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Åshild Gjellestad

# Care practices at the intersection between resistance and involuntary treatment and care

## A mixed-methods study of how health care professionals approach resistance to care and involuntary treatment among home-dwelling persons with dementia

VID

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## A mixed-methods study of how health care professionals approach resistance to care and involuntary treatment among home-dwelling persons with dementia

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## Content

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I dedicate this to my father. Without him, the idea for me to pursue a doctorate would not have been born.

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## Abstract

**Background:** The number of persons with dementia who live at home is projected to increase in the upcoming years. Most persons with dementia will eventually depend on assistance and support to be able to continue living at home. An increased need for assistance among those who develop dementia is associated with resistance to care. Encountering resistance to care and the use of forced treatment and care is common when working with home-dwelling persons with dementia. Care-related policies, laws and regulations for dementia care, structures for health and care services, and available economic and human resources all influence the care of home-dwelling persons with dementia. Increased expectations for user-involvement and the right to privacy in the home add complexity to challenging situations where nurses encounter resistance to care.

**Purpose of study:** The overall aim for the study was to contribute new knowledge and insight regarding care practices related to resistance to care. It examines how these are assessed and managed at the intersection between ethical, legal, and clinical judgement:

- To gain insights into formal decisions regarding forced treatment and care designed for home-dwelling persons with dementia (Article 1)
- To explore the use of trust-building interventions among home-dwelling persons with dementia who resist care, as described by healthcare professionals in documents regarding decisions related to forced treatment and care (Article 2)
- To explore nurses' professional judgement when encountering resistance to care among home-dwelling persons with dementia (Article 3).

**Methods**: The study employed a mixed-methods research design and applied critical realism theory. For study one, which resulted in the two first Articles, documents containing 108 decisions regarding forced treatment and care were analyzed using descriptive statistical analysis. Further trust-building interventions used in 88 of these decisions were analyzed qualitatively via thematic analysis. In study two (Article 3), 18 registered and licensed practice nurses participated in focus group interviews. The data were analyzed using qualitative thematic analysis. The results were finally combined, contrasted, and compared.

**Results:** 1) We found that care practices dedicated to home-dwelling persons with dementia who aim to avoid forced treatment and care have an emphasis on maintaining trust. Structural trust-building interventions are most frequently used, and relational trust-building is least frequently used. Values of autonomy, self-determination, and integrity appeared to be more illuminated than health risks and vulnerability. There seems to be a lack of communication and mutual understanding between health professionals regarding when risk and vulnerability should be assessed or acted upon among home-dwelling persons with dementia who resist care. Responsibility for the health and care rights of persons with dementia is shared between home health care services, general practitioners, family

members, and the person itself, and accountability seems to be nebulous when these agents encounter resistance to care.

2) There seems to be a misalignment between dementia care policy, legislation, and the structural prerequisites of home health and care services. The strong emphasis on the right to decide among those with dementia may imply that the perceived room for maneuvering relational interventions of the professional caretaker in home and health care practices has become limited. This explains the relatively low frequency but high value of relational interventions. Although forced treatment and care in some situations is justified by law, it is not described as justifiable in clinical nursing practice. The concept of forced treatment and care has a highly negative reputation and does not seem to be recognized as a suitable pretext for the interventions that are used to bypass or manage resistance to care.

## Conclusion and implications for future research:

We found that important factors that influence nursing care practices when encountering resistance to care among home-dwelling persons with dementia include *cultural context,* this encompasses policies related to dementia care and laws, *organizational structural* circumstances, namely structures regarding collaboration, divisions of responsibility and authority, understanding of roles, the presence or absence of relevant *clinical, ethical and legal competence*, and finally respect for the *autonomy and expressed preferences of the person with dementia*. All of these are embedded in professional judgement.

There seem to be contradictory values expressed in policies, regulations and in existing care structures. These include manifestations of the value of self-determination and individual responsibility and the risk of suffering and unmet care needs in nursing care practices. This vulnerability must be accounted for because it can impact the quality and the accessibility of care services for home-dwelling persons with dementia.

We found that coercion, restraint, and forced treatment and care are negatively laden concepts. There is a possibility that forced treatment and care is not documented and that unregulated grey-zone care is performed because the interventions are not recognized as coercion. It is crucial to patient well-being and patient safety that challenges associated with resistance to care among home-dwelling persons with dementia are discussed openly. *Involuntary treatment and care* may be better a concept to employ and “to think with” when conducting research and when communicating about the phenomenon.

There are unattended challenges regarding where family-related moral and legal responsibility ends and where health and care services-related moral and legal responsibilities start. In light of the coming trust reform, we argue that there is a need to illuminate this, especially considering the increased responsibility and expectations that are imposed on family members in future care for persons with

dementia. The moral versus the legal responsibility for home-dwelling persons with dementia should be explored and delineated.

## Sammendrag

**Bakgrunn:** Antall hjemmeboende personer med demens vil øke de kommende årene. De fleste personer med demens blir etterhvert avhengig av assistanse og støtte for å kunne bo hjemme. Økt behov for hjelp er assosiert med motstand hos personer med demens. Det å møte motstand mot helsehjelp og bruk av tvungen helsehjelp er vanlig i omsorg for hjemmeboende personer med demens. Politiske føringer, lover og retningslinjer for demensomsorg, strukturer for helse og omsorgstjenestene, og tilgjengelige økonomiske og menneskelige ressurser påvirker omsorg for hjemmeboende personer med demens. Økte forventninger om brukermedvirkning og retten til privatlivets fred tilfører ytterligere kompleksitet til utfordrende situasjoner der helsepersonell som sykepleiere og helsefagarbeidere møter motstand mot helsehjelp.

**Studiens hensikt:** Den overordnete hensikten med denne studien var å utvikle ny kunnskap og innsikt i omsorgspraksiser relatert til motstand mot helsehjelp og hvordan motstand blir vurdert og behandlet i krysningen mellom etisk, juridisk og klinisk skjønn.

- Innsikt i formelle tvangsvedtak fattet for hjemmeboende personer med demens (Artikkel 1)
- Utforske bruk av tillitsskapende tiltak i hjemmeboende personer med demens i forkant av tvangsvedtak (Artikkel 2)
- Utforske sykepleiere og helsefagarbeideres profesjonelle skjønn i møte med motstand mot helsehjelp fra hjemmeboende personer med demens (Artikkel 3)

**Metode:** Dette var en mixed-method studie, inspirert av kritisk realisme. I Studie 1, som resulterte i de to første artiklene, så brukte vi deskriptive statistiske analyser for å analysere 108 vedtak om tvungen helsehjelp. I 88 av disse vedtakene var tillitsskapende tiltak beskrevet. Disse ble analysert ved kvalitativ tematisk analyse. I Studie 2 (artikkel 3), så deltok 18 sykepleiere og helsefagarbeidere i fokusgruppe og enkeltintervju. Data fra intervjuene ble analysert ved kvalitativ tematisk analyse. Resultatene fra de to studiene ble til slutt kombinert, og ulikheter og likheter ble vurdert.

**Resultat:** 1) Vi fant at omsorgspraksiser til hjemmeboende personer med demens søker å unngå tvang og vektlegger å beholde tillit i relasjonen. Strukturelle tillitsskapende tiltak er oftest brukt, og relasjonelle tillitsskapende er minst brukt. Verdier som autonomi, selvbestemmelse og integritet ser ut til å være mer belyst enn helserisiko og sårbarhet. Det kan synes som om det er mangel på kommunikasjon og gjensidig forståelse mellom helsepersonell for når vurdering og handling relatert til risiko og sårbarhet hos hjemmeboende personer med demens som motsetter seg hjelp bør iverksettes. Ansvaret for helse og omsorgstjenester til hjemmeboende personer med demens er delt mellom hjemmesykepleien, fastlegene, familie og personen det gjelder, men det kan se ut som at forståelsen av hvem som er ansvarlig når personen gjør motstand er uklart.

2) Vi fant at politiske føringer, omsorgsideologier og anvendelse av lovverk kan være i utakt med helse og omsorgstjenestenes eksisterende potensiale. Den sterke vektleggingen av selvbestemmelse for personer med demens kan medføre at det oppfattede handlingsrommet for relasjonelle intervensjoner i demensomsorg er innskrenket. Dette kan være med å forklare den relativt lave frekvensen, men høye uttrykte verdien av relasjonelle tillitsskapende tiltak. Selv om tvungen helsehjelp er rettferdiggjort og hjemlet i lov for noen situasjoner, så er det ikke beskrevet som legitimt i klinisk sykepleiepraksis. Begrepet «tvang eller tvungen helsehjelp», er svært negativt ladet og ser ikke ut til å gjenkjennes som et passende begrep for å beskrive de tiltakene som gjøres for å omgå eller overgå motstand hos hjemmeboende personer med demens.

**Konklusjon og implikasjoner fremtidig forskning:**

Vi fant at faktorer som innvirker på helsepersonell sine møter med motstand mot helsehjelp inkluderer kulturell kontekst som for eksempel politiske og kliniske føringer og lovverk for demensomsorg, organisatorisk strukturelt rammeverk som for eksempel strukturer og system for samarbeid, ansvars og myndighetsfordeling, egen rolleforståelse, nivå av relevant klinisk, etisk, og juridisk sykepleie kompetanse, og endelig respekt for personen med demens autonomi og preferanser. Alt dette utgjør en del av den profesjonell dømmekraften som tas i bruk ved motstand mot helsehjelp.

Det kan se ut som verdier uttrykt i politiske føringer, lover og retningslinjer og i eksisterende omsorgsstrukturer i hjemmesykepleien kan opptre som selvmotsigende. Dette inkluderer den uttrykte verdien av selvbestemmelse og individuelt ansvar og risikoen for lidelse og udekte grunnleggende behov er en slik selvmotsigelse. Vi argumenter for at denne sårbarheten må i større grad tas høyde for, fordi det kan påvirke tilgjengelighet og kvalitet på tjenester til hjemmeboende personer med demens.

Vi fant at tvang, tvungen helsehjelp, helsehjelp med tvang er negativt ladede begrep. Det er en mulighet for at tvang ikke dokumenteres og at uregulert gråsone tvang gjennomføres på grunn av at tiltak for å hjelpe ikke gjenkjennes eller forstås som tvang. Det er avgjørende for kunne ivareta pasienten beste og pasientsikkerhet, at utfordringer som oppleves i møte med motstand til hjelp kan diskuteres åpent. En måte å tilnærme seg dette på er å ha systematiske refleksjoner om hvilke praksiser som kommer til utrykk i møte med motstand. «Ufrivillig behandling og omsorg» kan være et bedre begrep å bruke og «tenke med» både i forskning og i kommunikasjon rundt fenomenet.

Det finnes uavklarte utfordringer med hensyn til familiens rolle i møte med motstand, om hvor deres ansvar tar slutt og når helse og omsorgstjenestenes ansvar skal begynne. I lys av en kommende tillitsreform så kan det argumenteres for at det er behov for at dette bør belyses, spesielt i vurderingen av det økte ansvaret og forventningene som legges på familien i omsorg for personer med demens i fremtidige helsetjenester. Det moralske versus det juridiske ansvar må utforskes og beskrives.

## Original Articles

This thesis is based on the following Articles, which will be referred to in the text by their respective numbers:

1. Gjellestad, Å., Oksholm, T., & Bruvik, F. (2020). Forced treatment and care in home-dwelling persons with dementia. *Nursing Ethics*, https://doi.org/10.1177/0969733020948107

2. Gjellestad, Å., Oksholm, T., Alvsvåg, H., & Bruvik, F. (2022). Trust-building interventions to home-dwelling persons with dementia who resist care. *Nursing Ethics*, https://doi.org/10.1177/09697330211041745.

3. Gjellestad, Å., Oksholm, T., Alvsvåg, H., & Bruvik, F. Autonomy Conquers All: A Thematic Analysis of Nurses' professional judgement encountering Resistance to Care from Home-Dwelling Persons with Dementia. *Under review*. *BMC health services research. Submitted 04.january.2022.*

## List of abbreviations

ADL - Activities of Daily Living

DSM - Diagnostic and Statistical Manual of Mental Disorders

ICD - International Classification of Diseases

WHO - World Health Organization

## Operational definitions

Concepts related to forced treatment and care that are used in this study include; coercion, forced treatment and care, involuntary treatment, involuntary treatment and care, non-consensual care, and (physical) restraint .

The definition of resistance to care used in this study: when a person physically or verbally resists or attempts to avoid treatment or care.

The definition of forced treatment and care used in this study: when healthcare given without consent, i.e. when interventions of treatment and care are deployed despite the resistance of the patient, and/or contrary to the patient's will or knowledge.

The definition of home health and care services used in this study encompasses home nursing and other health care services in the home (Helsenorge, 2022) .

*Definitions of operational concepts*

**Care:** things that are done to keep someone healthy or safe. Selected synonyms include carefulness, closeness, conscientiousness, heed, heedfulness, and scrupulousness. Selected words that are related include advertence, attention, concentration, focus, observation, alertness, mindfulness, vigilance, watchfulness, dutifulness, responsibility, bother, effort particularity, and precision (Care, n.d.).

**Coercion:** the act, process or power of coercing. Selected synonyms include: compulsion, constraint, duress, force, and pressure. Selected words that are related include: fear, intimidation, menace, strength, strain, threat, violence (Coercion, n.d.).

**Decision**: is a written and documented decision that applies to rights and duties for one or several persons pursuant to The Case Management Act. It embeds the right to complain, therefore t is important that it is written and communicated to the person involved (Forvaltningsloven [The Case Managament Act], 1967).

**Force**: power or violence inflicted on a person or thing. Selected synonyms include coerce, compel, constrain, make, obligate, press, and pressure. Selected words that are related include bully, intimidate, high-pressure, menace, threaten, drag, and harass (Force, n.d.).

**Involuntary**: done contrary to or without choice; compulsory. Selected synonyms include coerced, forced, unintended, unintentional, unwilling, and will-less (Involuntary, n.d.).

**Neglect**: to afford minimal attention or respect to; to leave undone or unattended, especially through carelessness when basic physical provisions are lacking. Selected synonyms include disregard, ignore, overlook, and overpass (Neglect, n.d.). The World Law Dictionary defines medical negligence as the failure of a health care provider to do something which a reasonable health care provider would have done under the circumstance and which causes injury or death to the patient (Medical negligence, n.d.).

**Nonconsensual:** not agreed to by one or more of the people involved (Nonconsensual, n.d.).

**Resistance**: refusal to accept something new or different; effort made to stop or to fight against someone or something. Selected synonyms include defiance and opposition. Selected words that are related include disobedience, noncompliance objection, protest, and reservation (Resistance, n.d.).

**Restrain**: to prevent from doing, exhibiting, or expressing something; to limit, restrict, or keep under control; to moderate or limit the force, effect, development, or full exercise of; to deprive of liberty. Selected synonyms include constrain, contain, control, hold, inhibit, keep, regulate, and rule (Restrain, n.d.)

**Trust:** belief that someone or something is reliable, good, honest, and effective**.** Selected synonyms include confide, delegate, entrust, give over, and hand over (Trust, n.d.).

If not otherwise stated, all concepts/words in the section above are found under dictionary and thesaurus with synonym suggestions in the Meriam-Webster online Dictionary.

## Norwegian- English translations

Forhåndssamtaler- Advanced Care Planning (Friis & Førde, 2017)

Fremtidsfullmakt- Enduring power of attorney (Fremtidsfullmakt, n.d.)

Kommunalt pasient- og brukerregister (KPR)- Municipal Patient and User register

Livstestamente - Advanced Care Directive (Friis & Førde, 2017)

Statsforvalteren (Fylkesmannen) - County Governor (Statsforvalteren, 2022)

Vedtak: decision (Vedtak, n.d.)

Vedtak om tvungen helsehjelp (tvangsvedtak) etter kapittel 4A Pasient og brukerettighetsloven–Decision to apply forced treatment and care pursuant to Chapter 4A in the Patient and User Rights Act

# 1.0 INTRODUCTION

Providing healthcare services for home-dwelling persons with dementia who resist care is an ethical, legal, and clinical task that is both complex and challenging (Heggestad, Magelssen, Pedersen, & Gjerberg, 2020; Spigelmyer & Schreiber, 2019; World Health Organization, 2015). To continue living at home with dementia requires support and a combination of person-centered care and safe and appropriate housing (Woodbridge et al., 2018; World Health Organization, 2017). Family members report that resistance to care is not uncommon among persons with dementia who are living at home (Fauth, Femia, & Zarit, 2016). Situations of resistance to care among persons with dementia may become so challenging that it is perceived as nearly impossible to provide the intended, and often necessary, health and care services (Bingham, 2012); thus, forced treatment and care is frequently used (Mengelers et al., 2020; Moermans et al., 2018). This may occur in spite of adopting a person-centered care approach and in spite of attempts to provide individualized, flexible person-oriented care, efforts to forge a relationship of trust over months or years, or despite employing the resources and structural framework to achieve this within home health-care (McCormack et al., 2015; McCormack & McCance, 2006). In these situations, healthcare professionals have an extended responsibility of care, and they must determine how to reconcile the expression of resistance from the person with dementia with the person's need for treatment and care (Beauchamp & Childress, 2013; Kemp & Rendtorff, 2008; McCormack & McCance, 2006). In clinical practice, principles related to person-centered care and ethical and legal principles for care can appear to conflict (Bingham, 2012). Should the health professionals respect the decision of the patient to refuse treatment and care, or should they intervene?

In my previous job, I read many decisions to employ forced treatment and care that provided me with insight into the challenges that health professionals encounter. However, one of the stories* stood out.

> *Knut was a 75-year-old man with advanced dementia that lived at home with his girlfriend. He needed help with all ADL and received assistance 4-5 times a day from home health and care services in addition to daily help from his daughter. His health situation was deteriorating, and other serious conditions were suspected, but he did not want to undergo examinations. Nursing home placement was discussed, and short-term stays tried out, but he strongly resisted. He developed wounds that needed treatment and a minimum of personal hygiene was therefore important. He strongly resisted any kind of washing, attending of wounds or showering. Home health and care services decided that if cleaning the wounds could not wait, they would as last resort use force to wash him. Knut`s daughter was the key that allowed the nurses into the house. Her being there seemed to give him a feeling of safety, and she was used to maintain trust in the situation. As helping Knut became increasingly challenging more and more often, she would also be used to motivate and calm him when the nurses helped him shower. The daughter would lead him into the bathroom and hold on to his hands, while the*

> *nurses did the rest. However, with time Knut also resisted when his daughter was there, and she had to hold his hands with force. In the process of controlling the decision of forced hygiene, the County Governor's Office (CGO) attempted to assess which was worse, the daughter being part of forced personal hygiene or not. A crucial question we asked ourselves was whether the feeling of safety of having the daughter present would gradually transmute into a feeling of threat? What would it do to their relationship as father and daughter if she was part of the forced treatment and care? Ethically, clinically and legally the situation was very complex. We decided that the best solution for Knut was that his daughter was present when the home health and care services nurses came on their visit, but that she should not be part of the forced personal hygiene. However, she could be present to comfort him after. To this day, I still do not know if the decision was right. After living many years at home, the home health and care services finally decided that the Knut needed to move to a nursing home where the care-approach throughout the day could be more flexible and individually adapted.*

*(**Changes have been made to the story to protect anonymity).

Dilemmas with resistance to care can precipitate the use of forced treatment and care. The phenomenon extends beyond the scope of the situations described in this study. Through the completion of this PhD, I have gained insight and developed knowledge about the complexity that is embedded in situations of resistance to care and the use of forced treatment and care, especially those who are not mended even by years of person-oriented care and the use of trust-building interventions. For some patients, despite collaboration between family members, nurses and general practitioners, the optimal remedy is not clear-cut. This requires acute awareness and ethical, legal, and clinical competence to find an acceptable solution.

The study suggests that there are structures and mechanisms on the macro level embedded in: politics, marketization, laws, and dementia policies that may influence what happens on the meso level: in the organizational structures of home health and care services, and in the care practices emerging there. Resistance to care often is observed at the micro level, in relationships and in the actions of care unfolding between the individual health professional and the person with dementia. To resolve challenges of resistance, support from higher levels is needed. Therefore, there are several dimensions that are important to the understand the phenomenon of care practices when encountering resistance to care and in the use of forced treatment and care. Several of these aspects will be discussed.

## 1.1 Overview of study

To provide an overview of the study, a visualization of the different parts of the study is presented as follows in Table 1:

| **Table 1. Overview of study and research articles** | | | |
|---|---|---|---|
| Study purpose | The overall aim for the study was to impart new knowledge and insight into described care practices related to resistance to care and to examine how they were assessed and managed at the intersection between ethical, legal, and clinical judgement | | |
| Studies | **Study 1** | | **Study 2** |
| | **Article 1** | **Article 2** | **Article 3** |
| Title | Forced treatment and care in home-dwelling persons with dementia | Trust-building interventions to home-dwelling persons with dementia who resist care | Autonomy Conquers All: A Thematic Analysis of Nurses' Responses to Resistance to Care among Home-Dwelling Persons with Dementia |
| Research aim | To gain insights into formal decisions regarding forced treatment and care made for home-dwelling persons with dementia | To explore the use of trust-building interventions among home-dwelling persons with dementia who resist care | To explore nurses' professional judgement when encountering resistance to care among home-dwelling persons with dementia |
| Design | Cross-sectional study of documents concerning forced treatment and care | | Focus groups and individual interviews |
| Sample | 108 formal documents regarding decisions of forced treatment and care | 88 formal documents regarding decisions to implement forced treatment and care that described trust-building interventions | 18 registered and licensed practice nurses working in home-health care |
| Data collection | 16 closed- and open-ended questions | Open-ended questions with health professionals' descriptions of trust-building interventions | 3 focus group interviews, 3 individual interviews. Semi-structured interview guide |
| Data analysis | Descriptive statistical analysis Included re-coding of qualitative data into quantitative variables (quantification) | Qualitative template analysis of Clarke and Braun, inspired by a critical realist perspective | Qualitative template analysis of Clarke and Braun, inspired by a critical realist perspective |

## 1.2 PhD program and research area in which the thesis is situated

This project was conducted within the PhD program in Diaconal, Values, and Professional Practice at the Centre for Diaconal and Professional Practice. It was funded by the Faculty of Health Bergen at VID Specialized University. This PhD study focuses on how health professionals express that they encounter resistance to care in public home health and care services practices. It focuses on health professionals, especially nurses and professional care practices. Present study illuminates' values and norms regarding clinical, ethical, and legal care approaches. These norms are reflected in how respect for patient autonomy is valued and in the translation of legislation to health professionals' care actions when met with resistance to care from home-dwelling persons with dementia. This influences the content and performance of home health and welfare services on individual, relational, and organizational levels. The PhD study is therefore naturally situated within the theoretical framework of the PhD program, in which values and professional practice are two important pillars.

The PhD study`s research area encompasses health and social sciences related to care services to persons with dementia, and specifically within the home health and care services setting. Legislation guiding health professionals’ clinical practice is another important focus.

### 1.2.1 Project management

Project leader: PhD candidate, assistant professor/lecturer, MSN, RN, Åshild Gjellestad, Faculty of Health, VID Specialized University.

Main supervisor:
Associate Professor Frøydis K. Bruvik, Department of Public Health and Primary Care, University of Bergen.
Co-supervisors:
Associate Professor Trine Oksholm, Faculty of Health Bergen, VID Specialized University.
Professor Herdis Alvsvåg, Faculty of Health Bergen, VID Specialized University.

# 2.0 BACKGROUND

This chapter delineates the implications of dementia, the increased risk, and the existence of forced treatment and care when encountering resistance to care among home-dwelling persons with dementia. It also explores the approaches to and organization of home health dementia care and relevant legislation.

## 2.1 Dementia

Dementia is an umbrella term that encompasses conditions which can be caused by various brain disorders. The syndrome affects cognitive functions such as memory, insight, and logical thinking, and it eventually results in dependency on others for activities of daily living (ADL) (World Health Organization, 2017, 2020). Dementia is defined as a disability in the Convention on the Rights of Persons with Disabilities (CRPD)(UN General Assembly, 2007).

There is currently no cure for dementia, and person-centered care support has been discovered to be the most pivotal treatment and care (Kitwood & Brooker, 2019; McCormack et al., 2015; Terkelsen, Petersen, & Kristensen, 2019). The condition is associated with increased human and economic costs for the persons affected and their families (World Health Organization, 2020), in addition to unmet care needs related to personal safety, personal hygiene, and maintaining a meaningful daily structure (Black et al., 2019; Aaltonen & Van Aerschot, 2019). Persons with dementia face complex problems and symptoms in many domains, including cognition, neuropsychiatric symptoms, activities of daily living, and frequent comorbid physical illnesses (Livingston et al., 2020; Livingston et al., 2017). Physical health is important for cognition, and persons with dementia have more physical health problems than others of the same age. However, they typically receive less community health care, and they find it particularly difficult to access and to organize care. People with dementia also undergo more hospital admissions than other older people, including for illnesses that could be treated at home. In the COVID-19 epidemic, they have died in disproportionate numbers (Livingston et al., 2020), and they have been more vulnerable to isolation and loneliness (Lazzari & Rabottini, 2021). Risk assessment and management at all stages of the disease is therefore essential, but it should be balanced against the person's right to autonomy (Livingston et al., 2017). The general principle of *risk enablement* refers to allowing people to have an acceptable amount of risk, managed by using the least restrictive options. This strategy requires an assessment of the decisional capacity of the person with dementia regarding the risks they encounter. Previous research has demonstrated that the most common risks include a decreased ability to maintain safety, namely forgetting, apathy, decreased insight, or poor judgment. Common risks also include malnutrition due to not being able to plan to eat and drink; not understanding or remembering to take medication as prescribed; lack of safety at home due to falls, floods, fire, or gas escape and risks for other people; poor road safety, both in relation to walking and in driving; and finally, a potential vulnerability to crime and abuse inflicted by others (Livingston et al., 2017).

