; 2006; 2008) and Fjetland and Gjermestad (2018), I understand narrative agency as expressed through both verbal expressions and embodied *doing,* thus recognising the potential for expressing one's story in fleeting and repetitive everyday situations.

Further, narrative agency is viewed as a way of expressing both personal and political meaning, which sheds light on the concept of narrative resistance. In this thesis, acts of citizenship (Isin, 2008) are connected with a narrative lens that recognises the intentionality of people's expressions and actions. Constructing new stories of dementia can be a way of counter-narrating disabling master narratives in the dementia field (Baldwin, 2005), which have a tendency to become normalised, thus constraining the agency of subjects (Bamberg, 2004a, p. 360). McKenzie-Mohr and Lafrance (2017) propose the concept of "narrative resistance" and argue that through counter-narratives, people's stories tell and live resistance, implicitly or explicitly, to dominant oppressive narratives. Such counter-stories can emerge tentatively and in fragments and therefore require careful attention to hesitant and fleeting moments of resistance when they occur. In this thesis I take this approach specifically in the third article (Sund et al., 2023b) by connecting perspectives of narrativity and occupation with an activistic lens of citizenship. This allowed me to explore how active aspects of citizenship can be materialised in the mundane of everyday life.

2.6 A multidimensional framework

In the analytical process, an active stance regarding how the analysis will deal with existing theory on the subject understudy is required.
(Josephsson and Alsaker, 2015, p. 76).

Throughout the empirical fieldwork and analysis, the complexities that emerged about citizenship prompted me to approach it from three theoretical angles: theories of citizenship, occupation and narrativity. The need for theoretical expansion had both analytical and personal roots. As an occupational therapist entering this field, I found the phenomenon of citizenship as a practice challenging to grasp, due to how citizenship, in my view, often appear removed from the everyday lives people live. In my judgement, if the discourse on citizenship attends solely to the public and political issues of citizens on a societal level, this might contribute to the further alienation of people living with dementia in nursing homes, due to their reduced opportunities for participation at that level. However, combining multiple theories – as I have done – creates both opportunities and limitations in the production of knowledge.

In my view, combining these theories provides three openings. First, occupational theories opened up a notion of citizenship traditionally centred on citizens' rights and duties in society (Boje, 2017; Neveu, 2014). Adding occupational theory allowed me to explore the practices of citizenship within mundane aspects of the nursing home community: in particular, the unique agency of individual citizens. Second, the dialogue with citizenship theory expanded my understanding of occupational theory. According to O'Connor et al. (2022), the recognition of identity, growth and meaningful participation is one core theme underpinning citizenship discourse. These phenomena are also outlined as central aspects of social citizenship, as defined by Bartlett et al. (2010). Throughout the analytical work in this PhD study, Wilcock and Hocking's (2015) occupational dimensions were found to hold qualities that assisted in interpreting phenomena of growth and participation within the mundane as citizenship practices. Third, occupational theory provided an opportunity to expand the notion of belonging. While citizenship has traditionally conceptualised belonging in terms of membership in a nation state, the findings in this thesis support Nedlund et al. (2019), who argue that belonging also has a subjective side, making it similar to the understanding of belonging in occupational theory.

However, there are genuine tensions between the different theories used as a theoretical framework in the thesis. Wilcock and Hocking's (2015) occupational dimensions have scarcely been applied in research centred on nursing home living and were used by none of the articles in the literature review on citizenship presented in the introduction. Interpreting citizenship practices through these occupational dimensions can therefore be seen as novel. However, the limited use of these theories in the context of dementia might be due to their tendency to privilege a future time orientation and goal-oriented processes (Hammel, 2020; Hitch et al., 2014a), which might be exclusionary for people living with cognitive disabilities.

The choice of attending to occupational doing as expressions of agency also connects citizenship directly to what individuals do and the meanings these doings might hold. Meanwhile, this lens to limited degree provides the concepts necessary to critically explore citizenship as dimensions of rights, structures of power or political processes associated with democratic society. Getting this close to the everyday lives of the nursing homes limited the possibilities of recognising the discursive and normative sides of citizenship in society and professional practices. This topic is taken up and reflected on in the second section of the discussion, shedding light on how normative beliefs in society and professional practices open up some possibilities and close others. Further, exploring citizenship through an occupational lens might underline a normative belief privileging active participation, perhaps neglecting other ways humans engage as citizens within their societies. If the thesis had been conducted through different theoretical lenses (e.g., viewing citizenship through a lens of care) or attended to citizenship as dimensions of rights rather than agency, different interpretive possibilities – and thus knowledge – would have emerged.

There are also complexities in the relationship between citizenship theory and narrative theory. While I recognize that people can tell stories of meaning and intentionality in fragmented and diverse ways, I also acknowledge that this does not align with a traditional understanding of narratives as something coherent, emplotted and verbalised. Turning attention towards both verbal and embodied doing was an intentional strategy to make my interpretations more inclusive of the different ways people can express their citizenship. Nevertheless, as these stories were selected and re-told through me as a researcher, and interpreted through specific theories, an uncertainty remains as to which stories people themselves would have chosen to tell.

The reflections brought forward in this chapter demonstrate that the framework of multiple theories used as analytical lenses opened up some interpretive possibilities and closed down others. These challenges notwithstanding, the combination of citizenship, occupation and narrative theories in the exploration of citizenship set the premise for the analytical work of the thesis in two major ways. First, it turned our attention to what residents themselves did within their everyday lives and the interdynamic relationship between this doing and aspects of identity, belonging and growth. Second, it meant that both residents' doings and their verbal accounts were interpreted as narrative expression, recognising that occupation can be a means of enacting stories of meaning, intentionality and continued capacity in everyday life. By perceiving people as fundamentally intentional and capable, I attempt to interpret the meaning of both verbal and non-verbal expressions as practices of citizenship.

3.0 METHODOLOGY

In the previous chapters, I have provided arguments for why a study of citizenship for people living with dementia in nursing homes is called for, and outlined theories that have been central in the interpretation of the empirical material. In this chapter I report on how the study as a whole was conducted and reflect on issues that emerged during fieldwork and analysis influencing knowledge production. This includes providing information on underlying philosophical ideas shaping the study design and ongoing interpretations, as well as central ethical considerations related to conducting fieldwork in the nursing homes.

3.1 Philosophy of science and methodological design

If one wants to study how people live with illnesses such as the dementias, one needs to understand how people construct their social activities of their everyday lives.

(Antelius et al., 2018, p. 122)

This thesis explores everyday life in nursing homes through an ethnographically informed field study (O'Reilly, 2009: Hammersley & Atkinson, 2019) and is situated in a qualitative tradition built on theories of human experience and interpretation (Malterud, 2011). Epistemologically, this underlines an understanding of knowledge as both perspectival (Polkinghorne, 2007) and interpreted (Alvesson & Skõldberg, 2018), recognising the researcher as an active part of knowledge production (Stanley & Nayar, 2015; Malterud, 2011; O'Reilly, 2009). In contrast to a positivist ontology that views reality as something "out there" to be apprehended, identified or predicted, the ontological perspective in the interpretive framework understands realities as locally and specifically constructed (Laverty, 2003). As such, Laverty (2003) argues that the researcher's role is central, entailing interpretation and interaction between the researcher and participants. Similarly, Malterud (2011) argues that the researcher is an active part of a production of knowledge that is never complete, where developing new questions is more important than absolute truths. This highlights the interpretive and co-constructed aspects of knowledge upon which this thesis builds, where "data, and the meaning of data, is not an objective existing on its own 'out there somewhere' but, rather, a joint accomplishment" (Antelius et al., 2018, p. 135).

An important aspect of understanding knowledge as interpreted and contextual can be found in Alvesson and Skõldberg (2018)'s argument that paradigms, perspectives and concepts, as well as political interests, can bring out some interpretive possibilities while suppressing others. This is particularly relevant for the discussions in this thesis, combining different theoretical lenses to develop an understanding of citizenship practices. This is also linked to how authors from within the citizenship field underscore that developing knowledge and understanding citizenship as a concept and phenomenon is a fundamentally interpretive endeavour. Neveu (2014) argues that "citizenship can only be grasped contextually 'in a situation', when it is 'activated'" (p. 89), and that grasping the "low-noise" practices of citizenship requires considering citizenship as practiced and lived. Taylor and Wilson (2004) contend that citizenship is not reducible to a single definition, but that it requires and encourages interpretation. This, I believe, underlines the fluid and contextual qualities of citizenship itself, something that has both methodological and analytical implications. These topics are discussed in greater detail in the second half of the thesis, with critical attention on both citizenship as a concept and social phenomenon and the methods applied to explore it.

According to Creswell and Poth (2018), qualitative research embraces the idea of multiple realities. Thus, to gain knowledge of these realities, the researcher aims to get close to participants, exploring their experiences in their natural contexts (pp. 20–21). To seek an understanding of the lived experience of people with dementia, Antelius et al. (2018) promote ethnography as a relevant method (p. 123). According to O'Reilly (2009), the co-construction of data in ethnographic research involves direct and sustained contact between people, acknowledging the role of both theory and the researcher (p. 3). Underlined by an understanding of knowledge and citizenship as situated and contextual, ethnographic methods enabled me to spend time with residents and staff, gradually building insights into their experiences as well as the routines and happenings within the nursing home context.

While I would not designate this a phenomenological study, as I began fieldwork, I found myself inspired by some authors from within this tradition. Wright-St Clair (2015) argues that interpretive phenomenology goes beyond rich description and involves interpretation of the possible meanings of the data. One seeks to explore phenomena that may be taken for granted or concealed in some way, where moments of understanding can emerge through being immersed in and staying engaged with participants' stories (p. 55). Similarly, Finlay (2008) writes that the phenomenological process entails that researchers be fully open to what may appear, rather than seeking to be objective, distanced or detached. Applied to this study, the phenomenological aspiration to reveal aspects of the phenomenon of citizenship and its enactment meant being present beside residents, engaging in their activities, listening to their voices and observing their actions in an attempt to gain a sense of everyday life in the nursing home from their perspectives.

In this regard, Alvesson and Skõldberg (2018) argue that the interpretation of understanding has been increasingly linked to empathy. In this process researchers' uses imagination, trying to put themselves in the other's place, thinking and feeling themselves into someone else's situation. Similarly, Stafford (2003b) writes that, to understand the lived experience of the nursing home, we must enter it both bodily and rationally. I did experience ethnographic fieldwork as an almost embodied and emotional knowledge production, also feeling an ambivalence between knowledge production as something "reproducible" and general, and this emotional and embodied sense of knowledge. However, Finlay (2008) notes that, if persistent, the researcher will be rewarded with fleeting moments of disclosure, when the phenomenon reveals something of itself in a new way. Seeking to understand the nursing home through the level of curiosity and openness, as Finlay (2008) suggests, this study builds on the understanding that we can interpret meaning from human action and both embodied and verbal human expressions. Fjetland and Gjermestad (2018) argue that, while interpreting the verbal and non-verbal expressions of people living with profound intellectual disability is characterised by uncertainty, active citizenship can be shaped and brought forward through interpretive practices that assume people's expressions are intentional. However, doing so in this study does not mean that such interpretations express the truth of reality but represent some *truths* told through particular viewpoints.

O'Reilly (2009, p. 3) describes ethnography as iterative-*inductive* research, meaning that it evolves throughout the fieldwork as new understandings emerge and develop. However, the analytical process of this study may be more correctly termed "iterative-abductive", moving between an inductive understanding of everyday life in the nursing homes and analytical strategies informed by narrative methods (Polkinghorne, 1995). I opted to conduct the narrative analysis after fieldwork was concluded – which meant that theory acquired a more significant role in the analytical process. The development towards a narrative analytical strategy, inspired by Polkinghorne (1995), led to increased attention on how the phenomenon of citizenship was enacted and expressed in particular contexts by particular people. The role of theory will be further reflected on in both the chapter on analysis and in the methodological discussion.

Hammersley and Atkinson (2019) note that, while ethnographers draw on a range of sources, participant observation and informal conversation are often primary methods of gathering data. They write that ethnographic work usually studies people's actions and accounts in natural contexts and is largely unstructured. This means that it does not involve implementing a fixed and detailed research design from the start, and that it usually focuses on a few cases to facilitate in-depth investigation (p. 3). To explore aspects of everyday life in the nursing homes, a flexible and iterative ethnographic design was developed, in which the data were collected via participant observations, conversations, individual interviews and group interviews. Polkinghorne (2007) argues that, for the reader to make an informed judgement about claims, researchers must be clear about the nature of their collected evidence. The quality of the texts assembled in this thesis – namely fieldnotes and interview transcripts – is connected to the recruitment of the nursing homes (which nursing homes were selected and how), the methods chosen to produce data (is ethnography suitable in terms of the study aims), and the way data was produced (the researcher's role and ethnography as a craft). The following chapter therefore seeks to provide a detailed description of and critical reflection on the process of fieldwork and analytical strategies.

3.2 Recruiting Sea-Crest and Sunny Hill nursing homes

> *A variety of initial strategies may be adopted in seeking access, varying according to the nature of the setting and people in which one is interested.*
> *(Hammersley & Atkinson, 2019, p. 45)*

Hammersley and Atkinson (2019) write that gaining access in ethnography can be a formal process, e.g., in settings where boundaries are institutionalised or the study site is not easily accessed (p. 51). In this study, the recruitment process began by sending out a written invitation to leaders in five municipalities in the region to seek formal access via a network established by our institution (VID). While probability sampling, ensuring the sample represents the whole population in question might not be the goal in most ethnographies (O'Reilly, 2009, p. 194), choices still had to be made as to where to conduct the study.

The research question in the study set the parameters for searching for nursing homes to include in the study. The main inclusion criterion was units intended for long-term stay for people with dementia. The study aimed to produce knowledge about citizenship in an exploratory way. The goal was not to compare nursing homes with each other or assess their overall quality of care. For this reason, it was considered most important that the nursing homes wanted to take part in the study and engage with me as a researcher, not pre-defining what qualities the nursing home units should have to be eligible for inclusion. Both in ethnographic research (Hammersley & Atkinson, 2019) and in interpretive phenomenological research (Wright-St Clair, 2015, p. 57) recruitment is purposive, seeking out participants that have experience with the phenomenon of interest. After a positive response from two of the municipalities, separate meetings were held with representatives of their leadership, who chose which of their nursing homes and nursing home units to include in the study. After this step, the leaders of the nursing home units acted as gatekeepers (Hammersley and Atkinson, 2019, p. 51), protecting residents rights in regards to participation in research (NESH, 2021) and facilitating my access to the nursing homes.

Two nursing homes from different municipalities in the south-west region of Norway were included, hereinafter called Sea-Crest and Sunny Hill. At Sea-Crest, one large nursing home unit was included while at Sunny Hill two small units participated. This offered insight into the lives of people living in both large and small-scale units, as well as within different areas of the region. Data gathered from these two nursing homes were considered adequate for the purpose of in-depth exploration of and seeking insights into residents' everyday lives. This allowed me to spend sufficient time in fieldwork to explore the unique stories that emerged in their unique contexts.

3.2.1 Sea-Crest nursing home

Fieldwork took place at Sea-Crest nursing home during May and June of 2019. The nursing home is located in a rural area in a large municipality. A large unit on the second floor was included. Some residents living in the unit did not have a diagnosis of dementia (even though it was part of the admission criteria). Ten residents were therefore included in the study. The unit was divided into two groups, each with its own living room with access to a small terrace, small kitchen, and dining-room area. Residents could move freely between the two groups. The nursing home had an extensive programme of activities organised by a designated activity organiser. The unit was staffed by five people during the day and four people at evening shifts and weekends.

3.2.2 Sunny Hill nursing home

Fieldwork was conducted at Sunny Hill from October 2019 until January 2020. Sunny Hill nursing home is located in a medium sized municipality. Two small units at the nursing home participated, which I will call North and South. A total of 16 residents were included in the study at Sunny Hill. North Unit was locked with a code to prevent residents from leaving on their own and was reserved for people in need of close supervision in everyday life. They therefore had extra staffing. South Unit had an open door and was staffed by two people during the day, evening and weekend, while North was staffed with three. The units were situated on the ground floor with direct access to outdoor areas. Both units had a small kitchen area, dining room tables, and a living room area where residents gathered. The nursing home employed a volunteer coordinator. Fieldwork was conducted parallel in these two units since they collaborated closely and had joint leadership.

3.3 Conducting fieldwork

> *To understand the lived experience of the nursing home, we must enter into the experience bodily and not simply rationally. Along with interviewing, we must participate. Along with participating, we must take the role of the other. We must learn to listen to the sounds as they are listened to. We must watch and be watched.*
>
> *(Stafford, 2003b, p. 129)*

This thesis seeks to explore what characterises citizenship practices for persons living with dementia in nursing homes. The focus on practices as occupational *doing* meant a need for attention towards residents' actions and expressions within their nursing home environments. The primary method of gathering data was therefore participant observation (O'Reilly, 2009; Hammersley & Atkinson, 2019), which enabled me to interact with residents and staff in the three nursing home units, be present, listen and attempt to gain insight into life from residents' perspectives. In addition, I conducted individual interviews and group interviews with staff and support staff, listening to their descriptions and understandings of everyday life in the nursing homes. In total, 537 pages of written material were available for analysis after completion of fieldwork, amongst them written documentation from 123 hours of fieldwork, 13 interviews with staff, 9 interviews with support staff and 3 group interviews (See table 2 for an overview of the data). The following chapter outlines the methods used and discusses the challenges and opportunities that emerged during the research process and in relation to the production of knowledge in the thesis.

Table 2: Overview of data gathered

	Time in field-work	**Nr. Of visits**	**Field notes**	**Residents involved**	**Inter-views with staff**	**Group inter-views**	**Inter-views with support staff**	**Tran-scription inter-views**	**Tran-scription group interviews**
Sea-Crest	36 hrs.	16	62 p.	10 (9 women and 1 man)	5 (All women)	1 (2 staff, all women)	4 (all women)	113 p.	19 p.
Sunny Hill North	42 hrs.	14	57 p.	9 (All women)	5 (All women)	1 (4 staff, all women)	5 (all women)	182 p.	23 p.
Sunny Hill South	45 hrs.	15	60 p.	7 (All women)	3 (All women)	1 (3 staff, all women)			21 p.
In total	123 hrs.	45	179 p.	26	13	3 (9 staff)	9	295 p.	63 p.

3.3.1 Participant observation

O’Reilly (2009, p. 150) writes that while ethnography can include diverse methods of collecting data, its main method is participant observation. Meanwhile, according to Hammersley and Atkinson (2019, p. 108), there is an increasing tendency for qualitative research, even that which is labelled ethnographic, to rely too heavily on interview data. When designing this study, both participant observation and interviews were considered valuable methods for exploring the characteristics of citizenship and seeking insights into the perspectives of residents living with dementia. However, although I had originally planned to do so, I did not conduct in-depth interviews with nursing home residents. I experienced that during conversations residents often misunderstood what I was asking or had difficulty talking about the nursing home or the “now” in an abstract way. In addition, most residents had difficulty understanding my role in the units as a researcher and the concept of the research taking place. (This issue is discussed further in the chapter on ethical considerations.)

However, several researchers have promoted the opportunities that participant observation presents to include people with dementia in research. In a recent article, Glavind and Mogensen (2022) promote using ethnographic methods to explore the lifeworld of people living with dementia, and Phillipson and Hammond (2018) identify ethnographic observation as one effective method for involving people with dementia in research, providing opportunities for “more than talking” (p. 2). While formal sit-down interviews may be more difficult if people’s ability for reasoning about abstract issues, recalling events or reflecting on their meanings is reduced (Nygård, 2006), conversation in natural situations may be easier to perform (Nygård, 2006; Hubbard et al., 2003). Poland and Birt (2018, p. 13) assert that “by relying less on the semi-structured interview, the qualitative researcher may be more inclusive of those without standard spoken and written language”. However, while observations offer insight into the actions, interactions and processes of nursing home everyday life, they do not necessarily provide insight into the meanings people attribute to their actions (Malterud, 2011, p. 146-148). However, Hammersley and Atkinson (2019, p. 105) write that ethnographers may gain access to unsolicited accounts both by participating in exchanges in which they occur and by overhearing them. These naturally occurring oral accounts can be useful sources of both direct information about the setting and about the perspectives or concerns of those involved. During fieldwork, I sought to gain a sense of residents’ perspectives by observing their everyday actions, listening to their unsolicited verbal expressions in natural situations and engaging in conversations when the opportunity presented itself. As such, fieldwork meant learning to use myself as a research tool by developing social relations with participants (Antelius et al., 2018, p. 123). Recognising the value of getting close to participants in their natural settings in the production of experienced knowledge (Creswell & Poth, 2018, p. 24), I sought to inhabit a role between what Hammersley and Atkinson (2019, p. 87-89) describe as complete observation or complete participation, enabling a balance between interacting, asking questions, observing and documenting what people did and said. To do so, I needed to get to know residents and staff, which in turn also allowed them to know me, and to build trust and to be accepted in the nursing home environment.

In line with Antelius et al. (2018, p. 123), part of my goal was to attempt to interpret phenomena from residents’ point of view, seeking to see the world from their perspective and understand their experiences. Participant observations focused on common areas, where I took part in activities and routines of the nursing home units such as mealtimes and informal and organised events during the daytime, evenings and weekends. I spent time talking to and observing staff to increase my knowledge of their everyday work, the way they interacted with residents, their experiences working in the units and their interpretations of events and activities. However, most of my time was spent sitting beside residents, engaging in conversation or simply sitting and observing everyday life as it unfolded. I was not present during private intimate care situations. This was an ethical decision to respect residents' privacy and integrity, in line with the guidelines given by The Norwegian National Research Ethics Committees (NESH, 2021), as well as a choice to focus on the relational and social aspects of citizenship in everyday life in the nursing home.

According to Hammersley and Atkinson (2019, p. 83), the role of the ethnographer during fieldwork can vary and is a matter of ongoing negotiation, shaped by the researchers personal and social characteristics. I attempted to take on a role of "guest" in the units, talking to people, sometimes pitching in with small tasks such as pouring a cup of coffee, but not being immersed in daily tasks or care chores. I chose not to wear a uniform because I did not want the position of health professional. This was firstly because I did not want to be pulled into the role of being a "helper", which might have interfered with my ability to experience life from the residents' perspective. Secondly, in line with basic ethical norms of honesty and openness in research (NESH, 2021), I also considered it ethically questionable to wear a uniform, considering this might have made it more difficult, particularly for residents, to perceive my different role in the units. Still, I struggled with how I could make my role as a researcher visible for residents. Similarly, Bland (2002) writes about how she occasionally felt that her presence was "something of a mystery to residents and staff alike" (p. 42) during participant observation in nursing homes, despite her best efforts to be open and honest about who she was. She experienced challenges with making her role visible, as well as clarifying for herself the different roles she acquired during fieldwork. As previously mentioned, as I got to know residents, I realised that many of them had difficulty understanding that I was a researcher and what that meant. In addition, due to the social nature of the fieldwork, I found it challenging to inform residents that were present without disturbing their everyday lives and the social atmosphere of the nursing home units. (These aspects are discussed further in the chapter on ethical implications.) However, being a participant observer in the nursing homes provided an opportunity for me to observe and produce knowledge about residents' embodied competencies in everyday life and how they acted naturally in natural situations. Such information would not have been accessible through interviews but required being part of their everyday life over time.

3.3.2 Individual and group interviews with staff and support staff

Interviewing can be an important source of data, generating information that it would be difficult to obtain otherwise, both about the events described and about perspectives and discursive strategies (Hammersley & Atkinson, 2019, p. 107). O'Reilly (2009) writes that while the ethnographer talks, engages and asks questions, when possible, sometimes it is expedient to take someone aside for a more in-depth conversation to delve more deeply and reflect on events and beliefs (p. 125). While participant observations provided opportunities for increased insight into the actions of both residents and staff in the units, interviews enabled me to get to know the staff further and gain knowledge about the structures and organisation of the homes from their perspectives, as well as about their interpretations of particular events and situations from fieldwork. This information was important to my exploration of citizenship practices because it enabled another layer of understanding and contextualisation of the stories that emerged during my time as a participant observer in the nursing homes.

Hammersley and Atkinson (2019) write that in ethnography, decisions about who to interview are made over time as fieldwork progresses. The goal is not to achieve a representative sample of informants but to identify people with relevant knowledge who are willing to talk to the researcher (pp. 108-112). At first, the leaders of the nursing homes facilitated my access to their facilities and functioned as gatekeepers (Hammersley & Atkinson, 2019, p. 51); then, gradually throughout participant observations I began recruiting participants for interviews. According to Hammersley and Atkinson (2019, p. 108) possible interview participants can become apparent during participant observations. In this study, the field accessed was bounded by the nursing homes structures, meaning people that had direct or indirect experiences with life in the nursing homes. I used a combined strategy of purposive and ongoing sampling (O'Reilly, 2009, pp. 196–199) to recruit people having relevant experience.

At the outset I had planned to interview a strategic selection of participants, including residents, next of kin, staff, leaders, and support staff, who were to be identified as fieldwork progressed. However, due to ethical and recruitment issues during fieldwork, neither residents nor next of kin were interviewed as intended. While I did interact with residents in naturally occurring situations in the nursing home units, I struggled with the ethical side of conducting in-depth and recorded conversations with residents who seemingly did not understand they were part of research. In accordance with NESH (2021) ethical guidelines, I sought to avoid adding stress to residents' everyday lives, and therefore chose not to conduct private interviews. In addition, I attempted to recruit next of kin to be interviewed through written or oral invitations. However, I only succeeded in conducting one such interview. Some next of kin expressed they felt they had limited information to offer while others did not respond. Even though I believed that their experiences of nursing home life could have provided another layer of interpretation, I did not consider it crucial to be able to shed light on the citizenship practices explored in the thesis. Respecting that voluntary consent to participate in research should be given without external pressure (NESH, 2021), I chose not to press the issue.

After a period of fieldwork getting to know the context, residents and staff, I began asking staff and support staff who had been present during my time in the units if they would consider joining me for a sit-down interview. Most accepted, while some preferred not to participate. In total, I conducted 13 interviews with unit staff, amongst them nurses, health-care workers, and assistants or students. Nine interviews were conducted with leaders, activity organisers, occupational or physical therapists or dementia coordinators. All professionals who were interviewed – individually or in groups – were female. According to Malterud (2011), interviews provide insight into experiences and interpretations from people's unique perspectives, as well as into how they attribute meaning to these experiences (p. 130). Staff working in the units knew the residents well, and these interviews were closely centred on how staff experienced and understood different aspects of residents' everyday lives in the units. In the interviews with support staff, the focus was largely on aspects of the institutional frames and their influence on everyday life in the homes. Since the analysis in this study became focused on the everyday and mundane aspects of life in the nursing home units, the interviews with support staff are not reported from in the thesis. However, they were helpful during the research process as they provided contextual and institutional understandings of the nursing homes.

Hammersley and Atkinson (2019) write that interviewing in ethnographic studies will normally take a relatively unstructured form as a conversation in which the person being interviewed has leeway to talk on their own terms, in contrast to more standardised interviews. They further explain that ethnographers do not usually decide beforehand the exact questions they want to ask and do not ask each interviewee the same questions, though they will usually have a written or mental list of issues to be covered (p. 122). In this study, interview topics were developed as the fieldwork progressed and new insights emerged, and which questions were asked depended on the person's role in the nursing home. For example, nurses, unit leaders and activity organisers were not necessarily asked the same questions. Interviews with staff were conducted as a conversation: I asked questions about situations I had observed, the organisation of everyday life and activities, their perceptions of life in the nursing homes or institutional structures affecting everyday life in the units. Questions varied depending on the unit and between different staff in the same unit because specific situations or topics from fieldwork came into focus. In line with Hammersley and Atkinson (2019, p. 122), I had a set of written themes, questions or issues that were used as a dynamic guide in interviews and that was continuously developed throughout the research process. For an overview of the themes that were covered in interviews with staff in the units, please refer to attachment 1.