### *Diagnostic criteria*

There are many different forms of dementia, but Alzheimer's disease is the most common form of dementia and may contribute to 60 to 70% of cases (Livingston et al., 2017; World Health Organization, 2017). The International Classification of Diseases and Related Health Problems (ICD) 11th edition (ICD-11) (World Health Organization, 2020) and the American Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5) (American Psychiatric Association, 2013) are classification systems used to diagnose dementia. An important difference between the two sets of diagnostic criteria is that ICD-11 criteria are characterized by how dementia coincides with Alzheimer’s disease, wherein memory problems are more prominent. The criteria therefore do not necessarily apply to other dementia illnesses. The DSM-5 criteria are more general; for instance, they also encompass Lewy Body and Fronto Temporal Dementia, wherein other cognitive domains are typically impaired (Nationalt Videnscenter for Demens, 2020).

In the ICD-11, which is used in Norway, dementia is described as referring to neurocognitive disorders that are characterized by primary clinical deficits in cognitive functioning that are acquired rather than developmental. Dementia disorders are divided into eight subgroups: 1) Dementia due to Alzheimer’s disease; 2) dementia due to cerebrovascular disease; 3) dementia due to Lewy body disease; 4) frontotemporal dementia; 5) dementia due to psychoactive substances including medications; 6) dementia due to diseases classified elsewhere; 7) behavioral or psychological disturbances in dementia;  8) dementia from other specified causes; and 9) dementia due to an unknown or unspecified cause (World Health Organization, 2020). The boundaries between different forms of dementia are indistinct, and multiple forms often co-exist (World Health Organization, 2017).

### *Dementia in the DSM-5*

The DSM-5 was developed by the American Psychiatric Association in 2013 and consists of three major components: the diagnostic classification, the diagnostic criteria sets, and the descriptive text. The diagnostic classification is the official list of mental disorders recognized in the DSM. Each diagnosis includes a diagnostic code which is derived from the coding system used by U.S. health and care services professionals, known as the International Classification of Diseases, Ninth Edition, Clinical Modification (ICD-9-CM). For each disorder included in the DSM, a set of diagnostic criteria indicates symptoms that must be present (and the required duration) as well as a list of other symptoms, disorders, and conditions that must first be excluded to qualify for a particular diagnosis. The third area of the DSM is the descriptive text that accompanies each disorder (American Psychiatric Association, 2013).

### *Prevalence*

Dementia is one of the most paramount global public health challenges, and over 57 million people have dementia worldwide. This number is expected to rise to 152 million in 2050 (GBD Dementia Forecasting Collaborators, 2022). Dementia is increasing more in North Africa, the Middle East, and Eastern Sub-Sahara, relative to high-income Asian Pacific and Western European countries due to an aging population and a higher frequency of risk factors (GBD Dementia Forecasting Collaborators, 2022; Livingston et al., 2020). The World Health Organization (WHO) has made dementia a global public health priority (World Health Organization, 2017). Several risks factors are associated with the development of dementia. In a recent study, previously identified risk factors, namely lower education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, and low social contact (Livingston et al., 2017), were supplemented with three new risk factors: alcohol consumption, traumatic brain injury (TBI), and air pollution (Livingston et al., 2020).

In a recent Norwegian study (Gjøra et al., 2021), the total number of persons with dementia in Norway was estimated to be 101,118, and more than two thirds of these patients live at home. Previous studies of recipients of home health care services found that 41.5% of approximately 40,000 had dementia, and as many as 72% had experienced neuropsychiatric symptoms (NPS); in addition, 40% had used psychotropic drugs in the foregoing month (Wergeland, Selbaek, Hogset, Soderhamn, & Kirkevold, 2014). Future projections suggest that the number of people with dementia will more than double by 2050 and nearly quadruple by the year 2100 (Gjøra et al., 2021). The prevalence of dementia is increasing among persons who receive homecare services; many have NPSs and use psychotropic drugs. However, many remain undiagnosed (Wergeland et al., 2014).

### *Living with dementia*

Family caregivers are the most important resource available for people with dementia. Families of persons with dementia endure an extensive caregiver burden (Livingston et al., 2020). Care for people with dementia should emphasize physical and mental health, social care, and support (Livingston et al., 2020). Persons with dementia often receive homecare services for many years in Norway, and they may have frequent visits during a single day (Hoel et al., 2021). In a Norwegian national survey from 2015 examining resource use and disease course in dementia, the timespan from symptom debut until diagnosis, and from diagnosis until admission to an institution was approximately three years in both cases (Vossius et al., 2015). Neuropsychiatric symptoms and living alone were primary factors associated with a higher recourse use (Vossius et al., 2015). Multicomponent person-centered psychosocial interventions, namely psychosocial management and care support, education, and discussion with a psychiatrist or neurologist, have been found to mitigate neuropsychiatric symptoms in the short term (Livingston et al., 2020). In the last period, before moving to a nursing home, persons with dementia are mainly supported by family, and informal care is particularly high among co-residents (Ydstebø, Benth, Bergh, Selbæk, & Vossius, 2020).

With the development of dementia, the person's ability to make informed decisions dwindles. This imperils the autonomy of the person with dementia, who often becomes dependent on others to compensate for their lacking abilities (Livingston et al., 2020). Family caregivers report that the most difficult decisions to make as a substitute decision maker are how and when to receive health care services, such as placement in a nursing home (Koenig, Lee, Macmillan, Fields, & Spano, 2014; Larsen, Blix, & Hamran, 2018).The use of advanced planning or advanced directives in persons with dementia is disputed, especially with regards to whether their previously or currently expressed preferences should have preeminent moral and legal weight. The argument for emphasizing the latter is that having dementia is a cognitive transformative experience, that preferences change, and that this ought to be given moral weight in medical decision-making (Walsh, 2020). There are substantial differences between countries regarding legal issues related to the capacity to consent and the use of substitute decision makers (Livingston et al., 2017; Podgorica, Flatscher-Thöni, Deufert, Siebert, & Ganner, 2020). Decisions concerning the best interests of the person with dementia include considerations regarding what the person would have wanted rather than the decision maker's judgment of beneficence (Livingston et al., 2017). In Norway, next of kin has a right to participate and to decide, in collaboration with the health professional in charge, what is in the best interest of the patient if the person does not have capacity to make a decision or to consent. A person with dementia can be declared to have a lack of competence to consent to a given health care decision, but not to health and care services in general (Pasient- og brukerettighetsloven [The Patient and User Rights Act], 1999). Complex situations can develop related to the care of persons with dementia that need to be assessed and managed in the intersection between ethical, legal, and clinical judgement (Østenstad, 2011).

### *Unmet needs in persons with dementia*

In a systematic review and meta-analysis exploring the needs of people with dementia living at home, Curnow et.al. (2019) found that the most prevalent unsatisfied needs among home-dwelling persons with dementia were related to memory, food, household activities, and money (Curnow, Rush, Maciver, Górska, & Forsyth, 2021).

A recent exploratory cross-sectional study compared unmet needs among 447 community-dwelling dyads of people with mild to moderate dementia and their caregivers not yet receiving formal care. It spanned eight European countries and found unmet social needs in 15% of the study population, with company and daytime activities scoring the highest. This suggests that the social domain constitutes an important area to be targeted through interventions in the mild to moderate stages of dementia (Janssen et al., 2020).

A study by Beach at.al. (Beach et al., 2020) based on interviews with 4,024 community-dwelling older adults with ADL/IADL needs and mobility disabilities investigated the adverse consequences of unmet care needs. It found that they were prevalent among high-need/high-cost older adults, especially those with multiple indicators. High-need/high-cost older adults were more likely to report unmet needs and consequences of ADL-related and mobility-related issues. Specifically, 34% of those meeting all three criteria reported *wet or soiled clothing* in the past month due *to unmet toileting needs* (Beach et al., 2020, p. 465). This study replicates previous research revealing that greater levels of disability are associated with more adverse consequences of unmet needs (Beach et al., 2020).

A cross-sectional study by Black et. al. (2019) of 646 community-living persons with dementia and their informal caregivers found that unmet care needs are common among home-dwelling persons; this is associated with informal caregivers' ability to recognize and/or adequately address the needs of persons with dementia. Those with severe cognitive impairment had significantly fewer unmet needs than those with either moderate or mild impairment. However, persons with dementia with more neuropsychiatric symptoms had significantly more unmet needs. Few hours spent with one's caregiver each week was associated with a higher degree of unmet needs (Black et al., 2019).

Aaltonen and Van Aerschot (2019) conducted a study of 1,928 people with long-term illnesses or disabilities that limited their everyday activities. They found that people with memory problems have more care needs than those with other types of disability or illness. They receive more care but still have more unmet needs than others; about 25% reported not receiving sufficient help. Even combinations of informal and formal home care were insufficient to meet their needs. They concluded that there was insufficient care for people with memory problems and that the further development of home care services was necessary (Aaltonen & Van Aerschot, 2019).

## 2.2 Perspectives of dementia care

Views regarding dementia have changed over the years, but the essential elements have remained the same. Dementia is viewed as a progressive loss of mental function, and there is an association with aging, but it is not definite (Andrews, 2017). However, the understanding of what it means to be a person with dementia is dynamic and located within particular conceptual frameworks; ideas about the condition are reliant upon historically contingent assumptions (Knifton, 2019).

### 2.2.1 Dementia care in a historical context

Persons who cannot care for themselves and who are not easily cared for have always received special attention in the history of health care services (Andrews, 2017; Foucault, 1991; Vold, 2007). Dementia care has metamorphosed from family agreements regarding the support of elderly people, through pauper-systems, dollhouses, lunatic asylums, poorhouses, retirements houses, nursing homes, assisted living facilities and care homes, home health and care services, to the present, which prizes citizenship, dementia-friendly societies, and shared decision making, but with a continuously purified philosophy of dementia care (Vold, 2007). The current aging at home policy places substantial responsibility on the caregivers and the closest neighborhood.

Home health and care services in Norway are publicly funded and are a municipal responsibility (Holm, Mathisen, Saeterstrand, & Brinchmann, 2017). The large number of people affected by dementia poses major challenges related to provisions of health and care services (Helse- og omsorgsdepartementet [The Ministry of Health and Care Services], 2013). Home health and care services are liable for both people living in their own homes and for people living in supported housing (Daatland, Høyland, & Otnes, 2015). The exact time when home care in Norway first emerged is difficult to pinpoint, but in 1950, public funding was devoted to the service. In 1967, the National Insurance Act was enacted in Norway with the aim to compensate for expenses associated with sickness, disability, aging, and death. By the 1980s, municipalities had assumed responsibility for all primary health and care services (Otnes, 2015). Home health care services have been a pillar in the Norwegian health care sector ever since.

Compared to most other countries, the percentage of the population who receive health and care services is high in Norway. The number of people receiving healthcare at home is increasing; in 2020, the number of persons was 251,549 (Helsedirektoratet [Norwegian Directorate of Health], 2020). The prevalence of persons with dementia living at home is also increasing (Gjøra et al., 2021). In a Norwegian survey that included 1,000 recipients of home health care 70 years of age or older, over 40% had dementia pursuant to ICD-10 (Wergeland et al., 2014).
In Norway, there has been a considerable change in the care services landscape during the last 10 to 20 years. The government has recently launched their conception of what they call the “Trust Reform.” Its contents have not been established yet, but the aim is to provide people with greater welfare and better services (Kommunal og moderniseringsdepartementet [The ministry of municipality and of modernization], 2021). Home care services in Norway has been influenced by a New Public Management mindset wherein core elements include market orientation and consumerism (Fjørtoft, Oksholm, Førland, Delmar, & Alvsvåg, 2021; Vabø, 2007, 2012). In the late 20Th century and in the beginning of the 21st century, de-institutionalization gradually became the “new” policy, with an aim to foster societies where people can age at home, including persons with dementia (World Health Organization, 2017).

In recent decades, home health and care services have undergone stronger growth than the institutions. Home health and care services are based on allocated decisions of care that are based on assessments

of individual needs (Vabø, 2012). The ideal of living at home has led to the development of assisted living facilities. People who live in assisted living facilities pay for rent and electricity in the same manner as people do in private housing. Both receive services from home health care, but home health care is more likely to be provided in assisted living than in private housing (Otnes, 2015).
In the last 10 years, there has been a trend wherein less practical assistance such as house cleaning and snow-mowing is provided. The emphasis of the services is to offer assistance with health needs. In the last few decades, various specialized services in home health care have emerged, namely specialized dementia teams and 24-hour inpatient acute care (Fjørtoft, Oksholm, Delmar, Førland, & Alvsvåg, 2021; Sogstad, Hellesø, & Skinner, 2020). In Norway, all citizens are appointed a general practitioner, and primary medical care is provided by them; they then serve as the gatekeepers to more specialized services (Fastlegeforskriften [The General Practitioner Regulation], 2012; Malterud, Aamland, & Fosse, 2020). Today, dementia care is primarily undertaken in the community, and families provide the majority of care to persons with dementia who live in their own homes for a larger portion of their lives (World Health Organization, 2019b; Ydstebø et al., 2020). Eventually, placement in a nursing home or assisted living facility often becomes necessary for persons with dementia, and research has demonstrated that their displacement from their homes often occurs involuntarily (Larsen et al., 2018; Vossius et al., 2015).

Thus, for persons with dementia, many of the reasons and triggers behind institutionalization and forced treatment and care, such as dependency and adverse behavior, remain similar to those that existed 200 years ago (Andrews, 2017; Scheepmans, Milisen, et al., 2018). Dementia is presented as a "family-illness," implying that informal caregivers have the responsibility to make it possible for the person with dementia to continue living at home, through providing support for family caregivers regarding how to manage adverse behavior (Sørensen, 2015). Historically, long before the "age-wave" was invented, the challenges of dementia itself have hindered health and welfare providers from providing adequate care, let alone a life of dignity. However, ambivalence towards people living with dementia still seems to be embedded in the welfare state (Andrews, 2017). The condition of dementia is still associated with increased human and economic costs for the persons affected and their families (World Health Organization, 2020), in addition to unmet care needs for the person with dementia related to personal safety, personal hygiene, a meaningful daily structure, and participation in society (Bartlett & O'Connor, 2007; Black et al., 2019; Aaltonen & Van Aerschot, 2019).

### 2.2.2 Dementia care policies

Globally, dementia care and home health and care services are differently organized within each country. Increasingly more countries have developed national dementia care plans that provide guidelines for dementia care, and different care solutions are continuously attempted (World Health Organization, 2017). Particularly initiatives involving welfare-technology have been presented as means to prolong the ability of persons with dementia to continue living at home (Frennert & Baudin, 2019; Hofmann, 2013; NOU 2011:11, 2011; Sánchez, Taylor, & Bing-Jonsson, 2017). In 2017, 26 countries reported having existing dementia plans (World Health Organization, 2021). In high-income countries, the costs related to dementia are shared between informal care (45%) and social care (40%). In contrast, in low- and middle-income countries, social care costs are estimated to be 15%, which pales in comparison to the costs of informal care (World Health Organization, 2017).

European countries also vary in terms of health care and social service organizations, demographic patterns, and financial systems (Bökberg, 2015; Genet et al., 2011). There has been a transition from institutional care towards home care, and private and mixed services have increasingly supplanted public care (Genet et al., 2011). When examining the map of Europe, there are significant differences of dementia care across Europe, with countries in Northern and Central Europe generally scoring better than countries in Southern Europe (Alzheimer Europe, 2020). In England, Sweden, Denmark, and Norway, national guidelines for dementia care with a person-centered approach are developed (Rokstad, 2021). There are immense differences in the degree of family members' legal obligations to care for their next of kin through the course of the disease; this is due to differences in the organization of home health care, financial regulations and cultural expectations, and increases in informal care (Bökberg, 2015). Bökberg et al. (2015) found, in a cross-country comparative study of care and services at home for persons with dementia between eight European countries, that even if several types of care and service activities related to basic health care interventions are available, they are not utilized extensively (Bökberg, 2015).

In 2008, the Norwegian government initiated a care plan to gradually expand the municipal care services; it was called "Care Plan 2015." The care plan focused on increasing capacity through more personnel and an increased number of beds in long-term care. In 2012, the "Coordination Reform" was initiated with the aim to enforce prevention and early public health interventions and diminish institutionalized specialized care (Helse og omsorgdsdepartementet [The Ministry of Health and Care Services], 2009). Several dementia care plans (2015, 2020 and 2025) have been launched, focusing on early diagnosis, person-centered care services, participation, and developing dementia-friendly societies (Helse og omsorgdsdepartementet [The Ministry of Health and Care Services], 2020; Helse og omsorgsdepartementet [Ministry of Health and Care Services], 2015). The two most recent dementia plans were developed in collaboration with various stakeholders, including persons with dementia through regional dialogue meetings (Helse og omsorgdsdepartementet [The Ministry of Health and Care Services], 2020; Helse og omsorgsdepartementet [Ministry of Health and Care Services], 2015). In 2018, the quality reform *"A full life-all your life"* was launched with the goal of providing older people with increased help and support to manage life. It was concerned with the basic factors that often fail, namely food, activity, fellowship, health care, and the coordination of services (Helse- og omsorgsdepartementet [The Ministry of Health and Care Services], 2018). In later years, the concept of citizenship for persons with dementia has enhanced dementia care practices further by adding a contextual, environmental, and political approach through promoting age-friendly or dementia-friendly societies (Bartlett & O'Connor, 2007; Hebert & Scales, 2019; O'Connor & Nedlund, 2016).

With the aim of providing person-oriented dementia care services, there is an increased emphasis on aging at home as well as individualized and flexible services in global and national policy documents (Helse og omsorgdsdepartementet [The Ministry of Health and Care Services], 2020; Kitwood & Brooker, 2019; World Health Organization, 2017). Nevertheless, there are continuous challenges regarding how to balance quality, safety, and autonomy in the care of home-dwelling persons with dementia (Mengelers et al., 2019; Moermans et al., 2018; Sjostrand, Eriksson, Juth, & Helgesson, 2013).

## 2.3 Forced treatment and care

There is limited knowledge regarding the extension of forced treatment and care to home-dwelling persons with dementia. Furthermore, what is encompassed within the concept of forced treatment and care is not clear. Literature searches have revealed a scarcity of studies that examine the use of forced treatment and care in home healthcare, and research is recent and limited (Hamers, Bleijlevens, Gulpers, & Verbeek, 2016; Moermans et al., 2018; Scheepmans, Dierckx de Casterlé, Paquay, Van Gansbeke, & Milisen, 2017). This implies that research is new, although the phenomenon has existed for a long time(Foucault, 1991). Moreover, forced treatment and care among home-welling persons with dementia is complex because care is often provided in collaboration between health professionals and family members. However, legislation regarding patient rights and services aiming to prevent and regulate coercion exclusively applies to health professionals (Helsedirektoratet [Norwegian Directorate of Health], 2015; Townend et al., 2016).

In many parts of the world, coercive community practices have expanded; this has been exemplified in Dutch legislation such as the Care and Compulsion Act, which permits preventive coercive home health care. In many parts of the world, health interventions have been moved to outpatient settings. This has led to the introduction of more coercive community practices, especially in psychiatric outpatient care (Riley, Høyer, & Lorem, 2014; Van den Hooff, 2018). According to the current legislation in Norway, only health professionals can be responsible for forced treatment and care, but guidelines are vague regarding involvement of family (Pasient- og brukerettighetsloven [The Patient and User Rights Act], 1999). The discussion of hard and soft paternalism in healthcare services and how a person`s wishes may be overridden is highly relevant (Brodtkorp, Skisland, Slettebø, & Skaar, 2015; Skaar, Brodtkorp, & Slettebø, 2014). Dependency in ADL, disruptive behavior, and neuropsychiatric symptoms have been reported to be associated with resistance to care (Moermans et al., 2018; Scheepmans, Dierckx de Casterle, Paquay, & Milisen, 2018; Scheepmans, Milisen, et al., 2018) and have been identified as common among home-dwelling persons with dementia (Fauth et al., 2016). Persons with dementia who live at home with reduced insight and understanding of their own needs are in vulnerable situations. The boundaries between voluntary and forced care may be nebulous, and voluntary situations can quickly turn involuntary (Hem, Gjerberg, Pedersen, & Førde, 2010). Resistance to care combined with unmet needs, risks related to patient safety, and the need for providing respite to informal caregivers challenge health professionals and families to consider forced treatment and care at home. Placement in a nursing home or assisted living facility often becomes necessary (Koenig et al., 2014; Kwon & Tae, 2012; Vossius et al., 2015).

### *Resistance to care*

Resistance to care has been defined in various ways, ranging from the expressed communication of emotions, namely verbal anger and physical aggression, to noncompliance (Spigelmyer, Hupcey, & Kitko, 2018 b,). Mahoney defined resistance as “the repertoire of behaviors with which persons with dementia withstand or oppose the efforts of a caregiver” (Mahoney et al., 1999, p. 28). Spigelmyer et al. (Spigelmyer et al., 2018 b,) conducted a concept analysis of resistiveness and found that resistiveness was frequently used synonymously with other concepts such as aggression and agitation. This combination may hinder clear communication among and between health care disciplines. They developed a definition that synthesized definitions of resistiveness within disciplines of nursing, medicine, psychiatry, and dentistry (my highlights):

> *Resistiveness to care was defined from the perspective of the caregiver or care provider and considered to be deliberate acts invoked from the caregiving encounter that were either* ***verbal or physical*** *and were thought to be* ***meaningful responses*** *of the care recipients to their perceived environment, such as a* ***threat, or disability*** *and were means of* ***communicating needs, conflict, rejection****, or an* ***unwilling acceptance of an interaction*** *between a caregiver and a care recipient. Factors contributing to resistiveness to care included* ***distorted understanding (such as cognitive impairments and immature cognitive development)****,* ***dependence on another for care*** *(such as physical or psychological limitations), anxiety, apprehension or* ***unmet physical or psychosocial needs****. The resulting* ***effects of resistiveness to care*** *included* ***interrupted care, use of force, physical restraints or pharmacological restraints*** *to provide the care,* ***increase in distress****, and* ***discomfor****t for both caregiver and care recipient as well as* ***increased disruptive behavior*** *manifestations of the care recipient toward the care giving experience if resistiveness to care was not addressed when it occurs during the care giving interaction (Spigelmyer et al., 2018 b,, p. 11).*

Resistive behavior is often not easily identified by nursing staff and may be overlooked or underreported (Bharucha et al., 2008). Recent research has found that there is a lack of awareness among leaders about the challenges of resistance in the form of violence, neglect, and abuse in nursing homes (Myhre, Saga, Malmedal, Ostaszkiewicz, & Nakrem, 2020).

### *The prevalence of forced treatment and care in home health care*

International research has found immense variation in the prevalence of forced treatment and care in home health care. A systematic review from 2018 included eight studies that reported the use of restraint; four of them reported overall prevalence of physical restraint use; physical restraint (5%), physical restraints (7%) (e.g. waist belt in chair and bed, wrist or ankle ties, fixed table, deep, reclined chair, chair on board, locked wheel chair, bedrails, specials sheet, sleep suit), physical restraint used as an indicator of quality of care (9.9%), devices and all actions of restriction of freedom (24.7%) (e.g., bed against the wall (39%), adaption of house (25.8%), bedrails (24.1%), tilted chair or geriatric chair (16.2%), brakes on wheelchair (14%), and locking house 13.2%) (Scheepmans, Dierckx de Casterle, et al., 2018, pp. 129-133). The other studies in the review also reported use of restraints related to bedrails, removal of aids, tying the person to a chair/bed, restraining limbs/ use of mittens to prevent pulling out IV/feeding tubes or tearing skin, geriatric chairs/belts/trays to prevent standing up, overalls over clothes to prevent removal of clothes, vests, sleeping bag, forced or camouflaged medicine, psychotropic medicine to reduce excitement, and locking someone in a room (Scheepmans, Dierckx de Casterle, et al., 2018). A common factor in all the studies was the importance of the role of family or informal caregivers. They would often be the ones to request or initiate the use of restraint, and family played an important role in the decision-making process. Nurses were the second group who most frequently initiated restraint use. General practitioners were less involved, their roles being unclear and largely limited to the prescription of medication to control the patient's behavior. Some home care nurses reported that they wanted them to adopt a more active role in the decision-making process. Scheepmans et al. (Scheepmans et al., 2017) also found that patients themselves would request interventions in 18.7% of the situations. Specific reasons mentioned in a qualitative study of Scheepmans et al. (2014) and confirmed in a subsequent study by Scheepmans et al. (2017) were that the patients wanted to remain at home for as long as possible, which necessitated the use of restraints and the desire to delay admission to a nursing home and to provide respite for the informal caregiver. This study found that most restraints were used on a daily basis (Scheepmans et al., 2017). Scheepmans et.al. (2018) highlighted that *"understanding the negative consequences of restraint use starts by having a clear understanding of what "restraints" means or includes. A clear definition of the concept is a first step to increase awareness among healthcare providers. Other elements to increase awareness are a clear policy, education of healthcare providers, and available alternatives"* (Scheepmans, Dierckx de Casterle, et al., 2018, p. 135).

In previous research conducted by Moermans et al. (2018), forced treatment and care was defined as involuntary treatment and was reported to be used among 52% of the older adults receiving home healthcare. Non-consensual care was most frequently used (73%), followed by psychotropic drugs (43%) and physical restraints (38%). The use of involuntary treatment was associated with dependency of activities of daily life, cognitive impairment, informal caregiver burden, and aging (Moermans et al., 2018). Therefore, it is important to manage the neuropsychiatric symptoms (e.g., aggression, depression) associated with reduced cognitive ability. Informal caregivers (71%), followed by general practitioners (47%), most frequently requested the use of involuntary treatment, and nurses (81%) most commonly applied it. District nurses most frequently applied the involuntary treatment, followed by informal caregivers. Measures frequently employed by informal caregivers included bedrails and placing the bed against the wall (48%) for district nurses (43%); for general practitioners (72%), this was giving psychotropic medication. Moermans et al. (2018, p.136) identify previous research (Etters et.al., 2008, and Koller et. al., 2014,) that has uncovered caregiver burden, greater ADL dependency, poorer cognitive ability, living alone, and having a formal diagnosis of dementia as factors that are strongly associated with involuntary treatment. The prevalence of these factors is growing due to demographic and socio-economic evolutions (Moermans et al., 2018).

The study of Mengelers et.al. (2020) which included Belgium and the Netherlands found use of involuntary treatment in more than half of the home-dwelling persons with dementia (50.7%).Of this, nonconsensual care (82.7%) was the most common, followed by psychotropic medication (40.7%) and physical restraints (18.5%). Involuntary treatment use was associated with living alone, greater ADL dependency, lower cognitive ability, higher family caregiver burden and receiving home care in Belgium versus the Netherlands. Involuntary treatment was most often requested by family caregivers (Mengelers et al., 2020).

Family caregivers and general practitioners have been found to harbor more positive attitudes towards involuntary treatment relative to nursing staff and other healthcare professionals, indicating that they are more accepting of involuntary treatment (Mengelers et al., 2019). Other studies have found that nurses and family members are most often involved in the use of forced treatment and care (Scheepmans, Dierckx de Casterle, et al., 2018). It was often requested by family caregivers due to the need for safety and respite. General practitioners were found to be less involved (Scheepmans, Dierckx de Casterle, et al., 2018). Previous research supports the notion that informal caregivers are significantly less aware of the harmful effects of physical restraints (e.g., bruises, increased dependence, depression) and have a more positive perception of their use (Kurata & Ojima, 2014; Scheepmans et al., 2014).

In Norway, the Norwegian Board of Health Supervision reported that from 2009 to 2016, the reported decisions of forced treatment and care pursuant to the Patient and User Rights Act, Chapter 4a, more than doubled from 1,687 to 3,843 decisions in Norway (Oxford research AS, 2013; Statens helsetilsyn [Norwegian Board of Health Supervision], 2016). In 2009, the regulations in Chapter 4A of the Patient and User Rights Act were new, hence the low numbers. Up to this point, act of necessity/emergency care was the only option. However, the use of forced treatment and care has continued to increase, and in 2020, there were 5,138 formal decisions to implement forced treatment and care (Statens Helsetilsyn [Norwegian Board of Health Supervision], 2020). The report demonstrates that it takes years for the institutions to establish a culture for making these types of decisions. However, the use of forced treatment and care also existed before, and the report cannot be regarded as proof of the increased use of coercive practices. The registered use of forced treatment and care towards persons with dementia in Norway has mainly been within health institutions such as nursing homes. Supervisions performed by the regional health authorities, namely the County Governors, have several times revealed a lack of management and the use of unregulated forced treatment and care in nursing homes. As of 2017, information about municipal health and social care services is to be reported to the Municipal Patient and Users Register (Helsedirektoratet [Norwegian Directorate of Health], 2020). Forced healthcare is required to be reported on. In these registers, a total of 1,395 persons were reported to have received “forced healthcare” in 2020; however, data extracting information about home-dwelling persons with dementia are not available (Helsedirektoratet [Norwegian Directorate of Health], 2020). Previous evaluations of the use of forced treatment and care has argued that there is reason to believe that the unrecorded use of coercion can also occur in home health care (NOU 2019:14, 2019; Oxford research AS, 2013).

### 2.3.1 Legislation guiding dementia care

It is not within the scope of this thesis to provide a detailed presentation of the international legislation related to dementia care. However, a brief introduction to the status quo of relevant legislation in Europe and a description of the Norwegian laws relevant to persons with dementia will be provided.

Unfortunately, people with dementia are frequently denied the basic rights and freedoms available to others (World Health Organization, 2015). In the global action plan on the public health response to dementia, the World Health Organization (WHO) has placed immense emphasis on human rights through inclusive societies, meaningful lives, and access to care for persons with dementia (World Health Organization, 2017). There is extensive information regarding services and legislation related to persons with dementia through the Global Dementia Observatory. The Global Health Observatory data repository is WHO's gateway to health-related statistics for its 194 Member States. In 2017, it was reported that 13 countries had existing legislation specifically related to dementia, and 41 countries had other types of laws that applied to the rights of people with dementia (World Health Organization, 2021). The WHO states that to ensure that people with dementia can maintain a level of functional ability consistent with their basic rights, fundamental freedoms, and human dignity, they need integrated, person-centered, accessible, and affordable health and social care, including long-term care (World Health Organization, 2017, p. 15).

### *Patient rights in Europe*

Gradually, all Member States in the European Union are developing a legal approach to defining and implementing patients' rights (Gove & Georges, 2001; Townend et al., 2016). This encompasses patients' rights to self-determination, consent, privacy, confidentiality, and access to medical records. These rights are embedded in several individual human rights frameworks, such as the Barcelona Declaration of Bioethics (Kemp & Rendtorff, 2008). Townend et al. concluded that all 30 states will soon have a minimum set of patient rights (Townend et al., 2016, p. 35). Only several Member States, namely Austria, Bulgaria, Ireland, Italy, and Malta, are lacking a special law concerning patients' rights. However, the legal framework on patients' rights usually extends beyond the scope of a single patients' rights law. Other specific legal acts or governmental decisions addressing specific issues or aspects, the application of general principles derived from civil, criminal, or administrative law, or even direct references to the Constitution can complete the picture (Townend et al., 2016).

Even if in most cases the adoption of a patients' rights law signified an important shift towards a more patient-oriented approach, there are still laws defining the obligations of health professionals or deontological codes that continue to be the most important source for patients' rights (Townend et al., 2016, p. 31; World Health Organization, 2015) . In these laws references to the right to safe and quality treatment legislation may refer to the obligation of the physician, sometimes framed as a patient right, to adhere to a standard of care. The obligation of professionals to adhere to a certain standard of care is structurally ensured by the formal recognition via licensing and accreditation of healthcare professionals in almost all countries, and to a lesser degree (but increasingly), of healthcare institutions (e.g., hospitals) providing care (Townend et al., 2016). The balance between the duty to care through beneficence and the protection of human rights of freedom and privacy are at the crux of the discussion of forced treatment and care in home-dwelling persons with dementia, often discussed as soft paternalism (Griffith & Tengnah, 2011; Groves, 2006). In many countries, physical and chemical restraints are used extensively in care homes for older people and in acute care settings, even when there are regulations in place to uphold people's rights to freedom and choice (World Health Organization, 2015).

### *Patient rights and legislation relevant for dementia care in Norway*

In care for persons with dementia complex situations may arise that must be assessed and solved at the intersection between ethical, legal and clinical judgement (Syse, 2013; Østenstad, 2011). The juridical principles of purpose, proportionality, professional soundness, and predictability are important pillars of Norwegian legislation concerning the allocation and conduct of health and care services. Voluntariness could also be added as a guiding principal (NOU 2018:16, 2018).

There are several laws that have regulations pertaining to patient needs and forced treatment and care in Norway. Among these are the Patient- and User Rights Act chapter 4A, the Health Personnel Act chapter 2, section 7, and the Mental Health Care Act chapters 3 and 4 (Helse og omsorgstjenesteloven [The Health and Care Services Act], 2011). These are especially relevant for persons with dementia. Other relevant laws are the Health and Care Services Act chapter 9, and the Infection Control Act chapter 5 (Helsepersonelloven [The Act relating to Health Personnel], 1999; Pasient- og brukerettighetsloven [The Patient and User Rights Act], 1999; Psykisk helsevernloven [The Mental Care Act], 1999; Smittevernloven [Infection Control Act], 1994). The regulations established in these acts safeguard adequate services for patients and users and outline when involuntary treatment can be considered legal and when it cannot.

**Table 2. Norwegian Acts with regulations regarding forced treatment and care relevant to persons with dementia**

| | **Area of treatment and care** | | | | |
|---|---|---|---|---|---|
| | **Physical health care** | **Emergency health care** | **Mental health care** | **Municipal health care** | **Infection-control** |
| | *admission, examinations, personal hygiene, blood tests, pain relief | *antibiotics for sepsis, surgery and treatment fractures, vital examinations | *medication for mental health illness, admission | *basic needs, prevention of damage in emergency situations | *blood tests, treatment, isolation |
| **Patient and User Rights Act** | Chapter 4A | | | | |
| **Health Personnel Act** | | Chapter 2 (sec.7) | | | |
| **The Mental Health Care Act** | | | Chapters 3, 4 | | |
| **The Health and Care Services Act** | | | | Chapter 9 | |
| **The Infection Control Act** | | | | | Chapter 5 |

**examples of forced treatment and care situations*

There is an important distinction between the patient`s right to emergency care (pursuant to the Health Personnel Act, section 7, 1999) and planned forced treatment and care (pursuant to the Patient and User Rights Act, Chapter 4A, 1999). If it is deemed to be of vital importance, health personnel must immediately provide health care, even if the patient is incapable of giving consent, and even if the patient *objects* to such treatment. The purpose of this is, among other things, is to ensure patient safety. It  is when patients resist over time and the risk is not considered vital, but nevertheless serious harm, that the regulations in chapter 4A in the Patient and User Rights Act are applicable (Table 2).

### *Patients over 18 years who lack the capacity to consent*

If patients over 18 years of age do not have the capacity to consent, the health professional who provides healthcare can make the decision; this applies if the health care provided involves less invasive measures with regards to the extent and duration (section 4-6, first subsection 1 of The Patient and User Rights Act 1999).

For patients without capacity to consent healthcare that is considered invasive can be proffered if it is in the patient`s interest and if it is likely that the patient would have consented. The health professional responsible can make the decision; information from the family is gathered if possible, and the decision is made based on consultation with another competent health professional (section 4-6, second subsection of The Patient and User Rights Act 1999). This section is commonly used in dementia care and can also be considered paternalistic because the health professional decides what is ideal for the patient, and consent is presumed. Health care pursuant to the two paragraphs cannot be provided if the patients resists it, unless otherwise decided by law.

### *Healthcare for patients without the capacity to consent who resist care*

Chapter 4A of the Patient and User Rights Act was enforced in 2009 and provides the main legislative background for this study. It regulates necessary physical health care for persons who lack the capacity and competence to consent. The aim is to provide necessary health care, avoid significant harm to patients' health, and prevent and circumscribe the use of coercive measures (section 4A-1, subsection 1 of The Patient and User Rights Act 1999). The healthcare is to be adapted with respect to physical and mental integrity; it should be in optimal concordance with the patient's right to self-determination (section 4A-1, subsection 2 of The Patient and User Rights Act 1999).

The purpose of these regulatory requirements is to be able to provide necessary physical health care to patients who do not have the competence to provide consent and who refuse medical treatment. Forced interventions shall always be implemented as a last resort. "Trust-building interventions" is an integrated concept in Norwegian law and legislation (Helsedirektoratet [Norwegian Directorate of Health], 2015, 2017a), and such interventions are required to be used before considering forced treatment and care pursuant to section 4A-3, unless purposeless (Pasient- og brukerettighetsloven [The Patient and User Rights Act], 1999). The rationale for emphasizing trust-building in the relational space between the health professional and the persons with dementia in legislation is to secure necessary health care in the manner least invasive for persons who resist help (Pasient- og brukerettighetsloven [The Patient and User Rights Act], 1999). Forced treatment and care interventions cannot fully remedy the lack of recourse. There are strict terms and case management rules. If the patients persist in their resistance or if health professionals know that the patient would continue to resist healthcare, care can be given involuntarily under the following conditions: a) if omission would cause severe harm to the patient, b) the health intervention is considered necessary, c) the measures taken are proportional to the need for healthcare (section 4A-3, second subsection a, b and c of The Patient and User Rights Act 1999).

When a patient resists health care, and the health care is conferred despite the resistance, it is considered coercion (Pasient- og brukerettighetsloven [The Patient and User Rights Act], 1999). The starting point for section 4A is that patients to the highest possible degree should receive health care services they would have agreed to if they had been capable of consent. It is important to underscore that a patient without the capacity to consent may have rational reasons to resist health care. There are two specific pitfalls that must be considered in situations involving resistance to care: 1) unnecessary coercive practices and 2) negligence of unmet care needs, severe health damage, or death (Helsedirektoratet [Norwegian Directorate of Health], 2015).

If a decision applies for longer than three months, the County Governor must in every case assess whether there is still a need for health care. Decisions regarding admission to and retention in health-care institutions or treatment lasting upwards of three months may be brought before the courts. The County Governor's decisions may equally be brought before the courts should the treatment concern admission to or retention at a medical institution or should treatment last longer than three months.

*Capacity to consent*

In Norway, as in some other countries, the practice of declaring a person "legally incompetent" has been abolished, as it was considered a derogatory term (Gove & Georges, 2001; Vergemålsloven [Act Relating to Guardianship], 2010). According to the Norwegian Patient and User Rights Act (1999), persons who are 16 years and over have competence to consent to health care. The patient (16+) decides whether they want health care, chooses between available health care services, and decides who can access information. For patients over 16 who do not possess competence to consent, the family (next of kin) has the right to information and to decide together with the patient what is in the patients's interest. The capacity to consent may evaporate or dissipate if the patient, due to physical or mental disturbances, dementia, or intellectual disabilities, cannot understand what the consent concerns. In decisions regarding forced treatment and care, it is not sufficient that the person's capacity to consent is reduced; it must be concluded that the patient without a doubt lacks the capacity to consent in relation to the particular health need or intervention. If the person does not have the competence to consent in relation to the specific health need, the health professional in charge must make the decision regarding what constitutes necessary health care. The professional who provides health care decides whether the patient has the capacity to consent to the health care intervention. Health professionals have to make adaptions according to age, maturity, mental state, and experience to facilitate voluntariness to receive health care. A decision to implement forced treatment and care must be informed by next of kin and through an attempt to collaborate with the patient. Decisions regarding the negative capacity to consent must be grounded and written (Helsedirektoratet [Norwegian Directorate of Health], 2015).

In recent years, new tools to assess a person's competence have been increasingly used, such as "Aid To Capacity Evaluation (ACE)" (Etchells, E. (1999) translated to Norwegian by Dahlberg & Pedersen in 2011 (Dahlberg & Pedersen, 2011; Gove & Georges, 2001)). Many of these tools focus on four competencies of the patient, namely the ability to understand, to recognize, to reason, and to perform and make an active choice (Gove & Georges, 2001). Respecting autonomy includes more than enabling the patient to consent; autonomy can still be respected even if the patient no longer has the capacity to consent or has partial competence to consent, such as in daily decisions regarding personal hygiene. There are many situations in which a person with dementia is neither fully able nor completely unable to provide informed consent. She or he may require assistance in deciding. Nevertheless, there appears to be an increasing awareness of the need to involve people with incapacity in the decision-making process and to keep them informed about decisions made on their behalf (Gove & Georges, 2001). Assessments of a patient's competence to consent to health care must account for how invasive the health care will be and the complexity of the situation; it requires a higher level of competence to consent to open heart surgery than to take a blood test (Beauchamp & Childress, 2013, p. 119).

### *Advanced care planning directives*

In Norway, a guardian can adopt responsibility for personal and economic affairs and represent the person with dementia if they lose the capacity to make informed choices and actions; this can be done through a grant of power of attorney. It is possible for a person to privately formalize this decision in advance by writing a statement that is witnessed (no: fremtidsfullmakt). However, such a guardian cannot decide over health care needs concerning whether a person should need to receive forced treatment and care (Vergemålsloven [Act Relating to Guardianship], 2010). Advance care planning (no: forhåndssamtale) and advance care directives (no: livstestamenter) are increasingly used to safeguard shared decision-making and refer to instructions given in advance by the patient regarding different forms of interventions of treatment and care (Friis & Førde, 2017). However, none of these may be used with force. Regarding healthcare decisions where the patient actively resists, it is important to illuminate that these interventions cannot be executed without permission by law, such as Chapter 4A in the Patient and User Rights law (1999).

Advance directives stating that the person wishes for future treatment and care prior to incapacitation are becoming more common in European countries (Gove & Georges, 2001). The refusal of life-prolonging treatment is one example of this. Criticisms of the ethical challenges of implementing advance directives have been problematized for persons with dementia, and they illuminate that advance directives require highly detailed information regarding how to carry them out, such as at what stage of dementia the directive should start (Gastmans, 2013a).

# 3.0 THEORETICAL FRAMEWORK

To fulfill the aim of this study, which is to contribute insight and knowledge about the phenomena of care practices when encountering resistance to care, a broad theoretical perspective has been applied. The rather broad theoretical approach may be criticized because each theoretical perspective is in itself extensive, and it is impossible to devise a completely justified elaboration of each perspective. However, the study of care practices in which persons with dementia resist care is complex, and these practices are clinically, ethically, and legally challenging. Whereas each Article of this study imparted knowledge about more limited research questions regarding these care practices, the aim of this dissertation thesis was to understand and provide new insight into the phenomena.

In this study, selected philosophy and theory that add depth to the understanding of care, trust, professional practices, ethical principles, and paternalism related to care practices involving dementia care have been employed as a theoretical framework. The works by Martinsen (1989, 1993, 2005) and Løgstrup (1997, 2008) were deemed especially relevant to provide insight into the topics of care and trust because their work emphasizes persons in vulnerable situations. Alvsvåg`s (2018) reflections on Martinsen's work contributed additional insight. Together with the person-centered care philosophy approach, it provided important insights into important premises to care for persons with dementia who resist care (McCormack & McCance, 2006; Rokstad, 2021). Bourdieu's work (1977, 1991) on habitus, language, and symbolism was deemed central to the description of professional practices. Furthermore, the writings of Rendtorff and Kemp (2000) and Kemp and Rendtorff (2007, 2008), along with Delmar et.al. (2011) and Delmar (2012, 2018), Gastmans (2013b) and Abma, and Bendien (2019) have facilitated an important understanding of the use of bioethical principles in dementia care. Including previously mentioned theorists and philosophers, Foucault (1991) and Svendsen (2013) were found to offer important perspectives regarding paternalism in health and care services.

In this chapter, the theoretical assumptions regarding care and trust that are relevant to the clinical care of persons with dementia will first be presented. Secondly this chapter introduces the relevant elements of theory related to professional practice. It then presents the bioethical principles important to professional judgement when met with resistance among persons with dementia. Finally, it will elucidate the concepts of power and paternalism, which have important theoretical implications for understanding the legalization of forced treatment and care when extensive and severe health risks are at stake.

## 3.1 Theoretical assumptions of care and trust

The following section delineates some major theoretical assumptions relevant to care and trust in services for persons with dementia who resist care.

Care and trust are fundamental preconditions for our lives. Care means to act in the best interest of the other (Martinsen, 1993, p. 90), and trust refers to a presupposition of all human relations (Løgstrup, 1997, p. xxix). These are sovereign life utterances and precultural phenomena that exist in all cultures. They are fundamental and operate beyond human control. They are sovereign and universal among humans, similar to water, air, time, space, and food (Løgstrup, 1997; Martinsen, 1993).

Martinsen (2005) describes care as a trinity simultaneously consisting of the practical, relational, and moral. In Martinsen's writings she also discusses the boundaries that exist in caring relationships, in relation to which individuals must have respect and should not interfere. These boundaries cannot be trespassed. Martinsen calls them the untouchable zone; the implications of this concept also relate to the work of Løgstrup (Alvsvåg, 2018; Løgstrup, 2008; Martinsen, 2006). In persons with dementia who resist care, the untouchable zone can appear reinforced because the person resists care. A person who has been highly independent of others may fight harder to maintain independence than a person who has been comfortable complying with the needs and desires of others. Knowing the person`s life story is therefore relevant in person-oriented dementia care to respect integrity and untouchable zones. This implies a somewhat reticent position of the health professional and calls for ethical reflection upon professional conduct (Rokstad, 2021). Alvsvåg (Alvsvåg, 2018, p. 127) explains how Martinsen argues that moral practices are deeply embedded in the phenomenon of care. In nursing, it means to discover how the other will be optimally helped, and the basic preconditions to do this are empathy and reflection.

*Trust* is pivotal to care, especially in persons with dementia (Kitwood & Brooker, 2019). The phenomenon of trust has different dimensions and can be understood at different levels. From an ontological perspective, trust may be understood as something pre-cultural, something fundamental that exists in all humans and that is a sovereign expression of life (Eikeland, 2015; Løgstrup, 2008; Saevi & Eikeland, 2012). However, at the executive level and within health care organizations, trust is often understood as a product that can be worked on and manipulated (Bergh & Bjørnskov, 2011; Eikeland, 2015). The existence of trust is believed to be a fundamental asset when providing health care, and it is a prerequisite for the development of a functional care relationship between a health professional and a person with dementia (Bergh & Bjørnskov, 2011). In Alphonso Lingis's trenchant book *Trust: Theory Out of Bounds* (2004), Lingis builds upon Løgstrup`s (1997) work by returning to the core and to the trust that lies behind expectations and structures. Trust is believed to extend beyond what *I* know; it is connected with and adheres to the real individual, namely *you* (Lingis, 2004, p. 64). The person who trusts does not know whether the object of trust is worthy of the trust. The act of trust is thus a leap into the unknown (Lingis, 2004). Trust may be more easily recognized when not present, and Løgstrup (1997, p. xxix) argues that distrust requires a reason, whereas trust does not. There is therefore a difference in ontological status between trust and distrust. To trust is fundamental to being human, and it means to lay oneself open. If the expected response to this openness is not fulfilled, it evokes a feeling of strong emotional character, of betrayal, and of distrust (Løgstrup, 1997, p. 11).

Trust and care for persons with dementia are closely associated. Martinsen (2005) is also concerned with trust and builds upon Løgstrup (1997) in her approach to the phenomenon. She claims that the nurse must be proven worthy of trust, by using her professional judgement, which is always situational, to determine the best solution for the patient (Martinsen, 2005, p. 149). Thus, both Martinsen and Løgstrup contend that if someone has placed their trust in another person, such as a health professional, this demands something of the latter. How much is at stake in this relationship depends upon the condition in which the trustee is situated (Løgstrup, 1997, p. 17). If trust is only partial, or if the individual person learned to hold back earlier in their life, this has consequences for new relationships, such as those between healthcare professionals and patients (Løgstrup, 1997). This implies that in practical nurse-patient relationships, nurses may want to both maintain trust and rebuild trust. On a practical-empirical level, healthcare professionals have the power to carve out room for the sovereign life utterances that are given to us. Persons with dementia may feel insecure and unsafe because they do not manage to analyze the environment around them adequately, or it may be that they have always opposed it in similar situations (Rokstad, 2021). However, if the care approach does not account for this, distrust, rejection, and resentment may arise when expectations are not met (Løgstrup, 1997). The sovereign life utterances of trust, openness, compassion, love, and hope do not disappear because they are beyond our influence. However, health professionals impact how much space they give them in the relationships with the patients. Thus, resistance among persons with dementia can also result from a lack of space and from previous expectations that were not met.

Løgstrup (1997, 2008) conceptualizes trust as an ethical demand. He explains that there is an interdependence of human beings and an ethical demand of trust in a relationship that is unspoken. The ethical situation is one in which the fate of the other person is placed in one’s own hands, and it becomes one’s responsibility to do what is best for them. One holds a part of the other person`s life in one`s hand. In that way, it is therefore a demand to take care of that person`s life (Løgstrup, 1997).

An implication of Løgstrup`s (1997, 2008) argumentation regarding understanding trust as a fundamental part of being human on an ontological and pre-cultural level is a question of whether it is possible to develop trust and whether trust-building can be accomplished at the empirical and cultural level, as suggested in the Norwegian Patient and User Rights Act (1999). The rationale for emphasizing trust-building in the chapter of the law that regulates coercion is that health care is fundamentally voluntary and that this should be sought by building trust to ensure that the health professional is in a position in which he or she can secure necessary health care in the least invasive manner, for persons with dementia who resist help and who lack the capacity to consent (Pasient- og brukerettighetsloven [The Patient and User Rights Act], 1999).

## 3.2 Professional practice

Practice is a social phenomenon that is composed of organized activities (Green, 2009; Schatzki, 2012) (Schatzki, 2012). Several theorists have worked with permutations of practice, including Schatzki (2012), Bourdieu (1977), and Foucault (1991).

Care practices are shaped by ideas and intentions and always involve values (Kemmis, 2010; Schatzki, 2012). Values can both explicit (i.e. expressed in statements) and implicit (i.e. nonverbal and embedded in actions) (Jelstad Løvaas, 2022, p. 16), and can be described rather narrow as standards of right and wrong behavior. However, they may also be described as *existing in a constant process of reformulation and reassessment as we in organizations continually modify our practices and make small innovations in which things are done* (Espedal, Jelstad Løvaas, Sirris, & Wæraas, 2022, p. 5). Furthermore, practices exist in a particular context, and future and past dimensions of activity often determine what people do. Professional practices are suffused with the knowledge and traditions of that profession as well as interrelations with other professionals (Kemmis, 2010). Different participants in a professional practice may have different intentions and are often bearers of different roles to which different values and norms are attached (Kemmis, 2010). Integral features of professional practice are constituted and influenced by individual, cultural, structural, and material features. Situatedness matters, and where the practice takes place is therefore not neutral. What complicates practices of providing health care in a person`s home is that they become intertwined with the social life there (Schatzki, 2012).

If practices are considered open-ended (Schatzki, 2012), it is important to consider the factors influencing these practices. Care practices when encountering resistance to care can be interpreted through the perspective of both individual and extra-individual features, with various aspects influencing them (Kemmis, 2010). Practices must be examined within a context. Previous research has demonstrated that the architectural structure, the time of day, and staff-related factors may be decisive in nurses' decision-making about coercion; additionally, physical–material factors can, when suboptimal, become decisive in nurses' decision-making (Dierckx de Casterlé, Goethals, & Gastmans, 2015).

Bourdieu's outline for a theory of practice (1977) involves three major conceptual categories—*habitus*, *field*, and *capital*. At the heart of Bourdieu's social theory of practice lies the concept of *habitus.* According to Bourdieu, habitus is the "*system of durable, transposable dispositions, structured structures predisposed to function as structuring structures*" (Bourdieu, 1977, p. 72). Habitus is both deeply cognized and embodied at once. It reflects an understanding of one's place in the social world, and it embodies our understanding of the logic of society and the place we have in it.