In each nursing home unit, fieldwork was concluded by inviting staff to a group interview, the purpose being to discuss preliminary findings, interpretations, and experiences from fieldwork. While I had originally intended these to be focus group interviews (Malterud, 2012), I agreed with O'Reilly (2009) that the language of focus groups makes little sense in these contexts and the recommendation that we use the term group discussion instead in ethnographic fieldwork (p. 78). O'Reilly further notes that textbooks may be restrictive about the size, nature, management, and purpose of focus groups and therefore recommends a more flexible approach. The number of participants and the time available to conduct the group discussions did not meet my original intentions. In line with Malterud's (2012) recommendations for focus groups (p. 40), I had hoped that between five and eight staff members would attend, a number which would help facilitate discussion and interaction between the participants. Staff and leaders in both nursing homes considered the period between shifts in the afternoon to be the most suited time for group meetings. However, at the scheduled times of the group meetings, only two, three and four participants were able to attend. Of the nine professionals in total attending these group discussions, five had been interviewed individually previously. In addition, time constraints for staff led to shorter discussions than I had intended. In both individual and group interviews I had to constantly adjust to the temporal constraints of life in the nursing homes, where staff were pressed for time and naturally prioritised their responsibilities towards residents.

As in the individual interviews, I had a list of issues or topics which I wanted staff to discuss (see attachment 2), and before each group interview I read carefully through my field notes and researcher reflections to identify possible themes for discussion. The conversations in the three group discussions were also influenced by the relationships I had built with staff throughout fieldwork, as well as by the participants themselves. All three group interviews had a limited number of participants, something that influenced the degree of discussion. However, participants in the groups knew each other well. They were colleagues and had much shared experience. During the conversations, particularly in the groups with three and four participants, staff triggered each other to share thoughts and experiences in a way I most likely could not have achieved in an individual conversation. Both the individual staff interviews and these group discussions provided contextual information that helped shed light on the interpretations and understandings of constructed narratives during the analytical process. This is outlined further in the section on analysis.

3.4 Establishing data material – fieldnotes and transcription

As with other aspects of ethnographic research, then, recording, storing, and retrieving data must be viewed as part of the reflexive process.
(Hammersley & Atkinson, 2019, p. 166)

The written material available for analysis in this thesis consisted of fieldnotes and transcripts from individual interviews and group interviews. Starting out, I was unsure of how to document my fieldnotes. O'Reilly (2009) cautions that, even though ethnography is becoming more transparent, it's rare to see anyone's fieldnotes, and textbooks rarely tell us what to record and how (p. 71). The beginning of each fieldwork period felt a bit overwhelming. O'Reilly (2009) notes that it's important to write down as much detail as you can of your first impressions as seeing things for the first time as a stranger can make it easier to notice important moments (p. 72). I found it challenging to remember all the details in the beginning. I was confronted with a great deal of information, different people, sounds and impressions, and it was difficult to be able to write it all up. I sought to get to know residents and staff, to build trust and recognition, and to document as many of my observations, reflections, and emotions as I could. When I was at the nursing homes, I carried a pen and paper in my pocket. I had to identify places where I could sit down and write because it became clear quite early on that if I didn't take breaks to write down information a lot of details would be lost to me when writing it up later. I wrote wherever I could, sometimes standing at the kitchen counter, other times sitting down in an empty corridor, in an office or in the restroom.

All notes were written up on my computer every day after being in the nursing home. I strongly enforced my own rule of writing up my notes immediately following fieldwork every day so as to be able to remember the details of the day vividly. I created one document for each nursing home unit. After each day of participant observation, I filled out a table detailing both the timeline/description of events and thoughts and reflections (See table 3).

Table 3: Fieldnotes

Day and date	
Timeline/ description of events	Thoughts and reflections

Antelius et al. (2018, p. 126) point out that the writing of fieldnotes involves both perception and interpretation. I transformed what I saw into written text, selected what to write down and what to leave out, and chose a particular way of presenting it. This means that I didn't just observe and document my observations objectively, but also through a layer of my own preconceptions. As described by Hammersley and Atkinson (2019, p. 156-157), fieldnotes are selective and involve a trade-off between breath of focus, depth of detail and perception itself, considering that we can never take in all aspects of what is happening or all details of the environment. In line with recommendations from Hammersley and Atkinson (2019, p. 158) regarding the documentation of the timeline and series of events, I sought to be as descriptive as possible, diachronically documenting the time (and duration) of events and describing what happened, who was involved and, when possible, exactly what was said.

Hammersley and Atkinson (2019, p. 158) write that it is essential to avoid ambiguity with regards to which voices are represented when referring back to fieldnotes, for example, in terms of direct quotations, summaries or the researcher's own words. Therefore, I clearly marked direct quotations or descriptions and had a separate column for uncensored thoughts, reflection, feelings and analytical ideas, as well as ideas about possible connections to theory that emerged in the process. According to Finlay (2008), the process of bracketing is not a straightforward method of simply setting aside assumptions or an initial step of acknowledging subjective bias. It is a reflexive process in which one continuously seeks to become aware of one's own prejudices and assumptions. Writing this column helped me reflect on my own assumptions both in fieldwork and throughout the structured analytical process. For example, it helped me become aware, in the beginning of fieldwork, that I had a tendency to observe as an occupational therapist (focused on challenges and solutions) instead of observing with the level of curiosity and openness that I aspired to have.

The individual and group interviews were tape recorded if the participants consented. In one individual interview, the staff member did not consent, and I wrote down notes manually during the interview instead. Because of time limitations, most interviews were transcribed after fieldwork had ended. There are no standard rules for transcription procedures; however, the same procedures should be used for all interviews (Kvale & Brinkmann, 2015, p. 206-207). I transcribed the interviews myself. This was useful as it provided an overview of the material, as well as helping me to remember aspects, body language and other things that happened during interviews (which I could make a note of in the transcripts). Participants spoke in different dialects. To ensure anonymity, I transcribed all interviews into the primary Norwegian written language (*Bokmål*), except for words that were specific to that dialect or hard to "translate". The translations to English were produced towards the end of the analytical process, meaning only part of the data was translated. This enabled me to conduct the process of analysis in my native language. All the publications presented in the thesis were written in English.

3.5 Analysis – making sense of the data

> *It [narrative research] does not tell us whether to look for stories in recorded everyday speech, interviews, diaries, photographs, TV programmes, newspaper articles or the patterned activities of people's everyday lives; whether to aim for objectivity or researcher and participant involvement; whether to analyse stories particularly or generally; or what epistemological or ontological significance to attach to narratives.*
>
> *(Squire et al., 2013, p.1)*

This chapter outlines how the structured part of analysis was conducted in the thesis. It begins with a reflection on how the analytical goals of the study changed from a more traditional ethnographic analytical strategy to a narrative analytical strategy. The chapter ends with an outline of the analytical procedures in the three articles of the thesis.

3.5.1 From a paradigmatic to a narrative strategy

This study started out with the goal of exploring mundane aspects of residents' everyday lives, as well as the overall social and institutional structures of nursing home living, through a lens of citizenship. Hammersley and Atkinson (2019) write that ethnographic research has a characteristic funnel structure, becoming progressively more focused over its course. Moreover, well into the process of inquiry, the researcher may discover that the study sheds light on something different than the initial foreshadowed problems, highlighting that analysis may be as much about finding and developing research questions as answering those questions (p. 168). While designing the project, I planned to analyse data through an ethnographic strategy of coding, sorting, and creating order (O'Reilly, 2009, p. 35). I would produce data on phenomena that emerged across contexts, shedding light on emerging aspects of citizenship. I started by reading the material several times. I attempted to approach data inductively and iteratively, asking openly "what stories do fieldnotes tell, and how can they characterise citizenship?" I attempted to gain an impression of life in the nursing homes and identify patterns that could help to further structure the material. Through these inductive and intuitive readings, I started to get a sense of what fieldnotes were about. While there were similarities across contexts, there were many differences that seemed influenced by each nursing home unit's specific context, where people engaged in unique ways. What emerged clearly was the immense variety of ways residents expressed themselves through more than spoken words. Body language, speech, and actions all seemed to shed light on their ability for agency, while the context seemed to influence how they were enabled to express these abilities in nursing home everyday life.

My initial analytical strategy was in line with what Polkinghorne (1995) calls paradigmatic analytical procedures, or analysis of narratives, producing categories out of the common elements across the three nursing home units. I had a perception that coding and paradigmatic analysis across the database would lead to more robust findings through thick descriptions of recurring phenomena. I now questioned whether I would risk reducing people's unique actions within unique contexts to general or normative suggestions for citizenship. Or as Polkinghorne (1995) warn, knowledge that is abstract and formal, and that underplay the unique and particular aspects of each story. The question now remained of how to explore these phenomena of everyday agency in a meaningful and productive way.

To enable an interpretation of the differences and diversity of people's actions and behaviour, and to acknowledge the significance of the particular and special characteristics of each story (Polkinghorne, 1995), I chose to conduct narrative analysis. This strategy allowed for an in-depth exploration and interpretation of residents' everyday lives, both in terms of the contexts in which they took place and through the theoretical framework. Cortazzi (2001) argues that there is "increasing recognition of the importance and usefulness of narrative analysis as an element of doing ethnography (p. 2). Narrative is seen as a fundamental way humans organise their understanding of the world, and it can be analysed as both text, product, social processes or performance in action. Fieldnotes from participant observation in the nursing home units provided insight into small stories (Squire, 2013, p. 8) of everyday life, told through people's actions and unsolicited expressions. These fieldnotes provided one perspective on the everyday life and rhythms of the nursing homes, while interviews with staff added another perspective to broaden the narratives and provide context for the interpretations. The following sections provide further information about the understanding of narrative in the thesis and the steps taken in the analytical process.

3.5.2 The understanding of narrative in this thesis

Squire et al. (2013) contend that narrative research has acquired an increasingly high profile in social science recent years, although the definition of narrative itself is disputed. They further argue that there are no overall rules to guide such research, either regarding suitable materials or modes of investigation, and clear accounts of how to analyse data are rare. They outline different divisions in the narrative field, from event narratives recounting past events; experience-centred work exploring stories from speech, various media and everyday activities; and research focused on the patterns or functioning of stories. Another side of this division within narrative research is the opposition of small and big stories. According to Georgakopoulou (2006), small stories cover "under-represented narrative activities, such as tellings of ongoing events, future or hypothetical events, shared (known) events, but also allusions to tellings, deferrals of tellings, and refusals to tell" (p. 146). This is contrasted with big stories, which are typically centred on autobiographical interview narratives attending to personal experiences and past events.

Baldwin (2006), referring to Bamberg (2004b), argues that rather than insisting on a narrative trajectory maintained over time, small stories can privilege the fleeting and fragmented, contributing to the performance of identity in everyday interactions. He writes that given the present-ness of people living with dementia such a focus would be an effective means of recognising, acknowledging, and supporting the creation and maintenance of selves through everyday life (p. 107). Bamberg (2004b) writes that narratives situated in small-talk and chit-chat can be instrumental in local identity work, arguing for a focus on small, everyday narratives to examine how storytellers bring off and manage a sense of themselves in a given context. Meanwhile, Baldwin (2008) argues that narrative citizenship requires maximising opportunities for narrative expression, both on a personal level (for example, catching the small stories of brief interactions) and on an organisational and structural level, to ensure that the stories of people with dementia are heard and can contribute to the development of practice. In this study, narrative analysis was used to explore the possible meanings of people's actions and expressions in everyday life through constructing narratives of occupational and social engagement from fieldnotes, which can be seen as a small story focus. In constructing and interpreting these narratives, I acknowledge that they can hold meaning and express intention on the individual and personal level. However, additionally, as reflected in the discussion of the thesis, the telling of such stories is perceived as influenced by – and holding the potential to influence – larger societal narratives of dementia, the nursing home and citizenship. As such, I see the small and everyday stories of nursing home life as dynamically linked to master narratives of dementia in society that can contribute to support or supress people's opportunities to practice citizenship.

After the narratives were constructed, they were approached analytically to gain insight into the possible meanings of the things people said and did. In the articles, we take as our starting point that humans live storied lives and that lived experience can be a source of insight (Clandinin & Rosiek, 2006). According to Hydén and Antelius (2011) stories are a way of letting us "see" and experience the world through the "eyes" of other people and can be important tools for inviting others into and creating common shared worlds. While narrative inquiry often uses first-person interview data as the main material for analysis, both Josephsson and Alsaker (2015) and Hydén and Antelius (2011) argue for increased attention to people's occupations or actions. Considering that people living with dementia can experience communicative difficulties, Hydén and Antelius (2011) argue that narratives should be perceived as performed as well as told. They further argue that this redefinition of narratives stresses methodological issues, promoting combining narrative and ethnographic methods in the study of the stories of people with communicative disabilities. This thesis does not explore narratives in the traditional sense of verbally told or autobiographical stories. It explores stories through an occupational lens, recognising that people can express who they are, to themselves and others, through the things they do. Our ethnographic methods of gathering data enabled such an exploration, and by viewing narrative inquiry this way we had the opportunity to increase our understanding of the "unfolding, situated, and multifold character of human occupation" (Josephsson & Alsaker, 2015, p. 70).

3.5.3 Analytical approach in article 1

The first article of the thesis (Sund et al., 2022) is a literature review exploring previous research in the field of citizenship and dementia. The analytical process of the literature review in the article involved creating a narrative and descriptive summary (Evans, 2002) responding to three questions: 1) How is citizenship in nursing homes conceptualised? 2) How is it described as practice? And 3) Have these understandings changed over time? In addition, a tabular overview of article titles, authors, methods and conceptualisations of citizenship was constructed. Due to the limited number of publications on the subject of citizenship and dementia in nursing homes, it was considered useful to include articles with qualitative, quantitative and theoretical methodologies. The challenge related to including articles exploring citizenship using different methodologies was to ensure a stringent analysis that is clear for the reader. Considering that the aim of the literature review was to explore how citizenship for persons with dementia living in nursing homes has been conceptualised and described in the research literature, only articles that used the word "citizenship" were eligible for inclusion. The narrow focus of the review was important because there was a need to specifically map current knowledge in relation to the concept of citizenship in this context.

3.5.4 Analytical approach in articles 2 and 3

Article 2 (Sund et al., 2023a) and article 3 (Sund et al., 2023b) of the thesis analysed and interpreted data from fieldwork at Sea-Crest and Sunny Hill nursing homes. The analysis was inspired by the four analytical readings suggested by Fjetland (2015): 1) naïve reading, 2) thematic reading, 3) discursive reading and 4) interpretive reading. In addition, a synthesising step of constructing narratives was added, inspired by Polkinghorne's (1995) way of describing narrative analysis through constructing emplotted narratives from events and happenings. According to Polkinghorne (1995), narrative inquiry primarily requires diachronic data, meaning they contain temporal information about the sequential relationships of events, while synchronic data lacks these dimensions, e.g., being focused on the beliefs or Interpretations of informants. Narratives were constructed from fieldnotes, which contained diachronic data, while interviews containing synchronic data were highly useful in contextualising and interpreting these narratives.

All three authors read the written material and actively engaged in the analytical work in the articles. In the following section, I outline how the analysis was conducted and offer deeper insight into the results of each step than was possible in the articles. This is done to offer the reader a more thorough understanding of life within the nursing home units where the fieldwork took place. (The steps are also outlined in table 4.)

Naive reading

The naïve reading was done by reading the fieldnotes from all three units several times while asking "What are the fieldnotes about, and how is citizenship characterised in the stories?" The fieldnotes depicted an everyday life that seemed to involve a predictable routine in terms of what happened and when. Activities and events were different from day to day, but the "temporality" of the everyday seemed to have its regular structure and themes. Staff in all units expressed deep concern for residents' well-being and expressed aspirations of providing person-centred care, described in the second article as "environments of care", where staff constantly sought to prevent negative reactions and consequences for residents' well-being in the social environment. Staff's workdays were also characterised by many tasks and chores, including upholding chronological time for themselves and residents, planning and serving, engaging residents in activities, and ensuring their medical and care needs were met.

Inspired by Finlay (2008), I also sought to reflect on and engage with my own emotional and embodied experiences from fieldwork, exploring what insight such perceptions could add to my initial impressions. The naïve reading brought attention towards the apparent complexities of citizenship in the nursing homes. It appeared as more than self-determination or a right to activities and participation. The vulnerability of residents' well-being and their medical and care-based needs emerged as significant aspects of their citizenship, while their initiatives to engage shed light on their continued abilities. These impressions led me to three questions for further reading: Is there potential for citizenship in mundane everyday situations? Is residents' unrest or frustration expressions of citizenship? Are care and medical assistance prerequisites for citizenship?

Thematic reading

The thematic reading involved re-reading the fieldnotes, asking “What themes emerge, what happens in nursing home everyday life?” while making notes and brainstorming maps to identify possible themes. The thematic reading did not produce specific categories or themes directly presented as results but was an important part of getting a sense of what the fieldnotes were about. This step resulted in four preliminary themes: 1) activities, 2) social interactions, 3) expressions of will and 4) the need for support and safety. In the following section I provide a brief presentation of these themes.

Activities: Sea-Crest nursing home provided a varied organised activities programme for residents planned by a designated activities organiser. At Sunny Hill, residents participated in some activities outside the units, but most activities happened in the social environment of the units, initiated by staff and residents themselves. Meals appeared as a predictable temporal frame and often involved staff serving ready-made sandwiches or plates of food, as well as offering residents their medications during the meal. Some residents, particularly at Sunny Hill, made their own sandwiches, with support from staff if needed. Meals were only occasionally sit-down meals where staff joined residents at the table, except for in North Unit where residents seemed to have an immense need for staffs’ presence to avoid anxiety or confusion. After breakfast, residents often gathered in the living rooms. Time could be spent reading newspapers, watching TV, in conversations, playing games, knitting, having visitors, singing or listening to music, exercising or taking walks outside or in the corridor. Many residents sat with closed eyes or fell asleep in the common areas, particularly if there was nothing in particular going on. Some days specific activities or events were planned, often in the morning in the period between ten and twelve, such as singalongs, trips, concerts or events, and both nursing homes were regularly visited by children or others from the local community. While there seemed to be no set routines for residents’ involvement in daily chores, residents several times initiated such engagement themselves, including starting to clean or tidy up, or expressed wanting to help staff in their daily tasks.

Social interaction: Residents spent much time in the common areas of the nursing home units. When staff joined residents, this often led to engaging conversations. Residents sometimes interacted with each other, but most times they seemed to rely on staffs’ presence for such interactions to take place. Residents sometimes showed care for each other or for staff while other times interaction led to misunderstandings, residents correcting each other or frustration, for example if someone was noisy or showed “unacceptable” behaviour. Staff’s presence seemed highly important to enable social interaction and a positive social environment.

Expressing will: Some residents clearly stated their satisfaction with being in the nursing home while others expressed wanting to leave, saying someone was waiting for them or not understanding what “this” place was. Sometimes it could be difficult to understand what a resident was attempting to convey, and staff explained that many residents had difficulty answering questions about what was important to them or what they wanted. Expressions of will could be seen through verbal expressions or embodied or enacted expressions, such as body language, turning their head away, getting up and leaving, banging their cup on the table, trying the locked door, waving their arms or refusing to move. Some residents waited and didn’t make any “demands”; some expressed frustration and got irritated because they couldn’t leave, because they didn’t understand what was happening or because there was too much waiting or not enough to do.

Staff as safety: Residents appeared to have different levels of tolerance for activities and noise in the environment, and their need for assistance from staff varied. Some residents needed physical help, such as support while walking or assistance with feeding. Some residents expressed uncertainty, anxiety, pain, discomfort or sadness and sought physical contact with others, such as a hug, sitting close or holding hands. Residents’ reactions if staff were not present in the common areas differed immensely. At Sea-Crest, residents often sat calmly, waited, walked the corridors, fell asleep or sat beside each other without communicating. In South Unit, some residents sat calmly, others read the newspaper, some could be seen getting restless while others closed their eyes or fell asleep. In North Unit, staff leaving could lead to immense frustration, anxiety and confrontations between residents because of misunderstandings. In all three units, staff seemed to be a point of safety and important for residents’ well-being and opportunity to interact and engage in their environment.

Constructing narratives – an added synthesising step

The naïve and thematic steps of analysis led to a focus on occupational and social situations in which residents’ agency and abilities to act and interact emerged. An additional step of synthesis was then taken which entailed constructing narratives (Polkinghorne, 1995) to enable unique and unfolding narratives of such agency to come into light. In total, 26 residents were included in the study. However, our narrative analytical strategy gradually shifted the focus to some narratives that shed light on citizenship practices. This narrative ambition turned our attention away from providing a description of the whole social structure of the nursing home and resulted in constructing and interpreting narratives for some of the residents living there.

According to Polkinghorne (1995), the process of narrative analysis involves synthesising data rather than separating it into its constituent parts. Polkinghorne (1995) emphasises the possibilities within narrative-type inquiries that gather actions, events and happenings as data and use narrative analytical procedures to produce explanatory stories. He calls attention to the use of emplottment and narrative configuration as its primary analytical tool. Polkinghorne (1995, p. 7) writes:

> A story is a special type of discourse production. In a story, events and actions are drawn together into an organized whole by means of a plot. A plot is a type of conceptual scheme by which a contextual meaning of individual events can be displayed.

Moreover, he explains that the development of a story involves recursive movement from data to the emerging thematic plot, involving a hermeneutic to-and-fro movement between parts and the whole. In the second article (Sund et al., 2023a), we constructed narratives for three residents: May, Janne and Camilla. The plot emerged through repeated readings of the material. For example, May’s narrative was centred on her expressed desire to help staff in the nursing home, culminating in her contributing to their daily tasks through folding. According to Polkinghorne (1995), the production of stories requires diachronic descriptions of events and happenings, e.g., from interviews, documents or observations, in which we can search for pieces of information that contribute to the construction of the story. For the third article (Sund et al., 2023b), we searched the fieldnotes for situations that revealed social aspects of residents' engagement, shedding light on the phenomena of co-ownership and silence within the nursing home units.

Discursive reading

The function of narrative analysis is to answer how and why a particular outcome came about. Its purpose is not simply to reproduce observations but to provide the reader with insight and understanding (Polkinghorne, 1995). After constructing narratives, the discursive and interpretive reading focused on these specific constructed stories. In an effort to identify challenges and opportunities for citizenship in residents' stories and in their unique context we asked, "What is at stake in the stories?" Interviews with staff were searched to identify expressions that could shed light on these interpretations, allowing for an added perspective. The second article of the thesis (Sund et al., 2023a) sheds light on residents' contributions to the occupations of staff, how embodied initiatives could be enabled or restricted, and how occupational responsibility could mediate experiences of frustration. Residents' initiatives and desires to actively engage appeared important for their sense of self and their role in the nursing home; these initiatives were sometimes supported, other times redirected or denied. The narratives of the third article (Sund et al., 2023b) reveal a vulnerable balance between ownership and silence in the nursing homes. They shed light not only on opportunities arising within social interactions but also on the significance of staffs' presence, support and interpretive practices.

Critical, interpretive reading

According to Malterud (2011, p. 146), observational data often requires being anchored in a theoretical framework to be able to identify the researcher's perspectives clearly. In the critical interpretive reading, the constructed narratives became a point of interaction between the uniquely mundane and embodied events and actions of the nursing homes and the theoretical framework. During this phase, the main question was, "How can results be critically interpreted in terms of theory?" Josephsson and Alsaker (2015, p. 76) note the importance of taking an active stance on how analysis will deal with theory. Moreover, they remind us that while it can be fruitful to see the emerging analysis in dialogue with theory, this is not the same as using data to illustrate existing concepts or theory: "Rather, theory is brought into the dialectic move between interpretations and material that characterize hermeneutical interpretation" (pp. 76–77).

Theory was used to interpret the stories; at the same time, the stories were used in an attempt trying to clarify and re-conceptualise theory. Our analytical process was thus abductive (Alvesson & Sköldberg, 2018), starting from an empirical basis and going back and forth between narratives and theory to identify and refine the theoretical foundations that could provide an overarching pattern to interpret data. In the second article (Sund et al., 2023a), the critical, interpretive reading is reflected in the discussion. In the third article (Sund et al., 2023b), both the discursive and the theoretical interpretations are presented under the heading "Findings and interpretations", followed by a brief discussion about the implications of the findings.

Table 4: The analytical process:

	Naïve reading	Thematic reading	Constructing narratives	Discursive reading	Interpretive reading
Question	What are the fieldnotes about? How is citizenship characterised in the stories?	What themes emerged? What happens in nursing home everyday life?	What stories shed light on citizenship in the nursing homes?	What's at stake in the stories?	How can results be critically interpreted in terms of theory?
Approach	Fieldnotes were read several times as openly as possible to get a sense of everyday life and an intuitive impression of citizenship.	Fieldnotes were re-read several times and emerging themes were noted. Brainstorming maps were made to identity overall themes.	Fieldnotes were searched for situations of agency as a starting point for constructing narratives of specific people (article 2) or specific social situations (article 3).	The constructed narratives were interpreted in terms of the context in which they took place. Interviews with staff provided another layer of interpretation.	Narratives were interpreted in terms of the theoretical framework.
Results	*Everyday life of predictable routine *Environment of care ***Questions for further reading:*** * Is there potential for citizenship in mundane everyday situations? * Is residents' unrest or frustration expressions of citizenship? *Are care and medical assistance prerequisites for citizenship?	***Activities**: Organised or unstructured, falling asleep, everyday chores, meals as predictable temporal frame. ***Social interaction**: Spending time in common areas, caring and misunderstanding, staff supporting social interaction. ***Expressing will**: in verbal, enacted and embodied ways. ***Staff as safety**: Staff provides safety and physical and emotional support.	**Article 2:** *May *Janne *Camilla	**Article 2:** *Contributing to the occupations of staff. *Embodied initiatives can be enabled or restricted. *Occupational responsibility can mediate experiences of frustration.	**Article 2:** Interpreted through everyday citizenship (Nedlund et al., 2019ab) and occupational dimensions (Wilcock & Hocking, 2015). Suggest moments of becoming as an essential aspect of everyday citizenship.
			Article 3: *Interacting socially through music. *Sitting beside each other in the living room. *Being served breakfast in the dining room. *Active engagement in occupation.	**Article 3:** *Co-ownership through being and doing together. *Co-ownership and the phenomenon of silence. *Decreasing co-ownership through routines *Resisting calmness and the act of taking ownership.	**Article 3:** Interpreted through active and activistic citizenship (Boje, 2017, p. 203-205) and acts of citizenship (Isin, 2008). Suggest that activistic citizenship shed light on residents' expressions as holding transformative power.