Bourdieu explores positions in relation to practice, choice, and the possibility of action. The position refers to the places, professions, and traditions which have influenced the individual. Bourdieu (1977) presents dispositions as things that promote care practices via enabling work structures and divisions of roles and responsibilities. Habitus is a system of such dispositions, permanent manners of being, seeing, acting, or thinking (Bourdieu, 1977). Dispositions represent the bundle of recourses a person carries with them when they enter a field. In the present study, it could be related to how nurses are taught to act or think about autonomy and resistance, or about their role in decision-making, when they encounter resistance to care. All the capital or “goods” humans possess can be wielded to assert power (Bourdieu, 1977).

Language is a form of habitus, a practice that bears the traces of the social structures that it both expresses and reproduces (Bourdieu, 1991). Language therefore expresses the emergence of the dominant and legitimate language, a symbolic power, and it must be understood as a social-historical phenomenon (Bourdieu, 1991, p. 4). In modern industrial societies, the possibility of inter-relational symbolic mechanisms has diminished, and one must look closely for them. They can, however, still be identified as, for instance, accents of the upper class, English as the preferred publication language in research, and the use of medicalized language in inter-professional communication, all three having in common a symbolic power of domination. Within this lies a recognition of the right to speak that has associated forms of power and authority (Bourdieu, 1991, p. 8). However, for symbolic power to be exercised, it must be recognized (Bourdieu, 1991, p. 170). This is one of the reasons why it is important to know one’s audience and to know the language and what gives legitimacy and value to the people listening. These theoretical assumptions about practices can be used as analytical tools to study nursing care practices when encountering resistance to care and in the use of forced treatment and care for home-dwelling persons with dementia.

In this study, we understand nursing practices as not being predefined; they are not “clear cut,” and they are inherently somewhat amorphous (Archer, 1998). However, they *are* influenced and limited or promoted by contextual ideology, tradition, and the structures of home health care. The organizational framework of home health and care services is physically limited, time-limited, and recourse-limited, and extra-individual features such as staffing practices, allocated time frames for care, and geographical challenges all influence the possible nursing practices that can emerge during a visit. Temporality is another analytical aspect relevant to care practices, as timing and the use of time are related to power (Bourdieu, 1977). For instance, this can be manifested as a lack of response to inquiries from patients to nurses, or nurses to other health professionals, impeding progress and leaving the person waiting for assistance, for a response and disempowered. Previous research has demonstrated that nurses almost never make decisions concerning physical restraint alone. Care practices are highly influenced by other professionals, patients, family, and other contextual factors and are guided by a procedural–legal context (Dierckx de Casterlé et al., 2015). Thus, care practices occur within a cultural- discursive and social context (Kemmis, 2010). Therefore, context is highly relevant to consider when studying nursing care practices.

However, nursing care practices also depend on the professional judgement of the individual nurse, and they therefore always allow room for asserting a certain amount of individual agency within the constraints of the “conditions of possibility.” On the individual health professional’s level, capability i.e., knowledge, skill, memory attention and decision processes, and behavioral regulation, opportunity i.e., environmental context and recourses and social influences, and motivation i.e. social/professional role and identity, intention, goals, beliefs about capabilities and consequences, optimism, emotion, and reinforcement, will influence how the nurse acts in situations of resistance (Cane, O’Connor, & Michie, 2012; Michie, van Stralen, Maartje, & West, 2011). Alvsvåg elaborates on the differences between *evidence-based knowledge* and *professional judgement* where she argues that the latter includes wisdom, professional judgement, and person-oriented professionality (Alvsvåg, 2013). Alvsvåg builds on Martinsen (2005) that noted that professional judgement is built from connections between perception and impressions in the situation, the professional knowledge and previous experiences, and that person-oriented professionalism is to demand professional knowledge that affords the view of the person as a suffering person and which protects his integrity (Alvsvåg, 2018, pp. 126-127; Martinsen, 1993, 2005).

### 3.2.1 Framework for dementia care practices

Dementia care is a complex social phenomenon influenced by legislative and organizational care mandates on the macro-level, and by individual actions and interactions between professional care providers and between professional and informal care providers and the patients on the micro-level. Studies of dementia care practices, often focus on the micro-level of care (Kontos, Miller, Mitchell, & Cott, 2011). As dementia progresses, there may be changes in the person’s behavior that can be difficult to manage or distressing for the person and the caregivers around them. Contemplating what may cause the behavior and being aware of the person’s needs is therefore important. Several Alzheimer`s organizations emphasize that the form of dementia a person has and the symptoms that develop, have implications for both life expectancy and in determining what treatment and care support may be needed (Alzheimers Society UK, 2021; Alzheimers`s Disease International, 2019). Thus, organizing health and care services for home-dwelling persons with dementia who resist care can be a complex and challenging task because of all the factors that influence care and its` relationships (Dawson, Bowes, Kelly, Velzke, & Ward, 2015; Mengelers et al., 2020 a). Censuses, laws, and policy guidelines generally reflect how the thinking and terminology around dementia care has changed from unilaterally focusing on managing the difficult behavior of the person with dementia to illuminating the person`s needs and quality of life (Helsedirektoratet [Norwegian Directorate of Health], 2017a; Podgorica et al., 2020; Vold, 2007; World Health Organization, 2015). However, minimal research has examined which care approaches should be adopted and what the expected outcomes are when met with resistance from home-dwelling persons with dementias (Mengelers et al., 2020 a; Scheepmans, Dierckx de Casterlé, Paquay, Van Gansbeke, & Milisen, 2020).

### *Person centered care*

Person-centered care support has been found to be the most important treatment and care for dementia, as there is no cure (Kitwood & Brooker, 2019; McCormack et al., 2015; Terkelsen et al., 2019). However, how this philosophy of dementia care is understood and translated into clinical practice is not unambiguous. There appears to be a dissonance between the ideals of policy and practice as experienced by staff and service users (McCormack et al., 2015). For some, the approach may be understood solemnly as individualized care; for others, person-centered care may represent an entire set of values. Thus, in some health care services, it represents a mélange of methodological interventions, whereas in others, it permeates all thinking and approaches on a phenomenological level (Rokstad, 2021).

The philosophy of person-centered care emphasizes that persons with dementias need high-quality interpersonal care that meets their fundamental and individual needs, and it stresses that the care relation implies recognition, respect, and trust (Kitwood & Brooker, 2019). The special relevance of person-centered care for persons with dementia has the point of departure wherein the person is understood first and foremost as a person. A person with value and worth (Rokstad, 2021). When the person with dementia does not understand or resists care and treatment, the person-centered care approach can be valuable to prevent or reduce the use of forced treatment and care (Fazio, Pace, Flinner, & Kallmyer, 2018; Kitwood & Brooker, 2019; McCormack et al., 2015). An emphasis on the person's resources as opposed to an emphasis on the symptoms and challenges of the dementia syndrome is understood as fundamental to person-centered dementia care (Kitwood & Brooker, 2019). Dementia is understood as a combination of various factors, including organic brain failure, health, life-story, personality, and changes in social relationships (Rokstad, 2021, p. 32). Approaches that focus on building relationships, collaboration, and holistic care have become common (Rokstad, 2021). McCormack and McCance developed a person-centered nursing framework consisting of four constructs: 1) *prerequisites* that focus on the attributes of the nurse; 2) *the care environment*, which focuses on the context in which care is delivered; 3) *person-centered processes*, which focus on delivering care through a range of activities; and 4) *expected outcomes*, which are the results of effective person-centered nursing and encompass satisfaction in care, feelings of wellbeing, and creating a therapeutic environment (McCormack & McCance, 2006, p. 475). The individualized person-centered approach has become well-established as the expected approach within dementia care (Bartlett & O'Connor, 2007; Fazio et al., 2018).

There seems to be a common understanding that wellbeing and appropriate treatment and care to mitigate the consequences of dementia are important goals for care (Alzheimer Europe, 2020; Alzheimers`s Disease International, 2019; Livingston et al., 2020). Within empirical research, approaches that are individualized, scalable, and flexible have been identified as important in care services for persons with dementia (Dawson et al., 2015; Livingston et al., 2017). Trust-building interventions to reduce resistance and to prevent involuntariness are important to safeguard person-centered care for persons with dementia (Kitwood & Brooker, 2019; Ot.prp. nr. 64 (2005–2006), 2006; Pasient- og brukerettighetsloven [The Patient and User Rights Act], 1999). Care for people with dementia should emphasize physical and mental health, social care, and support (Livingston et al., 2020).

In later years, the concept of citizenship for persons with dementia has enhanced dementia care by emphasizing the importance of a macro-level focus which incorporates a contextual, environmental, and political approach, such as via the promotion of age-friendly or dementia-friendly societies (Bartlett & O'Connor, 2007; Hebert & Scales, 2019; O’Connor & Nedlund, 2016; World Health Organization., 2007). However, it continues to be a challenge to uphold and implement these philosophies of dementia care in home health care practice due to the constantly changing structures of care. The provision of dementia care within a system that is centered around cost-effectiveness, goal achievement, lack of personnel, and increased technology use is an extremely challenging and complex task (Rokstad, 2021).

In many areas, policy and practice developments are proceeding on the basis of limited evidence (Dawson et al., 2015). Holistic person-centered care appears to require extensive knowledge of the patient and illuminates the advantage of having few persons involved to establish a relationship of trust between the healthcare professional and the patient. New care service landscapes are developing which suggest increased specialization is the future; these new systems have established specialized services for different patient groups and their needs, patients with dementia being one of them (Sogstad et al., 2020). At the same time, care teams are increasingly implemented in which one team revolves around the general practitioner, registered nurses, and perhaps physiotherapists, who provide care that requires specialized knowledge in one team, and other care staff provide basic care in another (Blix, Stalsberg, & Moholt, 2021; Fjørtoft, Oksholm, Delmar, et al., 2021; Sogstad et al., 2020). However, the crucial question concerns where persons with dementia who resist care fit in the new landscape and how future dementia care practices evolve.

## 3.3 Ethical principles of care

The rights to liberty, respect for privacy and family life, and the prohibition of torture are codified in the European Convention of Human Rights (European Court of Human Rights, 1950).

In the early 1970s, bioethical questions (concerning all life) arose, and in the report from the European Commission on Basic Ethical Principles in European Bioetics and Biolaw. Vol. 1, the four ethical principles *containing respect for autonomy, respect for dignity, accounting for integrity, and care for the vulnerable* were presented as embedded and guiding values of Europe`s different cultures and legislation (Alvsvåg, Aadland, & Nitter, 2019; Rendtorff & Kemp, 2000). The respect for inherent dignity, individual autonomy, and the freedom to make one's own choices are guiding principles stipulated in the Convention of Rights of Persons with disabilities (CRPD) (UN General Assembly, 2007). On the basis of the Barcelona Declaration, in 1978, Beauchamp and Childress developed the four principles of biomedical ethics: *autonomy, non-maleficence, beneficence, and justice*(Alvsvåg et al., 2019; Beauchamp & Childress, 2013).

The bioethical and biomedical principles have been guiding tenets and are important foundations for modern legislation regulating patient and user rights, persons with dementia who resist care included. The application of core ethical principles such as autonomy and vulnerability in the context of dementia is thus both guided and regulated by legislation (Beauchamp & Childress, 2013; Kemp P.; Rendtorff J.D, 2007; Pasient- og brukerettighetsloven [The Patient and User Rights Act], 1999; UN General Assembly, 2007).

However, the understanding of the guiding principles is not straightforward. The bioethical approach builds on the foundational premise that we are vulnerable and all capable of being wounded by the uncompassionate (and sometimes paternalistic) actions of others (Rendtorff & Kemp, 2000). Similar to the sovereign-life utterances, it is something given as an absolute point of departure. It is an underlying assumption that children, persons with dementia and with developmental disabilities, persons who are incapacitated, and generally all the people who, perhaps without realizing it, are strongly dependent on other people, can be intellectually and/or physically incapable of protecting themselves. The Barcelona Declaration recognized a need for the protection of such vulnerable groups who require extra protection (Rendtorff & Kemp, 2000). The work of the Barcelona Declaration originated from the discourse surrounding bioethics related to the limits of the principle of respect for autonomy (Kemp & Rendtorff, 2008).

In the following, an introduction to the principles of autonomy, dignity, integrity, and vulnerability will be provided.

### *Autonomy*

The word "autonomy" derives from Greek and can be translated as "self-rule" (Beauchamp & Childress, 2013). Respecting a patient's autonomy means respecting their right to make independent decisions regarding his or her body and to support their decisions and wishes. In modern society and in health care, it is an ethical principle that autonomy must be respected regardless of the person's competence to consent (Beauchamp and Childress, 2013, p.101). This may be one of the reasons why self-determination is a protected value.

However, judgements of autonomy involving the assessment of the capacity to consent are complex and must be nuanced. According to Rendtorff and Kemp (2000) and Kemp and Rendtorff (2008), autonomy should not only be interpreted in the liberal sense of "permission." Instead, the following five aspects of autonomy have been suggested: 1) the capacity to create ideas and goals for life; 2) the capacity of moral insight, "self-legislation," and privacy; 3) the capacity of rational decision and action without coercion; 4) the capacity of political involvement and personal responsibility; and 5) the capacity of informed consent. It is emphasized that autonomy remains an ideal because there are structural limitations in exercising it due to human weakness and dependence on biological, material, and social conditions, lack of information for reasoning, etc. Autonomy in relation to small children, persons in a coma, and persons who are mentally ill should remain an open question (Kemp & Rendtorff, 2008; Rendtorff & Kemp, 2000).

In much empirical research and political guidelines for dementia care, autonomy is closely linked to self-determination, empowerment, and a person's right to choose (Delmar, 2018; Gastmans, 2013b; Helse- og omsorgsdepartementet [The Ministry of Health and Care Services], 2018; Helsedirektoratet [Norwegian Directorate of Health], 2017a). The unilateral focus has been criticized, and ethical frameworks for dementia care emphasize the need to balance autonomy, dignity, and vulnerability in care for persons with dementia (Delmar, 2018; Gastmans, 2013b). A failure to acknowledge vulnerability at the structural level may exacerbate unfulfilled care needs (Delmar, 2018; Fineman, 2010). A crucial element of the principle of respect for autonomy is the right to refuse treatment (Abma & Bendien, 2019). When impairment due to dementia progresses, it can be difficult to balance the person's right to self-determination and the duty of professional care responsibilities (NOU 2019:14, 2019). In recent years, the focus has shifted from the physician's obligations to care towards the quality of the patient's understanding and their competence to consent (Beauchamp & Childress, 2013, p. 121). Informed consent and voluntariness are important pillars of health care. The forces of this shift have been autonomy-driven.

### *Relational autonomy*

The theory of autonomy challenges the understanding of autonomy as self-determination and proposes that autonomy  is a "relational" concept (Alvsvåg et al., 2019, p. 112; Stoljar, 2011, p. 376). Relational autonomy was introduced as a concept that emphasizes the relations of dependence and connection as being constitutive of one's autonomy (Abma & Bendien, 2019). The idea of relational autonomy is that most of us need others to ask for advice, who are willing to give us advice, and who warn us against deleterious choices. Relational autonomy is an umbrella term which refers to a view of autonomy wherein all persons are dependent on others even when we act autonomously (Abma & Bendien, 2019; Mackenzie & Stoljar, 2000). The concept also differentiates between decisional and executive autonomy, which has been found to be important when assessing the capacity to consent in persons with dementia (Abma & Bendien, 2019). Decisional autonomy refers to the capacity to make one's own decisions, whereas executive autonomy refers to the realization of those decisions (Abma & Bendien, 2019; Naik, Dyer, Kunik, & McCullough, 2009). Naik et al. discuss the concept of *voluntariness* in the context of chronic illness, and it should be updated to include an emphasis of freedom. Freedom, understood as not merely free of coercion, but also free of internal impairments due to the person's condition that inhibits goal-directed actions. Impairments of intentionality or voluntariness can threaten the person with dementia`s ability to adhere to an agreed-upon treatment plan; for instance, the geriatric syndrome of self-neglect can have this affect (Naik et al., 2009). Supported by the bioethical principles, Naik et.al. (2006) posits that traditional understandings of self-determination and decision-making capacity may be inadequate for differentiating the capacity for self-care and protection in elders who self-neglect (Naik, Pickens, Burnett, Lai, & Dyer, 2006; Rendtorff & Kemp, 2000). In these situations, paternalism may be necessary to avoid care neglect (Alvsvåg et al., 2019, p. 113). The complexity of assessing autonomy among persons with dementia suggest that these two types of autonomy have to be known and applied by the care professionals who work with them (Abma & Bendien, 2019).

### *Dignity*

Dignity encompasses both the intrinsic value of the individual and the inter-subjective value of every human being in one's encounter with the other (Kemp & Rendtorff, 2008). This concept is linked to its etymological origin of "worthiness and proper." However, dignity means different things to different people. Dignity-preserving dementia care is therefore not easily defined (Tranvåg, Petersen, & Nåden, 2013). A meta-synthesis performed by Tranvåg et.al. in 2013 linked autonomy, integrity, and dignity in dementia care to having compassion for the person, confirming the person's worthiness and sense of self, and creating a humane and purposeful environment. They found that balancing individual choices for persons who are no longer able to make sound decisions against the duty of making choices on behalf of the person was a crucial aspect of dignity-preserving dementia care. Professional caregivers felt an ethical duty to protect the person from harmful consequences that would violate their physical integrity and their integrity as a whole. Persuasion and/or mild restraint were sometimes perceived as necessary and as conducive to integrity, especially in relation to medication and personal hygiene (Tranvåg et al., 2013). Thus, the respect for dignity and integrity are intertwined in care for persons with dementia.

### *Integrity*

The idea of integrity encapsulates respect for the untouchable core, the basic condition of dignified life, both physical and mental, which must not be subject to external intervention (Rendtorff & Kemp, 2000). Martinsen describes this as belonging to the untouchable zone of a person (Alvsvåg, 2018). Integrity accounts for the inviolability of the human being (Kemp & Rendtorff, 2008). Thus, respect for integrity encompasses respect for privacy, one's personal environment, and the patient's understanding of their own life and illness in body and soul (Kemp & Rendtorff, 2008). In care, it entails accounting for and respecting the life story of a person (Rendtorff & Kemp, 2000). Kemp and Rendtorff (2008) describe integrity as the most important principle for the creation of trust between physician and patient because it demands that the physician listens to the patient and effectively conveys the story about their life and illness.

### *Vulnerability*

Vulnerability is linked to its Latin origin "*vulnus*" and the possibility of suffering that is inherent to human beings. In the philosophical approaches that address this concept, it is common to conceive of vulnerability in relation to fragility, susceptibility to damage, and suffering. In addition to the universal and shared features of vulnerability in human beings, another shared feature of these perspectives is that they link our vulnerability with our inherent sociability and with the inevitable fact that we are dependent on one another (Delgado Rodriguez, 2017, p. 156).

Respect for vulnerability is a recognition of the finitude of life and particularly the earthly suffering inherent to human beings, and it requires caring for the vulnerable (Kemp & Rendtorff, 2008). All life is vulnerable, but it is especially important to respect the vulnerability and untouchability of those whose autonomy, dignity, or integrity are capable of being threatened. This principle requires not merely non- interference with the autonomy, dignity, or integrity of beings, but also that they receive assistance to enable them to realize their potential (Rendtorff & Kemp, 2000).

There has been extensive criticism of the concept of vulnerability, especially with regards to persons who are not capable of consent, as in the case of persons with dementia. This criticism argues that protection for the vulnerable carry the risk of being paternalistic. The protection measures established because of vulnerability may open the door to unjustified versions of paternalism (Delgado Rodriguez, 2017). This can be recognized in the shift from a person-centered care approach to a citizenship approach, where the latter emphasizes the person with dementia's recourses, rights, and potential to be active citizens of society (Bartlett & O'Connor, 2007). Thus, the development of age-friendly societies may prompt a shift in the emphasis from disability and vulnerability to citizenship for persons with dementia, which is important.

However, accounting for vulnerability is essential to policy making in the modern welfare state (Fineman, 2010; Kemp & Rendtorff, 2008). From a bioethical perspective, it entails caring for and contributing to realizing the potential of the other. Future demographic challenges surrounding care needs related to dementia must be accounted for. According to Martha Fineman`s (2012) theory of vulnerability, vulnerability is universal and constant; it is part of the human condition. From her perspective, "the concept of vulnerability reflects the fact that we all are born, live, and die within a fragile materiality that renders all of us constantly susceptible to destructive external forces and internal disintegration" (Fineman, 2012, p. 2). This entails a series of social protection and state responsibilities, as vulnerability cannot be eradicated, but it can be compensated for (Delgado Rodriguez, 2017; Fineman, 2008, 2010, 2017).

## 3.4 Power and paternalism in care

The use and abuse of power in health care has a lengthy and troublesome history (Andrews, 2017; Foucault, 1991; Vold, 2007). Michel Foucault`s (1926-1984) perspectives on power have been influential and have been used as a theoretical lens to examine the development of professional health and social care work practices. In the book *Madness and Civilization*, Michel Foucault chronicles how Western societies came to conceptualize "madness" and mental illness by the end of the 1700s and its development into modern health care (Foucault, 1991). In large psychiatric institutions, the ideals of family structure were reconstructed. Paternal authority belonged to the physician and the father as the head of the family. He knew best, and the children (the mentally ill patients) were in need of penitence for their sins; they needed to obey and learn; if not, they would be punished (Foucault, 1991, p. 226).

Power and paternalism are "naturally" still linked in discussions that relate them to professional health and care practices (Jacobsen, 2015). Paternalism, soft paternalism, and weak paternalism are the concepts most frequently used to define forced treatment and care in philosophical literature about forced treatment and care in health and care services (Alvsvåg et al., 2019; Dworkin, 1986; Foucault, 1991; Martinsen, 2005; Svendsen, 2013). According to Alvsvåg et.al. (2019, p.170), paternalism means that one person defines themselves as superior to another person and exercises a form of fatherly (paternal) intervention into another person's life . Hard paternalism does not consider whether an action is voluntary, *but judges exclusively whether the intervention will promote a person`s welfare, happiness, interests, values,* etc. If the agent chooses a suboptimal alternative of action, *it is legitimate to interfere to secure the best possible result* for the agent. Soft paternalism is understood as the *possibility to prevent someone from engaging in involuntary actions that would harm them, or to temporarily prevent them from engaging in these actions to examine whether they do them voluntarily*. Svendsen also describes the *weak paternalist* who considers it legitimate to interfere to guarantee that the person chooses the measures that are adequate to reach the goals the person has established

(Svendsen, 2013, p. 208). It is the definition of soft and weak paternalism that is closest to the justification of interventions of forced treatment and care in the Norwegian Patient and User Rights Act, Chapter 4A (1999).

The establishment of the person-centered care approach can be understood as a counterculture that arose towards the existing management of dementia care, shifting the emphasis from paternalism, protecting society, and performing necessary tasks, to a care approach wherein the *person* of dementia became the center of attention(McCormack et al., 2015). The philosophy of person-centered care has revolutionized conceptions of embedded paternalism in dementia care (Dewing, 2008; Kitwood & Brooker, 2019; McCormack et al., 2015; McCormack & McCance, 2006). Kari Martinsen (2005) also discusses paternalism. She discusses the moral challenge and posits that in caring for the other person, there is always a possibility of conflict, which may degenerate into abuse and ruthlessness, but also of compliance and the “sin of omission” (Martinsen, 2005, p. 157). The first arises as a result of overprotection and paternalism, the latter from respect for self-determination that is excessive (Martinsen, 2005). Neither excessive use of power or guardianship, nor sentimentality by solemnly responding to emotions and by negligence of needs due to compliance, are expressions of care according to Martinsen. This perspective is particularly relevant to care for persons with dementia who resist care because they are in vulnerable situations, because they are at higher risk of the use of force and restraint, and because they may suffer from unmet needs (Scheepmans et al., 2017; Scheepmans, Milisen, et al., 2018).

Martinsen states that the situation in which the health professionals act is complex, problematic, and characterized by dilemmas (Martinsen, 2005, p. 138). To care is to establish a connection or a relationship. Power and other forms of dependency are always present in such relationships; therefore, the existence of trust as a phenomenon is central in nursing care practices. However, the balance of power in care may be tipped either towards carelessness in the form of omission or towards guardianship and paternalism (Martinsen, 2005, p. 137). Paternalistic care is to deprive the other of participation in their own life, to assume that the professional knows what is best for the other. Through the tone or approach adopted by the professional, the patient becomes powerless (Martinsen, 2005, p. 145). Martinsen explains how professionality is needed to guide us through difficult and challenging paths of care. We sometimes need rules and norms to inform our actions. Where trust is broken, rules may help guide our behavior and guard the values that are threatened. Rules may help us when acting based on professionality alone becomes difficult (Martinsen, 2005, p. 149).

Along with Løgstrup (1997) and Abma and Bendien (2019), Martinsen states that relationships and dependencies are fundamental in human lives, and her perspective refutes the understanding of humans as individuals, autonomous and standing alone (Martinsen, 2005). Both methods of providing services, paternalism and sentimentalism, concur that the sensitivity of the other has disappeared. In neither of them will the health professional be able to inherit the vulnerability, sensitivity, or honesty that is necessary to retain the other person's trust. To elicit the other`s disclosure, professional judgement must balance distance and closeness in the relation and in the situation at hand. Martinsen emphasizes the value of a soft paternalism where the nurse, with knowledge, interest, and sensitivity toward the patient`s wellbeing, makes a professional judgement of the situation to secure what is best for the patient (Martinsen, 2005, p. 147)

Charlotte Delmar (Delmar, 2012, 2018; Delmar, Alenius-Karlsson, & Mikkelsen, 2011) builds on Martinsen (2005) and has also offered perspectives regarding the nurse-patient relationship and how fundamental aspects of care relationships such as dependence, trust, and power may be approached. In "*The excesses of care; a matter of understanding the symmetry of power*," Delmar (2012) discusses the excesses of care and its two outliers, paternalism against sentimentalism. She argues that it is an ethical demand to provide care that maintains the patient's latitude for action and fosters a relationship of trust. She illuminates that this is fundamental to care philosophy but not always possible to achieve in clinical practice (Delmar, 2012, p. 236). The asymmetry of power in the care relationship is elaborated upon, and Delmar argues for relationship-based caring, wherein patient actions are not constrained, and care does not degenerate into overprotectiveness or paternalism (Delmar, 2012).