3.6 Ethical considerations

Researchers should respect the participants' human dignity and consider their personal integrity, safety, and well-being.
(NESH, 2021, p. 18)

All Norwegian medical and health science research involving humans must be approved by the Norwegian Regional Ethics Committee (REK, 2014) before commencing. While this study did not gather medical data, it took place in a health context, and I was privy to a range of information about people's lives. Even though I did not consider it a medical project but rather a social science project, I still considered it important to have it assessed by the committee. The REK concluded that the study was not subject to the Medical and Health Research Act (Ministry of Health and Care Services, 2008). However, according to guidelines published by the Norwegian National Research Ethics Committees (NESH, 2021), if the researcher is to use information from confidential situations (e.g., between health workers and patients) a dispensation from confidentiality requirements must be provided. Due to the observational nature of the study, REK approved such a dispensation (attachment 3). Because the study processes information about people, it was also assessed by the Norwegian Centre for Research data (Attachment 4). The upcoming sections discuss ethical issues that arose when conducting fieldwork in the nursing homes, in line with the NESH guidelines (2021) and assessments by the Regional Ethics Committee and the Norwegian Centre for Research Data, with particular emphasis on the inclusion of people with dementia in research.

3.6.1 The inclusion of vulnerable groups in research

The research community has a social responsibility to gain experience with and develop knowledge about members of vulnerable groups.
(NESH, 2021, p. 29)

According to Baldwin (2008), people with dementia have been silenced in telling their stories based on the narrative that it is impossible to access their experiences because of dementia. People with dementia were earlier often neglected as participants in research, something that has gradually changed in recent decades along with changing paradigms (Bartlett & O'Connor, 2007; Bartlett et al., 2010; Hellström et al., 2007; Nygård, 2006). According to Bartlett and O'Connor (2007), the personhood lens recognises the importance of listening to the perspectives of people with dementia and "has effectively and explicitly brought the person with dementia into the picture" (p. 109), leading to an emphasis on creative and innovative methods to overcome issues with communication. Hellstrøm et al. (2007) write that while those carrying out studies involving people with dementia must work to ensure that their dignity is maintained, they argue that "the exclusion of people with dementia [from research] is itself an affront to their dignity" (p. 609). Fisher (2012) argues that practices related to informed consent and protection from invasions of privacy may sometimes have the unwanted consequence of limiting civil and human rights. For example, privacy concerns should be considered alongside other rights of citizenship, such as the right to freedom of expression. Through such a perspective, the author questions whether restrictions on the basis of perceived vulnerability might infringe on people's citizenship rights.

According to the NESH (2021) guidelines, people who cannot provide free and informed consent can only be included if the research cannot be conducted with people who have full capacity to consent, if it is valuable to the person or group that is the subject of the research and if the risks and inconveniences are insignificant. While it was considered essential to include people with dementia in this research if I was going to produce valid knowledge of the characteristics of their citizenship, it was important not to ignore their vulnerability. While the guidelines (NESH, 2021) state that researchers must protect the integrity and interests of vulnerable groups, they simultaneously promote the responsibility of the research community to gather and develop knowledge about members of these groups. Further, excessive protection may have negative consequences, leading to a lack of knowledge about their perspectives.

Meanwhile, according to the review by West et al. (2017), there is a lack of consensus in current research guidelines regarding ethical standards concerning recruitment and issues of risk in research. Similarly, Silva et al. (2020) argue that there is a lack of explicit and consolidated dementia-specific guidelines for research ethics, amongst others about the everyday ethical issues affecting participants with dementia in research. In this study there were specific ethical issues that had to be considered when including residents from the nursing homes. The following section discusses issues of informed consent to participate in research, the ethical implications of residents' apparent lack of awareness of my researcher role, and a continuous need for moral sensitivity (Heggestad et al., 2013b) while conducting fieldwork in nursing homes.

3.6.2 Including people with dementia in the study – consent and ethical issues

> *When research participants' capacity to provide consent is impaired or absent, researchers must safeguard their freedoms, rights, and human dignity.*
> *(NESH, 2021, p. 20)*

In this study, all residents with dementia living in the included nursing homes were eligible for inclusion. At Sunny Hill, all residents had dementia; at Sea-Crest, some residents did not and were therefore not asked to take part in the study. I did not document information about diagnosis; it was considered sufficient that staff confirmed that residents had dementia. According to the NESH (2021) guidelines, voluntary and informed consent should be obtained from participants in research, preferably in writing. NESH (2021) outlines that *voluntary* means that consent is given without external pressure or restrictions on freedom of choice. *Informed* means that sufficient and clear information is provided, clarifying what participation implies, why they are being asked to participate, what data is collected, how and by whom it will be used, and for what purposes. Providing informed consent can be a challenge for people in the late stages of the illness due to the cognitive decline associated with dementia. In line with the assessment by the Norwegian Centre for Research Data (Attachment 4), it was therefore planned that, in cases of reduced capacity to consent due to cognitive decline, residents' next of kin were to give consent on their behalf.

The first issue was how to assess residents' ability to consent. Heggestad et al. (2013b) critique assessments of consent capacity based on formal tests and procedures: "Instead of letting the participants go through cognitive screening, there is a possibility to let a nurse or a doctor who knows the patient well do a more general and holistic evaluation of the person's capacity to consent" (p. 33). Similarly, in this study, staff and leaders of the nursing home units, who knew the residents well, provided information to residents and made the assessment of whether they had capacity to provide informed consent to participate in the study. In addition to the formal information letter and consent forms (Attachment 5), an easy-to-read pamphlet was provided by the researcher to use as needed (Attachment 6). No residents were assessed as being fully capable of providing informed consent. Next of kin signed consent forms for all residents who participated in the study; however, in some cases, both residents and next of kin signed. I met no residents until written consent had been provided.

However, several authors argue that the one-off-consent model of such proxy consent is not sufficient to ensure the ethical inclusion of people with dementia in research, and a process consent model has been promoted by several researchers in the last decades (Dewing, 2002; Dewing, 2007; McKeown et al., 2010; Poland & Birt, 2018). McKeown et al. (2010) conclude that process consent models can provide an ethical and practical framework that ensures that consent is continuously assessed. Poland and Birt (2018) argue that while the ability for autonomous decision-making may decline over time, the researcher should look for signs of assent rather than fully informed consent. They explain the concept of assent in terms of a person's capacity to decide to take part, even if they can't give full consent. Further, they write that collecting data while the participant is engaged in their everyday activities can be seen as a non-threatening form of data collection: "…to interact ethically the researcher needs to repeatedly check the participant's continuing awareness of the interaction as a research event" (p. 9). However, the way ethnography rests on participants being involved collectively in a social world (Delamont & Atkinson, 2018) may constitute a challenge for the ethical aim of keeping residents continuously informed. Providing residents with continuous information about the research while being a participant observer in the common areas would have been disruptive to the social atmosphere of the nursing home units.

Instead, what Heggestad et al. (2013b) describe as moral sensitivity might be a useful concept for thinking about ethical challenges and considerations when including people with dementia in the study. They argue that it can be difficult to predict what ethical challenges might arise when including people with dementia and that it might be difficult to plan for all issues that might emerge during research. This was similar to my experience. I had planned to inform residents about my role and presence, conduct sit-down interviews with some of them and remain sensitive to negative reactions to my presence in the nursing home units. However, as I entered the field and started to get to know the residents, I found it challenging to know how to provide information about my role in the units and to determine whether residents were aware of what my role as a researcher involved. I constantly reflected on how my presence influenced both individual residents and the atmosphere and social environments of the units. How much information could I provide? How do I introduce myself? When do I withdraw, and to what degree do I inform?

Most days I experienced residents' reactions to my presence as positive; as time went by, many seemed to recognize my presence as familiar, and I could find myself sitting close to residents or with someone holding my hand. It seemed that most recognised me as something *different* from staff, such as a visitor, a student or someone's next of kin. At times someone seemed to react to my strangeness, particularly at the beginning of fieldwork, before they knew me in that social environment as some were wary of strangers. For example, at the beginning of fieldwork at Sunny Hill, one resident expressed concern because she didn't know me and preferred that I keep my distance. These perceptions were not static, and they changed from day to day, between residents and over the course of the fieldwork.

While doing fieldwork I paid close attention to any sign that my presence was unwanted. If I saw signs of discontent or that my presence was disruptive, I moved to another part of the environment or stopped fieldwork for that day. I was aware that my presence could disturb the sense of calm in the units, and if I was unsure of how my presence influenced the surroundings, I asked staff who knew residents well for their assessment. During the fieldwork I sought to provide tailored information about my role and presence. However, I considered that constantly reminding them about it or seeking ongoing consent would cause more stress then good. Therefore, I brought such topics up on some occasions when I assessed it to be okay. For example, I realised that one of the residents in South Unit was interested in talking to me about my presence, and we could talk about my role as a researcher and that I was doing I PhD. She had, along with her next of kin, signed her own consent form. According to staff she had thought about signing for several days before doing so. However, during conversations with me she brought up of her own accord that she denied having dementia.

This leads us to another issue that emerged that I had not properly considered beforehand, namely issues of transparency about diagnosis. Informed consent requires that information about why the person is being asked to participate be provided (NESH, 2021). McKeown et al. (2010) argue that because involvement in research builds on values of openness and honesty, questions about how to communicate regarding the focus on diagnosis is ethically important. When the resident in question denied having dementia (she did so on several occasions), I did not consider it ethical to enter into a discussion about this topic. I chose simply to listen to her stories and what she told me about her everyday life. However, I found this ethically challenging because she had co-signed the consent form and she was quite interested in the fact that I was doing research in the unit. In general, dementia was not a topic of conversation or something that was talked about. A resident could express difficulties, for example with remembering or finding the way, but the term dementia was not used. Since none of the residents themselves spoke of having dementia, neither did I. The word was not used in the "easy to read" pamphlet made available for residents either. To avoid harm to the participants, Heggestad et al. (2013b) also explain that while they provided information during fieldwork, they did not inform all participants about the dementia focus due to situational sensitivity. As long as the researchers did not know how the person would react if confronted with the dementia diagnosis, they considered it morally problematic to bring it up.

The risks of participation in this study were considered minimal, and for some residents it might even have been a positive experience due to the added social element of the researchers' presence. However, Heggestad et al. (2013b) note that while it is common to focus on physical harm in research when discussing risk, in their study, the risk of harm had more to do with stressing the residents mentally or socially. In my assessment, continuously providing information to residents during my time at Sea-Crest and Sunny Hill nursing homes and ensuring they knew about my role as a researcher or bringing up the topic of dementia would have done more harm than good, both for individual residents and for the social atmosphere of the units. For that reason, the information provided to residents was tailored to each person and situation with the aim of reducing stress and establishing positive communication between the residents and me as a researcher.

3.6.3 Informing and gathering consent from staff and leaders

In both nursing homes, information about the project was provided at meetings held with leaders and staff before commencing fieldwork. At Sea-Crest, next of kin were not invited to a physical meeting since the leader of the unit had experienced that few attended when invited to such meetings. At Sunny Hill, next of kin were invited to a physical meeting, but only two of the residents' next of kin attended. Formal consent forms containing written information about the project were provided to both staff and next of kin (Attachment 5), and information was posted on the nursing home boards.

In line with NESH (2021) guidelines and assessment from the Norwegian Centre for Research Data, signed consent was obtained from participants. Most staff at Sea-Crest had given signed consent before the fieldwork started; on some occasions a substitute or support staff signed consent forms then and there, either because they had a rare shift coinciding with observations or because they were taking part in an interview. At Sunny Hill, consent forms were signed during fieldwork. This meant that at every shift I talked to staff that hadn't already signed (consent was given only once by each staff member), provided information about the project and asked if they would consent to my presence. I found this useful because it enabled me to talk to each staff member, providing information and noting if they seemed wary about being observed. Still, this may have increased the pressure to participate. No one in either nursing home declined to be observed, even though some did express beforehand that it felt a bit strange.

In both nursing homes I sought to create predictability for staff. I wrote down when I was going to be present in their work calendar so they knew beforehand when I was going to be there. The staff were informed both orally and in writing that they were free to reserve themselves from being observed. This could be done by informing their leader or by telling me directly. None did this. When the leaders of an institution and a whole nursing home unit join a research project, it can be difficult for an individual person to say no to participating. They might feel obligated, or that they will ruin it for others, or that others will think they have something to hide. For these reasons, it was important to stress that participation in observation was voluntary and to pay attention to any expressions of discomfort related to my presence, both from residents and from staff working in the units.

3.6.4 People being directly or indirectly affected by research

According to the NESH guidelines (2021), researchers must consider how people might be directly or indirectly affected by research they haven't had the opportunity themselves to consent to. Researchers may gain access to information about people not included in the study, and in some instances (e.g., during observation of small groups or environments) it can be difficult to rule out people that haven't consented or had the opportunity to refuse participation. The NESH (2021) guidelines further state that researchers must be aware of unintended consequences of their research, e.g., that other members of a group can experience being unreasonably exposed. In this study, I did spend time in rooms where people who hadn't consented to be part of the research were present, including other nursing home residents who weren't participating in the research, professionals or others visiting the nursing home briefly, as well as during organised activities that included others from the nursing home or community, such as concerts and events. During my time as a participant observer in the nursing homes, I made sure I did not document any information about people who had not consented to take part in the research. Often it was challenging to ensure visitors were informed of the research taking place and to gather informed consent from all who were present. On many occasions, other senior citizens from other parts of the nursing home or from the community participated in such events, and at times I wasn't aware that such events were taking place until they did. I sought to provide information about my presence or asked the nursing home to do so beforehand. Other times this was not possible. For this reason, detailed descriptions of those activities and events were not documented. I kept the focus on the residents who were part of the study and did not write down information about or characteristics of others who were not included in the study.

3.6.5 Protecting data and confidentiality

In line with NESH guidelines (2021) and the Norwegian Centre for Research Data's assessment (attachment 4), measures were taken to ensure the anonymity of research participants and safe storage of data. When writing up the fieldnotes, I used initials for residents and I did not document any information about names or the geographical location of the nursing homes or the area in which they were located. After completing the fieldwork, I re-read the notes thoroughly to ensure anonymity, assigning pseudonyms for residents and fictitious names for the nursing homes and locations. Throughout the project, fieldnotes, recordings of interviews and interview transcripts were stored on encrypted hard drives, separate from participants' names and contact information. A separate document containing information about the participants was stored apart from all material about the study.

4.0 SUMMARY OF RESULTS

This thesis explores what characterises citizenship practices for persons living with dementia in nursing homes. Through the three articles of the thesis, I aimed to produce knowledge about the lived experiences of people with dementia through a lens of citizenship and contribute to the further conceptualisation of citizenship theories in the field. Exploring citizenship as mundane practices revealed fleeting and easily overlooked aspects that can influence the lives of citizens living with dementia in nursing homes. In the following chapter, I present the results and conclusions of each article before providing an overview of how these results respond to the main research question of the thesis.

4.1 Article 1 results

Citizenship for persons with dementia in nursing homes: A literature review

The first article of the thesis is a literature review of published peer-reviewed research which was conducted with the aim of establishing a baseline of knowledge about citizenship and dementia on which to build in the thesis and identifying knowledge gaps in current research. In the article, written with Kirsten Jaeger Fjetland and Halvor Hansich, we explore the following research question: *How is citizenship for persons with dementia living in nursing homes conceptualised and described in the research literature*? We produced a narrative summary of the 15 articles that met the inclusion criteria. As the included articles were briefly presented in the introduction, I focus on the main results of the review in this summary.

Citizenship emerged as a critique of dominant medical and care-based understandings, seeking to combat discriminatory practices through engagement, participation and upholding societal connections in residents' lives. The citizenship framework argues for dementia services that are rights-based rather than needs-based and proposes that people with dementia should be fully recognised as active subjects in their own life as well as in research. Relying on Goffman's (1961) concept of "total institution", the article investigates citizenship in terms of structures and perceptions of dementia that may put residents' citizenship under pressure. It discusses how basic structures of the nursing home, the socio-political context, and our understandings of dementia influence how residents can enact their citizenship.

The article concludes that citizenship practices may be under pressure from certain characteristics of the nursing home, such as institutional regimes, and limited by perceptions of abilities. Citizenship promotes opportunities for participation in activities and everyday chores and societal connections, where even minor acts can have significance. Citizenship is enabled through supportive networks, promotes the acceptance of risk, and acknowledges the intentionality and agency of the body. In the article, we call for more research exploring citizenship practices in nursing homes in a way that encompasses both residents' apparent needs and their abilities as citizens. This highlights that to support people living with dementia in nursing homes in living full lives, it is necessary to recognise sometimes contradicting knowledge paradigms in the dementia field as complementary.

4.2 Article 2 results

Within moments of becoming – everyday citizenship in nursing homes

Aiming to produce knowledge of citizenship within mundane aspects of nursing home life, the second article of the thesis, written with Halvor Hanisch and Kirsten Jaeger Fjetland, explored the following question: *"How do people living with dementia in nursing homes express and enact their everyday citizenship?"* After fieldwork, narratives of three residents were constructed and interpreted through the occupational dimensions of *doing*, *being*, *becoming* and *belonging*. Connecting occupational theory to the international conversation on citizenship offered an opportunity to explore the needs, capabilities and rights of people with dementia living in nursing homes.

The results show that residents in environments of care, sometimes acted in ways that expressed their agency and desire to engage in the nursing home. May, who clearly stated her desire to help staff, contributed through the occupation of folding. In terms of the occupational dimensions, May seemed to experience *belonging* in the nursing home, while her efforts showed her continued opportunity for *becoming* by acting on an identity as a contributor. Janne, in seemingly embodied ways, took the initiative to tidy up after herself at the end of the meal, although staff took over the chore she had begun, thus restricting her situationally relevant occupation. Janne's *doing* seemed triggered in familiar situations, shedding light on her opportunities for *becoming* through embodied moments of engagement. Such *doing* might not have been perceived by those around her as important for her sense of identity and restricted to protect residents from movement that could cause stress. Camilla often appeared frustrated and seemed to be on a quest for some understanding of where she was or what to do and seemed to find some sense of purpose through occupational responsibility in her nursing home unit. Camilla often did not seem to experience *belonging* in her environment and with the occupations of the nursing home, and her expressed frustrations were often met by calm. Engaging in *doing* with others seemed to strengthen her sense of *belonging* and taking on responsibility emerged as more than simply being offered an opportunity to participate but acknowledged her capacity for *becoming* and continued growth.

Through narratives of occupation, May, Janne and Camilla showed us how they could contribute by engaging in the occupations of staff, how embodied initiatives were enabled or restricted within their social environment, and how occupational responsibility could mediate experiences of frustration. Through this lens, residents emerged as more than receivers of care but as contributors to their environment. The narratives are interpreted in terms of *becoming*, an occupational dimension linked with the human need for growth and using one's abilities in line with one's own occupational potential. Our results suggest that residents' *becoming* requires recognition of their agency as ways of expressing aspirations and capabilities, as well as supporting spontaneous acts of agency within the context and situations in which they occur. As such, b*ecoming* and everyday citizenship add to the planning and tailoring of activities by staff by supporting initiatives that emerge in the moment. This does not undervalue residents' immense need for care, nor suggest that citizenship or *becoming* is a stable condition. We suggest that *becoming* emerges in moments of change when a person's vulnerable well-being takes a positive turn. The results of our study gives arguments to show how *becoming*, as an essential dimension of mundane and habitual everyday life, constitutes a part of citizenship, and that such citizenship is vulnerable and enacted within the ordinary. Our results emphasise the importance of everyday life perspectives in professional practice for persons living in nursing homes. A citizenship of *becoming* presupposes that institutional perceptions of activities as *offered* ought to be broadened to include supporting residents' natural desires to *do* and act within the mundane and ordinary of everyday life.

4.3 Article 3 results

Activistic citizenship in nursing homes: co-ownership in the mundane

To produce knowledge about the potentially transformative characteristics of a citizenship lens in the nursing home context, the third article, written with Kirsten Jaeger Fjetland and Halvor Hanisch, investigates mundane and relational everyday situations through a lens of active and activistic citizenship. It seeks to answer the question: *How can mundane social and occupational situations in nursing homes shed light on citizenship for people with dementia, and what is the potential of adding an activistic lens of citizenship to our interpretive practices*? We performed a narrative analysis of the fieldnotes from participant observations, interpreting constructed narratives through occupational perspectives, narrative theory and theories on citizenship.

In the first narrative, we get acquainted with Monica, May and Jasmine and a social situation where they took ownership within the living room of their unit, engaging with each other through music. While their ownership might have appeared to be an independent phenomenon, our interpretation suggests that it was enabled through support from and interactions between both material and social actors in the nursing home. Being and doing together, finding common ground for in which to interact, seemed to express a sense of togetherness, a belonging with each other as citizens in the nursing home. The staff who were present appeared to be simply walking alongside them, having no active part in the narrative. Their active choice to be present in the social environment underlined a perception of co-ownership between them and the residents in the unit.

However, sometimes residents in the nursing homes were observed sitting beside each other for long periods of time in silence. We interpret a narrative in which Tove, Kåre, Lisa and Klara are gathered in the living room for 45 minutes without interaction and suggest that silence might both express moments of rest and reflection, be imposed through lack of support, or be perceived as an expression of citizenship. Seeing silence as an act of citizenship suggests that withdrawing might be an expression of agency, a shared silence of resistance against an environment that does not sufficiently support social engagement. Such a perception contrasts with diagnostic perceptions that view silence as a symptom (apathy) and thus a natural consequence of dementia.

It was observed that co-ownership could decrease as a result of routines built on a group-based assessment of residents' limited abilities to contribute. We interpret a situation where breakfast is served. The meal was served in a regular fashion, where residents were given drinks, food and medication by staff and no food or drinks were placed within arm's reach of residents. We discuss that the staff's assessment of residents as unable to contribute more actively might be internalised by residents, storying themselves to fit with what is expected of them while awarding staff full ownership of the social environment. We propose there might be benefits from building on interpretive practices that assess residents as capable of agency and support that agency by sharing responsibility.

Residents were also observed acting in ways that might be interpreted as attempting to claim occupational ownership in the nursing home, as exemplified through the actions of Hilde and Alma. Staff expressed the aim of creating calm or encouraging seated activities in the unit, based on a group-based assessment of residents' occupational needs. Hilde and Alma acted in ways that did not seem to align with this aim, attempting to leave the living room, approaching the kitchen, or acting against staff's encouragement to sit down and rest. We suggest that viewing such actions as mundane forms of resistance sheds light on residents' ability to perform their citizenship and claim ownership within the nursing home.

The findings revealed a phenomenon of shared ownership between residents and staff, and a vulnerable balance between *silence* and active social and occupational engagement in the nursing homes. Through a lens of activistic citizenship, group-based assessments of residents' abilities or occupational needs are interpreted as constraining opportunities, and staff's options, to facilitate co-ownership. Co-ownership, as a phenomenon, highlights the possibility of a shared ownership between residents and staff in nursing homes. While residents being left full ownership of the room might decrease their actual ownership, staff taking full ownership through routines building on group-based assessments may have similar results. The activistic lens of citizenship as suggested in the article, underlines that we do not merely bestow residents with meaning and opportunity but should turn attention towards how both verbal and non-verbal expressions can be interpreted as meaningful and as possible expressions of resistance. This, we suggest, require a professional competence in actively interpreting residents as intentional.

4.4 Summary of results from the articles

What characterises citizenship practices for persons living with dementia in nursing homes?

The thesis seeks to answer the question of what characterises citizenship practices for persons living with dementia in nursing homes. The following section summarises three main characteristics of citizenship that emerges from the articles, which are then further elaborated and discussed in the next chapter. Our findings suggest that:

Citizenship can be practiced by supporting* becoming *and co-ownership within mundane aspects of nursing home life. *Becoming*, as a personal dimension of growth and development, were found to happen in moments when residents acted in line with own occupational potential. Such *becoming* were found to be vulnerable and fleeting, underlining the importance of supporting residents to act in natural ways within ordinary aspects of nursing home life. Co-ownership shed light on a professional competency and responsibility of interpreting residents as intentional and supporting a shared ownership of places and occupations in nursing homes. The results underline that both leaving residents full autonomy in the nursing home and following strict routines, may decrease residents' opportunities to take ownership. Viewing citizenship as vulnerable and mundane practices acknowledges the ordinary as a significant site for citizenship. Based on the results we suggest that citizenship within the mundane implies that institutional perceptions of activities as offered should be broadened towards recognising residents' natural desires to do within the mundane, requiring a recognition of residents' spontaneous expressions of agency.

Citizenship can emerge through inclusionary interpretive practices that recognise residents' abilities and the intentionality of their expressions (both verbal and enacted). Citizenship sheds light on how residents' expressions can be interpreted as mundane forms of resistance against constraining structures or perceptions. A citizenship lens challenges easily overlooked pathologising interpretations by recognising the intentionality of residents' actions and expressions. According to our results, citizenship would thus imply incorporating an understanding of agency in our interpretive practices that expects residents' expressions to be intentional, both in terms of personal meaning and resistance towards constraining structures. However, we suggest that such interpretive practices must build on both medical, person-centred and citizenship understandings to recognise the vulnerable and fluctuating aspects of citizenship as well as people's capacity to act as citizens.

Citizenship practices in nursing homes are under pressure by particular characteristics of the nursing home as an institution as well as by societal and professional perceptions of the abilities of people living with dementia.

5.0 DISCUSSION

This thesis explores what characterises citizenship practices for persons living with dementia in nursing homes. Based on the main results of the articles, two concepts are coined and promoted as important in this regard: *becoming* and co-ownership. In this chapter, I begin by outlining what is meant by suggesting these phenomena as characteristics of citizenship. Keeping these results in mind, I then critically reflect on some inclusionary and exclusionary tensions inherent to a citizenship lens, followed by a section about possible implications of citizenship for dementia policy. I end the discussion with a section reflecting on the methodological strengths and limitations of the thesis as a whole.

5.1 Citizenship in nursing homes – becoming and co-ownership in the mundane

She gave me a good hug; she was filled up, she could participate – the dignity, you know, the spark came, right.
(Excerpt from Camilla's narrative, Sund et al., 2023a)

The aim of this chapter is to further outline the phenomena of *becoming* and co-ownership, providing arguments for why, and in what ways, they are important to understand citizenship as both access and belonging (Nedlund & Bartlett, 2017). In this context, I understand access as relating to the conditions for and the contents of citizenship, while *belonging* speaks to the subjective experience of being a citizen in the nursing home community.

5.1.1 What is becoming *and co-ownership?*

The occupational dimension of *becoming*, emerging as a phenomenon in the second article of the thesis (Sund et al., 2023a), sheds light on residents' capacities for continued engagement and growth. The quote at the beginning of this chapter reminds us of Camilla's narrative in that second article (Sund et al., 2023a). While Camilla often appeared frustrated, a story of continued ability and agency emerged within those moments when she was engaged, and perhaps particularly those moments when she took on responsibility. While occupational theory tends to favour future time orientation (Hammel, 2020), constructed narratives from the nursing homes – such as Camilla's – are interpreted to demonstrate that *becoming* is not necessarily driven by cognitive intentionality or goal orientation. The argument provided is that *becoming* can emerge in moments when residents act in line with their own capabilities and desires. The phenomenon of co-ownership (Sund et al., 2023b), highlight the potential of an actual sharing of responsibility within the nursing home context. While the concept of *becoming* refers to personal growth and identity, the concept of co-ownership points to the professional and institutional responsibility of creating environments that facilitate *becoming*. In this thesis, I suggest that co-ownership builds on inclusive interpretive practices and promotes both residents' rights to quality services and their capabilities of contributing to their communities as citizens. The argument in connecting these phenomena is that, through co-ownership, residents' opportunities for *becoming* are strengthened, in turn holding the potential to mediate experiences of *belonging* within the nursing home community.