Delmar states that "*in the health care sector and our society in general, independence of others' help, self-dependence, self-determination, and the opportunity to choose and take responsibility for one's own life is a dominant value called autonomy"* (Delmar et al., 2011, p. 1). Delmar questions whether autonomy is always in the best interest of the patient, and she asks whether it is an unfortunate, or perhaps misunderstood, concept with high demands on patient activity that may result in the neglect of patient dignity (Delmar et al., 2011, p. 2). There is a dilemma between the value of independence (as the oft-preferred translation of autonomy) and the actual dependency on others that being a patient entails (Delmar et al., 2011).. She states that *"self-management has become such a dominant value that there is a risk of abandoning the patients"* (Delmar et al., 2011, p. 7). She poses a question that is crucial to the present PhD study: "*We may legitimately ask whether the ideal of self-management is always in the patient's best interest or whether it can pose a threat to the patient's dignity and integrity" (*Delmar et.al., 2011, p. 8). Her reflection upon the question is that emphasizing ideals of self-management and independence as foundations of nursing care may place the person in vulnerable position when that person is in dire need of professional care (Delmar et al., 2011, p. 8). Delmar (2018) thus supports the criticism of the ideals of new public management of self-management and involvement that she argues may result in failure to take responsibility and to allow care neglect. She views it as a pitfall in the moral responsibility of nursing. Nursing care is based on a relational view of humanity wherein one's moral responsibility for fellow human beings is a key element. Delmar highlights that nursing care must reclaim care as a value and to assess the right amount of responsibility distributed between the patient and the nurse, depending on the individual situation (Delmar, 2018, p. 322). Consistent with Martinsen (2005) and Delmar (2018), Annemarie Mol (2008), another Danish philosopher, also criticizes the neoliberal shift within health care organizations. She adds that good care is not equivalent to patient choice and that creating more opportunities for patient choice will not necessarily improve health care. The logic of care is not merely a logic of choice (Mol, 2008).

The development of legislation and bioethical principles has been important for the discourse surrounding power and paternalism in relationships between health professionals and patients. The Convention on the Rights of Persons with Disabilities that was enacted in 2008 has been crucial in the ongoing work to protect the rights, dignity, and empowerment of persons with disabilities, including persons with dementia (UN General Assembly, 2007). Human rights and legislation regarding patient rights have been developed to protect people from malpractice, to safeguard autonomy and dignity, and to be inclusive of persons with disabilities in society. The present discourse about power is driven by a human rights and patient rights perspective that emphasizes self-determination and freedom and strongly rejects the notion that health professionals should adopt paternalistic measures in treatment and care.

The place of coercion in the care of older people is therefore surrounded by a complex discussion within bioethics (Abma & Bendien, 2019). The discourse regarding paternalism is additionally complicated by the fact that the empirical research concerning the use of paternalistic approaches employs different concepts to measure and describe it in clinical dementia practice. These include involuntary treatment, non-consensual care, forced treatment and care, soft paternalism, resistiveness to care, restraint, and physical restraint (Gjellestad, Oksholm, & Bruvik, 2021; Martinsen, 2005; Mengelers et al., 2020; Scheepmans, Dierckx de Casterle, et al., 2018; Scheepmans et al., 2017; Spigelmyer et al., 2018 b,; Vandervelde et al., 2021). While the concepts above are more associated with dementia care research, the concept of coercion is more commonly invoked in mental health care (Hem, Gjerberg, Husum, & Pedersen, 2018; Svendsen, 2013; Wertheimer, 1987, 1993). Thus, within health and care services, there is no universal understanding of what the concept of paternalism, or forced treatment and care, constitutes because of differences in traditions, definitions, policies, and laws (Bleijlevens, Wagner, Capezuti, Hamers, & Workgroup, 2016; Moermans et al., 2018; Richardson, 2008; Scheepmans, Dierckx de Casterle, et al., 2018; Wickremsinhe, 2018; World Health Organization, 2019a).

The consequence of this is that the discourse surrounding the concept of forced treatment and care is not necessarily about the same phenomenon. However, one persistent characteristic is that the concept and the discourse surrounding it is highly value laden and controversial. All concepts of involuntariness are related to power in a patient-health professional relationship.

# 4.0 AIM OF STUDY AND RESEARCH QUESTIONS

In the following chapter the aim and research questions will be presented.

## 4.1 Aim of study

The overall aim for the study was to provide new knowledge and insight into described care practices related to resistance to care and how they were assessed and managed at the intersection between ethical, legal and clinical judgement.

This was examined and explored through two empirical studies that resulted in three Articles.

1. The aim was to gain insights into formal decisions of forced treatment and care to home-dwelling persons with dementia (Study 1- Article 1).

2. The aim was to explore the use of trust- building interventions to home-dwelling persons with dementia who resist care (Study 1- Article 2).

3. The aim was to explore nurses` professional judgements when encountering resistance to care among home-dwelling persons with dementia (Study 2 – Article 3).

# 5.0. PHILOSOPHY OF SCIENCE

The following chapter elucidates the underlying scientific, philosophical, and epistemological assumptions of the thesis. Research paradigms are characterized in terms of how they respond to basic philosophical questions, such as the following: What is the nature of reality? (ontology) and how do we learn about reality? (epistemology) (Polit & Beck, 2008). The underlying philosophical assumptions behind this study are influenced by critical realism.

My interest in critical realism as a research perspective was sparked by one of my first introductory courses, namely *"Philosophy of Science, Research Methods and Research Ethics,"* in the PhD program at VID and has developed steadily since then. The underpinning idea behind critical realism is that reality can exist independent of human thought, experiences, or knowledge of it; this is in accordance with how I understood the appearance of the phenomenon of forced treatment and care. It is an assumption that the power and potential for exercising forced treatment and care exists (on an ontologically real level) independent of our ideology, knowledge, and awareness about it, and regardless of whether it is experienced or reported. However, it is also an assumption that the interventions of forced treatment and care can be observed and experienced independently of the point of the departure for these actions. They are still experienced as forced treatment and care, even though the health professionals' intentions were to do what was necessary and assessed as optimal for the patient.

The approach to critical realism employed in this study is based on the early phase of Roy Bhaskar (1944-2014)(Bhaskar, 1998b). Critical realism was developed in the 1970s and was anchored in a critique of the positivist conception of empirical observations as the foundation for science that had dominated during the first two-thirds of the century (Bhaskar, 1998a). Other scientists, particularly Margareth Archer, Tony Lawson, and Andrew Collier (Archer, Bhaskar, Collier, Lawson, & Norrie, 1998), have provided important contributions to the philosophy.

Bhaskar, who was an English philosopher of science, initially named the philosophy "transcendental realism" in *A Realist Theory of Science (1975)* and later extended it to critical naturalism in *The Possibility of Naturalism (1978)(*Archer et al., 1998*)*. The concept of *transcendental* refers to a position that asks what reality must look like for scientific knowledge to be possible and beyond the precondition of human experience (Bhaskar, 1998a, p. xii). *Naturalism* refers to the possibility of providing an account of science that encompasses both naturalistic and social sciences, while acknowledging that the methods used are and must be different (Buch-Hansen & Nielsen, 2005, p. 37). The term "critical realism" was an amalgam of transcendental realism and critical naturalism (Bhaskar, 1998a, p. ix). Critical realism is a broad philosophical concept that has been applied in many branches of science, namely economics, information systems, and increasingly in nursing sciences

(Brown, Hecker, Bok, & Ellaway, 2021; Kontos et al., 2011; Mingers, Mutch, & Willcocks, 2013; Sayer, 2000; Schiller, 2016).

It is not within the scope of this thesis to impart a justified elaboration of all that is included in this philosophical position. I therefore have opted to integrate central aspects that were analytically relevant to this thesis.

## 5.1 Ontological perspective

Realist inquiry, based on the philosophy of critical realism, focuses on exploring the underlying mechanisms that drive social phenomena (Brown et al., 2021). Bhaskar argues that Western philosophical tradition had mistakenly reduced the question of *What is (ontology)* to the question of *What we can know (epistemology)*. An important aspect of the approach of critical realism is therefore to distinguish between the real world (what is) and the observable world (what we can know). In critical realism, ontology and epistemology are separated (Bhaskar, 1998b). Ontology, an intransitive dimension, has more fundamental characteristics than epistemology, which is a transitive dimension. Ontology cannot be reduced to epistemology and vice versa. Critical realism claims to integrate the *ontologically realistic point of departure* with *epistemological relativism and judgmental rationality* (Bhaskar, 1998a, p. xi).

The world as *we know and understand it* is constructed from our perspectives and experiences, through what is observable. Epistemology is *transitive* because knowledge changes over time. However, there is another dimension of reality, *the real world*, which exists and behaves in the same manner regardless of whether people exist or whether they know about the real world. Science is regarded as a social product, but the mechanisms it identifies operated prior to the scientific discovery (Bhaskar, 1998a, p. xii). Thus, according to critical realists, unobservable structures (hidden or taken for granted) belonging to the real domain can *cause* observable events. The social world can be understood only if people understand the structures that generate these events (Archer et al., 1998).

### *Reality as layered and stratified*

What differentiates critical realism from other paradigms is that Bhaskar uses various domains to describe reality (Figure 1). Reality is both multi-dimensional and stratified as well as open and differentiated (Bhaskar & Lawson, 1998, p. 5). Reality can be explained as (at least) a three-layered ontological model (Figure 1) that encompasses the empirical domain, consisting of experiences; the actual domain, consisting of events; and the real domain, consisting of objects, structures, and causal mechanisms (Bhaskar, 1998b; Brown et al., 2021; Buch-Hansen & Nielsen, 2005). Reality consists of the empirical and the actual domain, which constitutes what can be observed; critical realists claim that research most often refers to and is even reduced to this in empirical research; the third domain, which for critical realists possesses central significance and status, is therefore called the real domain

(Bråten, 2016, p. 125; Buch-Hansen & Nielsen, 2005, p. 27). Bhaskar argued that reality has even more *depth* than these three layers and that knowledge can penetrate deeply into reality without ever reaching the “bottom,” thus allowing for *further stratification within the real domain.*

*Similar perspectives*, even if not defined as critical realist, are recognized within the theoretical assumptions of Martinsen (2005), Løgstrup (1997), and Lingis (2004), who conceive of trust as a pre-cultural and sovereign life utterance, something that is independent and beyond human action and influence. Within the critical realist perspective, pre-cultural and sovereign life utterances would belong to the real domain. However, within this view, social structure may have a long time horizon compared to the human action level (Archer et al., 1998; Bråten, 2016). Social structures exist prior to individuals, at the same time as they are transformed and reproduced by individuals (Bråten, 2016). Agency, culture, and social structure are not mutually exclusive properties; they are simply concerned with and in interplay between different ontological levels (Bråten, 2016, p. 132). Therefore, the real domain does not exclusively relate to the pre-cultural phenomena; it also encompasses underlying cultural structures and mechanisms, including temporalization and temporal dimensions of social life, which may generate different phenomena (Bhaskar, 1998b; Bråten, 2016).

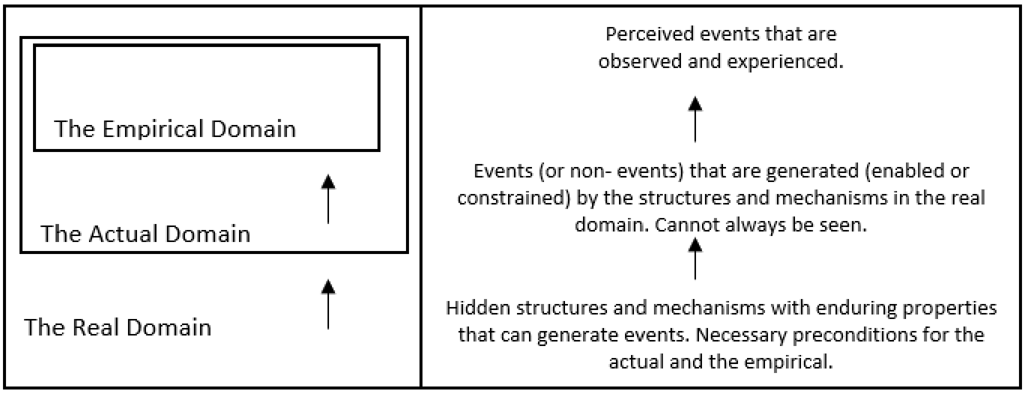


Figure 1. The stratified ontological domains of critical realism (inspired by Buch-Hansen and Nielsen (2005, p. 24)

Critical realists thus understand reality as hierarchically layered also within the real domain, wherein the highest level of the social reality of class structures is dependent on the existence of human, biological, or physical-chemical mechanisms on the lower levels (Figure 1) (Buch-Hansen & Nielsen, 2005, p. 29). However, the division of layers is unlimited, and the philosophy of critical realism does not precisely clarify which levels reality is comprised of (Buch-Hansen & Nielsen, 2005).

In the present study, the phenomena of care and trust can be understood as both belonging to the real domain, as they are pre-cultural and enduring properties, and to the actual and empirical domains, as observable actions or perceptions of quality dementia care or relief if given space, or as mistrust if space is not emphasized. Trust and care will continue to exist in humans independent of whether there are mechanisms that generate caring or trust-building actions on the lower levels. Cultural phenomena such as caring and trust-building actions are generated on the actual domain level. However, they may or may not be observed or experienced as such on the empirical domain level.

The phenomenon of paternalism is closely linked to the phenomenon of power. It may therefore be understood from a broader perspective rather than merely as the exercise of actions of forced treatment and care. However, paternalism is most frequently recognized on the actual level as actions of forced treatment and care and as measurable observations or experiences, such as decision-related documents, resistance to care, and registered unmet care needs on the empirical level. However, paternalism may also be understood to belong to the real domain, as the potential for abuse that is sometimes hidden in power structures in relationships. It can be argued that the intentions preceding actions of forced treatment and care do not truly matter if they are experienced as the use of coercion by the person with dementia. On the other hand, the paternalism is that observed or experienced in the actual and empirical domain can also be rooted in something that originates from the opposite, namely pre-cultural sovereign life utterances of compassion and care (in the real domain). The demand to take care of the other when the person cannot manage it themselves. This is in concordance with the perspectives of Martinsen (2005), Delmar (2012) and Delmar et.al (2011).

The phenomena of trust, care, and paternalism are thus similar but still fundamentally different. Trust and care can be understood as pre-cultural and have in common that they represent positive entities; we argue that they exist on an even deeper fundamental and existential level of the real domain relative to the phenomenon of paternalism. Trust-building interventions, care practices, and coercive practices are intertwined. They are enabled and/or constrained by underlying ideas or attitudes that generate them that are often hidden. When analyzing these phenomena, we therefore cannot merely study the objective outcomes, namely coercion versus no coercion, because it would not reveal the complexity of the phenomena. We also must examine the mechanisms and organizational and contextual factors influencing and causing these outcomes.

*Transitive and intransitive*

This transcendental model of critical realism is applicable both to the physical world and to the human-social world, with a recognition that the social world is in a much greater state of flux than the physical world, as social structures change more easily than, for instance, a tree (Bhaskar, 1998b).

Transcendent reality exists beyond human conceptualization (Bråten, 2016). Within the understanding of reality, core tenets of the philosophy of critical realism are that some objects or structures are intransitive, and some are transitive. The intransitive are the structures that continue to exist for a long time. Other objects or structures are transitive because they are more easily transmuted. Transitive knowledge relates to malleable qualities of our knowledge of reality; thus, the transitive dimension is comprised of the events and structures that make us understand the intransitive dimension. However, within the reality of the social world (Figure 1), there are structures that are deeper and more impervious to change than others. These are considered intransitive properties or powers not derived from cultural worldviews.

In relation to the present study, both care and trust are phenomena that belong to the intransitive dimension. Martinsen (2005) and Løgstrup (2008) describe them as sovereign life utterances; they are a pre-cultural, fundamental part of human beings that we are born into and born with and, that cannot be stripped from us. How they become translated into nursing action depends on individual knowledge, the particularities of the situation at hand, and the structures governing where care is provided. Thus, critical realism intends to describe both the pre-cultural world and the dialectics of the sociocultural forms.

From a critical realism perspective, paternalism may also be understood on an intransitive level wherein the power to conduct it exists independent of whether it generates observable coercive interventions or whether these are considered the best solution for the patient. Paternalism still exists even though persons perceive different actions of forced treatment and care very differently. Some persons may perceive being forcefully admitted to a nursing home as extremely intrusive, while others may experience the use of force in providing personal hygiene as worse. The power of paternalism as a phenomenon is therefore broader, something that persists over time and is not easily changed or influenced by actions.

### *Structure and agency*

The critical realist response to the “structure-agency problem” is that when analyzing social change, an analytical separation between the two entities is made so that the interaction between them can be studied (Archer, 1998; Buch-Hansen & Nielsen, 2005). The social sciences must consider both structure and agency. Critical realists presuppose that the social world is driven by causal mechanisms that exist even though these mechanisms may be inactive, not directly observable, or obscured or inhibited (Brown et al., 2021). These mechanisms act as tendencies. Margareth Archer (1998) has developed new perspectives regarding structure and agency. Unlike Bourdieu`s perspective on structure and agency, where the focus is on habitus and unconscious actions (Bourdieu, 1977), Archer’s perspective places a stronger focus on the agent. In the chapter about professional practices, we described Bourdieu's work as an important theoretical framework for understanding professional practices. However, in this thesis, the possibility of change that lies within open systems is an important presumption. Archer highlights the inherent capacities and capabilities of agents and the agency in all events (Archer, 1998). From Archer's perspective, within the process of change that she calls *the morpho-genetic cycle*, structure, agency, and culture are important entities (Archer, 1998). Social and cultural structures influence one's subjectivity, activity, behavior, identity, and values but do not determine them. This entails a structure-agency association that is understood as open-ended. In the present study, it implies that the lack of decisions to apply forced treatment or the use of trust-building interventions as the main intervention in the care of persons who resist it does not necessarily reflect that coercion is not used or that person-centered care is implemented. We must go deeper to find the structural and contextual mechanisms that generate these events (or non-events). The presumption of openness entails that the individual can also opt to diverge or to act different and intervene in grey-zone coercion; they could also demand that the risk assessment of the person with dementia is needed before continuing with the previous care path. According to critical realism, when analyzing the deeper structures or mechanisms that influence the individual's actions or perceptions, exploring the cultural context is central. However, cultural context is always influenced by time and space and must be analyzed within a socio-historical perspective (Bourdieu, 1991; Brown et al., 2021; Buch-Hansen & Nielsen, 2005).

### *Causality and explanation*

The primary purpose of critical realism is to identify and analyze deeper structures that manage, limit, and enhance human action (Brown et al., 2021; Buch-Hansen & Nielsen, 2005). Its predominant focus is to explain how phenomena ''work'' and thus how they might be manipulated (Brown et al., 2021). This differs from the view of Løgstrup (1997) that would state that the sovereign life utterances are beyond our control. We only have the power to give room for them in the relationships between us. In critical realism, the emphasis on a possible and plausible cause or explanation is stronger than in the tradition of other relativistic approaches. The assumption is that it is impossible to predict actions in the real world (except in closed laboratory experiments) because there are multiple mechanisms that may always influence the outcome. However, we may identify and explain possible causal structures and the mechanisms that may act on them to change actions (Buch-Hansen & Nielsen, 2005; Elster, 2007). Related to the phenomena investigated in this study, which are *care practices related to resistance to care and forced treatment and care*, Solem et al.'s research (2008) has provided useful insight. They argued that researchers have to ask whether what is real has importance or significance. Their perspective is that the critical realist perspective can be especially useful when dealing with sensible and vulnerable topics, which in their line of research was child welfare. The argument was as follows: *"we in some situations have a responsibility to judge and assess questions about use and misuse of power, abuse and neglect of needs"*(Solem et al., 2008, p. 93). They state that in these situations, it would be unethical and unprofessional to maintain the assertion that all meanings and understandings are equally true. We need to dare to judge. We need to dear to take a leap from empirical phenomena to underlying generative mechanisms. This does not stand in opposition to the hermeneutical approach of being aware and clarifying the researcher`s stance, pre-understanding, and influence on research participants (Solem et al., 2008).

In critical realism, the classic reasoning modes, namely induction and deduction, are believed to be insufficient to achieve ontological insight, since these are directed towards the empirical level – that which is capable of being observed. The concepts of abduction and retroduction, as alternatives to methodological reasoning, were first explained by Charles S. Pierce (1972) and used interchangeably (Archer et al., 1998; Bukve, 2016). Retroduction is the logical inference form of abduction that takes us backwards from observation to mechanism. Methodologically, it implies searching the empirical details for more general generative principles that can be assumed to create the empirical patterns we observe (Bråten, 2016, p. 125; Bukve, 2016). However, it is not the aim to develop one general theoretical law; rather, the concern is to find internal and external explanations that are complementary rather them competing. We transition from experiences in the empirical domain to possible structures or (causal) mechanisms in the real domain (Mingers et al., 2013). Abduction is thus a form of logical reasoning, "a leap of thought," that takes us from the concrete phenomena to the general category wherein we understand the phenomena as emerging from i.e *the graduates months long celebrations in Norway* (no:russefeiring) to *rites of passage* (Bråten, 2015). The rites of passage are from this perspective a regenerative social mechanism that constitutes a retroductive conclusion. In the present study, moving from *few decisions of forced treatment and care and reduced care when encountering resistance* in the empirical domain, to being part of a generative social mechanism of *contradicting policies and care practices* in the real domain, where the latter was identified in a process of retroduction.

## 5.2 Epistemological perspective

Epistemology can be described as the "theory of knowledge" (Carter & Little, 2007), and it both guides and is guided by methodology. This study can be placed on a methodological continuum where several methodological approaches were used. The principles of critical realism allow for several methodological approaches but emphasize that how we can learn about knowledge and how we can gather knowledge is primarily through induction, exploring what we observe or experience, and abductively synthesizing, elaborating, and crafting plausible explanations for the underlying structures that influence the observable practices (Archer et al., 1998).

It has become common to develop research designs that implement both qualitative and quantitative methodologies (Creswell & Creswell, 2018; Polit & Beck, 2008), and it is considered useful to develop knowledge incorporating both. Knowledge developed with different approaches may be especially useful when examining complex topics and may uncover mechanisms that influence social structures and agents in society and aid us with rational judgement. This critical realist perspective allows for the use of mixed-methods research (Brown et al., 2021; Schiller, 2016). Mixed-methods research synthesizes qualitative and quantitative approaches to provide a more complete understanding of a research problem (Creswell, 2014; Lipscomb, 2008; Polit & Beck, 2012). This is applicable when there are several approaches to research and the integration of different standpoints may produce the optimal results in many circumstances (Brown et al., 2021; Johnson, de Waal, Stefurak, & Hildebrand, 2017; Johnson & Onwuegbuzie, 2004). In this study, the choice of a mixed-methods framework corresponds to the complexity of the situations that professionals encounter when encountering resistance to care. The purpose of using knowledge gathered and analyzed in different ways and from different data sources was to provide enhanced insight and to enable a better understanding of the care practices that are associated with these situations.

## 5.3 My own preunderstanding

The personal perspectives, professional background, and social identity of the researcher influences research. Therefore, it is important to address, become aware of, and make explicit one’s personal stance, experiential knowledge, positions, and assumptions to understand bias (Creswell, 2013a; Polit & Beck, 2008). Transparency about biases, personal beliefs, and background indicates researcher reflexivity (Creswell & Creswell, 2018).

The background for this study is embedded in my previous work experiences. I have worked in nursing homes as a clinical nurse and as a project leader of a competence and quality development project, and I have been situated in an inspector’s role in the CGO doing supervision and inspection within health and care services.

First, it is necessary to clarify my understanding of forced treatment and health and care services. My perspective is that forced treatment and care should ideally be prevented and avoided. My understanding of forced treatment and care is broad. It includes interventions such as pressure, therapeutic lying, psychotropic medication, belts, forced hygiene, locked doors, and forced placement in an institution. This list is not exhaustive. It indicates that some interventions may be experienced as more invasive than others; however, they are all defined as involuntary and as forced treatment and care. It is considered to constitute use of force unless it is assessed as the optimal solution for the patient.  However, my perspective is also that in some situations, when everything else has been attempted, it may be more humane to intervene for a short period of time via forced medication to manage and prevent pain due to underlying medical conditions such as cancer, or to move a person into a nursing home to avoid death or serious injury.

Documentation and transparency of involuntary and forced treatment and care is a means of acknowledging and allowing difficult situations of resistance to care to be openly discussed. Few formal decisions regarding forced treatment and care do not necessarily reflect a reality of minimal coercion. They may only reflect the reported or culturally legitimate reality.

When entering this project, we, as a research team, discussed our preconceptions. We specifically discussed my preconceptions and embeddedness in the language and the “thinking” about law. My supervisors in this study include a geriatric nurse, a registered nurse, and a nurse and sociologist. They have extensive clinical experience within home health and care services, psychogeriatric care, and lung cancer nursing within hospitals. They also have extensive experience and competence with quantitative and qualitative research, ranging from large-scale randomized controlled trials to a range of approaches to qualitative research, including hermeneutic and phenomenological traditions. Empirically, their primary interests include persons with dementia and their caregivers, home health and care services nursing, and philosophies of care and contextual structures of nursing care. Their diverse backgrounds have precipitated interesting discussions both about the understanding of important phenomena in the study with regards to the methodological approach and about analysis and the validity of results.