The analytical concept of co-ownership emerged from situations observed in the nursing homes: situations in which residents were enabled to take an active social or occupational role and situations in which such engagements appeared limited. A situation in which residents were served a meal was interpreted in the third article (Sund et al., 2023b), where staff emerged as the owners and residents were the receivers within the dining area. Other narratives demonstrated situations in which residents seemingly initiated or were supported to take more active roles in the environment. Similarly, Baldwin and Greason (2016) write:

> We, however, would go further and argue that viewing LTC [long-term care] as a community of citizens, rather than the provision of professionalised services, requires us to re-envision the respective roles and responsibilities resulting from the current division between staff and residents. If citizenship involves participation in the day-to-day activities of the community, then such tasks could be shared amongst staff and residents. (p. 300)

The idea of co-ownership centres on creating a community in which residents and staff can both participate and contribute to the best of their abilities, experiencing a shared ownership of both spaces and responsibilities. Many factors would likely have impact in this regard, such as a range of material and social actors (Ursin, 2017), access and control over functional objects (Lee and Bartlett, 2021), as well as the degree of flexibility in how the nursing home is run (Ursin & Lotherington, 2018). Research has explored how to facilitate the engagement of people with dementia, for example through collaboration and scaffolding (Gjernes & Maseide, 2015), architectural design (Van Steenwinkel et al., 2017) and differentiated and individually tailored services (Strandenaes et al., 2019). The central point in this thesis is not to provide specific interventions or techniques for such facilitation, but to suggest co-ownership to be at the grounds of our nursing home services. Building on the results, two important aspects of such co-ownership will be discussed in the following sections. First, an environment of co-ownership that supports *becoming* might be characterised by going beyond a focus on provision towards supporting subtle expressions of agency in the mundane. This in turn underlines the significance of creating occupational contexts of familiarity. Second, the results imply that co-ownership must build on, and be informed by, inclusive interpretive practices that recognise the intentionality and power of mundane expressions of citizenship.

5.1.2 Going beyond provision – occupational contexts of familiarity

Inspired by an everyday citizenship lens (Nedlund et al., 2019ab), the articles of the thesis focused on residents' capabilities and opportunities for agency within the mundane. This shed light on a balance between recognising the therapeutic value of occupational provision and supporting participation and agency within mundane everyday life. The concept of agency became an important interpretive lens in the articles, connecting *becoming* to the initiatives and expressions of individuals. According to Boyle (2014), agency has to do with the ability to initiate social action or influence one's own circumstances. In this thesis, agency was found to emerge when residents seemingly expressed themselves or acted in ways that appeared natural to them in that moment. In the second article (Sund et al., 2023a), vulnerable and fleeting practices of citizenship emerged through the narratives of three nursing home residents: May, Janne and Camilla. While May verbally expressed her desire to help staff with their everyday chores, Janne often simply started doing in natural situations. Camilla, on the other hand, often appeared frustrated and on a quest for some sense of purpose, communicating her agency both verbally and through the expression of emotion. In the article, these verbal, embodied and emotional expressions were all interpreted as ways of communicating agency.

For example, when Janne initiated cleaning up after herself at the end of the meal, this competence to act appeared to be triggered within natural situations. Her actions seemed prompted by an embodied competence, a familiarity with such occupation that enabled her to momentarily take on a role as a contributor. Such an understanding recognises the inherent competency of the body (Kontos, 2005; Fuchs, 2020; Kontos & Grigorovich, 2018a, 2018b; Kontos et al., 2017). Similarly, Poland and Birt (2016) argue that even people living with advanced dementia can enact who they were and are through their bodily actions. However, we found that such expressions of agency are sometimes quite subtle and can thus be easily overlooked in the nursing home context. For example, while staff taking over Janne's initiatives to clean up could be interpreted as an act of care, it still constituted a breach of her opportunity to act in ways that appeared natural for *her*.

How might these results relate to, and perhaps contribute to expand, the current dominant theories of dementia? In line with the Norwegian dementia strategy (Norwegian Ministry of Health and Care Services, 2020), staff at Sea-Crest and Sunny Hill expressed an explicit ambition to provide person-centred care. Although Kitwood's (1997) theories have had an important impact on the quality of care for people living with dementia the last several decades, and continue to do so, they have also been critiqued for a lack of focus on agency. For example, Kitwood's (1997, p. 8) definition of personhood places the responsibility of providing personhood on "others" through defining it as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being".

An important part of the argument in this chapter is that building on a perception of personhood as bestowed may result in defining the initiation of social action (and thus agency) as a task of care staff, implying that they have a responsibility for "activating" residents. In such a lens, the care environment itself is responsible for residents being active, leaving the responsibility of defining the contents of citizenship to the professionals. However, O'Rourke et al. (2015) reported that one factor that influenced quality of life from the perspective of people living with dementia in their study was the theme "agency in life today". This was connected to the ability to express oneself, experience autonomy and independence, determine the structure of daily activities, and have a direction in life or achieve one's goals. Kaufman and Engel (2016) argue that Kitwood's person-centred care framework needs to be extended by adding the domain agency, while Smebye and Kirkevold (2013) found that participants with dementia in their study "were active agents who gained a sense of self by what they said and did" (p. 11), which contrasts with Kitwood's definition of personhood. Their personhood, as such, was not only bestowed by others but enacted by the residents themselves. The results of this PhD study imply that a citizenship of co-ownership builds on understanding people with dementia as active agents, underscoring the importance of supporting residents to engage in, and influence, their environments to the best of their abilities.

In an effort to broaden the dementia debate, Bartlett et al. (2010) discuss an expansion of Kitwood's framework of person-centred care, which recognises the psychological needs of people with dementia to experience comfort, identity, occupation, inclusion, attachment and love. They propose an extension towards a conceptual framework of social citizenship that recognises people with dementia as active agents. While recognising the importance of meaningful activities, they argue that in discussions of dementia, occupation has too often been narrowly defined and discussed only in terms of its psychosocial and therapeutic value. They propose extending the concept of inclusion to encompass participation, arguing that inclusion tends to imply mere presence, whereas participation, as a more active verb, recognises that people with dementia have agency, seek control and can act in ways that have subjective meaning (pp. 39–45). The results of this thesis, which highlight that people with dementia can act in intentional ways, shed light on a distinction between narrow or institutional perceptions of engagement in activities and the broader and more complex aspects of participation that are exemplified in the narratives of May, Janne and Camilla in the second article (Sund et al., 2023a).

The report by Sudmann (2017) summarising the research underlying the theme “activities and community” in the Norwegian quality reform “A full life – all your life” highlights the importance of engagement in activities. In relation to nursing homes, the report promote the provision of activities such as music, exercise, generational meetings, being with animals and a range of other creative, social and physical activities, as well as the right to one hour of physical activity per day. However, Killett et al. (2013) found that while some care homes in their study considered activity and engagement only in terms of structured activities, everyday activities and interactions between staff and residents had a positive impact for a wider range of residents and on a more consistent and regular basis. In addition, for several care homes, the provision of activities was the first thing to be dropped in times of staff shortage. This sheds light on an institutional perception of activities as something provided, and therefore something that can be denied or withdrawn when deemed necessary by the nursing home. In this regard, Mondaca et al. (2018) argue that the deeper meaning of everyday activities can remain invisible if staff represent an institutional routine, leading residents to give up attempts to influence everyday practices.

In this study, many residents seemed to enjoy having activities provided and the opportunity to engage alongside others. However, a vulnerable and fleeting side of citizenship emerged, where residents, in moments of familiarity, initiated and acted on their continued abilities. In this regard, Førsund et al. (2018) report that people with dementia highlight being familiar with place as key to maintaining daily activities and retaining a sense of independent living, whereas belonging was described as the experience of being familiar with a setting and being in the right place. According to Fuchs (2020), the more a person’s behaviour can be guided by familiar routines, the less reflection and meta-perspective is required, a notion that underlines a need for occupational contexts of familiarity in nursing homes. Research amongst others suggest that contributing to domestic tasks can give some nursing home residents a sense of normality or continuation of their previous everyday life (Milte et al., 2016), and activities of preparing meals and eating together may be particularly valued in creating a sense of home in the nursing home (Dekker & Pols, 2020). However, while staff at both Sea-Crest and Sunny Hill nursing homes explicitly expressed the significance of providing opportunities for occupational engagement to residents, there did not seem to be set routines for residents to contribute to daily chores that might provide such experiences of familiarity within the occupational context.

The narratives brought forward in this thesis show how residents, on several occasions, initiated involvement in daily chores, initiatives that was sometimes supported and other times not. Thus, the results of this study underscore that the everyday routines of the occupational context influenced residents' opportunities for access to participation in the mundane aspects of nursing home life. This sheds light on an everyday discrimination that may be difficult to detect. Ward et al. (2016) argue that everyday discrimination is cumulative and often goes unseen in the minor actions and activities of the everyday:

> Behind the headlines of neglect, abuse and ill-treatment which have driven much of the debate on rights in relation to dementia, our study shows that on a day-to-day basis the struggle for self-determination, belonging and social participation takes place around far more mundane encounters. (p. 407)

The results of this thesis underlines that such everyday discrimination might be influenced by social or physical environments that do not support the expression of agency, and that opportunities can be reduced if we define the contents of citizenship primarily as the right to receive services and care. Of relevance here might be the way Ursin (2017) points to a need for a shift in perspective from care to citizenship, from patient to citizen and from health services to an everyday life perspective. Similarly, Mondaca et al. (2018) argue that what is missing in the culture of care is attention to everyday life as a whole. The occupational dimensions by Wilcock & Hocking (2015) recognises the significance of all the things we do in everyday life for our sense of self, our experience of *belonging* and our opportunities for continued growth. If citizenship is about participation in one's own everyday life, ensuring the *provision* of occupation is only one part of the contents of such citizenship. Thus, the main argument of this chapter – building on the results of the articles – is that a citizenship of *becoming* and co-ownership requires going beyond the right to, or provision of, occupation, towards an emphasis on supporting residents' opportunities to act on their own identity and capacities in ordinary aspects of everyday life. This, in turn, requires a balance in nursing homes between providing occupational opportunities and recognising subtle expressions of participation and agency within the mundane.

5.1.3 Between inclusive and exclusionary interpretive practices

As reflected in the theoretical chapter, I perceive citizenship as being both an inclusionary and exclusionary concept and phenomenon. Citizenship can include or exclude, in terms of formal rights in relation to the state, but also more subtly, through what Nedlund and Bartlett (2017) describe as normative ideas about good governance and the good citizen. This sheds light on how the way we frame groups of citizens in certain ways can influence their opportunities. In the previous chapter, I presented arguments for the recognition of residents' mundane expressions of agency as significant characteristics of a citizenship of *becoming* and co-ownership. This chapter turns particular attention towards how interpretive practices in nursing homes can include or exclude residents from access to participation and thus opportunities to practice citizenship.

To begin, the argument for promoting awareness surrounding interpretive practices in the dementia field is not a new one. As a reaction to the dominance of a pathological understanding of dementia in the 1990s, the introduction of person-centred care was part of a new effort to understand and interpret the perspectives and psychological needs of people living with dementia, viewing behaviour as communication and not merely an expression of disease (Kitwood, 1997). According to Bartlett et al. (2010) person-centred care added a more humanistic interpretive lens to understand the needs, behaviours and expressions of people with dementia while recognising the unique perspective of the person (pp. 18–21). Meanwhile, reports suggest that people living with dementia still experience discrimination due to reductionist understandings of their status and capabilities. Peoples et al. (2023) conclude that many people living with dementia are still often viewed within a medical framework that focuses on symptoms and behaviour rather than autonomy and citizenship. The first article of the thesis (Sund et al., 2022) positions citizenship within a critique of dominant medical and care-based perspectives that can limit people's opportunities in everyday life. In the article, we discuss how institutional regimes are influenced by perceptions of dementia, and how pathologising expressions and actions can lead to care focused on bodily needs and managing challenging behaviours. Further, we note that such pathologising perceptions may lead people to view the behaviours and actions of those living with dementia as lacking intention and personal or political meaning.

In the third article of this thesis (Sund et al., 2023b), we bring forward narratives that exemplify how interpretive practices, such as group-based assessments of residents' abilities, can influence residents' opportunities for participation in nursing home everyday life. One narrative shows how staff took full ownership of the dining area, serving food and drink while ensuring that no plates of food were within arm's reach of residents. In interviews, several staff explained that this was due to residents' limited abilities to contribute more actively. Building on the group-based interpretation that none had the ability to do so, all residents were served, and there were no apparent opportunities for residents to contribute more actively during these meals. This sheds light on how interpretive practices built on a perception of inability can contribute to the establishment of routines that limit opportunities for participation.

Further, in the third article of the thesis (Sund et al., 2023b), we suggest that an activistic citizenship lens could broaden and provide a contrast to the biomedical and psychosocial discourse in dementia. To investigate the perspective of activistic citizenship we turned to Isin's (2008) theorisation of "acts of citizenship". Isin (2008) argues that while much literature explores citizenship as habitus and practices, the concept of acts of citizenship recognises that breaking with such practices can be acts of claiming citizenship. However, while activistic citizenship is traditionally centred on citizens' fight for justice in political arenas of society (Boje, 2017, p. 205), for people living with dementia lived space may gradually decrease as the disease develops (Førsund et al., 2018). For example, at Sea-Crest and Sunny Hill, the everyday lives of residents centred on the nursing home units and closely surrounding areas. Residents spent much time in the common areas and in interactions with others and appeared reliant on staff's presence and support in most aspects of their everyday lives. While active citizenship can be problematic for people living with dementia due to reduced resources or leverage to access justice in a political way (Nedlund & Bartlett, 2017, p. 55), Neveu (2014) argues that citizenship can be found in practices that challenge norms and habits in mundane aspects of everyday life. This draws attention to the nursing home as an arena where citizenship can be claimed and contested. However, the results of this thesis imply that for residents to be able to claim citizenship their expressions must be perceived as inherently intentional. This underscores the importance of how residents living with dementia are interpreted, and how these interpretations in turn might inform professional practices in this context.

In this regard, previous publications in the field have called attention to the phenomenon of resistance, advocating for broadening our understanding of dementia beyond a biomedical perspective. In the study by Dupuis et al. (2012), their analysis demonstrated that staff interpreted residents' behaviour through a lens of pathology. Thus, the pathological status of the person rather than the behaviour itself determined their intentionality, leading to redirection or distraction as a common response. According to Capsticks and Chatwin (2016), an ongoing paradigm shift in the dementia field might entail a movement from a biomedical perspective viewing behaviour as symptoms towards recognising it as a form of cultural resistance. However, Steele et al. (2020) argue that a deeply concerning dynamic within care homes continues to be a pathologising and subversion of resistance that effectively prevents individuals from challenging power relations. One way of challenging interpretive practices that limits people's opportunities might be what McKenzie-Mohr and Lafrance (2017) describe as counter-storying, by turning attention to fleeting and fragmented expressions of resistance. In the following paragraphs I reflect on some of the lessons learned by doing so in this thesis.

When Camilla, from the second article of the thesis (Sund et al., 2023a), was standing in the middle of the room shouting that she wanted to leave, her resistance against the locked door was clearly articulated. She verbalised it and both her actions (by having put her jacket on) and her emotions (she was angry) showed her intent. Even though Camilla's resistance was unequivocal, the door remained locked, and she was not allowed to leave. This may have been due to a lack of resources to accompany her or the possible consequences if staff had allowed her to leave (e.g., Camilla getting lost or refusing to return to the nursing home). Consequently, when Camilla expressed dissatisfaction, staff responded by encouraging calm. Suggesting that we view Camilla's anger in these situations as acts of citizenship underscores that her expressed feelings of captivity in the nursing home are valid and can be seen as resistance against restrictions on her human right to freedom of movement (UN, 1948). In contrast, if her anger is interpreted as an expression of cognitive decline, responses might include redirection or distraction, as found by Dupuis et al. (2012). While it is not in the scope of this thesis to prescribe what detailed actions should be taken by staff to mediate this situation, interpreting Camilla's actions as valid resistance highlights a professional and institutional responsibility to take action to improve her situation.

While Camilla's resistance against the locked door was unequivocal, our interpretation of the narratives constructed from the nursing homes shed light on how resistance can be much more subtle and difficult to detect. The results from the third article of the thesis (Sund et al., 2023b) reveal a vulnerable balance between withdrawal and active social and occupational engagement. In the nursing homes, residents sometimes sat beside each other for long periods of time without interacting, particularly if staff were not present. Referencing Fivush (2010), we discuss the difference between *being silent*, which can be a time for rest or quiet reflection, and *being silenced*. *Being silenced* may refer to not being allowed to speak or to one's voice not being given credibility. Instances of withdrawal, for example residents closing their eyes or falling asleep, were seen on many occasions during fieldwork, something that has been shown in previous studies as well (Holthe et al., 2007;

Mjørud et al., 2017). A case study by Morgan-Brown and Brengan (2016) measuring occupation and social engagement in one residential setting for older people with mental health problems and dementia showed that residents in the sitting room were passive and unengaged 82.73% of the time, while staff were busy 98.84% of the time. While getting older or living with dementia might mean an increased need for rest, building on the results of the third article (Sund et al., 2023b), I suggest that we recognise situations where residents dis-engage, close their eyes or fall asleep in the common areas as potential examples of both being *silent* and being *silenced*. Doing so, residents' need or right to withdraw, as well as their subtle expressions of resistance, may become visible.

However, one common interpretation of situations of withdrawal (and anger such as in the situation of Camilla above) may be that they represent behavioural and psychological symptoms in dementia (BPSD). According to Wolverson et al. (2021), BPSD is perhaps the most common term used to refer to changes in behaviour occurring in dementia. It is based on medical constructs that construe behavioural symptoms as symptoms to be treated. Further, terms like "challenging behaviour" or "behaviour that challenges" come from psychosocial constructs focused on interpersonal contexts and caregiver responses. In Dementia Plan 2025 (Norwegian Ministry of Health and Care Services, 2020), under the headline "Behaviour that Challenges", we find the following description:

> Behavioural and psychological symptoms in dementia (BPSD) are often a part of the dementia disorder […]. Some behavioural symptoms, such as apathy, may create few challenges for the environment, while other symptoms, such as aggression, lack of inhibition, irritability and deviating motor behaviour, can create more challenges for the environment. (p. 69, my translation)

Wolverson et al. (2019; 2021) explored the opinions of both people with dementia and professionals on the language used to describe such changes in behaviour. People with dementia (Wolverson et al., 2021) were concerned that the language used put them at risk, particularly when these behaviours were regarded as symptoms to be treated without adequate consideration of the person or their context. Among professionals (Wolverson et al., 2019), while there was agreement that some medical terminology explicitly linked behaviour to dementia, some preferred this terminology because it removed any blame from the individual and was therefore less stigmatising. Others strongly disliked these terms because they situated the problem in the person and not the system. Moreover, the notion of symptoms in dementia could distract from seeing behaviour as valid human responses, leading professionals to dismiss people's experiences too easily.

As in the situation of Camilla expressing anger, viewing withdrawal as possible resistance connects to how our interpretive practices are informed. The master narrative of apathy in dementia, which links withdrawal or passivity directly to the disease, may lead us to view withdrawal as normal within the nursing home context. In contrast, the phenomenon of co-ownership (Sund et al., 2023b) shed light on a balance between withdrawal on one hand and participation on the other, a balance that emerged as directly linked to the presence and support by staff. Considering residents' ownership of the rooms they inhabited seemed to decrease both when left full autonomy and when staff assigned themselves full ownership, a need for conscious effort when it comes to sharing the responsibility within rooms and situations in nursing homes emerges. Interpreting withdrawal as possible resistance, as suggested here, does not mean that we should overlook residents need to rest. However, it underlines that withdrawal can be valid resistance to an environment that does not support co-ownership. Consequently, as argued by Boyle (2008), expecting incapability or passivity may lead residents to internalise and accommodate these expectations and therefore act in line with what is expected or normal in the context.

In addition to recognising anger and withdrawal as possible expressions of resistance, I would like to end this chapter by reflecting on situations where residents were seen to take the initiative to contribute within their environment. Hilde and Alma (Sund et al., 2023b) both approached, and sought to contribute to, arenas of the occupational context over which staff normally had ownership. The article suggests that staff's aspiration to maintain a calm environment could lead them to automatically encourage residents to be calm. Because staff had experienced that overstimulation could cause residents to become agitated or frustrated, situationally relevant expressions of agency were sometimes redirected or stopped. This sheds light on how an interpretive lens of protection and care might both create a calm atmosphere and limit citizenship opportunities by favouring staff as in control of the environment. The point by perceiving such initiatives as acts of citizenship is not to deny staffs' responsibility of tailoring the environment to prevent illbeing. What is highlighted is the need to recognise that such actions can be a way of resisting a narrative of dependence, thus, as demonstrated by Laliberte-Rudman (2002), using occupation as a way of distancing oneself from a potential stigma of old age.

This chapter has provided arguments to suggest that interpretive practices in nursing homes can include or exclude residents from access to participation and thus opportunities to practice citizenship. The main argument is that interpreting residents through a group-based or pathology perspective may lead to reduced access to participation. Incorporating a lens of activistic citizenship into our interpretive practices recognises that residents' actions can be valid human responses to constraining or discriminatory structures. This broadens our understanding of the expressions of people living with dementia, encouraging us to recognise that emotion, withdrawal and attempts at actively contributing can all be forms of resistance against structures that insufficiently support residents' opportunities for co-ownership. However, such interpretive practices find themselves within a broader socio-political context, underlined by inclusionary and exclusionary tensions inherent to the concept of citizenship itself. In the next chapter, I reflect on some of these tensions, contextualising the results in a broader discourse of citizenship, dementia and nursing home living.

5.2 A critical look at the normative and interpreted qualities of citizenship

Some current debates revolve around the question of what citizenship "is". But like "democracy", citizenship is not reducible to a single definition; rather it requires and encourages interpretation.
(Taylor & Wilson, 2004, p. 155)

This thesis explores citizenship by turning attention towards the actions and verbal expressions of residents in mundane aspects of nursing home everyday life. This approach was selected because it contributed towards more inclusive understandings of what might be perceived as practices of citizenship for people living in nursing homes. As previously stated, occupational theories opened up my perception of what citizenship could entail, beyond the traditional understanding of citizenship as rights and duties in society (Boje, 2017; Neveu, 2014). However, while the choice of theories and analytical strategies in this thesis opened up some interpretive possibilities, they closed down others. In this chapter, I turn my critical attention to some normative tensions in the citizenship field, as well as some limitations resulting from the analytical choices applied in this thesis.

5.2.1 Interpreting citizenship – normative tensions of inclusion and exclusion

Shortly before submitting this thesis, I attended a symposium on citizenship arranged by the CitPro network at VID Specialized University. Two Canadian researchers, Katie Aubrecht and Christine Kelly, gave a talk on ageism and the deinstitutionalisationg of long-term care. In this talk, they posed illuminating questions about the potential exclusionary and discriminatory characteristics of the nursing home as an institution. The talk was informed by a paper (co-authored with colleague Rachel Herron), in which they claim that ageism is the least challenged form of discrimination globally. They argue that, while other groups (e.g., in disability and mental health) have challenged institutionalisation for decades, such movements in terms of older people have been scarce. They touch upon central questions, such as whether institutionalised living for older people is inherently discriminatory (Herron et al., 2021).

> [A]ging is often regarded as something in need of management or even containment in ways that naturalize institutionalization. Even in conventional disability studies scholarly work and activism that advocates for deinstitutionalization, there is an assumption that disabled people may age into LTC [long-term care] but should not live their younger adult lives there. On this, I wonder if our focus is on deinstitutionalization assumptions and relationships that naturalize the institutionalization of older people. (Herron et al., 2021, p. 188)

The authors also question whether we, as a society and health system, have internalised the belief that institutionalisation is the only way to care for the complex care needs of older adults (Herron et al., 2021). While these ideas might appear far removed from the mundane explorations of citizenship in this thesis, I bring them into the discussion because they demonstrate how our normative understanding of old age and dementia in society influences how we perceive people's rights as citizens. In Norway, for example, the national guidelines –"Quality Health and Care Services for People with Developmental Disability" (Norwegian Directorate of Health, 2021) – explicitly state that they are grounded in human rights and the CRPD (UN, 2006). Meanwhile, the national guidelines for dementia

(Norwegian Directorate of Health, 2017) neither engage with the Norwegian Equality and Anti-Discrimination Act (2017) nor human rights conventions such as the CRPD (UN, 2006). However, the guideline clearly promote the vision of person-centred care. In its broadest implication, it can be interpreted that younger people living with disabilities are recognised in policy as citizens with the right to live full lives in society, while people with dementia as citizens are entitled to professional and dignified medical and care services. Turning attention towards potential discriminatory structures of policy or societal institutions underlines how normative beliefs in policy, but also society and professional practices, can open up possibilities for some and close them for others.

Leaning on authors such as Baldwin (2008), Bartlett et al. (2010) and Hydén and Antelius, (2017), the overall narrative of dementia has been discussed in the introduction, demonstrating a traditional master narrative of dependency and care. Exploring citizenship in a context traditionally built on medical and care-based theories reveals a tension between citizenship as a concept and phenomenon and the nursing home as an institution. This sheds light on the negotiated, fluid and interpreted side of the citizenship lens, and thus its complexities and potential vulnerabilities. In this regard, Taylor and Wilson (2004) write:

> [C]itizenship itself does not propose a particular interpretation of the world nor a particular political solution to problems; rather it provides a framework of ideas about human roles and relationships around which people can weave their own beliefs, opinions and strategies. (p. 155)

The authors (2004) argue that what citizenship is “requires and encourages interpretation” (p. 155). If citizenship builds on ideas about human roles and relationships on a broad level, then it follows that our historic and current beliefs in society and professional practices influence what we perceive as citizenship for particular groups of people. Questions such as those raised by Kelly and Christine (Herron et al., 2021), regarding the potential discriminatory qualities of the nursing home as an institution, shed light on some inclusionary and exclusionary tensions inherent to a citizenship lens. What is citizenship and for whom? Are there objective criteria for citizenship or is citizenship a subjective experience of being a citizen, of belonging to a community and having the opportunity to participate to the best of one’s ability? According to Neveu (2014), inclusive citizenship is a vulnerable and changeable phenomenon. She argues that all discussions about citizenship can enforce norms or open up new possibilities, illuminating its inherent tensions. This in turn underlines that citizenship is a complex phenomenon to explore. In this thesis, citizenship is explored as something enacted and experienced, not something objective out there to be apprehended. Interpreting citizenship is understood to mean that what it entails – and who is included or excluded – depends on the position one holds.

For example, a fundamental question may be whether the nursing home, as an institution, represents an impeachment on the rights of an ageing population, or a way of ensuring that their rights as citizens are fullfilled when illness leads to difficulties with independent living. While such questions cannot be answered in this discussion, they are relevant because they shed light on the exclusionary and inclusionary qualities of citizenship – and that our normative understandings in society decide what we consider citizenship and for whom. In this thesis, I opted to explore citizenship by turning attention to mundane expressions of agency seen as citizenship practices. This in turn meant that I, to limited extent, analysed how broader societal or political structures and understandings influenced the lives of residents at Sea-Crest and Sunny Hill. Interpreting narratives from nursing home everyday life in this thesis, analytical attention remains at the level of the individual. While the occupational lens contributes to increased knowledge about mundane forms of agency in residents' lives, it to limited degree provides concepts necessary to critically explore citizenship as dimensions of rights, structures of power or political processes associated with democratic society. In addition, exploring citizenship through an occupational lens might underline a normative belief privileging active participation, perhaps neglecting other ways that humans can engage as citizens within their societies. This is discussed in the next chapter.