Through my personal experiences of living and studying in other cultures, moving between work cultures in Norway, and the professional journey of a PhD study, I have realized that what is considered legitimate language and knowledge in one place is not necessarily valid in another. It is strongly influenced by tradition and culture; therefore, words, language, and research knowledge also must be accommodated to fit the setting if they are to exert an effect. However, setting time aside to enable communication is the first step. This has implications regarding how to understand and how to communicate research between research institutions and clinical practice and between researchers in a global context.

# 6.0 STUDY DESIGN, MATERIALS, AND METHODS

When designing a framework for research, we need to consider the purpose to be achieved (Greene, Benjamin, & Goodyear, 2001, p. 30). A mixed-methods research design was selected for this study both due to the complexity and the sparse previous research concerning the phenomenon of forced treatment among home-dwelling persons with dementia. The scarcity of previous research was also the reason why we opted to start with the reported or formal use of forced treatment and care. The fact that the use of coercion is strictly regulated by law was another reason for this choice. By collecting and analyzing both quantitative and qualitative data in Study 1; Article 1 and 2, and by allowing the qualitative explorative design of Study 2; Article 3 to be informed by the results of Study 1, we gained greater insight into the phenomenon relative to what we would have accomplished using only one methodological approach.

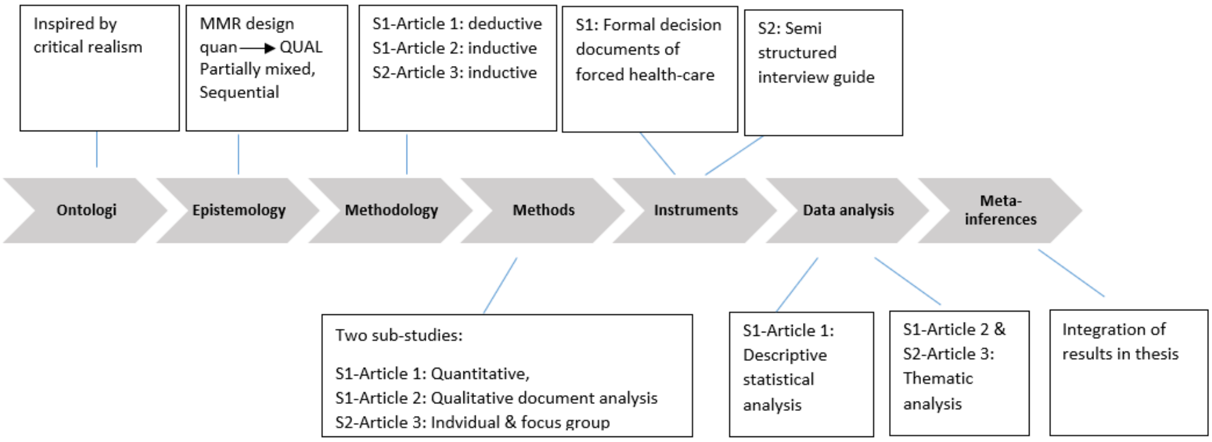
## 6.1 Mixed-methods research design

Mixed-methods designs have become increasingly common in recent decades, and most published mixed-methods studies have endeavored to answer questions that could not be answered by one paradigm alone (Creswell, 2013b, 2014; Creswell & Creswell, 2018; Fetters, Curry, & Creswell, 2013; Johnson et al., 2017; Johnson & Onwuegbuzie, 2004; Leech & Onwuegbuzie, 2009). The concept of combining quantitative and qualitative data in a study is straightforward. However, definitions of mixed-methods research are not always clear-cut (Polit & Beck, 2008, p. 603). The definitions of mixed-methods research that this thesis adheres to include the following: "*the class of research where the researchers mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language into a single study"* (Johnson & Onwuegbuzie, 2004, p. 17). The following is a shorter definition that incorporates series of studies into the definition: "*research that involves collecting, analyzing, and interpreting quantitative and qualitative data in a single study or in a series of studies that investigate the same underlying phenomenon."* This definition was presented by Leech and Onwuegbuzie (2009). This thesis is understood as one study that builds upon a series of studies that investigate the same phenomenon, namely *care practices encountering resistance and in use of forced treatment and care.*

The mixed-methods design is often represented by three dimensions: (a) level of mixing (partially mixed versus fully mixed); (b) time orientation (concurrent versus sequential), and (c) the emphasis of approaches (equal status versus dominant status) (Leech & Onwuegbuzie, 2009, p. 268). The combination of methods in the present study provided us with both an overview of the extension of forced treatment and factors associated with this, and insight into how health professionals describe using these interventions in clinical practice. It also endeavors to explore how they describe care practices when encountering resistance to care. Using the typology of Leech and Onwuegbuzie, the thesis can be defined as employing a *partially mixed sequential dominant status design*. The present study is described as overall partially mixed because the quantitative and qualitative elements are conducted both concurrently (data collection) and sequentially (Study 2- Article 3 builds on Study 1- Articles 1 and 2) before being mixed during the data interpretation stage in the thesis.

### 6.1.1 Phases and materials

In this study, the first phase of data collection involved both quantitative and qualitative data. Subsequently, a quantitative analysis and qualitative analysis of these data were conducted using the same document (Figure 2). In the second phase of the study, we explored how nurses working in health and care services for home-dwelling persons with dementia described encounters with resistance to care.



S= study
MMR = Mixed Method Research

Figure 2 . Model for coherence of study

Study 1 resulted in two Articles. In Study 1-Article 1, which was a cross-sectional study, we collected decision documents regarding forced treatment and care and analyzed the prevalence, involvement, and type of forced treatment and care through a statistical analysis. In Study 1-Article 2, we used free text concerning descriptions of trust-building interventions conducted prior to and during interventions of forced treatment and care that originated from the same documents as in Article 1. The analysis of the quantitative (Article 1) and qualitative data (Article 2) of Study 1 were partly integrated and mixed. Free text concerning trust-building interventions was coded to categorize trust-building interventions into three variables (structural interventions, relational, and person-oriented); these were used as a priori themes for the qualitative template analysis.

In phase two, in Study 2- Article 3, we applied a qualitative design wherein we explored how nurses providing home care nursing responded and made decisions when met with resistance to care among home-dwelling persons with dementia. Study 2-Article 3 builds upon Study 1 and elaborates and imparts further insight into the knowledge gained from that study. Study 2- Article 3 illuminates what influences professional judgement when those with dementia start to resist care. Study 2 has thus far resulted in one article.

### 6.1.2 Integration of methods

The quantitative and qualitative data of Study 1were collected at the same time using the same instrument. The data sets were analyzed separately; however, the quantitative results in Study1-Article 1 informed the qualitative approach, and the results from Study 1- Article 2 informed the next qualitative data collection in Study 2 - Article 3. The data of this study were analyzed separately from Study 1. The mixing of results took place alongside the data interpretation process of the thesis, wherein the results from Study 1- Articles 1 and 2 and Study 2 - Article 3 were integrated, and meta-inferences were made. Figure 3 presents a visual overview of the mixing of methods, and Table 5 presents an interpretation of the findings from the three articles.

Fetters (2020) encourages joint displays in the presentation of the integration of mixed methods results. Joint displays refer to a "*table or a figure that can be used to represent a juxtaposed representation of findings of qualitative or quantitative strands of a project, it includes or implies specific linkages or areas of commonalities across the qualitative and quantitative strands that can be expressed as constructs or domains, and that contains and interpretation, often called a meta-inference, about the meaning of the two types of results when considered together"* (Fetters, 2020, p. 194).

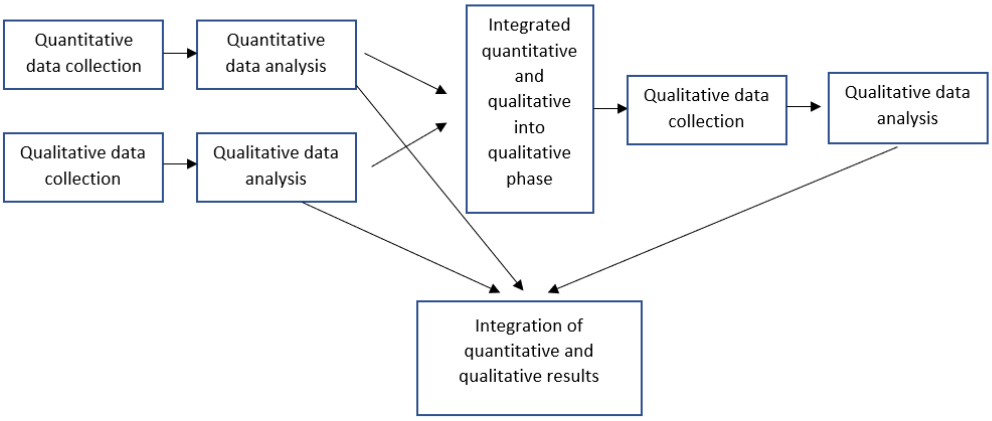


Figure 3. Illustration of mixed-methods design: *partially mixed sequential dominant status design*

The quantitative and qualitative findings were compared, contrasted, and combined, and the integrated findings are presented in a joint display under Chapter 8 and are further discussed in Chapter 9.

The results from the statistical analysis of Study 1-Article 1 concerning a) the prevalence and extent of forced treatment and care; b) which professions and persons were involved; c) whether the person with dementia lived in a private original home or in an assisted housing facility; d) and the likelihood of some of these variables occurring in association with the types of coercion used, provided more knowledge than if we would have analyzed the documents merely qualitatively. In Study 1- Article 2 qualitatively exploring the descriptions of trust-building interventions and the reasons for and means of applying these prior to the use of forced treatment and care provided more insight than we would have gained by analyzing this aspect of the decision documents concerning forced treatment and care using only descriptive statistics. Furthermore, using the results from both parts of Study 1 to inform the design of Study 2 - Article 3 provided us with another perspective that we would not have gained using only one methodological approach.

In the initial process of preparing data for statistical analysis, some data had to be coded into variables, such as whether the person had dementia and what types of trust-building were used. The results for the variables of trust-building interventions were never used in Article 1 because we wanted to save them for Article 2. When we explored the written text in the documents that was the basis for Article 2, other themes emerged as more suitable to describe qualitatively the trust-building interventions. However, the process of recoding we performed in Study 1 to prepare for statistical analysis is presented in 6.2.1, and the findings from that analysis that provided interesting associations with the themes we identified in Study 1- Article 2 and Study 2- Article 3 will be presented in section 8.4.1

## 6.2 Study 1

*Research design:* This was a descriptive cross-sectional study in which all documents concerning forced treatment and care were enforced between 1 January 2015 and 31 December 2016 from each of the participating county governors.

*Sample selection:* We aimed to gather all documents concerning forced treatment and care that were made over a two-year period. Therefore, all CGOs in Norway were invited to participate because they receive and control the formal documents (Appendix II).

*Data collection:* The national health authorities in Norway have developed a standardized form in order to ensure that coercive healthcare decisions are processed and documented according to law (Helsedirektoratet [The Norwegian Directorate of Health], 2019). The decision documents used in this study are based on the standardized form.

In September 2017, we developed a manual for extracting decisions regarding somatic coercive health care from the case management system in cooperation with the CGOs in Hordaland (Appendix III). This was done to enhance the quality of data collection. Seventeen CGOs in Norway were invited to participate through a formal letter with information about the research project. Each CGO was required to extract relevant data from their own electronic case management systems. Case management actions that were performed and documented after the decision to provide forced treatment and care was submitted were not included in the study. A prepaid envelope with the return address on it was attached to the invitation letter. An e-mail reminder was sent two weeks later after the letters were posted. The principal researcher (ÅG) and a case manager at one CGO were available for questions regarding the data collection process. After the suggested submission date passed, the non-responsive CGOs were contacted via telephone or e-mail. Eight CGOs participated by anonymizing the data before sending them to the principal researcher. The principal researcher collected the data from one CGO herself with advance permission from The Regional Ethical Committee for Medical and Health Research Ethics number 2017/788.

The response rate of the study was 53%, with nine out of 17 counties participating. Five CGOs did not participate due to a lack of resources, and three did not answer the request. The manual for extracting data was used and provided important insight in the data collection process (Appendix III). The documents were anonymized before being brought out of the CGOs. Inclusion criterion were documents describing patients with dementia receiving home health care. Patients with psychiatric diagnoses or intellectual disabilities in addition to dementia were included. Documents with missing pages or in which the cognitive impairment was caused by other reasons were excluded from the study. One hundred and eight of the 116 collected documents were included in the study.

*Data collection instrument*: A standardized form for decisions regarding forced treatment and care has been developed by the national health authorities in Norway to guarantee that such decisions are processed and documented according to law (Appendix IV). The instrument is a guide for decision-making that consists of 16 closed- and open-ended questions. The law requires that trust-building interventions are carried out prior to the use of forced treatment and care. When decisions regarding forced treatment and care are made, the decisions are documented in the patient's medical record, and copies of the decision forms are submitted the CGO`s, who serves as the regional supervisory and inspection health authority.

### *Preparing for Statistical Analysis*

The decision documents consist of structured questions with both closed- and open- ended questions where the answers are found in free text. To be able to perform a statistical analysis, some data therefore had to be recoded. The recoding of such data into variables was conducted through collaboration with the co- authors and the statistician.

### 6.2.1 Study 1- Article 1

The aim of this study was to gain insights into formal decisions of forced treatment and care made for home-dwelling persons with dementia.

The following three research questions guided Study 1-Article 1:

1) What is the prevalence rate of formal decisions to apply forced treatment and care among home-dwelling persons with dementia?
2) What types of interventions of forced treatment and care are used for home-dwelling persons with dementia?
3) Who is involved in decisions of forced treatment and care for home-dwelling persons with dementia?

The sample involved in this study consisted of 108 formal decision documents of coercive health care regarding patients with dementia living at home between 1.1.2015 and 31.12.2016 (Figure 4).

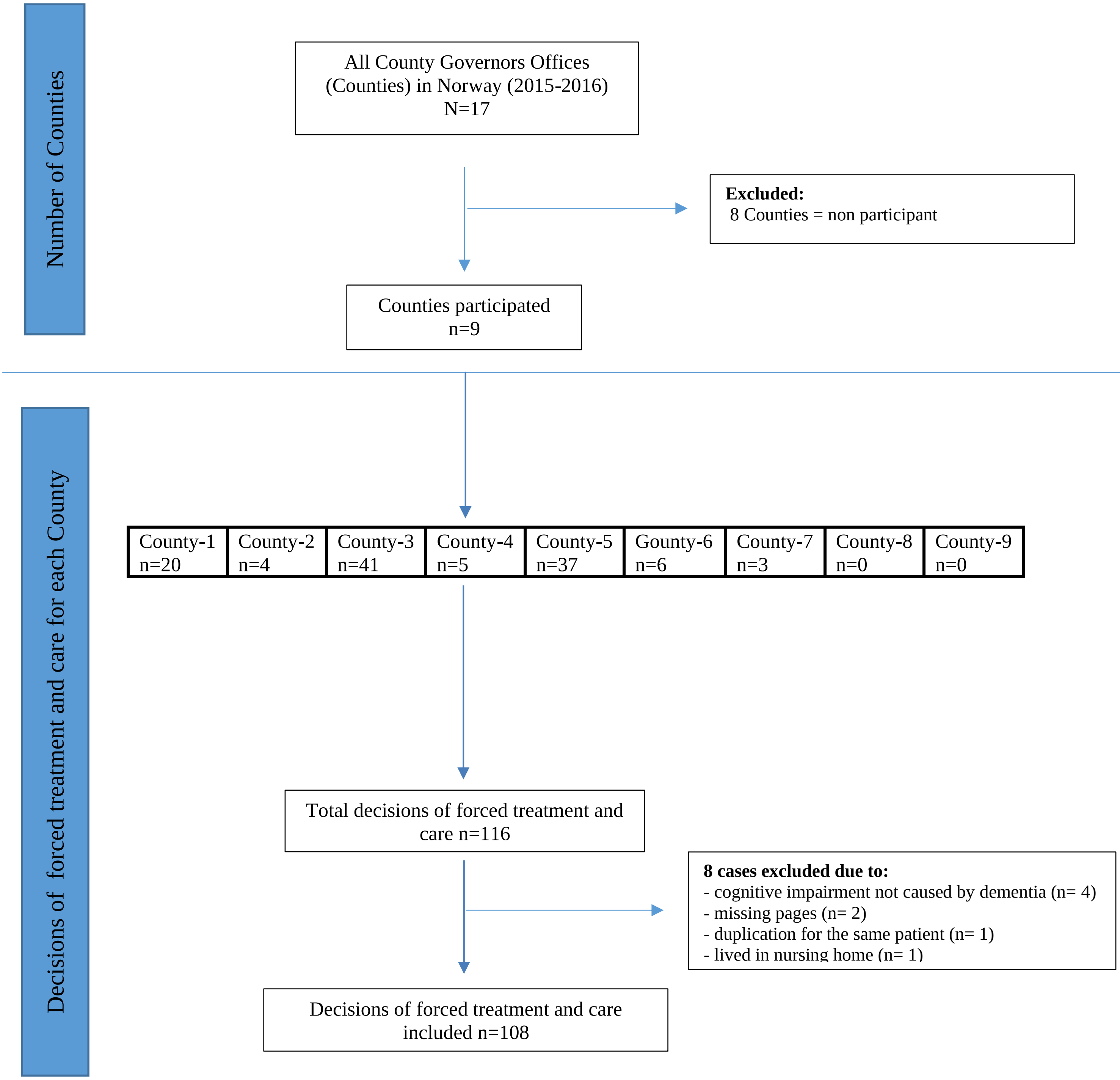


Figure 4. Flowchart of recruitment and data-collection process from CGO`s (Counties).

### *Preparing for Statistical Analysis*

The variable of dementia ranges from free text explicitly documenting dementia as a diagnosis to text describing cognitive impairment due to dementia for this patient. By reading through the text of each document, an assessment was made regarding whether the patient`s lack of capacity to consent was caused by dementia. Only the documents related to persons with dementia were included.

Age was presented using a categorical variable based on the median age of 79 years (range: 34–99). Question 6 in the decision form originally had eight options: admission, detention, physical restraint, prescriptive medication, intervention into the body, electronic surveillance, care or other interventions, and dental treatment (Appendix IV). In the present study, due to limited numbers in some of the categories, the eight options were recoded into the three categories listed in Textbox 1. If more than one option was checked for question 6, the entire text was read to identify the primary intervention of forced treatment and care described in the document. “Living situation” was included in the categorical variables “Ordinary housing” (living alone and living with family) and “Assisted housing” (care homes not defined as health institutions). Family involvement was limited to either “involved” or “not involved.” Interdisciplinary participation was reported as “yes” or “no.”

**Textbox 1: Content of standardized form for decisions regarding forced treatment and care**

1. Name of the patient
2. Name and position of the professional responsible for healthcare
3. Description of health status of patient
4. Assessment of capacity to consent
5. Description of trust-building interventions
6. Decisions of forced treatment and care + explanation of how to implement the intervention
    a. admission to a health institution (nursing home or hospital)
    b. assistance with ADL
    c. other medical and safety decisions
7. Inter-disciplinary assessment
8. Professional assessment of whether a decision of coercive healthcare meets legal requirements
9. Information from family about what the patient would have wanted
10. Wholesome assessment of interventions of forced treatment and care
11. Timeframe for the decision (maximum 1 year)
12. Documentation related to the notification of the decision is provided to the
    1) patient, 2) family, and 3) chief/senior responsible health professional
13. Copy of the decision of forced treatment and care is sent to the County Governor`s office
14. Date of decision and signature of the person authorizing the decision
15. Attachments
16. Information about the right to appeal

*Analysis*

Continuous data were described using mean, median, and range, and categorical data was described using counts and percentages. Crude differences between groups were assessed using the chi-squared test for discrete variables. Statistically significant results were modeled by performing multiple logistic regression analysis with possible associated variables and presented as odds ratios (ORs) and adjusted odds ratios (AORs) with 95% Confidence interval (CI). All tests were two-sided. Probability values (*p-values)* below 0.05 were considered statistically significant. All analyses were performed using SPSS version 26. We collaborated with a statistician to design the relevant statistical analysis and to control the interpretations of the results. The group of co- authors read and recoded all the decision documents together as a group, document by document.

This was a cross-sectional study with categorical data. The nature of the data has implications for what type of statistical analysis is suitable (Altman, 1991; Aalen et al., 2018). Categorical data, where individuals are categorized into one or two or more mutually exclusive groups, can be analyzed by looking at the number of individuals falling into a particular group or an analysis of frequencies. When we compare two groups or more, the data are often presented in a frequency or cross-tabulation table (Altman, 1991, p. 229). When the sample sizes are small, the use of the continuous chi-squared distribution to approximate frequencies implies the introduction of some bias. Yates continuity correction can be used to reduce this bias (Altman, 1991, p. 252).

The variable for young versus old was set at 79 years based on the mean age of the data. The types of decisions of forced treatment and care were initially analyzed for all registered decisions (one document could have more than one reason for coercion, as the professional responsible would mark several boxes). The type of forced treatment and care was then recoded into one reason for forced treatment and care, in adhere to what was described as the main challenge in the document (Textbox 1). The latter was selected as the statistical analysis used in the study because it described the decision of forced treatment and care in a more clinically accurate and reliable manner. The original categories can be found in Appendix IV.

Crude associations between pairs of categorical data were assessed using chi-square tests for independence (with Yates continuity correction). The associations between the categorical variables (age, sex, living situation, professional responsible for care, interdisciplinary participation, and family involvement) and the given decision of forced treatment and care (admission, other medical and safety decisions, and assistance with ADL) with p-values below 0.05 were considered statistically significant. All analyses were performed using SPSS version 26 (IBM Corp., NY, USA).

Logistic regression models enable us to predict the probability of a particular outcome in relation to several prognostic variables (Altman, 1991, p. 355). In this study, models of univariate and multiple logistic regression were used to present the relative risk for associations between gender, age, interdisciplinary participation, the living situation of the patient, who is the responsible decision maker, and the risk related to the given decision of forced treatment and care.

Statistically significant associations suited for binary logistic regression were presented as ORs and AOR with 95% confidence intervals (CIs). In the logistic regression analysis, categorical data (age, sex, living situation, professional responsible for care, interdisciplinary participation, and family involvement) were included as independent variables. The given decision of forced treatment and care (admission, other medical and safety decisions, and assistance with ADL) were defined as three dependent categorical variables.

### 6.2.2 Study 1- Article 2

The aim of this study was to explore the use of trust-building interventions among home-dwelling persons with dementia resisting care, as described by healthcare professionals in documents concerning decisions of forced treatment and care.

A qualitative thematic analysis was performed on documents with texts describing trust-building interventions of care. Thematic analysis can be conducted using various of philosophical positions. It is therefore fundamental to clarify from which position the study is conducted (Braun & Clarke, 2006). A critical realist perspective of clinical practice emphasizes the importance of context and the multidimensional factors that may influence it, and it elucidates the complexity of situations (Archer, 1998; Mingers et al., 2013; Schiller, 2016). In our study, this perspective proved useful for exploring descriptions of ethically and clinically challenging situations in which trust-building interventions were initiated to avert the use of coercion with home-dwelling persons with dementias who resisted care.

### *Participants*

From the total 108 decision documents collected in the study, 88 had descriptions of trust-building interventions. These were extracted and formed the basis of this study. The documents were written by health professionals in charge of and providing home health care services to home-dwelling persons with dementia. Altogether, the 88 decisions comprised 352 pages, with a total of 30 pages describing trust-building interventions. These varied from a couple of lines to a little over a page for each document (for each person with dementia).

### *Data collection*

Most (102 of 108) decisions were documented using a standardized form developed by the national health authorities in Norway (Appendix IV) to ensure that decisions regarding forced treatment and care are processed and documented according to law (Helsedirektoratet [Norwegian Directorate of Health], 2012, 2015; Helsedirektoratet [The Norwegian Directorate of Health], 2019).

### *Research context*

In the standardized form, there are open spaces in which descriptions of the trust-building interventions applied prior to the use of forced treatment and care can be documented. All the documents provided descriptions of persons with dementias with limited insight into their own situations and who could no longer take care of their own needs. Many were described as experiencing unsettlement, anxiety, and confusion. Severe somatic health needs were also reported as a rationale for needed interventions (Textbox 2).

**Textbox 2. Reasons for trust-building interventions reported in 88 documents concerning forced treatment and care in Norway (2015-2016)**

| Risky and adverse behaviors | Somatic reasons |
|---|---|
| • Threat to themselves or to others<br>• Wandering outside in slippers and nightwear<br>• Taking the bus without finding their way back home<br>• Not being able to cope in traffic<br>• Opening the door naked<br>• Lighting up fires and smoking inside<br>• Living in houses filled with garbage and with an odor of urine | • Weight-loss, malnutrition, anemia<br>• Infectious wounds<br>• Incontinence<br>• Lack of personal hygiene- several years without showering<br>• Diabetes<br>• Hypertension<br>• Hypothyroidism<br>• Tooth decay<br>• Cancer and edema<br>• Hallucinations |

*Preparation of data*

We started with three a priori themes, defined as *structural, relational, and individual trust-building interventions*, to initiate the analysis of the data set. These a priori themes were regarded as appropriate and useful categorizations of levels of interventions in this particular data set when considered in relation to previous research on person-centered care, existing guidelines for legislation regarding forced treatment and care of persons with dementia, and a systems approach (Helsedirektoratet [Norwegian Directorate of Health], 2015, 2017a; Kitwood & Brooker, 2019).

These a priori themes were also considered suitable for recoding to variables to be prepared for descriptive statistical analysis. Structural trust-building interventions were defined as interventions that implied increased visits, extra staff, few persons to relate to, adaptation of time/hour for assistance, physically adapted environment, size of ward (in assisted housing), extensive experience and dementia competence of staff, calm environment, and fenced sensory garden. Relational trust-building interventions were defined as interventions wherein staff do something active in relation to communication with the person with dementia, via their communication method or adapted and repeated information. Individual trust-building interventions were defined as person-oriented interventions that could involve using family members when providing care to maintain trust in the situation; this could also encompass the use of music, food, care plans, extra staff, and accompanying the person with dementia.