5.2.2 Citizenship – a demand for activeness?

Interpreting constructed narratives of nursing home everyday life in this study meant focusing attention on how residents actively participated. However, is active participation always the "quality" for which we should strive? In the introduction, I presented critiques about viewing people solely through a care lens (Baldwin, 2008; Bartlett et al. 2010; Hydén & Antelius, 2017) and argued for the significance of adding agency to our understanding of person-centred care (O'Rourke et al., 2015; Kaufman & Engel, 2016; Smebye & Kirkevold, 2013). But can there be too much focus on active participation, on being agentic and on taking responsibility? And might this, in turn, constitute another tension that include some and exclude others?

In this thesis, citizenship is explored through a lens of occupation, which can be seen as both a strength and a limitation. Informed by the occupational perspective, I take as a starting point that humans are occupational beings, and that this influences our sense of self and our experiences of *belonging* (Wilcock & Hocking, 2015). While a strength of the occupational lens may be that it enables interpreting citizenship as connected to lived everyday life, it connects citizenship to active doing, which might be an exclusionary ambition in itself. From a normative occupational perspective, a high degree of engagement is connected to well-being, while a low degree of engagement is linked to occupational injustice and ill health. While some authors within occupational science measure degree of or gaps in occupational engagement, argued as a concern for citizenship (Morgan-Brown et al., 2019; Bergström et al., 2021), does a high degree of occupational engagement necessarily mean a stronger sense of citizenship? For example, Sandvoll et al. (2020) report that activities that some people may perceive as passive may not be experienced that way by residents, and that it might be natural for residents to withdraw from social roles or relationships. Leven and Jonson (2002) report that occupation should recognise both active doing and being in presence of doing. They underline the importance of not only promoting the active qualities of *doing*, but acknowledge that for some, participating by observing others *do* can be experienced as equally meaningful as being actively engaged oneself.

In their article about micro-citizenship, Baldwin and Greason (2016) argue that micro-citizenship can be beneficial, through its impact on the asymmetrical power relationships that exist in many long-term care facilities. Further, they write: "If seen as citizens rather than 'clients' or 'residents', people living with dementia in LTC [long-term care] facilities become equals within the community, contributing as much as they receive" (p. 298). The results of this study, centred on a citizenship of *becoming* and co-ownership, promote a balance of ownership, thus impacting such asymmetrical power relationships. However, while the results are specifically centred on residents' capabilities and agency, this should not undervalue residents' immense need for support and care. Ambitions of creating an environment where residents contribute as much as they receive might place a demand for activeness on residents that they may not desire, or be able, to achieve. In this regard, Sudmann (2017) argues that an uncritical focus on citizenship and participation can be experienced as new burdens, and that when experiencing severe illness or disability, "one should have the option to choose passive activity, passive participation and passive ageing, and be allowed to say no thanks to exercise, rehabilitation, serious conversations, consolation or song" (p. 72, my translation). This highlights a point made by Neveu (2014), which is that citizenship can enforce norms or open up new possibilities. In this regard, norms of active participation as a responsibility, underlined by political aspirations of active aging (Meld. St. 15 [2017–2018]), can be experienced as burdens instead of an opportunity.

Relating this discussion to the results of this thesis, I would like to add one important clarification. While the transformative aspects of an activistic citizenship lens may emerge if we pay attention to possible expressions of resistance, as suggested in this thesis, this does not mean that residents must deliberately seek to be activistic. According to Fjetland and Gjermestad (2018), in severe disability, active aspects of citizenship can be seen as relational, expressive and narrative phenomena. They underline that people can emerge as active citizens through interpretive practices that recognise all expressions as intentional. This means that, although people with cognitive disabilities may experience difficulties in claiming citizenship, they can emerge as active citizens through the interpretive practices of others. As such, narrativity can be seen as a way of materialising citizenship through attention to a wide range of expressions taking both verbal and non-verbal forms. Following this, and building on the results of this study, I suggest that the phenomenon of co-ownership does not equal a demand for active participation. It implies that citizenship is negotiated in relationships, building on a professional competence in interpreting residents as intentional and capable of taking responsibility under the right conditions.

5.2.3 Citizenship – a negotiated and fluid concept and phenomenon

The narratives presented and interpreted in this thesis focus on residents having the physical capacity to move about and express themselves verbally. Although this study applied a narrative perspective to both verbal and non-verbal utterances, one limitation is that narratives of those without verbal language or more profound disability are scarce in the narratives. This may be because most residents included in the study had the capability for such physical and verbal interaction. This underscores a methodological limitation in how the process of recruitment also excluded some voices in the research, a topic further emphasised in the methodological discussion. It is important to recognise that the active parts of citizenship brought forward in this thesis does not mean that everyone living in nursing homes can, or desires, to act in such ways. The results also shed light on a vulnerable side of citizenship practices, as residents' capabilities become visible within moments alongside an indisputable need for medical services and care. As argued in the first article of the thesis (Sund et al., 2022), a framework of multiple theories is needed if we are to support both the needs and rights of people living with dementia – something further underlined by the combined results of the thesis. But what does this actually mean?

Taylor and Wilson (2004) argue that all citizens might not be equally endowed, meaning that some citizens may have more rights (and duties) than others. They highlight that, while all citizens can enjoy the protection of the law, only some are given the chance to make the law. While nursing home living may appear far removed from the political arenas where laws are made, this thesis argues that people with dementia can still be acknowledged as capable of expressing their own needs and resisting conditions that restrict their lives. However, for people living with dementia in nursing homes, this might often entail relying on others to pay attention and interpret these expressions as meaningful. This, in turn, underscores a vulnerability in the concept of citizenship because, if citizenship is fluid and informed by different beliefs, opinions and strategies (Taylor & Wilson, 2004), people will interpret both explicit and subtle expressions of citizenship differently.

In this regard, I promote – through the third article of the thesis (Sund et al., 2023b) – "adding an activistic lens" to the interpretive practices in nursing homes. By this, I mean that the professionals can approach signs of discontent or disconnect by negotiating different questions. For example, staff in the nursing homes explained how physical discomfort, pain or illness could cause frustration and discomfort, and that many residents were unable to verbalise these issues. The staff therefore always looked for signs of underlying physical reasons for changes in behaviour, informed by biomedical knowledge. They also explained that overstimulation and misunderstandings in the social environment could cause anxiety or irritability. An important part of their responsibilities was thus to regulate the degree of stimuli within the environment. I observed, on many occasions, how staff supported well-being through attending to both bodily needs and psychological stress – which appeared to increase residents' well-being. What I suggest by adding a lens of activistic citizenship is that, when a resident acts in certain ways, one should also question whether the behaviour could be a form of resistance towards social, physical or institutional structures that constrain their opportunities as citizens.

This underlines the negotiated qualities of citizenship, and how interpretive practices can include or exclude people from practicing citizenship. According to Ursin and Lotherington (2018), the ability to shift between knowledge regimes in the dementia and nursing home context is a critical mechanism. Bartlett et al. (2010) also argue that extending person-centred care towards citizenship does not mean replacing the significant contributions of the person-centred paradigm:

> The point of contrasting citizenship with personhood in this way is not to polarise debate within the field of dementia studies, or to imply that citizenship is somehow a superior concept to personhood. On the contrary […] personhood and citizenship are intertwined and are both important to the field and to understand dementia. (pp. 38–39)

In this thesis, theories are combined because, in different ways, they each add to the inclusivity of citizenship for people with dementia. For example, the attention towards intentionality does not imply a linear understanding of narrativity, but turns attention towards the importance of being recognised as an intentional being with something meaningful to express. Building on inclusive perceptions of narrativity (Baldwin, 2008; Fjetland & Gjermestad, 2018), the privileging of cognitive intentionality and goal orientation of occupational theory is critiqued, arguing that occupational *becoming* can emerge through embodied competence and supportive environments, within moments in the present. However, when people have a reduced ability to verbally express their intentions or desires, interpreting their actions and embodied or disjointed verbal expressions will always be wrought with uncertainty, underscoring the vulnerability of citizenship itself. While we cannot know whether our interpretations are correct, in line with the intentions of recognising social positions and upholding rights of personhood – as promoted by the definition of social citizenship (Bartlett et al., 2010) – this PhD study underlines a need to continue working on theories and perspectives that support our attempt to do so. If not, many residents living with dementia in nursing homes might be denied opportunities to practice their citizenship, due to fixed and exclusionary perceptions of its characteristics.

5.2.4 Citizenship - transformative power and inclusion

Underlined by the experiential and analytical results of this thesis, the notion that we can define and clarify the exact qualities of citizenship for *all* residents living in nursing homes appears doubtful. While several studies have shown that people living in nursing homes attach significance to a life of continuity and continued agency (Cook et al., 2015; Milte et al., 2016; O'Rourke et al., 2015), people living in this context have different backgrounds, abilities and needs, something that emerged clearly through my fieldwork at Sea-Crest and Sunny Hill. This highlights a vulnerability inherent to the nursing home institution itself, constructed by collective perceptions of the needs of older people with disabilities. In the first article of the thesis (Sund et al., 2022), we argue as follows:

> Some common characteristics [of the nursing home] may be people living close together, not choosing who they live with, to varying degrees being allowed to leave by themselves, and where institutional routines may set the stage for everyday life. (p. 39)

The article concludes that certain nursing home characteristics, such as inflexible institutional regimes, might place citizenship under pressure. While the intention of citizenship is to lay a foundation for a just and inclusive society, as underscored by both Boje (2017) and Neveu (2014), different groups move in and out of inclusion, fighting for recognition and distribution of resources and a voice. However, do people living with dementia in nursing homes have the opportunity to fight for redistribution for themselves? Do they have a voice (in society), or does their voice end in the context of the care relationship? Is the nursing home as an institution discriminatory due to its inherent characteristics, or can citizenship be upheld in this context through co-ownership in the mundane, as argued in this thesis? These are questions in need of further attention in practice, research and policy.

O'Connor et al. (2022) argue for the need to develop a dynamic citizenship approach, not a one-size-fits all-solution, to better account for the unconditional and total inclusion of people with dementia as citizens. Bridging the concepts of *becoming* and co-ownership does so by recognising residents' capabilities, as well as their need for support, inclusive environments and recognition as agents. However, it does not provide a how-to guide for citizenship, considering that what counts as citizenship is not universal, but rather contextual. This leads me to a question that I would like to reflect on in the conclusion of this chapter. This question relates to a statement I made in the third article (Sund et al., 2023b), regarding wanting to explore "the transformative power of citizenship". Can the citizenship lens be useful to promote better living conditions for people living with dementia in nursing homes – and, if so, how?

According to the *Merriam-Webster Dictionary* (2023), the word "transformative" means "causing or able to cause an important and lasting change in someone or something". Why do I think that citizenship is able to cause change? The short answer is that it might help us ask different questions and therefore view the nursing home from a slightly different angle than if we adhere solely to a lens of biomedicine or care. Jönson and Harnett (2016) argue that, in care facilities, we tend to make residents the primary reference group for each other, where restrictions can be seen as fair because all are affected equally. The authors argue for a rights-based disability lens centred on people's right to a life that is as close as possible to the lives of others. By changing theoretical positions, we might change what we are able to recognise. For example, citizenship might turn attention to mundane forms of discrimination in the nursing home that may be frequent and perhaps therefore rarely questioned. If such discrimination continues to be overlooked, there will be no cause for protest and no movement towards change. In the third article of the thesis (Sund et al., 2023b), I link this to the use of an activistic lens of citizenship, demonstrating that asking a slightly different question ("Can withdrawal be resistance?") can challenge biomedical constructs that directly link withdrawal to apathy and thus a consequence of dementia. The point here is not to challenge that apathy in dementia exists (because I do not doubt it does), but that automatically assuming that withdrawal is caused by dementia exempts the social or physical environment from any responsibility.

The citizenship lens turns attention to broader aspects of inclusion and exclusion in society and policy, underlining that citizenship is a field with inherent tensions. On the one hand, collective rights and normative standards tell us who are entitled to certain services or influences; on the other hand, the individual has needs, experiences and ways of living that are unique to them. Ensuring that collective rights are secured and individual needs are met is challenging, perhaps particularly in a field that is so fundamentally and normatively infused by a lens of medicine and care. The discussions in this chapter highlight the interpretive and fluid qualities of citizenship. I emphasize how citizenship can enforce norms of activeness in society if we fail to recognise that people can practice citizenship in both active and subtle ways. The discussion promotes the importance of interpretive practices that view each individual as intentional and as holding the potential for being active. The chapter has shed light on inherent tensions in the field of citizenship that contextualises the empirical results brought forward in this thesis. This paves the way for suggesting some potential implications of citizenship for Norwegian dementia policy, which is the aim of the next chapter.

5.3 What are the potential implications of citizenship for Norwegian dementia policy?

> *[H]aving agency is of importance in the context of small stories of everyday citizenship practice that are related, shaped by, but also constitute and are manifested in the big and wider social, political and historical stories.*
> *(Nedlund et al., 2019a, p. 6)*

This thesis has explored what characterises citizenship practices for persons living with dementia in nursing homes, highlighting the recognition, and support, of residents' capacity for participation and agency. Meanwhile, O'Connor et al. (2022) call for more research embedding subjective experiences within a broader socio-political context. While this thesis does not directly investigate policy, lived experiences are influenced by the political and the professional contexts in which people's lives are lived. This might be particularly true in a politically constructed welfare institution such as the nursing home, which is directly regulated by government laws, strategies and aims. The following section therefore sheds light on three possible implications of a citizenship of *becoming* and co-ownership for the development of future policy in the dementia and nursing home field. First, while the current Norwegian dementia plan tends to remain focused on the provision of activities in nursing homes, future plans might benefit from addressing agency and participation as central aspects of residents' everyday lives. Second, I suggest that future dementia policy should address that what is termed "behaviour that challenges" in the dementia strategy may represent more than expressions of needs, but also valid resistance. Last, I argue that a central implication of citizenship entails taking issues and regulations related to discrimination into account more explicitly, when developing recommendations for the dementia and nursing home field.

5.3.1 Recognising participation and agency within the mundane

The espoused goal of person-centred care in Norwegian policy highlights a professional responsibility to provide residents in nursing homes with a social environment tailored to support their quality of life and well-being (Norwegian Ministry of Health and Care Services, 2020). However, Ursin and Lotherington (2018) argue that when a person moves to institutionalised care, relations of agency and citizenship might be disrupted, turning citizenship upside down. In the first article of the thesis (Sund et al., 2022) we discuss how particular aspects of nursing home life might put pressure on citizenship, such as institutional routines or structures, or to citizenship being limited according to perceptions of abilities. Analysing narratives from fieldnotes taken at Sea-Crest and Sunny Hill revealed that citizenship practices could emerge within mundane everyday occupations. In terms of the importance of activities in nursing homes, the current Norwegian Dementia Plan states:

> It is well documented that meaningful activities, both physical and social, have positive effects on physical and mental health. It is therefore important that persons with dementia are offered meaningful activities, tailored to the individuals' needs and interests.
> (Norwegian Ministry of Health and Care Services, 2020, p. 35, my translation)

While the emphasis of expanding definitions of agency and opportunities for growth and participation were found to be core themes of citizenship by O'Connor et al. (2022), the results of this thesis suggest that while residents' needs for occupational engagement were broadly recognised in the nursing homes, expressions of agency could be subtle or fleeting and thus easily overlooked. Residents' participation and agency seemed to require more than being offered activities in which they could engage. It also appeared to revolve around being recognised as intentional beings able to act on one's own occupational nature and contribute towards one's environment. *Becoming* appeared contingent on an occupational context of familiarity that supported residents in acting on their own capabilities within the mundane. Creating such a context requires a recognition of ordinary and mundane aspects of everyday living in the nursing home, as well as recognising that residents might have the ability to contribute to their environments as more than receivers of care. Failing to recognise residents' abilities to act in agentic ways may lead to a continued focus on "activating" residents, thus neglecting the many ways they might express their desires in natural situations in everyday life. One implication of a citizenship of *becoming* and co-ownership regarding Norwegian policy might therefore be that, while current plans tend to remain focused on provision of activities, future plans might benefit from recognising agency and participation as central aspects of residents' occupations in their everyday lives.

5.3.2 Behaviour that challenges – as valid resistance

In the first article of the thesis (Sund et al., 2022), citizenship emerges as a critique of the dominant medical and care-based knowledge-paradigms, promoting the recognition of people with dementia as active subjects in their own lives. Although our current theories and a range of publications have critiqued the pathological interpretations of people living with dementia for many years, these interpretations seem to still linger in practice. According to Andrews (2004), one of the key functions of master narratives is that they offer people a way of identifying what is assumed to be a normative experience, while its power derives from its internalisation. In the context of dementia, citizenship emerges as a contested idea or practice due to the cognitive and behavioural consequences that are associated with the diagnosis. However, a central theoretical contribution of the third article of the thesis (Sund et al., 2023b) is to create a link between activistic aspects of citizenship and mundane citizenship practices by drawing our attention to possible narrative resistance (McKenzie-Mohr & Lafrance, 2017). This highlights a moral purpose of citizenship implying that all members of the community have the chance to exercise meaningful forms of control and participate in shaping society (Donaldson & Kymlicka, 2017, p. 855). The Norwegian dementia plan promotes the explicit goal of involving people with dementia in decisions about their own life, in line with a person-centred framework (Norwegian Ministry of Health and Care Services, 2020). Meanwhile, the plan reports that many people living with dementia experience that others make decisions on their behalf, and that their right to self-determination isn't sufficiently emphasised by their environment:

> Lacking knowledge about dementia in society makes people think that a dementia diagnosis is the same as losing one's abilities for assessment and decision-making immediately. Dementia progresses over time, and people with dementia want to use their competence and experiences to make decisions on own behalf as long as possible. (p. 14, my translation).

Further, the dementia plan recommends that people diagnosed with dementia write a future power of attorney to ensure that their future wishes are respected. However, it does not provide strategies as to how residents living in nursing homes can influence their close social environments or the socio-political context in which their lives are lived. The results of this thesis underline a need for inclusive interpretive practices, suggesting that residents can express their desires and needs both verbally and through emotional and embodied expression. However, for these expressions to be *heard* requires that professionals' working in this context seek to interpret these both in terms of needs and as possible resistance. This sheds light on the relationality of citizenship, found to be a core foundation of dementia and citizenship by O'Connor et al. (2022), recognising varying, complex and synergistic relationships that contribute to citizenship. The interpretive practices of nursing homes influences how residents are recognised as holding the capacity for expression and influence. Interpreting residents from a group-based perspective or interpreting their actions and expressions primarily in terms of a context of pathology or care may lead to a *silencing* of possible expressions of resistance. If future policy recognises that what is termed "behaviour that challenges" in the dementia strategy represents more than expressions of needs but also expressions of resistance, it may encourage us to recognise mundane everyday life as a site where residents can practice their citizenship in both active and subtle ways.

5.3.3 Addressing discrimination in dementia policy

This thesis begins by asking why a study on citizenship in nursing homes is necessary. It builds on reports, stories and research problematising discriminatory living conditions for people with dementia in this context. National and international studies and reports suggest that people living in nursing homes may experience constraining institutional structures and routines (Harnett, 2010), lack of freedom (Heggestad et al., 2013a), and occupational deprivation (Causey-Upton, 2015; Du Toit et al., 2019; Knecht-Sabres et al., 2020; Morgan-Brown & Brangan, 2016; Morgan-Brown et al., 2019). A report by Kjørholt et al. (2015) about the human rights situation in Norwegian nursing homes reveals that there are practices that are in breach of human rights, and the authors urge the Norwegian government to assess whether the limited self-determination in nursing homes is in line with human rights and Norwegian law. Meanwhile, this thesis sheds light on how discriminatory practices may be subtle and fleeting, influenced by residents' access to participation within their everyday lives. In relation to the nursing home, a perceived tension between the nursing home as a home and a hospital has been reported. Stafford (2003a) writes that:

> [D]aily life (meaning making) in the nursing home is inherently problematic because the participants carry out their existence in the contested cultural domains of hospital/home. The medical domain of treatment and clinical care, as believed in and acted on by the overseers, overlaps with the domestic domain of home and family, which shapes the orientation and mindset of the residents. (p. 12)

This points to the home as typically associated with autonomy and freedom, while the hospital is associated with procedures, structures and medical care. If the nursing home is viewed as a medical facility whose primary function is to fulfil medical needs and safety for residents, by consequence its hospital logics will be dominant. This sheds light on the inherent inclusionary and exclusionary characteristics of the nursing home as an institution, as discussed in the previous chapter. A citizenship lens may help us question taken-for-granted aspects of nursing home everyday life by offering a normative position that recognises residents' right to live life in the same manner as others. This has implications for both lived everyday life in nursing homes and for policy and guidelines in the dementia field.

Meanwhile, reports express concerns about current and future recourses and economy in the welfare sector. Over 30,000 people currently reside long-term in nursing homes in Norway (Norwegian Central Statistical Office, 2022), and it is estimated that people living with dementia will more than double by 2050 (Gjøra et al., 2021; WHO, 2017). According to Vossius et al. (2015), the average cost of an illness-trajectory in dementia is 2.9 million NOK, of which 60% of these expenses is related to nursing home stays. According to the Official Norwegian Report "Time for Action" (NOU, 2023:4), while the number of people over the age of 80 will increase in Norway over the next decades, there will be a decrease in the number of people who are of working age. At the same time, the Norwegian population has been entitled to an increasing number of health-related rights over the last couple of decades, through the Patient and User Rights Act (1999). However, neither these rights, nor the current dementia plan, entitle people to explicit rights that can be claimed in terms of participation and agency within the mundane of nursing home life. If such rights are not clearly identified, people with dementia may become victims of the future demographic conflict between resources, the economy and social rights.

In Norway, the National Guideline for Dementia provide recommendations for professional practices in the field (Norwegian Directorate of Health, 2017). They refer to a range of laws that regulate health and care services in dementia, amongst them the Patient and User Rights Act (1999), the Health and Care Services Act (2012) and regulations such as the Dignity Guarantee (Ministry of Health and Care Services, 2011). However, neither the Norwegian Equality and Anti-discrimination Act (2017) or the CRPD (UN, 2006) are amongst the regulations on which the guideline builds. While the CRPD aims to combat discrimination against people living with disability with the goal of supporting their full and effective participation in society, Cahill (2018, p. 45) argues that dementia rarely features in official reports on disability and is underreported in disability studies. As argued in the previous chapter, the lack of focus on discrimination in dementia policy might position people with dementia as entitled to professional and dignified care in nursing homes, contrasted with the notion of full inclusion and participation in society as associated with the CRPD. As a defining feature of citizenship discourse (O'Connor et al., 2022), a central implication of citizenship in the Norwegian socio-political contexts would thus be to take issues and regulations related to discrimination more explicitly into account when developing recommendations for the dementia and nursing home field.

5.4 Methodological discussion

> *The purpose of the validation process is to convince readers of the likelihood that the support for the claim is strong enough that the claim can serve as a basis for understanding of and action in the human realm.*
> *(Polkinghorne, 2007, p. 476).*

This thesis contributes to our understanding of citizenship by turning attention towards the actions and expressions of residents living with dementia, shedding light on opportunities as well as challenges for the practices of citizenship within the nursing home context. Participant observation and in-situation conversations with residents provided some insight into the rhythms, doings and social interactions of the nursing homes. However, there are both advantages and challenges associated with the methodological choices and analytical approaches used in the study, which influences the production of knowledge. In this chapter, I bring forward some limitations related to the recruitment and methods applied in the study, and the ways in which the choices made enabled exploration of some aspects of citizenship practices in nursing homes while excluding others.

5.4.1 Exploring citizenship – a narrow perspective

Baldwin (2015) suggests that the characterisation of others in the stories we tell about them is an ethical issue. He writes that we can construct people in ways that focus on deficits, failings, impairments, challenging behaviour and loss of self, as seen in the diagnostic overshadowing in the dementia field. Alternatively, we can construct stories focused on the maintenance of personhood and the strengths and abilities that individuals retain. One of the contributions of this thesis relates to how attention is centred on residents' actions and expressions as telling stories of capabilities and intentionality. McKenzie-Mohr and Lafrance (2017) argue that in long-term care, the story of decline may be difficult to shake, and for emergent counter-stories to gain influence they must be taken up more broadly in social discourse. The way narratives are constructed and interpreted in this thesis can be perceived as an attempt of bringing new stories of dementia and nursing home living to light in society and research. By mostly focusing on residents' capacity for acting, these narratives tell a counter story to societal narratives of inability in dementia. I consider this a strength of this study and important reasons for being able to bring forward the knowledge that has been produced.

However, this approach meant that the thesis had a narrower focus than originally planned. The narrative analytical approach (Polkinghorne, 1995) required staying engaged with a selection of stories and perspectives. In this study, one of the significant voices that was *lost* through this strategy was that of the professionals. While I had originally aimed to explore the perspectives of both residents and staff, as well as institutional aspects influencing life in the nursing homes, the iterative and flexible research design (Hammersley & Atkinson, 2019) allowed for gradual changes. While these changes were found necessary to be able to engage more thoroughly with mundane everyday phenomena that emerged, they led to a limited focus on the challenges staff experienced in their effort to support residents. Although it was a conscious choice, the decision to follow this methodology also meant that staff and leaders' perspective on issues of structure and organisation and their views on citizenship received limited attention.

This limited attention to the professional perspective is important because if citizenship is relational and enabled through supportive environments, then professionals working in nursing homes play a pivotal role in its realisation. Considering that a core theme underpinning citizenship is the emphasis on positioning stigma, discrimination and exclusion as critical aspects of the dementia experience (O'Connor et al., 2022), paying more attention to the experiences of the professionals might have contributed to a more critical perspective on citizenship. According to O'Reilly (2009) critical ethnography attempts to expose hidden agendas, challenge oppressive assumptions and connect actions to broader structures of power and control (pp. 52–53). The phenomenological inspirations of this study (Finlay, 2008; Wright-St Clair, 2015), exploring subtle and emerging phenomena of citizenship, meant that the power of citizenship as a rights-based, critical and conflict-oriented lens might not have been used to its full potential. In addition, the limited attention to the professional perspective is an ethical issue. While interviews were conducted with staff and support staff in the nursing homes, these interviews were only analysed to provide context and added perspectives to the interpretation of constructed narratives from participant observations. As these professionals provided consent to participate in research (NESH, 2021) and took time to share their knowledge with me as a researcher, one would expect this data to be included more broadly in analysis and publications. However, these interviews still provided important information to understand the contexts during fieldwork and were therefore an important part of the research process.

5.4.2 Exploring citizenship – limitations in regards to recruitment

If citizenship is interpretive and depends on the perspectives and positions one holds, as discussed previously in this thesis, different people may experience and practice citizenship in different ways. This underlines that this study's focus on a limited number of nursing homes, mostly female participants and residents who actively engaged, limits the scope of the results. Whilst planning and recruiting nursing homes to participate in the study, I aimed to include two or three nursing home units. This choice was made to enable me to spend sufficient time in each unit while concluding work on the thesis within the timeframe allotted. However, while I do not aim to produce generalised *truths* about citizenship practices, these choices imply some critical limitations in terms of whose stories could be brought forward.

The nursing home units that were included were intended for people living with dementia. The professionals in both nursing homes were explicit about providing person-centred care, and leaders in both nursing homes highlighted the importance of staff having knowledge and skills in relation to working with people with dementia. However, the unit at Sea-Crest was larger than the two units at Sunny Hill – the latter being closer to the recommendations in the national guidelines for dementia of around eight residents (Norwegian Directorate of Health, 2017). Vossius et al. (2018) report that nursing home units tailored for people living with dementia in Norway have 20% higher staffing than regular nursing home units. In addition, their estimates indicate that 50% of nursing home time is allocated to direct care in regular units, while this figure increases to 70% in specialised dementia units. Although this cannot be stated with certainty, considering that the results of this thesis underscore the importance of staffs' presence and support, the knowledge produced would likely be very different if the study took place in units not intended for people with dementia. However, the observations at Sea-Crest showed fewer active initiatives from residents than at Sunny Hill. Meanwhile, there was nothing to suggest that residents there had more severe dementia or more physical disabilities. I lack the grounds to determine why these differences occurred, but I would speculate that staff being less present in the common areas where residents spent much of their time, as well as there being more distance (physically) between residents in the nursing home, could be part of the reason.

Another important limitation was that only one male resident was included, and in terms of the staff and leaders, no males were interviewed. This was not done by design but because most of the residents and staff were female in the included nursing homes. Even though a higher percentage of women than men might live long-term in nursing homes (Norwegian Directorate of Health, 2023), this is a critical bias. I neither pay attention nor reflect on other differences in the included participants, such as age, sexual orientation or ethnicity, and it is important to recognise that both the male perspective and such differences may influence how people express or enact themselves in the everyday. However, although most participants were female, I find it questionable to position them as belonging to a homogenous group; this means that the results cannot be assumed to encapsulate all females in nursing homes, either. As such, I would caution the reader to view the results as contextualised knowledge on how citizenship can be practiced within nursing homes and make their own interpretation on the relevance results might hold in other contexts.

As previously argued, I perceive citizenship as a simultaneously inclusive and exclusive concept and phenomena, continuously developing, which underscores its interpretive qualities. Through this thesis, I have attempted to interpret and bring forward stories that shed light on residents' capabilities. This in turn has led to neglect stories that attend to the challenging or more negative sides of nursing home living, and also the private sides of life, such as the personal needs for care and comfort that appeared so vital for residents' well-being while I was conducting fieldwork. In addition, I rarely entered residents' rooms, which might be seen as their place of privacy and thus an important arena for practicing citizenship. However, I chose not to do so because, while we know much more about residents' needs in terms of care, the literature review presented in the introduction reveals a need for more knowledge about residents' abilities and opportunities for agency within nursing home everyday life. My intention here is not to undervalue residents' care or medical needs, but to bring forward narratives that may counter the master narrative of dependency in this context.

5.4.3 Exploring citizenship – my role as researcher

While the focus of ethnographic inquiry can vary greatly, an important feature is a concern with action, with what people do and why (Hammersley & Atkinson, 2019, p. 170). One strength of this study relates to how the iterative and flexible methodology allowed me to engage in the nursing home units over time, be present in their specific contexts and spend time trying to get to know both residents and staff. This led to an increased understanding of the vulnerability of citizenship, supported relationally, enabled in embodied ways and influenced by the characteristics of the nursing home context. Discussing these results in terms of the overall socio-political context contextualises them in light of dementia policy, providing suggestions for future policy and practice.

An ethical question, underlined by researchers' responsibility of truthfulness and clarity in interpretation (NESH, 2021), relates to whether residents and staff would recognise themselves in the results. A range of data was obtained from the nursing homes, but only a small selection of it is actually reported. For example, the analytical procedures meant that Sea-Crest nursing home, in particular, received limited room in publications: for example, the second article only discussed constructed narratives from Sunny Hill. One important reason for this was that the fieldnotes from Sunny Hill were fuller and contained more descriptions of residents' doings and interactions within the social environment, making them more available for narrative construction. As I started fieldwork at Sea-Crest nursing home, I needed time to learn how to be a participant observer, as well as document what I saw and heard. In addition, the unit at Sea-Crest was larger, and I spent more time alone with residents there than in the units at Sunny Hill. Due to the medical needs of some of the residents who were not included in the study, staff were often engaged in individual care situations in residents' rooms, and I therefore observed less interaction in the common areas at Sea-Crest. While residents at Sea-Crest frequently participated in organised activities, documenting the details of these events were challenging due to the business of them and ethical considerations (NESH, 2021) regarding the people participating in them who hadn't consented to participate in the research.

Meanwhile it is important to recognise that because I was involved in the everyday lives of residents and staff, what people did and said might have been influenced by my presence. For example, some of the staff at Sea-Crest specifically said that my presence had positively changed their behaviour, making them more conscious of how they interacted with residents. Iphofen and Tolich (2018) argue that emotional, political and personal responsiveness is inevitable in qualitative research. Moreover, they note that "a reflexive researcher is one who is well aware of the consequences of the impact of their mere presence, as well as the consequences of how they report their research engagement" (p. 2). For example, in the third article of the thesis (Sund et al., 2023b), one of the constructed narratives shows how residents gathered for long periods of time while staff was occupied elsewhere. It is possible that staff avoided being in the living rooms when I was there to avoid being observed. Or perhaps another likely interpretation, that they saw me as an added resource and assumed that I would respond if something happened, freeing them to attend to other pressing issues. However, according to Hammersley and Atkinson (2019, p. 17), the fact that the presence of researchers may have an effect of people does not necessarily undermine the validity of findings. Not knowing for sure why residents were alone in the living room does not undermine the knowledge that can be derived from these situations, and I therefore do not consider the observer effect as an error but as part of the basic relational nature of such a study. How frequently such stories occur or whether they happened because I was there, is not the central issue. I placed importance in trying to understand how people's actions and expressions could be interpreted as citizenship.

5.4.4 Interpreting citizenship – acknowledging uncertainty

Polkinghorne (2007) writes that different kinds of knowledge claims require different kinds of evidence and arguments to convince readers that the claim is valid. Aiming to increase insights into citizenship practices in nursing homes in this thesis, I sought to approach fieldwork as inductively as possible. While informed by my preconceptions of dementia, nursing home living and humans as occupational beings, I did not have pre-defined categories I aimed to explore. Doing fieldwork meant getting close to residents and attempting to understand their experiences. I wanted to experience the nursing home rationally, embodily and emotionally, and as Finlay (2008) argues, to open myself to being moved "by an Other" (p. 3). In the analytical process, data were initially approached naively and inductively, in an attempt to understand aspects of residents' everyday lives. Narratives were then constructed that centred on persons with dementia as the protagonists and staff as supporting characters. Within the narratives brought forward in the articles, I aim to tune into the residents' perspectives, seeking to understand their experiences. However, doing so has limitations. The interpretations cannot be seen as actually representing their voice, but as one interpretation of that voice through my particular theoretical framework.

Further into the analysis, theories took a more prominent role in interpretations, which both hold the potential to inform and obscure the actual intentions of residents themselves. However, in line with Alvesson and Skõldberg (2018, pp. 4–5), narratives were not produced to corroborate theory; rather, theory was used to interpret the stories. Similarly, Josephsson and Alsaker (2015) argue that, in narrative analysis, theory is brought into the hermeneutic dialectic move between interpretation and the material (p. 76). Theories of citizenship, occupation and narrativity were brought into the conversation to aid in the interpretations of the narratives. Occupational theory was brought into the conversation to interpret the dynamic relationship between residents' doing and their *being*, *belonging* and opportunities for continued development and growth (*becoming*). My understanding of narrativity recognises that stories do not need to be linear or coherent but can be told in moments and in episodic ways. Through narrativity, we recognise the storied nature of human beings, and – connected with occupation – we recognise that stories can be told both through verbal accounts and a wide range of doing.

However, the methods chosen has had an important impact on what type of knowledge could actually be produced. Seeking to understand citizenship through observing the actions of others is an uncertain enterprise. Is citizenship a subjective experience or something that can be objectively observed and defined? Malterud (2011) writes that we need to be careful about using observational material to explore interpretations of individuals' meaning-worlds because underlying motives, or what people actually think, cannot be determined from observational data. She argues that internal validity is easier to achieve using a descriptive approach focused on behaviour and expressions rather than by aiming for a high degree of abstraction regarding interpretation (p. 148). In this study, unsolicited expressions documented from everyday life provided useful insights into residents' perspectives in natural situations. However, they did not necessarily enable insights into individuals' interpretation of themselves, their subjective reality and the meaning they assigned to the things they did. However, the results of this study do not represent, or aim to represent, the internal experiences of being residents in nursing homes. It explores observable actions and expressions that in turn are interpreted as citizenship content. In this regard, Kontos (2005) argues that fundamental aspects of selfhood are manifested in the ways the body moves and behaves, whereas the body itself is a communicative agent imbued with intentionality and purposefulness. Fuchs (2020) similarly contends that the continuity of the person is not merely rooted in memory but also sedimented in the body, arguing that, even though the self-as-object may be reduced or lost (the ability to reflect on one's own existence), the self-as-subject is connected to the implicit memory of the body. By turning attention towards the embodied doings of residents, I view the actions and expressions of people with dementia as representing a way of telling stories of identity and belonging in embodied ways.

Hansson et al. (2022) describe occupational identity as both an internal sense of being and an external expression of being through doing. While we might not have access to people's private and inner sense of being, this study attempts to interpret such external expressions of doing as stories that can hold meaning on an individual level (attending to the small stories of the everyday) and on a societal and political level (recognising that mundane stories can impact societal and political master narratives). Meanwhile, I recognise that the decision not to conduct interviews with residents limited the opportunity for gaining in-depth knowledge about how they experienced or attached meaning to aspects of their everyday life. In hindsight, I wonder if there might have been missed opportunities or if I might have underestimated residents' abilities to speak up for themselves due to my fear of doing something that would violate ethical guidelines (NESH, 2021), such as disturbing residents or causing anxiety. Spending more time in private conversation and using inclusionary methods (e.g., visual methods, see: Shell, 2014; Geneo & Dupuis, 2013; Phillipson & Hammond, 2018) to conduct interviews might have made it possible to gain more knowledge of how residents themselves perceived everyday life.

Narrative analysis allowed specific stories to be brought to light, amplifying nursing home everyday life and the voices of some of the residents residing there. This allowed me to describe actions and social processes, as well as to interpret the possible meanings and significance of these. However, these interpretations are conducted from the specific viewpoint of citizenship and occupation, meaning that the knowledge produced is influenced by my position as a researcher and the theories applied. Attempting to understand everyday life from the perspective of residents does not mean that the interpretations represent what residents actually thought or *the truth* about nursing home everyday life or citizenship. Rather, they represent one of many possible truths, in line with a subjective, contextually bound and multiple perception of knowledge. Glavind and Mogensen (2022) argue that we should avoid assuming that coherence and continuity are the only ways of being in the world. However, attempting to grasp how residents experienced everyday life by paying attention to both their verbal expressions and actions still leaves us with a degree of uncertainty. According to NESH (2021) guidelines, interpretation must build om research-based theories, concepts and perspectives. Engaging with the uncertainties of our interpretations and considering and testing different theoretical possibilities and ways of understanding throughout the analysis process have been important dimensions of knowledge production. By accepting the uncertainties within our interpretations of residents' stories, both those told verbally and those interpreted through their actions, and engaging with this uncertainty, we have been able to highlight what we perceive to be important essences of residents' citizenship.

5.4.5 Exploring citizenship – relevance for practice

According to Pinnegar and Daynes (2006), narrative inquiry involves moving away from generalisability, embracing the power of the particular for understanding experience. This also meant that when analysing the fieldnotes, the validity of the stories was not assessed in relation to how frequently something happened (as might be the case with paradigmatic analytical procedures) but rather in terms of what could be learned from each story. By discussing the narratives in terms of theory, we sought to make the stories relevant for other contexts and to make their implications clear.

Meanwhile, O’Connor et al. (2022) promote the future involvement of people with dementia in citizenship research, noting that the exploration of citizenship continues to be led by academics. This would require more knowledge about how people living with dementia experience their own citizenship. This study was not designed and developed together with people with dementia. It is therefore prudent to question its relevance to those living with this condition. However, it builds on research and reports documenting that many living with dementia experience that their opportunities are restricted. While the thesis is grounded on being present in residents’ everyday lives, the articles provide an academic and analytical perspective on and interpretation of the stories that are brought forward. However, caution is advised, as O’Connor et al. (2022) explain in the conclusion of their article:

> Hard questions need to be asked as to whether current conceptualizations of citizenship adequately capture the requirements and perspectives of people living with dementia, particularly in a world that is increasingly cognizant of the need for recognizing human rights and for eliminating stigma and discrimination. (p. 2346)

The framework applied in this doctoral study recognised both the communicative and occupational abilities of residents. The study’s ontological views of humans as occupational (Wilcock & Hocking, 2015) and narrative beings (Baldwin, 2008) complemented each other and made it possible to see residents’ *doings* as a form of communication, thus becoming a way of acknowledging and attempting to understand their perspective. As such, this approach might be seen as a creative way of attempting to include residents’ “voices” in the research, a need emphasised by the communicative challenges experienced by the researcher during fieldwork. Most of the articles in the review by O’Connor et al. (2022) explored citizenship in the early stages of dementia. The strength of combining theories of citizenship, narrativity and occupation as I have done in this thesis, is that it gives us the opportunity to ground our interpretations in mundane sides of life, bringing forward subtle and perhaps often taken-for-granted aspects of citizenship practices in the lives of people with dementia in nursing homes.

6.0 SUMMARY AND IMPLICATIONS FOR FUTURE RESEARCH

This thesis produces knowledge about the characteristics of citizenship practices in the everyday lives of people with dementia in nursing homes. In this chapter, I provide a brief summary of its results and discussions, suggesting inclusionary definitions of a citizenship of *becoming* and co-ownership to guide future research, professional practice and policy.

Citizenship through practices of *becoming* and co-ownership:

The thesis contributes to knowledge about citizenship as practiced within mundane aspects of everyday life, suggesting *becoming* and co-ownership as central characteristics of citizenship in nursing homes. Co-ownership is suggested as an active professional and institutional responsibility of creating nursing home communities where residents are interpreted as intentional and capable, as well as supported to share responsibilities, spaces and influence occupational opportunities. The occupational dimension of *becoming* (Wilcock & Hocking, 2015) is demonstrated as the personal dimension of development and growth in which people with dementia act in line with their own occupational potential. In the everyday lives of people living with dementia in nursing homes, *becoming* was found to emerge in vulnerable and fleeting moments, thus needing continuous recognition and support to be upheld. In this thesis, it is argued that an environment of co-ownership (that thus supports *becoming*) might be characterised by going beyond a focus on the provision of occupational opportunities and services, towards recognising subtle expressions of agency in the mundane. Neglecting to do so might reduce the contents of citizenship to centre on mere provision of services and neglect the ways people with dementia can still contribute to their communities. Recognising that people with dementia can act in purposeful and intentional ways contributes to expand person-centred care towards citizenship and acknowledges residents' rights, and capabilities, as citizens.

Citizenship through inclusive interpretive practices in professional practice:

The results of this thesis imply that interpretive practices in nursing homes can include or exclude residents from access to participation and thus opportunities to practice citizenship. It is suggested that interpreting residents from a group-based perspective or through a pathologising lens may lead to reduced access to participation. I argue that fleeting and fragmented expressions of possible resistance, such as anger or withdrawal, can be seen as resistance against an environment that does not sufficiently support co-ownership. This is contrasted with interpretive practices that view such behaviour as behavioural and psychological symptoms in dementia (BPSD). Amongst others, it is discussed that linking withdrawal directly to the disease (such as apathy in dementia), may lead us to view passivity as normal within the nursing home context. It is therefore argued that co-ownership must build on, and be informed by, inclusive interpretive practices that recognise that even mundane acts can express intentionality and possible resistance in the nursing home. Incorporating a lens of activistic citizenship in our interpretive practices recognises that residents' actions can be valid human responses to constraining or discriminatory structures. Such interpretive practices should in turn inform welfare services about necessary changes to support the citizenship of residents in nursing homes.

Addressing citizenship in dementia policy:
In Norway, we are on our third dementia plan. These plans are important government documents pointing the way for future strategies and improvement, both on a societal and service level. Findings from this thesis point to three implications of a citizenship of *becoming* and co-ownership for dementia policy that should be considered in developing future regulations in the dementia and nursing home field: First, that future plans might benefit from explicitly addressing the concepts and phenomena of citizenship as agency and participation in residents' everyday lives; second, that recognising that "behaviour that challenges" can express both needs and valid resistance towards constraining structures; and third, that Norwegian policy should take regulations relating to discrimination, such as the CRPD, more explicitly into account when developing future recommendations in the field.

Questions for future research

The results of this thesis contribute to furthering our knowledge about citizenship in the nursing home context. However, by connecting and discussing previous research, socio-political conditions and my theoretical framework with data from empirical fieldwork, I am perhaps left with more questions than I have answered. Considering that this thesis was not designed in collaboration with people with dementia, future research should explore these results from the perspective of people living with dementia, as well as professionals in nursing homes. Would people living with dementia in nursing homes agree that an important characteristic of citizenship revolves around being enabled to engage in agentic ways in the mundane, and having one's expressions interpreted as both intentional and possibly activistic? Further, would the characteristics of citizenship be described differently from a male perspective or if attention were focused on the private arenas of the nursing home? Considering that this study took place within two nursing homes in the south-west region of Norway, how might the results differ depending on geographical locations and types of nursing home units, both in Norway and internationally?

Another question that emerges concerns how we can construct occupational environments of familiarity in a context that, by design, houses people with diverse backgrounds, functional abilities and interests. Is the nursing home as an institution discriminatory due to its inherent characteristics, or can citizenship be upheld in this context through co-ownership, as suggested in this thesis? And as a natural extension, if citizenship can be supported through co-ownership, how might this change our understanding of the professional role and responsibility in the nursing home context? Exploring such questions also implies further attention to the way government publications in the dementia field rarely engage with the concept of discrimination. This underlines a need for more knowledge about the position of the nursing home in the current paradigm shift towards citizenship, as well as the need to address possible implications of the CRPD in terms of nursing home living.

REFERENCES

Alvesson, M., & Sköldberg, K. (2018). *Reflexive methodology: New vistas for qualitative research* (3rd ed.). Sage.

Andrews, M. (2004). Counter-narratives and the power to oppose. In M. Bamberg & M. Andrews (Eds.), *Considering counter-narratives: Narrating, resisting, making sense* (pp. 1–6). John Benjamins.

Antelius, E., Kiwi, M., & Strandroos, L. (2018). Ethnographic methods for understanding practices around dementia among culturally and linguistically diverse people. In J. Keady, L.-C. Hyden, A. Johnson & C. Swarbrick (Eds.), *Social research methods in dementia studies: Inclusion and innovation* (pp. 121–139). Routledge.

Baldwin C. (2005). Narrative, ethics and people with severe mental illness. *Australian and New Zealand Journal of Psychiatry*, *39*(11-12), 1022–1029. https://doi.org/10.1080/j.1440-1614.2005.01721.x

Baldwin, C. (2006). The narrative dispossession of people living with dementia: Thinking about the theory and method of narrative. In J. Milnes, C. Horrocks, N. Kelly, B. Roberts, & D. Robinson (Eds.), *Narrative, memory and knowledge: Representations, aesthetics and contexts* (pp. 101–109). University of Huddersfield.

Baldwin, C. (2008). Narrative(,) citizenship and dementia: The personal and the political. *Journal of Aging Studies, 22*(3), 222–228. https://doi.org/10.1016/j.jaging.2007.04.002

Baldwin C. (2015). Narrative ethics for narrative care. *Journal of Aging Studies*, *34*, 183–189. https://doi.org/10.1016/j.jaging.2015.02.014

Baldwin, C., & Greason, M. (2016). Micro-citizenship, dementia and long-term care. *Dementia, 15*(3), 289–303. https://doi.org/10.1177/1471301216638762

Bamberg, M. (2004a). Considering counter-narratives. In M. Bamberg & M. Andrews (Eds.), *Considering counter-narratives: Narrating, resisting, making sense* (pp. 351–371). John Benjamins.

Bamberg, M. (2004b). Talk, small stories, and adolescent identities. *Human Development, 47*(6), 366–369. https://doi.org/10.1159/000081039

Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies, 21*(2), 107–118. https://doi.org/10.1016/j.jaging.2006.09.002

Bartlett, R., O'Connor, D., & Mann, J. (2010). *Broadening the dementia debate: Towards social citizenship*. Policy Press.

Bergh, S., Holmen, J., Saltvedt, I., Tambs, K., & Selbæk, G. (2012). Dementia and neuropsychiatric symptoms in nursing-home patients in Nord-Trøndelag County. *Tidsskrift for den Norske laegeforening*, *132*(17), 1956–1959. https://doi.org/10.4045/tidsskr.12.0194

Bergström, A., Fallahpour, M., & Vikström, S. (2021). Occupational gaps reported by proxies for persons with dementia residing in a nursing home. *Scandinavian Journal of Occupational Therapy*. https://doi.org/10.1080/11038128.2021.2016947

Bland, M. (2002) Patient observation in nursing home research: Who was that masked woman? *Contemporary Nurse*, *12*(1), 42–48. https://doi.org/10.5172/conu.12.1.42

Boje, T. P. (2017). *Civilsamfund, medborgerskab og deltagelse*. Hans Reitzels Forlag.

Boyle, G. (2008). Autonomy in long-term care: A need, a right or a luxury? *Disability & Society*, *23*(4), 299–310. https://doi.org/10.1080/09687590802038795

Boyle, G. (2014). Recognising the agency of people with dementia. *Disability & Society, 29*(7), 1130–1144. https://doi.org/10.1080/09687599.2014.910108

Bradshaw, S. A., Playford, E. D., & Riazi, A. (2012). Living well in care homes: A systematic review of qualitative studies. *Age and Ageing*, *41*(4), 429–440. https://doi.org/10.1093/ageing/afs069

Bradwell, C. (2021). Co-creating resilience with people living with dementia through intergenerational arts. *Research in Drama Education: The Journal of Applied Theatre and Performance, 26*(1), 137–152. https://doi.org/10.1080/13569783.2020.1841619

Cahill, S. (2018). *Dementia and human rights*. Policy Press.

Cahill, S., & Diaz-Ponce, A. M. (2011). "I hate having nobody here. I'd like to know where they all are": Can qualitative research detect differences in quality of life among nursing home residents with different levels of cognitive impairment? *Aging & Mental Health*, *15*(5), 562–572. https://doi.org/10.1080/13607863.2010.551342

Canning, S., & Blakeborough, D. (2019). Intergenerational dance in long-term residential care: Social citizenship in dementia care. *BC Studies*, *202*, 167–178. https://doi.org/10.14288/bcs.v0i202.190767

Capstick, A., & Chatwin, J. (2016). The carnival is not over: Cultural resistance in dementia care environments. *Pragmatics and Society*, *7*(2), 169–195. http://dx.doi.org/10.1075/ps.7.2.01cha

Causey-Upton, R. (2015). A model for quality of life: Occupational justice and leisure continuity for nursing home residents. *Physical & Occupational Therapy In Geriatrics*, *33*(3), 175–188. https://doi.org/10.3109/02703181.2015.1024301

Centre of Diaconia and Professional Practice (n.d.). *Programme Description for PhD of Diaconia, Values and Professional Practice, VID Oslo*. https://www.vid.no/site/assets/files/12804/studieplan-ph.d-i-diakoni-verdier-og-profesjonell-praksis-engelsk-2018-2019-vid.pdf?1cpbju

Clandinin, D. J., & Rosiek, J. (2006). Mapping a landscape of narrative inquiry: Borderland spaces and tensions. In J. Clandinin (Ed.), *Handbook of narrative inquiry: Mapping a methodology* (pp. 35–75). Sage. https://doi.org/10.4135/9781452226552

Cook, G., Thompson, J., & Reed, J. (2015). Re-conceptualising the status of residents in a care home: Older people wanting to "live with care." *Ageing and Society*, *35*(8), 1587–1613. https://doi.org/10.1017/S0144686X14000397

Cortazzi, M. (2001). Narrative analysis in ethnography. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, & L. Lofland (Eds.), *Handbook of ethnography* (pp. 1–20). Sage. https://doi.org/10.4135/9781848608337

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

Dekker, N. L., & Pols, J. (2020). Aspirations of home making in the nursing home. In B. Pasveer, O. Synnes, & I. Moser (Eds.), *Ways of home making in care for later life* (pp. 183–201). Springer Singapore.

Delamont, S., & Atkinson, P. (2018). The ethics of ethnography. In R. Iphofen & M. Tolich (Eds.), *The SAGE handbook of qualitative research ethics*. Sage. https://doi.org/10.4135/9781526435446

Department of Children, Equality and Inclusion (2015). *FN konvensjonen om rettighetene til mennesker med nedsatt funksjonsevne (CRPD) – Norges første rapport* [The FN-convention on the rights of persons with disabilities (CRPD)—Norway's first report]. https://www.regjeringen.no/contentassets/26633b70910a44049dc065af217cb201/norges-forste-rapport-til-crpd-komiteen.pdf

Dewing, J. (2002). From ritual to relationship: A person-centred approach to consent in qualitative research with older people who have dementia. *Dementia*, *1*(2), 157–171. https://doi.org/10.1177/147130120200100204

Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia*, *6*(1), 11–25. https://doi.org/10.1177/1471301207075625

Donaldson, S., & Kymlicka, W. (2017). Inclusive citizenship beyond the capacity contract. In A. Shachar, R. Baubõck, I. Bloenraad, & M. Vink (Eds.), *The Oxford handbook of citizenship* (pp. 838–859). Oxford University Press.

Du Toit, S. H. J., Shen, X., & McGrath, M. (2019). Meaningful engagement and person-centred residential dementia care: A critical interpretive synthesis. *Scandinavian Journal of Occupational Therapy*, *26*(5), 343–355. https://doi.org/10.1080/11038128.2018.1441323

Dupuis, S. L., Wiersma, E., & Loiselle, L. (2012). Pathologizing behavior: Meanings of behaviors in dementia care. *Journal of Aging Studies*, *26*(2), 162–173. https://doi.org/10.1016/j.jaging.2011.12.001

Evans, D. (2002). Systematic reviews of interpretive research: Interpretive data synthesis of processed data. *Australian Journal of Advanced Nursing*, *20*(2), 22–26.

Eyers, I., Arber, S., Luff, R., Young, E., & Ellmers, T. (2012). Rhetoric and reality of daily life in English care homes: The role of organised activities. *International Journal of Ageing and Later Life*, *7*(1), 53–78. https://doi.org/10.3384/ijal.1652-8670.11132

Finlay, L. (2008). A dance between the reduction and reflexivity: Explicating the "phenomenological psychological attitude." *Journal of Phenomenological Psychology, 39*(1). https://doi.org/10.1163/156916208X311601

Fisher, P. (2012). Ethics in qualitative research: "Vulnerability," citizenship and human rights. *Ethics and Social Welfare*, *6*(1), 2–17. https://doi.org/10.1080/17496535.2011.591811

Fivush, R. (2010). Speaking silence: The social construction of silence in autobiographical and cultural narratives. *Memory*, *18*(2), 88–98. https://doi.org/10.1080/09658210903029404

Fjetland, K. J. (2015). *Medforfatterskap I Tilrettelagt Arbeid?: En Studie Av Narrativ Praksis I Relasjonen Mellom Arbeidstaker Og Arbeidsleder I Tilrettelagt Arbeid, VTA* [Co-authorship in facilitated work? A study of narrative practice in relations between employees and supervisors in organizes work] (Doctoral dissertation). University of Stavanger.