The information about the different variables of trust-building interventions were transferred to SPSS document by document. The variables related to structural, relational, and individual trust-building interventions, respectively, were registered as “yes” or “no.” We also had one variable that registered whether trust-building interventions were used at all, including the three variables, registered as “yes” or “no.” The categorical data were described using counts and percentages (Table 5). All analyses were performed using SPSS version 26. A statistician was used to design the relevant statistical analysis and to control the interpretations of the results.

These data were not used in Study 1-Article 1 or Article 2. However, they inform the overall results of this thesis.

*Analysis*

Inspired by critical realism, a qualitative inductive thematic analysis was conducted based on the following six steps by Braun and Clarke: Step 1: Become familiar with the data; Step 2: Generate initial codes; Step 3: Search for themes; Step 4: Review themes; Step 5: Define themes; Step 6: Write-up (Braun & Clarke, 2006). The thematic analysis used was inspired by template analysis, as described by Brooks et al. (Brooks, McCluskey, Turley, & King, 2015), which is similar to Steps 1 and 2 delineated by Clarke and Braun; this approach enables researchers to start with a priori themes identified in advance. Such themes may be temporal and redefined or removed if they do not prove useful for the analysis. Step 3 involved organizing the emerging themes into meaningful clusters and beginning to define how they relate to each other within and between these groupings. Step 4 involved defining an initial coding template. Step 5 was to apply the initial template to further data and modify as necessary. Step 6 entailed finalizing the template and applying it to the full data set (Brooks et al., 2015).

*Data analysis process*

The data analysis process was performed in two phases. To obtain a general impression, the first author (ÅG) read the entire data set of 88 decision documents, and all text concerning trust-building interventions was identified and extracted from the PDF files of the original documents and transcribed into a separate Word file. Three of the researchers/authors (ÅG, TO, FB) then conducted an initial analysis of the text. Preliminary coding using the three a priori themes of structural, relational, and individual trust-building interventions was executed for 10 documents. Subsequently, we applied this template to the whole data set individually and then together as a research team. Where coding diverged, we discussed until a consensus was reached.

The whole research group (ÅG, TO, HA, FB) underwent a new process of deciding whether to keep the previous three a priori themes in the further analysis after a re-reading of several documents. In this process, we decided to remain open to new themes that could be identified. All text concerning each theme was then transferred into three separate Word documents to facilitate further analysis. The document number followed the text in the process to enable the possibility of returning to the original text. However, in accordance with the view of Brooks et al. (2015), the a priori themes did not have a protected status. During the process of analysis, other themes, such as safeguarding care, were identified as being more fitting names for the data than the initial a priori themes. At this point, the categories of the a priori themes were therefore removed. The data were then coded into themes and subthemes, and finally, the themes were organized into meaningful clusters, and the relations between them were identified. The analysis was an iterative process, and we transitioned from the context of the text to the individual parts of the text, allowing the parts to inform each other. An overview of the final themes, subthemes, and the overarching theme is provided in Figure 5.

| Overarching theme | Balancing safe care with the person’s integrity | | |
|---|---|---|---|
| Main themes | Safeguarding care | Protecting integrity | Optimizing the environment |

Figure 5. Final themes of trust-building interventions in Article 2 (Study 1)

## 6.3. Study 2- Article 3

The aim of this study was to explore nurses` professional judgement when encountering resistance to care from home-dwelling persons with dementia.

### *Design*

The second study had a qualitative design; data were collected through both focus groups and individual interviews. Initially, only focus groups were planned for, but due to Covid-19 restrictions, we needed to deescalate one of the focus groups and to interview the remaining participants individually. The home health care managers did not want to merge health professionals who usually did not work together because of the infection risk. Altogether, 18 nurses from home health and care services participated in the study. The interviews were conducted over a period of five months from December in 2020 to April 2021.

### *Sample and participants*

A purposive sample was used in the study. Inclusion criteria were that participants must be either Licensed Practice Nurses or Registered Nurses or have had experience with providing care to home-dwelling persons with dementia (Table 3). Although assistants without health education most likely could have informed the study well, the nature of the themes we wanted to discuss called for reflections on a professional level that should not be expected by assistants. We therefore excluded this staff group from the study. The participants are hereafter referred to as nurses.

| Table 3. Participants background in focus group and individual interviews | | | | | | |
|---|---|---|---|---|---|---|
| **Participation** | **Age mean (range)** | **No. of participants** | **Years of experience mean (range)** | **Education** | **Participants continued education*** | **Experience dementia team** |
| **Focus group 1** | 56 (46-62) | 6 | 27 (20-35) | LPNs | 6 | 0 |
| **Focus group 2** | 52 (44-61) | 5 | 17 (7-32) | 3 RNs<br>2 LPNs | 1<br>2 | 5 |
| **Focus group 3** | 49 (43-57) | 4 | 10 (3-18) | 4 RNs | 1 | 0 |
| **Individual interviews** | 50 (34-66) | 3 | 17 (2-31) | RNs | 3 | 3 |
| **Total** | 52 (34-66) | 18 | 19 (2-35) | 10 RNs<br>8 LPNs | 13 | 8 |

*RN`s = Registered nurses bachelor level. LPN`s = Licensed practice nurses high school level. *Continued education included: ABC dementia course (4), geriatrics (3), psychiatry (1), palliation (1), nutrition (1), pedagogics (1), intensive care nurse (1), master of evidence-based practice (1).*

### *Organizational context*

The nurses worked in community home health and care services with allocated lists of patients where tasks were predefined and dependent on persons with dementia health and care service needs.

### *The interview guide*

To develop an interview guide, a reference group that consisted of clinicians of home health and dementia care, researchers of elderly care, nurse specialists in municipal care, and representatives from dementia organizations was used to inform and discuss the relevance of the study. Together with the research team, who had extensive experience in qualitative studies and dementia care, a semi-structured interview guide was developed and piloted with three clinicians from the reference group to assess the relevance and understanding of the questions and to increase the validity of the findings. An overview over the main themes introduced is presented in Figure. 6.

| Themes of discussion |
|---|
| Experience with and what they do in situations of resistance to care |
| Decision-making in situations of resistance |
| Collaboration partners/structures |
| Limitations of home health-care |
| Self-decision in persons with dementia versus persons without dementia |
| Covid-19 implications for dementia care |

Figure 6. Main themes of the interview guide Article 3 (Study 2)

The themes introduced in both the focus groups and individual interviews were formed as open-ended questions and allowed the participants to discuss the factors they considered relevant.

### *Data collection*

Data were gathered through three focus group interviews with four to six participants in each group and three individual interviews. One focus group was mixed with both types of nurses working together in a dementia team (five nurses), one focus group had registered nurses (four nurses), and one had licensed practice nurses (six nurses). The three individual interviews were with registered nurses (Table 3).

The participants were recruited from municipal home-health care services in different geographical zones within one municipality. The principal researcher contacted the municipality through an application to their research gateway and was provided with a research coordinator to facilitate contact with a contact person, in this case the special nursing advisers of the home-health care departments. Potential participants in the study were identified and contacted by the special nurse advisor in the particular department of home health and care services in the municipality. If interested in participating, the health professionals received a personal invitation letter with information about the study (Appendix VI). Attached to the letter was an informed consent form (Appendix VI). The focus group participants submitted the consent form right before the focus group interview. In collaboration with the contact person, an appropriate time and location for the interview was selected. For the individual interviews, the principal researcher contacted the participant directly via text message after they had agreed to this. These interviews had to be conducted by telephone due to Covid-19 restrictions. The consent form was sent to the participants by their leader, and they printed it out, signed it, photographed it, and returned it to the principal researcher as a scanned document.
The practical implementation of the interviews was delayed and moderated due to restrictions related to the Covid-19 pandemic. Due to the continuously changing guidelines, the principal researcher had telephone and e-mail communication with the contact person to accommodate necessary changes. All three focus-group interviews were postponed from the original dates.

The principal researcher (ÅG) was the first moderator (M1), and the three supervisors assisted as co-moderators (M2) during the focus group interviews, each in one interview. We used two tape-recorders to ensure the audibility of the recordings, and we used name tags to enhance communication within the group. All the interviews were conducted between one and four in the afternoon. Light refreshments that adhered to Covid-19 guidelines were served. Seating was preplanned to secure spacing. We used faced masks until seated. The individual interviews were all conducted by the principal researcher (ÅG) via telephone. The conversations were on speaker and were recorded using a digital voice recorder.

Each interview (focus and individual) lasted between 70 and 90 minutes. The interviews started with an introduction of the moderator(s) and participant(s).

### *Analysis*

The interviews were transcribed verbatim by the principal researcher (ÅG) and an external transcriber. ÅG transcribed two focus group interviews, and the external transcriber transcribed one focus group interview and the three individual interviews. A drawing of where the participants were seated was made to facilitate the transcription and separation of voices within the focus groups. All co-authors read the transcriptions and were part of the process of analysis.

Inspired by critical realism, a qualitative inductive thematic analysis was conducted following the six steps by Braun and Clarke (2006); 1) first, to obtain a general impression and to become familiar with the material, the first author (ÅG) read through all the transcribed interviews several times searching for patterns and meanings. Transcripts were checked back against the original audio recordings for accuracy. The co-authors (TO, HA, FB) individually read through all the interviews, with a particular emphasis on the interview they participated in, searching for patterns and meanings and initial ideas for coding. 2) The research group then met to discuss meaning, patterns, and coding and to examine possible themes. Notes were written in the margins, and colors were used to mark patterns for coding. 3) The list of codes was then analyzed by the first author (ÅG) and sorted into groups that appeared to belong together; potential themes. main themes, and subthemes were identified. The first author (ÅG) went back to the transcribed interviews to validate that the new themes corresponded with the content of the data. 4) The themes were then reviewed with the co-authors. The analysis was an iterative process, and we transitioned from the context of the text to the individual parts of the text, allowing the parts to inform each other. The principal researcher double checked transcriptions against recordings when using citations. 5) Final themes were than thoroughly refined, defined, and named. 6) The final themes were delineated in an article. During this process, the themes were reviewed by two research groups, in which the first author (ÅG) revived important feedback. A new round of refinement was conducted.

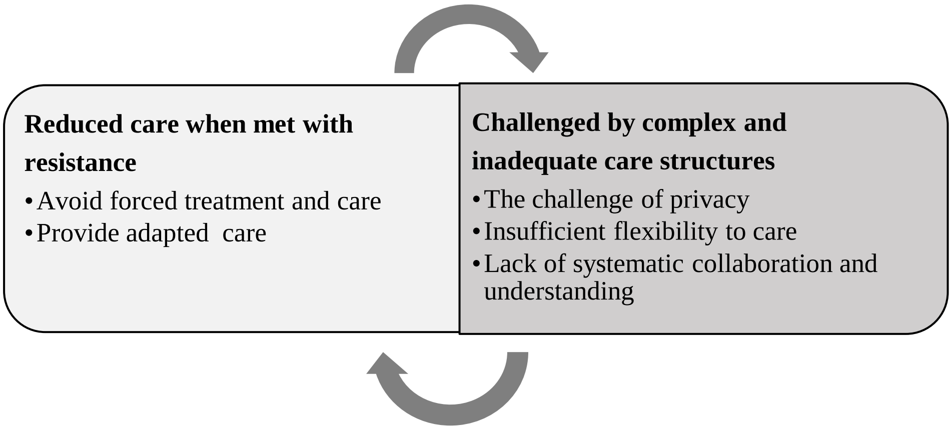


Figure 7. Final themes of nurses’ encounters with resistance to care Article 3 (Study-2)

Two main themes were identified**:** 1) challenged by complex and inadequate care structures; and 2) adapting care according to circumstances (Figure 7).

Subthemes of main theme one included the following: lack of systematic collaboration and understanding, insufficient flexibility to care, and the challenge of privacy. Subthemes of main theme two included the following: avoid forced treatment and care to protect autonomy, reduced care.

During translation from Norwegian to English, text quotes were transcribed verbatim and then modified to guarantee equivalence in meanings and interpretations. All quotes used in the manuscript were marked to identify which nurse and which focus group it came from to make it possible to return to the data and double-check for relevance. All names associated with the quotes have been changed to protect the identities of the nurses.

*Limitations*

Although a brief introduction to the concept of resistance and the topic was provided prior to each interview, the nurse's understanding of what is defined as resistance and forced treatment and care may have influenced the study. Forced treatment and care was intentionally not defined in the introduction because we wanted the nurses to describe their experiences of what happened when encountering resistance to care.

## 6.4 Reference group

A reference group with members who in different ways have experience or competence with persons with dementia who live at home has been connected to the project. It was established the autumn of 2017, had its first meeting in January 2018, second meeting in January 2019, and third meeting in September 2020, and last and final meeting in January 2022. The reference group has served as an advisory group and has offered input regarding directions specifically for Study 2- Article 3 in the project.

There were five members of the reference group: spouse to person with dementia, a representative from the National Public Health organization, Dementia, in Bergen, a professor at the Center for Care research in Vestland, an advisor at Centre for Development of Institutional and Home Care Services in Vestland, the leader for the department of home health and care services in the municipality of Bergen, an advisor at the competence center for dementia in the municipality of Bergen, and a PhD candidate and colleague with recent clinical experience from home health and care services.

## 6.5 Translation

Translation of juridical terms in the documents is complicated and was done to the best of our ability. To inform translation we used previous terminology in research of the same legislation (Sparby, Olsvold, Bogetun, & Obstfelder, 2016), help pages at the university of Oslo for Norwegian legislation in English (UiO University of Oslo, 2021), together with translated ACTs that are searchable at the Norwegian national legal web pages (Lovdata.no), as well as the World Law Dictionary (World Law Dictionary, n.d). A jurist with extensive experience from working at a CGO read text related to legislation and gave important input on use, meaning and translation of juridical terms.

# 7.0 ETHICAL CONSIDERATIONS

The study involves sensitive topics for patients, family members, and health professionals. The documents and the qualitative data that were gathered were therefore anonymized and stored in locked storage which only the principal researcher could access. The interviews were stored at the research server of VID. Study 1-Articles 1 and 2 was a retrospective document-based study that did not involve direct contact with patients or healthcare professionals. The study was granted ethical approval from the Regional Ethics Committee (REK) (reference number 2017/788) (Appendix I). Moreover, it was presented to and received no objections from the Norwegian Center for Research Data (NSD) (reference number 54897) (Appendix I).

In Study 2-Article 3, permission to conduct the study was conferred by the Norwegian Centre for Research Data (NSD) (reference number 515138/2020)(Appendix V). The study handles sensitive topics for the health professionals involved. The interviews were transcribed verbatim by the principal researcher (ÅG) and an external transcriber. A drawing depicting where the participants were seated was made to facilitate transcription and separation of voices of the focus groups. The external transcriber signed an agreement of confidentiality and non-disclosure. The transcriber received the sound files on an encrypted memory chip sent via recorded delivery that requires a signature by the recipient. The text and sound files were deleted after the transcription job was finished. Interviews were transcribed, and the names and personal information of the participants were anonymized in this process. The study was executed in concordance with the ethical guidelines for research in the Helsinki Declaration (The World Medical Association, 2013). The findings are presented in such a manner that neither the participating home care staff nor the persons with dementia they assisted can be identified.

Both studies are associated with sensitive stories about patients that may be easily recognized. Discretion was used when gathering, analyzing, and presenting data from the study.

# 8.0 MAIN FINDINGS

This mixed-methods study was inspired by critical realism. This methodological approach implies a synthesis and integration of results, which is elucidated in 8.4. It also implies the use of abductive reasoning to identify possible underlying structures that may influence how care practices in the health and care services are described. The integrated results will be discussed in Chapter 9. In the following text, the main results for each of the three Articles that were written from the two studies will be presented, followed by a presentation of the integrated results.

## 8.1 Article 1

This study demonstrated that the prevalence rate of formally documented decisions concerning forced treatment and care is much lower than that reflected by findings in previous studies. This study included forced admission as a coercive intervention belonging to home health and care. The logic behind this was that the foregoing process as well as the decision of admission was initiated in the home health and care services.

The three types of forced treatment and care most frequently identified were  as follows:

a) Decisions of admission (57%)
b) Other medical and safety decisions (27%)
c) Assistance with activities of daily living (16%)

Although physicians were typically responsible for the decisions, nurses and family members were often involved in the process. Interdisciplinary collaboration was common (82%). Family participation in forced treatment and care raises ethical dilemmas.

a) Physicians were responsible in (77%) of the decisions
b) Nurses were responsible in (22 %) of the decisions
c) Family members were involved in (84 %) of the decisions

Logistic regression analysis demonstrated that persons with dementia who lived in ordinary housing had a higher probability of being coercively admitted to a health institution, were more likely to be coercively admitted to a health institution by a physician than by a nurse, who lived in assisted housing had higher odds of being subjected to other forced medical or safety decisions (Table 4).

**Table 4. Binary logistic regression analysis of the likelihood of decisions pertaining to forced treatment and care**

| | All decisions n = 108 | Decisions of forced admission n = 62 | | | Other forced medical and safety decisions n = 29 | | |
|---|---|---|---|---|---|---|---|
| **Variables** | n (%) | n (%) | OR | AOR | n (%) | OR | AOR |
| **Age (≤79 years)** | 55 (51) | 35 (57) | | | 13 (48) | | |
| **Gender (female)** | 74 (69) | 41 (66) | | | 19 (66) | | |
| **Living situation:** | | | | | | | |
| **ordinary housing (1)** | 67 (62) | 56 (90) | 30 [10-88] | 42 [12-147] | 6 (21) | | |
| **assisted housing (1)** | 41 (38) | 6 (10) | | | 23 (79) | 13 [5-37] | 13 [4-42] |
| **Family involvement** | 91 (84) | 52 (84) | | | 23 (79) | | |
| **Interdisciplinary collaboration** | 89 (82) | 52 (84) | | | 22 (76) | | |
| **Professional responsible (physician/dentist)** | 83 (77) | 61 (98) | 64 [8-500] | 39 [4-380] | 15 (52) | | |

*Empty cells in the table—logistic regression analysis was not performed for chi-square tests when number of decisions of forced treatment and care in the categories < 5 or analysis was not significant (p > 0.05).*

However, in some of the OR (odds ratio) and AOR (adjusted odds ratio) analyses, the confidence interval was wide, which caused uncertainty about the result. Therefore, these results should be interpreted with caution.

There were no significant differences in terms of age, gender, family involvement, or interdisciplinary collaboration between persons with dementia living in ordinary housing and those living in assisted housing.

## 8.2 Article 2

We identified 88 documents in which trust-building interventions were described. Some decision-related documents contained more than one intervention, and altogether, 144 different trust-building interventions were registered.

*"Balancing safe care with the person's integrity"* was an overarching theme that permeated the descriptions of trust-building interventions used for home-dwelling persons with dementia. The trust-building interventions used in the most challenging situations did not differ from the interventions that previous research has identified as suited in general for dementia care. The main reasons for implementing trust-building were related to descriptions of poor hygiene, inadequate nutrition, risk of falling, and the need for increased supervision. The following three main themes were identified when the data were analyzed: *safeguarding care*, *protecting integrity*, and *optimizing the environment*.

### *Safeguarding care*

Safety was referred to as both an objective term of "patient safety" and as a subjective term to describe the person with dementia`s "feeling" of safety. To be able to *safeguard care*, the health professionals needed to gain access, and they emphasized creating trust by exhibiting a careful and calm approach to the situation. They also highlighted that the structure included the level and intensity of care and that the collaboration and competence of the care team were important trust-building interventions to safeguard care.

### *Protecting integrity*

Many of the persons with dementia resisted interference in their daily routines. We found that the health professionals strived to *protect integrity* through an individual approach, adjusting to habits and respecting preferences. It was described as a continuous dilemma that the increased presence of health professionals could result in increased suspicion and reluctance on the part of the person with dementia. Interventions therefore required flexibility and time, allowing more time at each visit or to come at the preferred time of the person with dementia.

### *Optimizing the environment*

The health professionals highlighted the importance of an optimized physical environment inside and outside as beneficial for wellbeing. In the assisted living facilities, they referred to small units of seven to eight persons, private rooms and bathrooms, having their personal belongings, and the adaptation of common areas for persons with dementia. Easy access to adapted gardens and outside areas were highlighted as fortunate.

For persons with dementia living in their own private homes, the physical environment was less emphasized. The identified adaptations here were more related to security and patient safety than to trust-building. Fewer changes implemented in private homes may also be explained by the fact that familiar surroundings provide greater feelings of safety for the person with dementia. From a public health or aging at home policy perspective, there might be the potential for increased collaboration between local community, home health and care services, and patients and their families in optimizing outdoor environments.

The study indicated that the health professionals went to great lengths to respect the person`s wishes for autonomy and to continue living at home. The results from Article 2 describe trust-building interventions that are implemented prior to applying forced treatment and care.

We identified two knowledge gaps related to the following: 1) how to perform appropriate assessments of situations involving home-dwelling persons with dementia when met with resistance to care; 2) and whether environmental initiatives may also benefit home-dwelling persons with dementia who are not easily cared for.

In preparation for Article 2, the written text about trust-building interventions in the decision documents was coded (quantitized) into variables suitable for statistical analysis. Of these, 57 (65%) belonged to the variable of structural trust-building interventions, 51 (58%) to individual trust-building interventions, and 36 (41%) to relational trust-building interventions (Table 5).

## 8.3 Article 3

The results from Study 1-Article 1 and 2 informed the design of Study 2-Article 3. In this study, we interviewed nurses about their encounters with resistance to care and the use of forced treatment and care. Two main themes were identified. First, they described being challenged by complex and inadequate care structures and expressed that they would adapt care according to circumstances.

There were three subthemes within the first main theme: lack of systematic collaboration and understanding, insufficient flexibility of care, and the challenge of privacy. They lacked systematic collaboration and mutual understanding with the general practitioners and their leaders in situations involving resistance to care. The lack of communication and support when facing resistance influenced their ability to provide effective dementia care because decisions were stalled. The nurses stated that limited time and lack of staff were common challenges faced in home care and that persons with dementia were at risk of receiving less care than cognitively clear patients. Furthermore, there were unique challenges in private home care that could be difficult for the nurses to endure, such as the feeling that they violated the person with dementia`s right to privacy and to decide to live in their own homes. The nurses all considered it more damaging to proffer forced care in a private home than in a nursing home. Another challenging factor involved in entering a private home was the need to relate to the family members. Our findings indicate that nurses' responses to resistance to care from home-dwelling persons with dementia were influenced by the structural and contextual factors.

In the second main theme, there were two subthemes: avoid forced treatment and care to protect autonomy, and reduced care. There was a general understanding among the nurses that they should not and could not use coercion. When encountering resistance, the nurses considered the possible damages due to forced care to be higher than the risks of missed health care. However, there were gray areas. Several nurses stated that they sometimes did cross the line and used forced treatment and care even if a decision regarding this had not been made. We found that when persons with dementia resisted care, the nurse's main approach was pragmatic and involved attempting to provide adequate care. They endeavored to provide effective care as much as possible considering the circumstances. Nevertheless, care practices were characterized by a strong commitment to avoid forced treatment and care, usually by reducing and adapting care to the circumstances.

Related to main theme two, we also identified that central parts of the guidelines embedded in the law were not applied, especially with regards to assessing the capacity to consent and the person's necessary health care needs and whether this ought to be judged differently in persons with dementia. A fundamental question that arose from this study concerned whether nurses in home and health care services experience that autonomy, understood as "self-determination conquers all," even when severe health damage is at stake.

## 8.4 Integration and overall results

In the following, a mixed-methods analysis of the main approaches of trust-building interventions of nursing care when encountering resistance among home-dwelling persons with dementia is first presented in 8.4.1. The overall results are presented in 8.4.2 and subsequently addressed in the discussion chapter (Chapter 9).

### 8.4.1 Integration of findings regarding trust-building interventions from Study 1 and Study 2

We developed a joint display to present an interpretation of the main findings regarding trust-building approaches from Study 1-(the quantitative findings about trust-building interventions that were not included in Article 1 or 2), findings from Study 1-Article 2, as well as findings from Study 2-Article 3 (Table 5). A joint display refers to a "*table or a figure that can be used to represent a juxtaposed representation of findings of qualitative or quantitative strands of a project…and that contains an interpretation, often called a meta-inference, about the meaning of the two types of results when considered together*" (Fetters, 2020, p. 194).

**Table 5. An interpretation of quantitative and qualitative findings regarding trust-building interventions**

| **Study 1** | **Study 1 (Article 2)** | **Study 2 (Article 3)** | **Study 1 and Study 2** |
|---|---|---|---|
| **Quantitative findings* n*(%)*** | **Qualitative findings** | **Qualitative findings** | **Interpretation of mixed findings** |
| Structural<br>57 *(65)* | Optimizing environment<br>Safeguarding care | Challenged by complex and inadequate care structures.<br>Adapting care to circumstances | The interpretation of findings regarding structural interventions of care was contradictory. **Article 1** identified that structural interventions were **frequently used prior to a decision** of **forced treatment and care**, however. **Article 2** emphasized the importance of more visits and dementia friendly environment. However, **Article 3** found that structural interventions **were reduced with resistance. Explanations** for this could be that structural interventions were not perceived as feasible to conduct when meeting resistance. **Lack of collaboration and mutual understanding, lack of flexibility and privacy issues made it worse to adapt and to make decisions**. |
| Individual<br>51 *(58)* | Protecting integrity<br>Safeguarding care | Adapting care to circumstances | Findings from **all three articles suggested** that individual interventions were used, with the **main purpose of protecting autonomy and integrity.** |
| Relational<br>36 *(41)* | Safeguarding care | Challenged by complex and inadequate care structures | **Articles 2 and 3** highlighted **the importance of relational interventions**, however **Article 1** found them to be the **least frequently applied**. **Explanations** for this could be that relational interventions change character and become difficult conduct at home when the level of resistance is high. Persons with dementia that **resist care risk losing access to and receiving poorer health** care. |

**Trust- buildings interventions (n = 144)*

In Table 5 we have combined the results from the two studies and interpreted them. To the left of the table, counts and percentages of types of trust-building interventions from Study 1 are found (quantitative findings not included in Article 1 or 2). They demonstrate the prevalence of the various trust-building interventions (n= 144) found in the 88 documents that were included in Article 2. The second column contains the qualitative themes of trust-building prior to forced treatment and care identified in the free text about trust building interventions in Study 1-Article 2. The third column indicates the qualitative themes nurses encounter with resistance described in Study 2-Article 3. The last column provides an interpretation of the mixed findings when considered together.