Fjetland, K., & Gjermestad, A. (2018). Medborgerskap og alvorlig utviklingshemming [Citizenship and severe developmental disability]. *Tidsskrift for velferdsforskning*, *21*(2), 148–162. https://doi.org/10.18261/issn.2464-3076-2018-02-04

Fuchs, T. (2020). Embodiment and personal identity in dementia. *Medicine, Health Care and Philosophy, 23*(4), 665–676. https://doi.org/10.1007/s11019-020-09973-0

Førsund, L. H., Grov, E. K., Helvik, A. S., Juvet, L. K., Skovdahl, K., & Eriksen, S. (2018). The experience of lived space in persons with dementia: A systematic meta-synthesis. *BMC Geriatrics*, *18*(1). https://doi.org/10.1186/s12877-018-0728-0

Genoe, R., & Dupuis, S. (2013). Picturing leisure: Using photovoice to understand the experience of leisure and dementia. *Qualitative Report*, *18*(11), 1–21. https://doi.org/10.46743/2160-3715/2013.1545

Georgakopoulou, A. (2006). Thinking big with small stories in narrative identity analysis. *Narrative Inquiry*, *16*(1), 122–130. https://doi.org/10.1075/ni.16.1.16geo

Gitlin, L. N., & Hodgson, N. A. (2018). *Better living with dementia. Implications for Individuals, families, communities, and societies*. Academic Press.

Gjernes, T., & Måseide, P. (2015). Dementia, distributed interactional competence and social membership. *Journal of Aging Studies*, *35*, 104–110. https://doi.org/10.1016/j.jaging.2015.08.002.

Gjødsbøl, I. M., Koch, L., & Svendsen, M. N. (2017). Resisting decay: On disposal, valuation, and care in a dementia nursing home in Denmark. *Social Science & Medicine, 184*, 116–123. https://doi.org/10.1016/j.socscimed.2017.05.022

Gjøra, L., Strand, B. H., Bergh, S., Borza, T., Brækhus, A., Engedal, K., Johannessen, A., Kvello-Alme, M., Krokstad, S., Livingston, G., Matthews, F. E., Myrstad, C., Skjellegrind, H., Thingstad, P., Aakhus, E., Aam, S., & Selbæk, G. (2021). Current and future prevalence estimates of mild cognitive impairment, dementia, and its subtypes in a population-based sample of people 70 years and older in Norway: The HUNT study. *Journal of Alzheimer's Disease*, *79*(3), 1213–1226. https://doi.org/10.3233/JAD-201275

Glavind, I. M. L., & Mogensen, H. O. (2022). Fragile storytelling: Methodological considerations when conducting ethnographic fieldwork among people with Alzheimer's disease. *Qualitative Research in Health*, *2*, 100103. https://doi.org/10.1016/j.ssmqr.2022.100103

Goffman, E. (1961). *Asylums: Essays of the social situation of mental patients and other inmates*. Anchor Books.

Grigorovich, A., & Kontos, P. (2018). Advancing an ethic of embodied relational sexuality to guide decision-making in dementia care. *Gerontologist, 58*(2), 219–225. https://doi.org/10.1093/geront/gnw137

Grigorovich, A., Kontos, P., & Kontos, A. P. (2019). The "violent resident": A critical exploration of the ethics of resident-to-resident aggression. *Journal of Bioethical Inquiry*, *16*(2), 173–183. https://doi.org/10.1007/s11673-019-09898-1

Hammel, K. W. (2020) *Engagement in living: Critical perspectives on occupation, rights, and wellbeing*. Canadian Association of Occupational Therapists.

Hammersley, M., & Atkinson, P. (2019). *Ethnography: Principles in practice* (4th ed.). Routledge.

Hansson, S. O., Björklund Carlstedt, A., & Morville, A. L. (2022). Occupational identity in occupational therapy: A concept analysis. *Scandinavian Journal of Occupational Therapy*, *29*(3), 198–209. https://doi.org/10.1080/11038128.2021.1948608

Harnett, T. (2010). Seeking exemptions from nursing home routines: Residents' everyday influence attempts and institutional order. *Journal of Aging Studies, 24*(4), 292–301. https://doi.org/10.1016/j.jaging.2010.08.001

Harnett, T., & Jonson, H. (2017). "They are different now"—Biographical continuity and disruption in nursing home settings. *Journal of Aging Studies*, *42*. https://doi.org/10.1016/j.jaging.2017.05.003

Health and Care Services Act. (2012). *Act relating to municipal healthcare services* (LOV-2011-06-24-20). https://lovdata.no/dokument/NL/lov/2011-06-24-30/KAPITTEL_3#%C2%A73-2a

Heggestad, A. K. T., Nortvedt, P., & Slettebø, A. (2013a). “Like a prison without bars”: Dementia and experiences of dignity. *Nursing Ethics*, *20*(8), 881–892. https://doi.org/10.1177/0969733013484484

Heggestad, A. K., Nortvedt, P., & Slettebø, Å. (2013b). The importance of moral sensitivity when including persons with dementia in qualitative research. *Nursing Ethics*, *20*(1), 30–40. https://doi.org/10.1177/0969733012455564

Hellström, I., Nolan, M., Nordenfelt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics, 14*(5), 608–619. http://dx.doi.org/10.1177/0969733007080206

Herron, R., Kelly, C., & Aubrecht, K. (2021). A Conversation about ageism: Time to deinstitutionalize long-term care? *University of Toronto Quarterly*, *90*, 183–206. https://doi.org/10.3138/utq.90.2.09

Hitch, D., Pépin, G., & Stagnitti, K. (2014a). In the footsteps of Wilcock, part one: The evolution of doing, being, becoming, and belonging. *Occupational Therapy In Health Care, 28*(3), 231–246. https://doi.org/10.3109/07380577.2014.898114

Hitch, D., Pépin, G., & Stagnitti, K. (2014b). In the footsteps of Wilcock, part two: The interdependent nature of doing, being, becoming, and belonging. *Occupational Therapy in Health Care, 28*(3), 247–263. https://doi.org/10.3109/07380577.2014.898115

Holthe, T., Thorsen, K., & Josephsson, S. (2007). Occupational patterns of people with dementia in residential care: An ethnographic study. *Scandinavian Journal of Occupational Therapy*, *14*(2), 96–107. https://doi.org/10.1080/11038120600963796

Hubbard, G., Downs, M. G., & Tester, S. (2003). Including older people with dementia in research: Challenges and strategies. *Aging & Mental Health, 7*(5), 351–362. https://doi.org/10.1080/1360786031000150685

Hydén, L. C., & Antelius, E. (2011). Communicative disability and stories: Towards an embodied conception of narratives. *Health, 15*(6), 588–603. https://doi.org/10.1177/1363459310364158

Hydén, L.-C., & Antelius, E. (2017). Introduction: From empty vessels to active agents. In L.-C. Hydén & E. Antelius (Eds.), *Living with dementia: Relations, responses and agency in everyday life* (pp. 1–13). Palgrave MacMillan.

Iphofen, R., & Tolich, M. (2018). Concluding thoughts: The virtues of a reflexive qualitative researcher. In R. Iphofen & M. Tolich (Eds.), *The SAGE handbook of qualitative research ethics (pp. 1–3)*. Sage. https://doi.org/10.4135/9781526435446

Isin, E. F. (2008). Theorizing acts of citizenship. In E. F. Isin & G. M. Nielsen (Eds.), *Acts of citizenship* (pp. 15–43). Palgrave Macmillan.

Isin, E. (2017). Performative citizenship. In A. Shachar, R. Baubõck, I. Bloenraad, & M. Vink (Eds.), *The Oxford handbook of citizenship* (pp. 500–523). Oxford University Press.

Isin, E. (2019). Doing rights with things: The art of becoming citizens. In P. Hildebrandt, K. Evert, S. Peters, K. W. Schaub, & G. Ziemer (Eds.), *Performing citizenship: Bodies, agencies, limitations* (pp. 45–56). Palgrave Macmillan.

Josephsson, S., & Alsaker, S. (2015). Narrative methodology: A tool to access unfolding and situated meaning in occupation. In S. Nayar & M. Stanley (Eds.), *Qualitative research methodologies for occupational science and therapy* (pp. 70–83). Routledge.

Jönson, H., & Harnett, T. (2016). Introducing an equal rights framework for older persons in residential care. *Gerontologist*, 56(5), 800–806. https://doi.org/10.1093/geront/gnv039

Kaufmann, E. G., & Engel, S. A. (2016). Dementia and well-being: A conceptual framework based on Tom Kitwood's model of needs. *Dementia (London, England)*, *15*(4), 774–788. https://doi.org/10.1177/1471301214539690

Kielsgaard, K., Horghagen, S., Nielsen, D., & Kristensen, H. K. (2021). Moments of meaning: Enacted narratives of occupational engagement within a dementia town. *Journal of Occupational Science*, *28*(4), 510524. https://doi.org/10.1080/14427591.2020.1859403

Killett, A., Bowes, A., Brooker, D., Burns, D., Kelly, F., La Fontaine, J., Latham, I., O'Neill, M., Poland, F., & Wilson, M. (2013). *What makes a real difference to resident experience? Digging deep into care home culture: The CHOICE (Care Home Organisations Implementing Cultures of Excellence) research report*. Prevention of Abuse and Neglect in Care of Older Adults. https://research-portal.uea.ac.uk/en/publications/what-makes-a-real-difference-to-resident-experience-digging-deep

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Open University Press.

Kjørholt, E. S., Sæther, M. L., & Thorsnes, I. E. (2015). *Temarapport. Menneskerettigheter i norske sykehjem* [Thematic report. Human rights in Norwegian nursing homes]. Nasjonal institusjon for menneskerettigheter ved UiO, Norsk senter for menneskerettigheter, Det juridiske fakultet.

Kjøs, B. Ø., & Havig, A. K. (2016). An examination of quality of care in Norwegian nursing homes—a change to more activities? *Scandinavian Journal of Caring Sciences*, *30*(2), 330–339. https://doi.org/10.1111/scs.12249

Knecht-Sabres, L. J., Del Rosario, E. P., Erb, A . K., Rozko, M., & Guzman, R. (2020). Are the leisure and social needs of older adults residing in assisted living facilities being met? *Physical & Occupational Therapy In Geriatrics*, *38*(2), 107–128. https://doi.org/10.1080/02703181.2019.1702134

Kontos, P. (2005). Embodied selfhood in Alzheimer's disease: Rethinking person-centred care. *Dementia, 4*(4), 553–570*. https://doi.org/10.1177/1471301205058311*

Kontos, P., & Grigorovich, A. (2018a). Integrating citizenship, embodiment, and relationality: Towards a reconceptualization of dance and dementia in long-term care. *Journal of Law, Medicine & Ethics*, *46*(3), 717–723. https://doi.org/10.1177/1073110518804233

Kontos, P., & Grigorovich, A. (2018b). Rethinking musicality in dementia as embodied and relational. *Journal of Aging Studies, 45*, 39–48. https://doi.org/10.1016/j.jaging.2018.01.006

Kontos, P., Grigorovich, A., Kontos, A. P., & Miller, K. L. (2016). Citizenship, human rights, and dementia: Towards a new embodied relational ethic of sexuality. *Dementia*, *15*(3), 315–329. https://doi.org/10.1177/1471301216636258

Kontos, P., Miller, K. L., & Kontos, A. P. (2017). Relational citizenship: Supporting embodied selfhood and relationality in dementia care. *Sociology of Health & Illness*, *39*(2), 182–198. https://doi.org/10.1111/1467-9566.12453

Kontos, P., Grigorovich, A., & Colobong, R. (2020). Towards a critical understanding of creativity and dementia: New directions for practice change. *International Practice Development Journal, 10(3).* https://doi.org/10.19043/ipdj.10Suppl.003

Kvale, S., & Brinkmann, S. (2015). *Det kvalitative forskningsintervju* [The qualitative research interview]. Gyldendal akademisk.

Laliberte-Rudman, D. (2002). Linking occupation and identity: Lessons learned through qualitative exploration. *Journal of Occupational Science*, *9*(1), 12–19. https://doi.org/10.1080/14427591.2002.9686489

Laverty, S. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods. 2*(3), 21–35.

Lee, K., & Bartlett, R. (2021). Material citizenship: An ethnographic study exploring object–person relations in the context of people with dementia in care homes. *Sociology of Health & Illness*, *43*(6), 1471–1485. https://doi.org/10.1111/1467-9566.13321

Leven, N. V., & Jonsson, H. (2002). Doing and being in the atmosphere of the doing: Environmental influences on occupational performance in a nursing home. *Scandinavian Journal of Occupational Therapy*, *9*(4), 148–155. https://doi.org/10.1080/11038120260501172

Malterud, K. (2011). *Kvalitative metoder i medisinsk forskning: en innføring* [Qualitative methods in medical research: An introduction]. Universitetsforlaget.

Malterud, K. (2012). *Fokusgrupper som forskningsmetode for medisin og helsefag* [Focus groups as research method for medicine and healthcare]. Universitetsforlaget.

Marshall, T. H. (1992). Citizenship and social class. In T. H. Marshall & T. Bottomore (Eds.), *Citizenship and social class* (pp. 3−51). Pluto Press.

Marsh, P., Courtney-Pratt, H., & Campbell, M. (2018). The landscape of dementia inclusivity. *Health & Place*, *52*, 174–179. https://doi.org/10.1016/j.healthplace.2018.05.013

McKenzie-Mohr, S., & Lafrance, M. N. (2017). Narrative resistance in social work research and practice: Counter-storying in the pursuit of social justice. *Qualitative Social Work, 16*(2), 189–205. https://doi.org/10.1177/1473325016657866

McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, *19*(13-14), 1935–1943. https://doi.org/10.1111/j.1365-2702.2009.03136.x

Meld. St. 15 (2017–2018). *A full life—all your life. A quality reform for elders*. Ministry of Health and Care Services. https://www.regjeringen.no/no/dokumenter/meld.-st.-15-20172018/id2599850/

Merriam-Webster. (n.d.) Practice. In *Merriam-Webster.com dictionary*. Retrieved September 28, 2023, from https://www.merriam-webster.com/dictionary/practice

Merriam-Webster. (n.d.) Transformative. In *Merriam-Webster.com dictionary*. Retrieved October 7, 2023, from https://www.merriam-webster.com/dictionary/transformative

Milte, R., Shulver, W., Killington, M., Bradley, C., Ratcliffe, J., & Crotty, M. (2016). Quality in residential care from the perspective of people living with dementia: The importance of personhood. *Archives of Gerontology and Geriatrics*, *63*, 9–17. https://doi.org/10.1016/j.archger.2015.11.007

Ministry of Health and Care Services. (2008). *Act on medical and healthcare research* (LOV-2008-06-20-44). https://lovdata.no/dokument/NL/lov/2008-06-20-44

Ministry of Health and Care Services. (2011). *Ordinance for a dignified care of the elderly.* (FOR-2010-11-12-1426). https://lovdata.no/dokument/SF/forskrift/2010-11-12-1426

Mjørud, M., Engedal, K., Røsvik, J., & Kirkevold, M. (2017). Living with dementia in a nursing home, as described by persons with dementia: A phenomenological hermeneutic study. *BMC Health Services Research*, *17*(1), 93. https://doi.org/10.1186/s12913-017-2053-2

Mondaca, M., Josephsson, S., Katz, A., & Rosenberg, L. (2018). Influencing everyday activities in a nursing home setting: A call for ethical and responsive engagement. *Nursing Inquiry*, *25*(2), e12217. https://doi.org/10.1111/nin.12217

Morgan-Brown, M., & Brangan, J. (2016). Capturing interactive occupation and social engagement in a residential dementia and mental health setting using quantitative and narrative data. *Geriatrics*, *1*(3), 15. https://doi.org/10.3390/geriatrics1030015

Morgan-Brown, M., Brangan, J., McMahon, R., & Murphy, B. (2019). Engagement and social interaction in dementia care settings: A call for occupational and social justice. *Health & Social Care in the Community*, *27*(2), 400–408. https://doi.org/10.1111/hsc.12658

Nedlund, A.-C., Bartlett, R., & Clarke, C. L. (2019a). Everyday citizenship: A way to broaden our view of life with dementia. In A.-C. Nedlund, R. Bartlett, & C. L. Clarke (Eds.) *Everyday citizenship and people with dementia* (pp. 1–12). Dunedin.

Nedlund, A.-C., Bartlett, R., & Clarke, C. L. (2019b). Recognising everyday citizenship and dementia: What is known and what more needs to be done. In A.-C. Nedlund, R. Bartlett, & C. L. Clarke (Eds.) *Everyday citizenship and people with dementia* (pp. 91–95). Dunedin.

Nedlund, A.-C., & Bartlett, R. (2017). Citizenship in-and-as-practice: A framework for improving life with dementia. In L.-C. Hydén & E. Antelius (Eds.), *Living with dementia: Relations, responses and agency in everyday life* (pp. 49–67). Palgrave MacMillan.

Neveu, C. (2014). Practicing citizenship from the ordinary to the activist. In E. Isin & P. Nyers (Eds). *Routledge handbook of global citizenship studies* (pp. 86–95). Taylor and Francis. https://doi.org/10.4324/9780203102015

Norwegian Central Statistical Office. (2022). *Sjukeheimar, heimetenester of andre omsorgstenester* [Nursing homes, home services and other care services]. https://www.ssb.no/helse/helsetjenester/statistikk/sjukeheimar-heimetenester-og-andre-omsorgstenester

Norwegian Directorate of Health. (2017). *National guidelines for dementia*. https://www.helsedirektoratet.no/retningslinjer/demens

Norwegian Directorate of Health (2021). *Quality health- and careservices for people with developmental disability*. https://www.helsedirektoratet.no/veiledere/gode-helse-og-omsorgstjenester-til-personer-med-utviklingshemming

Norwegian Directorate of Health. (2023). *Use of municipal health- and careservices for people with dementia*. https://www.helsedirektoratet.no/rapporter/bruk-av-kommunale-helse-og-omsorgstjenester-blant-personer-med-demens

Norwegian Ministry of Health and Care Services. (2015). *Dementia plan 2020*. https://www.regjeringen.no/contentassets/3bbec72c19a04af88fa78ffb02a203da/dementia_-plan_2020_long.pdf

Norwegian Equality and Anti-Discrimination Act. (2017). *Act relating to equality and a prohibition against discrimination* (LOV-2017-06-16-01). https://lovdata.no/dokument/NL/lov/2017-06-16-51

Norwegian Ministry of Health and Care Services. (2020). *Dementia plan 2025*. https://www.regjeringen.no/contentassets/b3ab825ce67f4d73bd24010e1fc05260/demensplan-2025.pdf

Norwegian National Research Ethics Committees. (2021). *Guidelines for research ethics in the social sciences and the humanities*. https://www.forskningsetikk.no/en/guidelines/social-sciences-humanities-law-and-theology/guidelines-for-research-ethics-in-the-social-sciences-humanities-law-and-theology/

Norwegian Regional Ethics Committee. (2014). *Regionale komiteer for medisinsk og helsefaglig forskning.* https://rekportalen.no/#hjem/home

NOU (2023:4). Time for action—staff in a sustainable health- and care service. https://www.regjeringen.no/no/dokumenter/nou-2023-4/id2961552/

Nygård, L. (2006). How can we get access to the experiences of people with dementia? Suggestions and reflections. *Scandinavian Journal of Occupational Therapy*, *13*(2), 101–112. https://doi.org/10.1080/11038120600723190

O'Connor, D., & Nedlund, A. C. (2016). Editorial introduction: Special issue on citizenship and dementia. *Dementia, 15*(3), 285–288. https://doi.org/10.1177/1471301216647150

O'Connor, D., Sakamoto, M., Seetharaman, K., Chaudhury, H., & Phinney, A. (2022). Conceptualizing citizenship in dementia: A scoping review of the literature. *Dementia*, *21*(7), 2310–2350. https://doi.org/10.1177/14713012221111014

O'Reilly, K. (2009). *Key concepts in ethnography*. Sage.

O'Rourke, H. M., Duggleby, W., Fraser, K. D., & Jerke, L. (2015). Factors that affect quality of life from the perspective of people with dementia: A metasynthesis. *Journal of the American Geriatrics Society*, *63*(1), 24–38. https://doi.org/10.1111/jgs.13178

Patient and User Rights Act. (1999). *Act on patient and user rights* (LOV-1999-07-02). https://lovdata.no/dokument/NL/lov/1999-07-02-63

Peoples, H., Varming, J., & Kristensen, H. K. (2023), Social citizenship when living with dementia: A qualitative meta-study. *Journal of Occupational Science*, *30*(3), 453–471. https://doi.org/10.1080/14427591.2022.2061040

Persson, T., & Wästerfors, D. (2009). "Such trivial matters": How staff account for restrictions of residents' influence in nursing homes. *Journal of Aging Studies, 23*(1). https://doi.org/10.1016/j.jaging.2007.09.005

Phillipson, L., & Hammond, A. (2018). More than talking: A scoping review of innovative approaches to qualitative research involving people with dementia. *International Journal of Qualitative Methods*, *17*(1). https://doi.org/10.1177/1609406918782784

Pinnegar, S., & Daynes, G. J. (2006). Locating narrative inquiry historically: Thematics in the turn to narrative. In J. Clandinin (Ed.), *Handbook of narrative inquiry: Mapping a methodology* (pp. 3–34). Sage. https://doi.org/10.4135/9781452226552

Poland, F., & Birt, L (2016). The agentic person: Shifting the focus of care, *Aging & Mental Health*, *20*(8), 771–772. https://doi.org/10.1080/13607863.2016.1146873

Poland, F., & Birt, L. (2018). Protecting and empowering research with the vulnerable older person. In R. Iphofen & M. Tolich (Eds.), *The SAGE handbook of qualitative research ethics* (pp. 1–22). Sage. https://doi.org/10.4135/9781526435446

Polkinghorne, D. E. (1995). Narrative configuration in qualitative analysis. In J. A. Hatch & R. Wisniewski (Eds.), *Life history and narrative* (pp. 5–23). Falmer Press.

Polkinghorne, D. E. (2007). Validity issues in narrative research. *Qualitative Inquiry*, *13*(4), 471–486. https://doi.org/10.1177/1077800406297670

Representative for Equality and Discrimination. (2015). *Ombudets rapport til FNs komité for rettighetene til mennesker med nedsatt funksjonsevne – et supplement til Norges første periodiske rapport* [Report from the representative for equality and discrimination to the UN Committee on the rights of persons with disabilities—a supplement to Norway's first periodic report]. https://www.ldo.no/globalassets/03_nyheter-og-fag/publikasjoner/crpd2015rapport.pdf

Robertson, J. M., & McCall, V. (2020). Facilitating creativity in dementia care: The co-construction of arts-based engagement. *Ageing and Society, 40*(6), 1155–1174. https://doi.org/10.1017/S0144686X18001575

Rokstad, A. M. M. (2014). *Se hvem jeg er! Personsentrert omsorg ved demens* [Look who I am! Person-centred care in dementia]. Universitetsforlaget.

Sandvoll, A. M., Hjertenes, A.-M., & Board, M. (2020). Perspectives on activities in nursing homes. *International Practice Development Journal*, *10*(Suppl). https://doi.org/10.19043/ipdj.10Suppl.006

Scott, S. (2009). *Making sense of everyday life*. Polity Press.

Shell, L. (2014). Photo-elicitation with autodriving in research with individuals with mild to moderate Alzheimer's disease: Advantages and challenges. *International Journal of Qualitative Methods, 13*(1), 170–184. https://doi.org/10.1177/160940691401300106

Silva, O., Cascio, M., & Racine, E. (2020). Person-oriented research ethics and dementia: The lack of consensus. *Anthropology & Aging*, *41*(1), 31–51. https://doi.org/10.5195/aa.2020.211

Simpson, P., Wilson, C. B., Brown, L. J. E., Dickinson, T., & Horne, M. (2018). "We've had our sex life way back": Older care home residents, sexuality and intimacy. *Ageing & Society, 38*(7), 1478–1501. https://doi.org/10.1017/S0144686X17000101

Smebye, K. L., & Kirkevold, M. (2013). The influence of relationships on personhood in dementia care: A qualitative, hermeneutic study. *BMC Nursing*, *12*(1), 29. https://doi.org/10.1186/1472-6955-12-29

Squire, A., Andrews, M., & Tamboukou, M. (2013). Introduction: What is narrative research? In M. Andrews, C. Squire, & M. Tamboukou (Eds.), *Doing narrative research* (pp. 1–26). Sage.

Stafford, P. B. (2003a). Introduction. In P. B. Stafford (Ed.), *Grey areas: Ethnographic encounters with nursing home culture* (pp. 3–22). School of American Research Press.

Stafford, P. B. (2003b). Homebodies: Voices of place in a northern American community. In P. B. Stafford (Ed.), *Grey areas: Ethnographic encounters with nursing home culture* (pp. 121–151). School of American Research Press.

Stanley, M., & Nayar, S. (2015). Deepening understandings. In S. Nayar & M. Stanley (Eds.), *Qualitative research methodologies for occupational science and therapy* (pp. 8–20). Routledge.

Steele, L., Carr, R., Swaffer, K., Phillipson, L., & Fleming, R. (2020). Human rights and the confinement of people living with dementia in care homes. *Health and Human Rights*, *22*(1), 7–19.

Strandenæs, M.G., Lund, A., & Rokstad, A.M.M. (2019). Facilitation of activities for people with dementia in day care: A qualitative study exploring the experiences of staff. *Journal of Multidisciplinary Healthcare*, *3*(12), 503-513.

Sudmann, T. T. (2017). *Aktivitet og fellesskap for eldre* [Activity and community for the elderly] (Report no. 06/2017). Senter for omsorgsforskning, vest. https://www.regjeringen.no/globalassets/departementene/hod/fellesdok/leveheleliv et/kunnskapsoppsummering/delrapport2_aktivitet_fellesskap_141117.pdf

Swaffer, K. (2015). Dementia and prescribed dis-engagement. *Dementia*, *14*(1), 3–6. https://doi.org/10.1177/1471301214548136

Taylor, L., & Wilson, F. (2004). The messiness of everyday life: Exploring key themes in Latin American citizenship studies. Introduction. *Bulletin of Latin American Research*, 23(2), 154–64.

The CRPD-coalition (2019). *Alternativ rapport til FN-komiteen for rettighetene til mennesker med nedsatt funksjonsevne. Første CRPD-rapportering fra sivilt samfunn i Norge* [Alternative report to the UN-Committee on the rights of persons with disabilities. The first CRPD-report from civil society in Norway]. https://ffo.no/globalassets/rapporter/210x260_alternativrapporten-norsk.enkels.pdf

United Nations. (1948). The universal declaration of human rights (UDHR). New York.

United Nations. (2006). *Convention on the rights of persons with disabilities*. New York.

Ursin, G (2017). Praktisering av medborgerskap: En studie av hverdagslivet til familier som lever med demens. *Norsk sosiologisk tidsskrift*, *1*(6), 436–452. https://doi.org/10.18261/issn.2535-2512-2017-06-02

Ursin, G., & Lotherington, A. T. (2018). Citizenship as distributed achievement: Shaping new conditions for an everyday life with dementia. *Scandinavian Journal of Disability Research*, *20*(1), 62–71. https://doi.org/10.16993/sjdr.35

Van Steenwinkel, I., Dierckx de Casterlé, B., & Heylighen, A. (2017). How architectural design affords experiences of freedom in residential care for older people. *Journal of Aging Studies*, *41*, 84-92.

Volpp, L. (2017). Feminist, sexual, and queer citizenship. In A. Shachar, R. Baubõck, I. Bloenraad, & M. Vink (Eds.), *The Oxford handbook of citizenship* (pp. 153–177). Oxford University Press.

Vossius, C., Selbæk, G., Ydstebø, A.E., Benth, J.S., Godager, G., Lurås, H., & Bergh, S. (2015). *Resssursbruk og sykdomsforløp ved demens (REDIC)* [Resource use and disease course in dementia]. Alderspsykiatrisk forskningssenter, Sykehuset Innlandet.

Ward, R., Campbell, S., & Keady, J. (2016). “Gonna make yer gorgeous”: Everyday transformation, resistance and belonging in the care-based hair salon. *Dementia, 15*(3), 395–413. https://doi.org/10.1177/1471301216638969

West, E., Stuckelberger, A., Pautex, S., Staaks, J., & Gysels, M. (2017). Operationalising ethical challenges in dementia research-a systematic review of current evidence. *Age and Ageing*, 46(4), 678–687. https://doi.org/10.1093/ageing/afw250

World Health Organization. (2017). *Global action plan on the public health response to dementia 2017-2025.* World Health Organization. https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017---2025

Wilcock, A. A., & Hocking, C. (2015). *An occupational perspective of health*. Slack Incorporated.

Wolverson, E., Birtles, H., Moniz-Cook, E., James, I., Brooker, D., & Duffy, F. (2019). Naming and framing the behavioural and psychological symptoms of dementia (BPSD) paradigm: Professional stakeholder perspectives. *OBM Geriatrics*, *3*(4), 080. https://doi.org/10.21926/obm.geriatr.1904080

Wolverson, E., Dunn, R., Moniz-Cook, E., Gove, D., & Diaz-Ponce, A. (2021). The language of behaviour changes in dementia: A mixed methods survey exploring the perspectives of people with dementia. *Journal of Advanced Nursing*, *77*(4), 1992–2001. https://doi.org/10.1111/jan.14787

Wright-St Clair, V. (2015). Doing (interpretive) phenomenology. In S. Nayar & M. Stanley (Eds.), *Qualitative research methodologies for occupational science and therapy* (pp. 53–69). Routledge.

APPENDIXES

Appendix 1: Themes for individual interviews

Introduction:

- Questions related to the person's roles and responsibilities in the nursing home.
- Initial questions about the person's experience of nursing home life (e.g., a typical day).

Everyday life, activities and participation:

- Questions about routines, the social environment and activities in everyday life and questions about activity programmes (e.g., access to the outdoors, physical activities, spontaneous activities and communication, music, participation in daily chores etc.).
- Questions about the organisation of meals.
- Questions about residents' participation in life outside the nursing home.
- Questions about challenges (residents' motivation for activities, difficulties expressing wishes, sensitivity to stimuli, social environment and social interactions).

Self-determination and dementia:

- Questions about residents' opportunities and capabilities for choice and for influencing routines in the nursing home.
- Questions about balancing self-determination and safety.
- Questions about how residents are informed about issues related to their health, important events, routines, menus, activities etc.
- Questions about residents wanting to go home or not understanding where they are.
- Questions about the units being open or locked and about risk.
- Questions about staff presence in the common areas.
- Questions about behaviour experienced as challenging and the use of force.

Structures and organisation:

- Questions about staffing and access to support staff/functions.
- Questions about balancing medical responsibilities and a focus on activities and social engagement.
- Questions about routines for documentations and procedures.

Conclusion:

- Open questions allowing the person to add to what has already been said or elaborate on what they think is important to create conditions for a good life in the nursing home.

Appendix 2: Themes discussed in group interviews

- Discussions about staff's experiences of having a researcher in the nursing home unit.
- Discussions about balancing the need for activities and calm.
- Discussions about how to identify residents' needs for activities and social engagement, and residents' opportunities for choice.
- Discussions about residents initiating engagement, e.g., engaging in chores and taking on responsibilities.
- Discussions about what staff perceive as important for a meaningful life in the nursing home and creating a home in the nursing home.
- Discussions about engaging within the safety of the nursing home unit and taking part in life outside the nursing home.
- Discussion about what staff perceives as important for them to experience their work as meaningful.

Appendix 3: Assessment from Regional Ethics Committee (REK)

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Knut W. Ruyter	22845518	17.09.2018	2018/1324/REK sør-øst A
			Deres dato:	**Deres referanse:**
			12.06.2018	

Vår referanse må oppgis ved alle henvendelser

Kirsten Jæger Fjetland
VID vitenskapelige høgskole

2018/1324 Medborgerskap i sykehjem - En studie om medborgerskap gjennom hverdagsaktiviteter for personer med demens

Forskningsansvarlig: VID vitenskapelige høgskole
Prosjektleder: Kirsten Jæger Fjetland

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst) i møtet 23.08.2018. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10.

Prosjektbeskrivelse (revidert av REK)

Studiens problemstilling: Hva kjennetegner medborgerskapspraksis for personer med demens i sykehjem? Medborgerskap knyttes til hvordan beboere kan delta aktivt i meningsfulle aktiviteter, og ta egne valg pa viktige livsomrader. Studiens mål er 1) å produsere kunnskap om hvordan medborgerskap realiseres gjennom hverdagsaktiviteter, og 2) beskrive institusjonelle rammer, maktstrukturer og samhandlingsrelasjoner som pavirker dette. Etnografisk metode anvendes for a undersøke medborgerskap i 2-3 demensavdelinger. Hverdagen pavirkes samtidig av institusjonelle krefter som kan være vanskelig a identifisere. Metoder inspirert av institusjonell etnografi anvendes for å utforske hvordan disse pavirker medborgerskap i avdelingene. Prosjektmedarbeider vil være til stede 1-2 dager per uke i avdelingene over en periode pa 2-6 maneder. Primære metoder for datainnsamling er deltakende observasjon, intervju med beboere, parørende, ansatte og ledere, samt analyse av relevant skriftlig material.

Vurdering

Komiteen mener at prosjektet klart faller utenfor REKs virkeområde, i tråd med den fremleggelsesvurdering som allerede er avgitt (2018/1290).

Komiteen har imidlertid vurdert behovet for å gi dispensasjon fra taushetplikt for annen forskning. Dette innvilges da prosjektet anses forsvarlig å gjennomføre, samt at data innsamles, oppbevares og benyttes på en sikker måte.

Vedtak

Med hjemmel i helsepersonelloven § 29 første ledd, jf. forskrift «Delegering av myndighet til den regionale komiteen for medisinsk og helsefaglig forskningsetikk etter helsepersonelloven § 29 første ledd og forvaltningsloven § 13d første ledd» har komiteen besluttet å gi fritak fra lovpålagt taushetsplikt.

Godkjenningen gjelder til 31.12.2022.

Av dokumentasjonshensyn skal opplysningene oppbevares i 5 år etter prosjektslutt. Opplysningene skal oppbevares avidentifisert, dvs. atskilt i en nøkkel- og en datafil. Opplysningene skal deretter slettes eller anonymiseres.

Prosjektet skal sende sluttmelding på eget skjema, jf. helseforskningsloven § 12, senest et halvt år etter prosjektslutt.

Dersom det skal gjøres endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende endringsmelding til REK, jf. helseforskningsloven § 11.

Klageadgang

REKs vedtak kan påklages, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst A. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst A, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Knut Engedal
Professor dr. med.
Leder

Knut W. Ruyter
Avdelingsdirektør

Kopi til:bard.maland@vid.no; VID vitenskapelige høgskole ved øverste administrative ledelse: post@vid.no

Appendix 4: Assessment from Norwegian Centre for Research Data (NSD)

VID vitenskapelig høgskole
Marianne Sund
marianne.sund@vid.no

Vår dato: 21.01.2019 Vår ref: 60972/AMS/LR Deres dato: Deres ref:

VURDERING AV BEHANDLING AV ALMINNELIGE KATEGORIER AV PERSONOPPLYSNINGER OG SÆRLIGE KATEGORIER AV PERSONOPPLYSNINGER I PROSJEKTET: MEDBORGERSKAP I SYKEHJEM - EN STUDIE OM MEDBORGERSKAP GJENNOM HVERDAGSAKTIVITETER FOR PERSONER MED DEMENS

NSD - Norsk senter for forskningsdata AS viser til meldeskjema innsendt 01.06.2018. Meldingen gjelder behandling av personopplysninger til forskningsformål. NSD beklager lang vurderingstid. Dette skyldes stor pågang av saker og overgang til nytt lovverk. Siste avklaringer kom fra REK 19.09.2018 og fra forsker 09.01.2019.

Etter avtale med den behandlingsansvarlige, VID vitenskapelig høgskole, har NSD foretatt en vurdering av om den planlagte behandlingen er i samsvar med personvernlovgivningen.

Resultat av NSDs vurdering:

NSD vurderer at det vil bli behandlet alminnelige kategorier av personopplysninger og særlige kategorier av personopplysninger om helseforhold i dette prosjektet frem til 31.12.2022.

NSDs vurdering er at behandlingen vil være i samsvar med personvernlovgivingen, og at lovlig grunnlag for behandlingen er samtykke og allmenn interesse.

Vår vurdering forutsetter at prosjektansvarlig behandler personopplysninger i tråd med:
- opplysninger gitt i meldeskjema og øvrig dokumentasjon
- dialog med NSD, og vår vurdering (se under)
- VID vitenskapelig høgskole sine retningslinjer for datasikkerhet, herunder regler om hvilke tekniske hjelpemidler det er tillatt å bruke

Nærmere begrunnelse for NSDs vurdering:

1. Beskrivelse av den planlagte behandlingen av personopplysninger

Formål
Studien søker å besvare problemstillingen; Hva kjennetegner medborgerskapspraksis for personer med demens som bor i sykehjem? Medborgerskap innebærer at mennesker har muligheter til å utøve rettigheter og plikter, opprettholde personlig integritet, valgfrihet og deltakelse. Studien fokuserer på mikro-medborgerskap, som handler om å muliggjøre deltakelse i sykehjems

hverdagen, og involvere personer med demens i daglige gjøremål som oppleves personlig meningsfulle. Studiens mål er å 1) produsere kunnskap om hvordan medborgerskap realiseres gjennom hverdagsaktiviteter i sykehjem, og 2) beskrive institusjonelle rammer, maktstrukturer og samhandlingsrelasjoner som påvirker realisering av medborgerskap.

Metode
Gjennom etnografisk feltmetode søker en innsikt i hverdagslivet i sykehjemsavdelingene. Det er derfor behov for anvendelse av flere metoder, herunder observasjon ved hjelp av Dementia Care Mapping, deltakende observasjon, samtaler/intervjuer, gruppeintervju og analyse av skriftlig materiale (informasjon som ikke er unntatt offentlighet, som omfatter for eksempel rutiner, prosedyrer, lovverk etc).

Andre vurderinger
REK har vurdert at prosjektet ikke er omfattet av bestemmelsene i Helseforskningsloven, men har vurdert at forsker har behov for dispensasjon fra taushetsplikten for å gjennomføre feltarbeid på sykehjem. Dette er gitt i vedtak 2018/1324/REK sør-øst A. Godkjenningen gjelder til 31.12.2022.

Personvernprinsipper
NSDs vurdering er at behandlingen følger personvernprinsippene, ved at personopplysninger;

- skal behandles på en lovlig, rettferdig og åpen måte med hensyn til den registrerte
- skal samles inn for spesifikke, uttrykkelig angitte og berettigede formål og der personopplysningene ikke viderebehandles på en måte som er uforenelig med formålet
- vil være adekvate, relevante og begrenset til det som er nødvendig for formålet de behandles for
- skal lagres slik måte at det ikke er mulig å identifisere de registrerte lengre enn det som er nødvendig for formålet

2. Lovlig grunnlag for å behandle alminnelige og særlige kategorier personopplysninger

Behandlingen kan finne sted med hjemmel i personvernforordningen art. 6.1 a), art. 9.2 a)

NSD vurderer at den planlagte behandlingen av personopplysninger er lovlig fordi det skal innhentes samtykke fra de registrerte/fra pårørende. Samtykke innhentes ved at deltakere/pårørende signerer på samtykkeskjema i papirform.

NSD vurderer at den planlagte behandlingen av personopplysninger er lovlig fordi:

- det skal innhentes uttrykkelig samtykke fra de registrerte og
- forsker har oppfylt den særskilte rådføringsplikten

Samtykke innhentes ved at deltakerne signerer på samtykkeskjema i papirform.

Det behandles samtidig opplysninger om personer uten samtykkekompetanse.

NSD vurderer at den planlagte behandling av personopplysninger er lovlig fordi:

- det er nødvendig for å utføre en oppgave i allmennhetens interesse
- formålet er knyttet til vitenskapelig forskning.
- samfunnets interesse i at behandlingen finner sted klart overstiger ulempene for den enkelte

- det iverksettes nødvendige tiltak (garantier) for å sikre de registrertes rettigheter og friheter
- forsker har oppfylt den særskilte rådføringsplikten

Det anses som nødvendig å inkludere personer med redusert eller manglende samtykkekompetanse i prosjektet siden deres perspektiv på demens mangler i forskning og media. Formålet med prosjektet er å bidra til livskvaliteten for personer med demens og å gi bedre forståelse for dem og deres tilstand. Det er derfor avgjørende at de er inkludert og at stemmene deres blir hørt.

Det anses ikke som potensielt belastende å delta i prosjektet. Det opplyses at vedkommende vil motta tilpasset informasjon om hva deltakelse innebærer. Samtykkekompetansen skal vurderes av helsepersonell som kjenner vedkommende godt sammen med nærmeste pårørende. Dersom det vurderes at samtykkekompetansen er manglende, vil vedkommende uansett få tilpasset informasjon om prosjektet. Hvis vedkommende gir uttrykk for ubehag eller vegrer seg for å delta, vil de ikke inkluderes i prosjektet. Det skal innhentes samtykke fra pårørende for å redusere personvernulempen.

Det vurderes at den valgte fremgangsmåten for inklusjon av personer uten samtykkekompetanse, bidrar i betydelig grad til å redusere personvernulempen ved deltakelse. Det vurderes videre at opplysningene vil kunne komme gruppen som helhet til gode.

3. De registrertes rettigheter

For den samtykkebaserte delen av prosjektet vurderer NSD at de registrerte har krav på å benytte seg av sin rett til informasjon, innsyn, retting og sletting av personopplysninger, begrensning og dataportabilitet.

De registrerte kan utøve sine rettigheter ved å ta kontakt med prosjektansvarlig.

NSD finner at informasjonsskrivene datert vil gi de registrerte og pårørende, tilstrekkelig informasjon om hvilke rettigheter deltakerne har. Informasjonsskrivene vil gi god informasjon om hva deltakelse innebærer og hvilke personopplysninger vil behandles.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har VID vitenskapelig høgskole plikt til å svare innen en måned. Vi forutsetter at prosjektansvarlig informerer institusjonen så fort som mulig og at institusjonen har rutiner for hvordan henvendelser fra registrerte skal følges opp.

4. Informasjonssikkerhet

Datamaterialet vil bestå av lydopptak og transkripsjoner fra intervjuer og notater fra deltakende observasjon. Direkte personidentifiserende opplysninger skal behandles separat fra det øvrige datamaterialet.

Stipendiaten har veileder ved OsloMet som også skal ha tilgang til datamaterialet. NSD anbefaler at datamaterialet overføres kryptert mellom institusjonene eller at veileder får tilgang ved VID vitenskapelige høgskole.

NSD forutsetter at personopplysningene behandles i tråd med personvernforordningens krav og institusjonens retningslinjer for informasjonssikkerhet. Forsker har redegjort for hvordan behandlingen skal skje i tråd med retningslinjene i e-post mottatt 09.01.2019. NSD har ingen innvendinger til den planlagte behandlingen.

5. Varighet

Ifølge meldeskjema skal personopplysninger behandles som en del av dette prosjektet frem til 31.12.2022.

Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan bli identifisert. Det gjøres ved å:
- Slette navn og kontaktopplysninger
- Slette eller grovkategorisere bosted og andre bakgrunnsopplysninger
- Slette eller sladde bilder, videopptak og lydopptak

VID vitenskapelige høgskole må kunne dokumentere at datamaterialet er anonymisert.

Meld fra om endringer
Dersom behandlingen av personopplysninger endrer seg, kan det være nødvending å melde dette til NSD via Min side. På våre nettsider informerer vi om hvilke endringer som må meldes. Vent på svar før endringen gjennomføres.

Informasjon om behandlingen publiseres på Meldingsarkivet og nettsider
Alle relevante saksopplysninger og dokumenter er tilgjengelig:
- via Meldingsarkivet for ansatte med internkontrolloppgaver ved VID vitenskapelige høgskole.

NSD tar kontakt om status for behandling av personopplysninger
Etter avtale med VID vitenskapelige høgskole vil NSD følge opp behandlingen av personopplysninger underveis ved planlagt avslutning og annet hvert år frem til 31.12.2022.

Vi sender da en skriftlig henvendelse til prosjektansvarlig og ber om skriftlig svar på status for behandling av personopplysninger.

Se våre nettsider eller ta kontakt ved spørsmål. Vi ønsker lykke til med prosjektet.

Med vennlig hilsen

Ida J. Jondahl
Ida Jansen Jondahl
seksjonsleder

Anne-Mette Somby
spesialrådgiver
for Anne-Mette Somby
Øivin L Straume

Appendix 5: Information letter and consent form

Vil du delta i forskningsprosjektet

”Medborgerskap i sykehjem – en studie om medborgerskap gjennom hverdagsaktiviteter for personer med demens”?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å øke kunnskap om hverdagslivet for personer med demens som bor i sykehjem. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

Formål

Prosjektet skal undersøke hvordan medborgerskap realiseres gjennom hverdagsaktiviteter i demensavdeling i sykehjem, og hvordan institusjonens rammer og strukturer påvirker dette. Ved medborgerskap menes blant annet hvordan den enkelte beboer gis mulighet til å delta aktivt i hverdagslivets aktiviteter, gjennom selvbestemmelse og mulighet til å ta egne valg på viktige livsområder. Prosjektet er et doktorgradsstudium, og innebærer at det skal gjennomføres en feltstudie i 3 sykehjemsavdelinger for personer med demens. Feltarbeidet innebærer at prosjektansvarlig Marianne Sund er til stede som deltakende observatør i hver avdeling over en periode på omtrent 1-1 ½ måned, der hun også vil ha samtaler og intervjuer med beboere, pårørende, ansatte og ledere.

Hvem er ansvarlig for forskningsprosjektet?

Marianne Sund er prosjektleder for studien. Ansvarlig institusjon er VID vitenskapelige høgskole.

Hvorfor får du spørsmål om å delta?

Du forespørres om deltakelse fordi du enten er beboer, nærmeste pårørende eller ansatt/leder ved demensavdeling hos noen utvalgte sykehjem. Sykehjemmene som forespørres om deltakelse identifiseres gjennom kontakt med ledelse i et utvalg kommuner i Sør-Rogaland.

Hva innebærer det for deg å delta?

- Marianne Sund skal være deltakende observatør i sykehjemsavdelingen over en periode på omtrent 1-1 ½ måned. Hun vil være til stede 2-4 dager i uken gjennom perioden, etter avtale med avdelingen. I denne perioden vil du kunne treffe Marianne i avdelingen og snakke med henne dersom du ønsker. Hun vil særlig være opptatt av hvordan hverdagslivet i avdelingen leves og oppleves av beboere, ansatte, pårørende og ledere. Hun ønsker å bruke tid til å bli kjent med dere, og lære ***av*** dere som kjenner sykehjemshverdagen best. Hun skriver egne notater fra observasjonene. Noen personer kan bli spurt om Marianne kan få lov til å følge dem gjennom en dag eller ved spesielle aktiviteter eller hendelser. Dette vil være helt frivillig.
- Underveis i perioden vil noen personer bli spurt om å delta i intervju, og hver person står fritt til å velge om de ønsker å bli intervjuet. Intervjuene vil vare mellom ½-1 ½ time, og det tas lydopptak som deretter skrives direkte ned og anonymiseres.
- I etterkant av observasjonsperioden vil noen personer kunne bli spurt om å delta i gruppeintervju. Hver person står fritt til å velge om de ønsker å delta. Gruppeintervjuene vil vare omtrent 1-1 ½ time, og det tas lydopptak som deretter skrives direkte ned og anonymiseres.

Det er frivillig å delta

Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger
Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket.

Det er kun jeg (Marianne Sund) og mine veiledere i doktorgradsstudiet, Kirsten Jæger Fjetland og Halvor Hanisch, som vil ha tilgang til opplysningene om deg. Navn og kontaktopplysninger vil jeg erstatte med en kode som lagres nedlåst på egen navneliste atskilt fra øvrige data. Lydopptak og andre data som er gjenkjennbart vil lagres kryptert på ekstern harddisk og oppbevares nedlåst. Det utarbeides en doktorgradsavhandling og vitenskapelige artikler på bakgrunn av informasjonen som er innhentet. Artikler publiseres i internasjonale tidsskrifter. Opplysningene anonymiseres slik at du ikke kan gjenkjennes i publikasjoner.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?
Prosjektet skal etter planen avsluttes 31.12.22. All informasjon om deg anonymiseres ved prosjektslutt, og lydopptak og personopplysninger slettes.

Dine rettigheter
Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?
Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra VID vitenskapelige høgskole har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Hvor kan jeg finne ut mer?
Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- VID vitenskapelige høgskole ved;
    - Prosjektansvarlig Marianne Sund. Tlf: 416 98 647. E-mail: marianne.sund@vid.no
      eller
    - Veileder Kirsten Jæger Fjetland. Tlf: 51972242. E-mail: kirsten.jaeger.fjetland@vid.no
- Vårt personvernombud: Nancy Yue Liu. Tlf: 938 56 277. E-mail: nancy.yue.liu@diakonhjemmet.no
- NSD – Norsk senter for forskningsdata AS, på epost (personverntjenester@nsd.no) eller telefon: 55 58 21 17.

Med vennlig hilsen

Marianne Sund (prosjektansvarlig) og Kirsten Jæger Fjetland (veileder)

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet «Medborgerskap i sykehjem», og har fått anledning til å stille spørsmål. Jeg samtykker til:

- ☐ at det gjennomføres deltakende observasjon i avdelingen
- ☐ å delta i individuelt intervju
- ☐ å delta i gruppeintervju

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, ca. 31.12.22

(Signert av prosjektdeltaker, dato)

Stedfortredende samtykke:

I de tilfeller der en beboer grunnet demens vurderes til å ha redusert eller manglende samtykke til og forstå hva samtykket innebærer, og deltakelse vurderes til å være i samsvar med personens ønsker og interesser, kan nærmeste pårørende samtykke på vegne av personen.

Som nærmeste pårørende til _ (Fullt navn) samtykker jeg til at hun/han kan delta i prosjektet.

Sted og dato   Pårørendes signatur

Pårørendes navn med trykte bokstaver

Appendix 6: Easy-to-read information letter

Informasjon om forskningsprosjekt i avdelingen der du bor

Jeg heter Marianne Sund. Jeg er ergoterapeut og doktorgradsstudent. Jeg ønsker å lære mer om hvordan hverdagen er i avdelingen der du bor. I dette brevet vil jeg fortelle litt mer om hva dette innebærer, slik at du har mulighet til selv å velge om du ønsker å være med.	

Hva skal jeg studere?
Jeg ønsker å lære mer om noe som kalles medborgerskap. Det handler om;

- Hvordan du har mulighet til å delta i aktiviteter du opplever som meningsfulle, og
- Hvordan du har mulighet til å ta egne valg i hverdagen på områder du opplever som viktig.

Målet med dette er at vi sammen kan lære noe som andre også kan ha nytte av å høre om.

Hva skal du gjøre?
Å være med i studien innebærer ikke at du må gjøre noe spesielt, du skal leve hverdagen din akkurat som vanlig. Jeg vil være til stede i avdelingen din noen dager i uken, over et par måneder, for å bli godt kjent med dere. Det kan hende jeg spør deg om du ønsker å snakke med meg om hvordan du opplever hverdagen, men dette velger du helt selv. Jeg ønsker å se hvordan hverdagen er og snakke med både deg og andre om hvordan dere opplever hverdagen.

Taushetsplikt og samtykke
Jeg skal skrive artikler som gis ut slik at andre også kan få nytte av kunnskapen. Ingen vil kunne vite hva du har fortalt meg i samtale. Jeg har taushetsplikt og sørger for at ingen kan kjenne igjen personer eller sted.

Du kan velge selv om du ønsker å delta. Snakk gjerne med noen i familien din eller de som jobber på avdelingen om dette. Hvis du ønsker å vite noe mer kommer jeg gjerne innom for å slå av en prat om det du måtte lure på.

Med vennlig hilsen
Marianne Sund

ARTICLES OF THE THESIS

Article 1 – published:

Sund, M., Hanisch, H., & Fjetland, K. J. (2022). Citizenship for persons with dementia in nursing homes: A literature review. In K. J. Fjetland, A. Gjermestad, & I. M. Lid (Eds.), *Lived citizenship for persons in vulnerable life situations: Theories and practices* (pp. 29–45). Scandinavian University Press. https://doi.org/10.18261/9788215053790-2022-02

Abstract

This literature review explores citizenship conceptualizations and practices for persons with dementia living in nursing homes. Citizenship emerges as a critique of dominant medical and care-based understandings, and seeks to combat discriminatory practices through engagement, participation and upholding societal connections in residents' lives. By viewing these understandings as complementary, we may begin to bridge the gap between residents' apparent needs and their capabilities as citizens.

Article 2 – published:

Sund, M., Jaeger Fjetland, K., & Hanisch, H. (2023). Within moments of *becoming* – Everyday citizenship in nursing homes. *Scandinavian Journal of Occupational Therapy*, *30*(2), 239–250. https://doi.org/10.1080/11038128.2022.2085621

Abstract

Background
Humans are occupational beings. Our occupational choices depend on the opportunities available to us, and within nursing homes, institutional rules or structures may limit occupational engagement. An everyday citizenship lens acknowledges the importance of people's rights as citizens as well as engagement in mundane aspects of the everyday, highlighting diverse expressions of agency.
Aims/objectives
To show how older residents living with dementia in nursing homes can realize their everyday citizenship.
Methods
A phenomenologically inspired ethnographic study was conducted in nursing home units in Norway, exploring everyday citizenship through narrative analysis.
Results
Within everyday environments of care, the narratives of May, Janne and Camilla tell stories of spontaneous initiatives towards contribution and responsibilities, highlighting their continuous occupational natures.
Conclusion
Becoming can be seen as constitutive of self and identity, through residents' actions and contributions within the mundane and ordinary of everyday life, as an essential part of everyday citizenship.
Significance for practice
A citizenship of becoming presupposes that institutional perceptions of activities being offered ought to be broadened towards supporting residents' natural desires to do and act within the mundane and ordinary of everyday life.

Article 3 – published:

Sund, M., Hanisch, H., & Fjetland, K. J. (2023). Activistic citizenship in nursing homes: Co-ownership in the mundane. *Dementia*, *22*(3), 594–609.
https://doi.org/10.1177/14713012231155307

Abstract

The traditional narrative of dementia, focused on cognition as constructive of personhood, has been challenged by person-centred care as well as a rights-based citizenship lens. However, reports of everyday discrimination leading to occupational deprivation and pathologising interpretations of people living with dementia in nursing homes highlight the need for further investigation. The purpose of this study was to investigate the transformative power of mundane and relational enactments of citizenship in nursing homes, exploring the potential of adding an activistic lens of citizenship to our interpretive practices. Through an ethnographic study in Norwegian nursing homes, a narrative analysis of fieldnotes and interview transcripts was conducted. Narratives were interpreted using narrative theory, occupational perspectives and theories of citizenship. Findings reveal a phenomenon of shared ownership between residents and staff, and a vulnerable balance between silence and active social and occupational engagement in the nursing homes. Further, they shed light on how group-based assessments of residents' abilities or occupational needs may constrain opportunities, and staffs' options, to facilitate co-ownership. We suggest that a lens of activistic citizenship implies interpreting residents' behaviours as mundane forms of subtle resistance. A professional and ethical responsibility building on such interpretive practices may turn attention towards structures that constrain residents' expressions of citizenship.