### 8.4.2 Overall results

Using a mixed-methods approach and critical realist approach, we have aimed to examine, explore, and integrate the results from the two studies to gain increased insight into the phenomenon of care practices when encountering resistance and the use of forced treatment and care in the professional caretaker-patient relationship.

- The quantitative results from Study 1-Article 1 suggest low numbers of reported forced treatment and care. This was supported by qualitative findings in Study 2-Article 3 that suggested that although forced treatment and care may be justified by law, the concept is laden with negative perceptions and not described as justifiable in clinical practice. Neither findings from articles 1, 2 or 3 indicated that care practices when encountering resistance typically lead to documented use of forced treatment and care. In situations where the possible need for forced treatment and care were assessed, interventions of nursing care assistance with ADL were the least emphasized. We found that both studies indicate that care practices are characterized by an aim to avoid coercion and emphasize maintaining and building trust (Table 5).

- The findings about use of structural trust-building interventions were contradictory. The quantitative findings about trust-building interventions from Study 1 that were not included in Article 1 or 2 indicated that structural trust-building interventions were more frequently used (65%) compared to individual (58%) and relational (41%) trust-building interventions (Table 5). This was supported by the qualitative findings in Study 1-Article 2 that emphasized increased care level and intensity of care prior to the use of coercion. The descriptions of structural interventions emphasized optimizing the environment in care homes; size of units, personal belonging, access to outside areas, prevent falls, safe kitchen facilities, heating equipment, sensors and alarms and social activities. Further they emphasized safeguarding care; level and intensity of care, visits, staffing, adapt time for assistance and interprofessional collaboration was illuminated. However, qualitative findings in Study 2-Article 3 were contradictory with regards to structural interventions, suggesting that the intensity of care was reduced with resistance. We identified that there were challenges of complex and inadequate care services structures that were rooted in lack of systematic collaboration and understanding, insufficient flexibility to care and there were challenges with intervening due to patient privacy. Care was reduced because of the resistance. Explanations for this could be that structural interventions were not perceived as feasible to conduct when meeting resistance and that lack of collaboration and mutual understanding, lack of flexibility and privacy issues made it more challenging.

- The quantitative findings about trust-building interventions from Study 1 that were not included in Article 1 or 2 suggest that individual interventions were extensively used. This was supported by the qualitative findings from Study 1- Article 2 , and Study 2- Article 3 suggesting that the main purpose was to protect autonomy and integrity (Table 5). This was done through adapting care to the individual situation and to be proportional with the level of resistance. The values of autonomy, self-determination, and integrity seemed to be more illuminated than health risks and vulnerability when providing care to home-dwelling persons with dementia. They would adapt care to the circumstances and to the level of resistance, trying to avoid forced treatment and care and to protect autonomy.

- The interpretation of findings regarding relational trust-building was contradictory. The quantitative findings (1 that were not included in Article 1 or 2 ) suggest that relational trust-building was the least commonly used (Table 5). However, qualitative findings in Study 1-Article 2 suggested that the perceived value of relational trust-building interventions was high, and nurses employed a calm approach to maintain trust (Table 5). They would try to safeguard care by trying to get into a position where they could help. They built trust by a careful and calm approach, and by using competent and experienced staff, and by using clear communication with few words, hand-leading and eye contact. Interdisciplinary staff would collaborate in challenging situations. Considering the contradictions, we focused especially on the relational approach in Study 2-Article 3, in which we explored how nurses encounter resistance to care. In Article 3 we identified that relational interventions were challenged by complex and inadequate care service structures i.e. insufficient flexibility to use more time on persons who resisted care than others and challenged by not wanting to trespass and intrude privacy. The findings from Article 3 suggested that relational care interventions were considered crucial but were challenged by resistance due to organizational and cultural circumstances i.e., lack of flexibility and the privacy of the home.

  The explanation for why relational interventions seemed to be the least frequently used may be that although relational trust-building interventions are considered necessary throughout the entire trajectory of dementia, they might change character with the development of resistance. Even if relational trust-building interventions were previously used to get in position to care, they may no longer be considered possible to use if the situation becomes thwarted. In a care relationship in which resistance to care gradually increases, the diminished perceived possibility of using relational trust-building at home, that could be due to both stalled situations or a lack of resources or flexibility to follow up, may be the starting point for making a decision regarding forced admission to a nursing home. Article 3 imparted further insight into the above-described challenge, wherein the process of gradually approaching the person with dementia over weeks and months was described in detail, and in which the process of building trust was considered equally important relative to the health-care outcomes themselves, because they were the gateway to enter the position to care. However, persons with dementia who resisted care were described as losing access to care compared to other patients and possibly ended up receiving less and poorer quality of care.

- In Study 2-Article 3 we found that responsibility for health and care rights of persons with dementia was *shared* among home health care services, general practitioners, family members, and the person themselves; however, accountability seems to be fragmented, and the division of roles appears to be unclear. The findings indicate that there is a perceived lack of communication and mutual understanding between health professionals regarding when risk and vulnerability should be assessed or acted upon among home-dwelling persons with dementia who resist care.

- One explanation to the contradictions we found when interpreting the mixed findings of the two studies is that there may possibly be a misalignment of understandings embedded in care policy, legislation, and in the structure and potential of home health and care services. On the macro-level, the strong emphasis on autonomy for persons with dementia may have indicated that the perceived room for interventions of the professional caretakers in home and health care practices has become limited. On the micro-level, the value of self-determination, the risk of losing trust, and the lack of time and flexibility can possibly push nursing care practices towards the withdrawal of rather than implementation of relational interventions.

The overall results will be discussed in Chapter 9.

# 9.0 DISCUSSION

In the following, there will first be a discussion of the methodological strengths and weaknesses of the study; the main findings will then be presented, first on the micro-level examining care practices when encountering resistance, and then at the macro-level through a discussion of dementia policies in relation to nursing care practices.

## 9.1 Methodological strengths and weaknesses of the study

We consider the strengths of this study to be the unique data concerning the formal and reported use of forced treatment and care and the extent of detailed descriptions of trust-building interventions and care practices applied when encountering resistance to care among home-dwelling persons with dementia. To our knowledge, there is little, if any, previous research with this perspective.

This study has limitations. The prevalence of the documented use of forced treatment and care in home-dwelling persons with dementia in Norway was limited and the prevalence in the present study is much lower than in other studies. There may be several possible explanations for this, such as the previously mentioned differences in definitions such as being limited to physical restraint (Bleijlevens et al., 2016). In the study of Moermans et.al. (2018) the definition of involuntary treatment was similar to the definition we used in this study, however, forced admission was not included. Other factors that limits comparisons of prevalence, is that methods for measuring prevalence varies (Mengelers et al., 2020; Scheepmans, Dierckx de Casterle, et al., 2018). In our study, the prevalence rate is exclusively restricted to the formal and reported use of forced treatment and care. In other studies, health professionals are the ones who report whether forced treatment and care is used among individual home-dwelling persons with dementia (Mengelers et al., 2020; Moermans et al., 2018). However, considering the methods of measurement applied in previous research, there may be dark numbers with regards to the applied use of forced treatment and care in Norwegian home health and care services, especially for nonconsensual care i.e. ADL assistance, that would more closely resemble those results. Our findings indicate that formal decisions are most frequently made by physicians, and some decisions i.e. medication and admission require a physician or interpersonal collaboration. Our approach could therefore be considered a methodological weakness with regards to identifying applied involuntary care in nursing practices. It was not within the scope of this study to collect data from persons with dementia, their families, nor general practitioners. Data concerning attitudes towards forced treatment and care and collaboration about situations with resistance to care in home-dwelling persons with dementia from these groups would have provided important additional insights into these phenomena.

The logic behind our research approach was that Norway has a legislation that has decided that involuntary treatment should be documented, and therefore it was relevant to examine the status of this first, related to home-dwelling persons with dementia. To our knowledge there has not previously been conducted a systematic documentation of formal decisions forced treatment and care such as in the present study. Secondly, we wanted to find out what type of involuntary treatment was used and by whom and we wanted to explore what happens in situations with resistance. We have limited data about what the drivers or motivations behind making a formal decision of forced treatment and care are. As previously noted, the phenomena of forced treatment and care is more extensive than the scope of this study. Nevertheless, this study adds important insight and knowledge into the understanding of the law, about use of trust-building interventions and about nursing care approaches to resistance to care.

Due to the strong communicated ideology of voluntariness, self-determination, and evasion of forced treatment and care, we have to take into consideration that there is a possibility that the nurses in the interviews were cautious about admitting to using any form of forced treatment and care. To avoid this, we intentionally did not use the concepts of forced treatment and care or coercion in the invitation letter, nor in the introduction to the individual or focus group interviews, nor in the wording of the questions during the interviews. We focused the questions around resistance to care. Our experience was that the nurses were open and talked freely during the discussions, and they expressed a need to reflect upon these topics. Nevertheless, the concept of forced treatment and care arose in every interview.

## 9.2 Care practices when encountering resistance

Resistance to care is the starting point for the consideration and judgement of whether to employ an involuntary intervention. This entails that the capacity to consent is a necessary assessment to conduct continuously when the person with dementia starts to resist health care. An assessment of the possible reasons for resistance to care is also important because a fundamental principle of health care is that it is voluntary (Pasient- og brukerettighetsloven [The Patient and User Rights Act], 1999). In present study we have limited information about what the nursing assessments, when met with resistance to care, were based on. It should be emphasized that persons with dementia, like every other person, may have valid reasons to resist care. However, resisting health care may often be rooted in the fact that the person with dementia does not understand the consequences of refusing treatment (Mengelers et al., 2020; Spigelmyer, Hupcey, Smith, Loeb, & Kitko, 2018 a).

To what extent the person with dementia understands what is going on around them may also influence whether they resist a health intervention (Spigelmyer et al., 2018 b,). It is therefore crucial to both enable and assess their co-decision and consent capacity. Resistance from a person with dementia does not necessarily mean that they do not want or need to be cared for. The nurses in our study emphasized the importance of searching for ways to avoid coercion, which is considered a strength in care for persons with dementia. Embedded in the act of resistance may be very contradictory emotions, such as fear and a social and moral responsibility to not become a burden, or a wish to be left alone (Gastmans, 2013a). It is important to discern *what they think* they are refusing (Levine, 2017). Resistance to care may have many explanations, and it is important to map out the possible reasons for it. Thus, the question of how to optimally provide care for persons with dementia who no longer are capable of self-care, who are ill and in need of care, but who resist it, is not easy to answer.

In the book “Philosophy of Freedom” Svendsen (2013) elaborates on legitimate reasons for refusing health care and relates it to mental illness. He exemplifies using a situation wherein a patient with a life-threatening disease refuses treatment; even when there is a treatment available with minimal side effects, the patient will be allowed to refuse. This is grounded in a belief that the person`s right to self-determination weighs heavier than what is considered the optimal medical choice for the patient. However, the picture becomes more complicated if the person has a mental disorder because it may be that the person is not capable of making decisions about their treatment (Svendsen, 2013, p. 233). In Article 1, we found that the documented reasons for forced medical interventions and admissions to hospitals were based on the need for life-saving medication such as insulin, or the need to examine the person due to an underlying somatic condition. Comorbidities are common in persons with dementia (Browne, Edwards, Rhodes, Brimicombe, & Payne, 2017); therefore, the competent assessment of various factors, such as organic brain failure, health, life story, personality, and changes in social relationships, are necessary (Kitwood & Brooker, 2019; McCormack & McCance, 2006). When a person resists care in such situations it may have serious implications for their health and wellbeing.

Within nurses` professional assessment and judgment lies the power and responsibility to act or not to act when encountering resistance to care. We argue that, in addition to knowing the person and gathering information from relevant family members, it is necessary to have the necessary competence to professionally assess the understanding of resistance of the person with dementia that is the closest to the truth or to what they really want. This requires a certain level of clinical, ethical, and legal competence and professional judgement (Alvsvåg, 2013; Martinsen, 2005; Syse, 2013; Østenstad, 2011).

### 9.2.1 Understanding autonomy

In our findings it appeared to us that nurses’ care practices when encountering resistance were associated with how they understand autonomy among persons with dementia. Our findings indicate that the definition of autonomy was understood as almost juxtaposed with self-determination. When home-dwelling persons with dementia resisted care, the health professionals' respect for self-determination appeared to override their concern for vulnerability. Voluntariness was highlighted as the threshold for the possibility to provide care, and although the nurses had thoughts regarding whether the person with dementia could understand the consequences of their choices, the expressed choice in the given situation of the person with dementia was most frequently complied with. The understanding of autonomy as closely related to self-determination can be recognized from empirical research and political guidelines for dementia care, where autonomy has increasingly been linked to self-determination, empowerment, and the person's right to choose (Delmar, 2018; Gastmans, 2013b; Helse- og omsorgsdepartementet [The Ministry of Health and Care Services], 2018; Helsedirektoratet [Norwegian Directorate of Health], 2017a).

However, in the literature on bioethics, autonomy is presented as a *limited* concept for persons whose capacity to consent is reduced, and it is illuminated that it cannot operate as the only ethical principle to ensure ethical and legal protection when it is applied to patients with a mental disorder (Rendtorff, 2002, p. 236). We argue that there needs to be a stronger link between the judgement of autonomy and the judgement of vulnerability in nursing care practices when encountering resistance. The necessity of linking these two has been highlighted in previous research on ethical frameworks for dementia care that emphasize the need to balance autonomy, dignity, and vulnerability in care for persons with dementia (Delmar, 2018; Gastmans, 2013b). In this context, Delmar (2011) asks an important question concerning how much responsibility vulnerable patients should be expected to shoulder in the decision-making process. In our study the nurses provided an example with an elderly man with dementia that lived under what they called *"undignified circumstances"* related to personal hygiene and sanitary conditions of the house. The nurses stated that they would never have wanted to live under these circumstances, but that for him it was quality of life to stay at home, despite the undignified living environment. Staying home trumping everything else.

Another relevant question that is associated with Delmar`s (2011) question is as follows: when meeting resistance, should the health professionals aim to respect the person`s wishes that might have been communicated before the development of dementia, "the then self," or should they respect the current communication regarding the person's expressed wishes, or "the now self"? In one of the focus groups a nurse told us a story about a woman with dementia that had tried to keep her weight as low as possible throughout her whole life. The nurse, that now assisted her with nutritional interventions, said that her assessment of what would be considered adequate nutrition for this patient had to be put on a lower level than for other patients. She needed to consider the whole life trajectory of the person with dementia and the aim was to provide as good care as she could, adapting it to the circumstances.

This prompts questions concerning how to understand resistance. In Europe, advanced directives for stating a person`s desire for future treatment and care prior to incapacitation due to dementia have become increasingly common and enabling self-determination for future health care is considered a cornerstone of clinical and legal guidelines (Gastmans, 2013a; Gove & Georges, 2001). The Netherlands are one of the countries with the longest experiences of advanced directives that include persons with dementia in relation to death assistance when dementia reaches a certain stage (Gastmans & Denier, 2010). We agree with Gastmans note of that decision-making aids offer people mental comfort by allowing them to plan for the future, even after having lost their decision-making capacity (Gastmans & Denier, 2010). However, although early diagnosis and the possibility of care planning have many positive effects, the ethically questionable facets also must be accounted for. Gastmans (2010) asks important questions about what happens if the person with dementia has previously stated that their life is no longer worth living if they no longer can recognize their children. However, how should one determine the act of recognition? (Gastmans & Denier, 2010).

Even if the advanced directives do not have the same form or legal status in Norway as in the Netherlands, and assistance with death is illegal, persons with dementia still have the option of writing or stating a type of advanced planning or directive. These directives are considered important documentations of the person with dementia`s future wishes (Friis & Førde, 2017; Vergemålsloven [Act Relating to Guardianship], 2010). They do not include consent for future coercion. There are challenges with implementing advanced directives, and the challenge is amplified when a person with dementia resists interventions. What if the advanced directive states that a person does not want to move to a nursing home, but they become unsafe and are in danger if left alone at home? Should one let them stay at home? What are the legal and ethical statuses of the directives against law, and do the advanced directives trump the law? We support Gastman's (2010) assertion that using decision aids that refer to the person's "then self" do not truly facilitate a solution to the problem with resistance to care but in dire need of help. What are the ethical and legal implications if the person with dementia resists? How can we guarantee that their wishes, perhaps stated 10 to 15 years ago, are still valid? Levi and Green posit that a person's preferences and values can change because of people's abilities to adapt to even the most severe debilities; as a result, previously communicated wishes may no longer reflect a recent change of heart (Levi & Green, 2010). This position is supported by other bioethicists (Walsh, 2020).

On the other hand, there are opposing arguments that promote these directives as they offer the person with dementia a possibility to have a say regarding their wishes for the future. Increasingly, websites where these types of documents can be downloaded are becoming more common (Gaster, 2019). As more people face chronic illnesses such as dementia alone, due to demographic developments, healthcare professionals will be increasingly confronted with types of directives stating a person`s wish and questions regarding autonomy and important health decisions. What then constitutes good care for the person with dementia when they resist help? We argue that it increasingly requires professional competent judgement to provide care and aid self-determination and user participation among persons with dementia that do not understand their health care needs, and that resist help, when they live at home. Persons with dementia are not only physically vulnerable, but are also extraordinary vulnerable psychologically, relationally, socially, and morally (Gastmans, 2013a). They may be exposed to moral and social pressure of taking decisions about a future they do not know how will unfold. The ethical demand that Løgstrup (1997, 2008) discusses becomes heavy in situations in which health professionals literally hold something of the other person`s life in their hands (Gastmans, 2013a; Løgstrup, 2008).

This leads to a crucial question regarding whether paternalism may ever be justifiable. Before the enactment of rather recent laws regulating forced treatment and care were enforced, paternalism has been used and justified to protect persons with dementia from harming themselves or others (Syse, 2013; Vold, 2007). However, paternalistic measures have also left patients beholden to the paternal authority of the physician and staff, restrained, medicated, or deprived of freedom; health professionals have had the power of definition and have decided what was best for the patient (Foucault, 1991). Thus, the introduction of bioethics, biomedicine, and laws and regulations related to difficult ethical and clinical health care dilemmas were meant to protect patient rights and to expand quality dementia care. However, in subsequent decades, we have observed that the voices of patients that have been subjected to coercive measures (especially in mental health care) have claimed legitimate attention, as they have questioned the health outcomes and illuminated the negative experiences of being exposed to coercion (Norvoll & Pedersen, 2016). Even if the experiences of persons with dementia have not received equal attention in media when involuntary treatment and care are concerned, it may be assumed that the experience of being subjected to forced health care is equally intrusive for them, even though the aim of the health professional may be to protect them from harm and to do good.

Nevertheless, we argue that situations exist in which not interfering can be worse than interfering with forced treatment and care, where involuntary treatment is necessary. In these situations, the interventions must be proportional; they must be done in the least intrusive manner, and the outcome of the intervention must be better than the outcome would have been without the intervention. If we, without further assessment of wishes, values, and capacity to participate in the relevant decision, treat persons with that lack of capacity to consent as if they do, our approach risks ignoring the genuine interests of the person. There are obvious situations related to pain relief or preventing a person from freezing to death or getting hurt in traffic in which, despite their resistance, it would generally be accepted as more humane to intervene. Previous research on ethical dilemmas concerning persons with dementia who wished to live at home found that they sometimes accepted some kind of forced intervention if it would make it possible for them to continue living at home (Smebye, Kirkevold, &

Engedal, 2016). Considering this, it is a concern that we in Article 1 found that nurses much less than physicians made decisions of forced treatment and care. On the other hand, findings from both Article 1 and Article 3 demonstrate that nurses emphasize inter-professional collaboration in professional judgement which may be related to their insight into the complexity of these situations. Difficult assessments of what are the less intrusive interventions must be made. Therefore, health professionals need competence in professional judgement regarding how to balance autonomy against vulnerability, in addition to their knowledge about the individual person.

In our findings, some nurses described interventions that they justified and that could be regarded as forced treatment and care. In these care situations, it was perceived as less intrusive or damaging to intervene than to not intervene at all. However, these situations, which were related to non-consensual care, were not reported as a decision of forced treatment and care because the nurses did not recognize them as such, nor did they perceive themselves as having the authority to make such a decision. In one example, there was a man who was soiled and wet due to incontinence when the nurses came to care for him who did not want to be assisted to clean up. The nurses had to balance the value of his expressed resistance and self-determination against the need to protect him from developing wounds. They weighed the time they would spend washing him with force against the time he would value being and feeling clean. When we analyzed the quantitative data in Article 1, we found that assistance with ADL was one of the least frequent decisions of forced treatment and care documented (Table 5) (Gjellestad et al., 2021). This finding is interesting because in previous research, the need for assistance with ADL was one of the factors most closely associated with resistance and the use of forced treatment and care (Scheepmans, Dierckx de Casterle, et al., 2018; Scheepmans, Milisen, et al., 2018). This may suggest that these care practices of forced hygiene are not necessarily classified as forced treatment and care, and that these interventions a characterized by unformalized coercion. To our knowledge there is limited information of how involuntary treatment is experienced by persons with dementia. Research on patient experiences of being subject to coercion within mental health has found that *how the intervention* is carried out and for how long is more important than *whether the intervention* is carried out (Norvoll & Pedersen, 2016). We argue that, with the support of Syse (2013), aiming for evaluation of whether legislation is “working” as intended, and for increased transparency must be a goal. To discuss openly challenging situations of care contributes to protection of human and patient rights.

### 9.2.2 Maintaining trust

Trust was explicitly described as something fundamental to the relationship between the caretaker and the person with dementia (Table 5). In our studies trust was alternately described as something fundamental to humans, something pre-cultural and something that resulted of the interaction of trust-building, something cultural. Considering the theoretical assumptions of Løgstrup (1997), Martinsen

(2005) and Lingis (2004) it can be argued that what the nurses did was not to build trust, but to maintain trust, because trust is not of our own making; it is given. It was the fear of breaking trust and creating distrust that motivated the nurses in the present study. The nurses explained that they considered the use of force a threat to the relationship of trust, and the nurses seldom found a reason to risk breaking trust. They referred to months and years of adapted follow-up of individual patients to maintain trust. Løgstrup's (1997) view supports this understanding, and he contends that unlike trust, distrust requires a reason, and since trust always emerges in relationships with others, it is often more easily recognized when not present (Løgstrup, 1997, p. xxix). The home health and care structure of the services found in present study may be anchored in person-centered ideology. However, the weight of the responsibility of perhaps being the only person that the patient accepts to let in may be a burden to the individual nurse, something that was identified in our study. This care management may also imply limitations with regards to including or drawing on others to find the good solutions.

However, trust was also regarded as something that could be produced through nursing care practice. There were descriptions of nurses using weeks and months of gradual approximation to build trust when introduced to new patients. Even in situations in which their goal was to provide needed health care but in which they did not manage to do this, they emphasized that at least they had built trust. By building and maintaining trust, nurses were able to at least monitor the patient regularly. Thus, the cultural product of trust that originated from a sovereign life utterance was considered both a means to enter a position to care and a health intervention outcome in itself. We argue, that like autonomy, trust also needs to be linked with vulnerability. The situation of the person with dementia who resists care is often a vulnerable one, wherein he or she is completely dependent on the nurse`s intervention to prevent suffering. Løgstrup has expressed *that how much is as stake in a relationship depends on the condition that the trustee is in* (Løgstrup, 1997, p. 17). The care relationship between the person with dementia and the nurse demands something of the latter which includes a professional assessment of self-determination against the capacity to consent; this assessment is balanced against a judgement of risk and vulnerability. From our findings we were left with an impression that nurses did not emphasize the risks of severe health damages as equivalent to the value of self-determination. They expressed that the persons with dementia`s needs were not always covered, but they indicated that they could only provide care that "was as good as possible under the existing circumstances".

The ethical demand on the professional caretaker to take care of the other thus increases significantly with a reduced capacity to consent. To be able to maintain the society's and individual's trust in the health and care system, care practices will have to find a means to ensure that home-dwelling persons with dementia will receive necessary support and help in the future if they lose the capacity to consent and that their autonomy will be protected. This ethical and clinical challenge can be traced back to the starting point of the works that ended with the Barcelona Declaration in 1998 of bioethical principles

(Kemp, 1999). The group addressed the limits and difficult considerations concerning autonomy among persons with reduced cognitive capacity; they questioned whether *respect for the individual only consists in the respect of their autonomy* (Kemp, 1999, p. 2). Considering the high value of self-determination found in our studies, it may also be pertinent to ask *whether unmet care needs is the price we must pay for autonomy in persons with dementia who continue to resist care.* The evidence indicating whether the emphasis on self-determination for persons with dementia who resist care actually promotes patients' wishes, preferred treatments and patient safety is to our knowledge scarce.

### 9.2.3 The resistance to nursing care model

Based on the findings and in consideration of the theoretical assumptions underpinning the studies, we have developed a model (Figure9). This model illustrate how professional judgement that consists of clinical, ethical, and legal competence, whether present or not, the cultural context at the macro level, the local organizational structures at the meso level, and the individual patient`s preferences, influence nurses` care practices when encountering resistance to care from home-dwelling persons with dementia at the micro level (Figure 9).

Figure 9. The resistance to nursing care model by author Å.G.

*Clinical competence* means that providing *care* and maintaining and building *trust* are considered central clinical nursing competences when encountering resistance to care among persons with dementia (Helsedirektoratet [Norwegian Directorate of Health], 2015; Martinsen, 2005; Rokstad, 2021). Our findings indicate that maintaining trust is important to be able to provide care. Trust can be perceived both as fundamental to life; it can characterize a process, and it can be defined as an outcome (Løgstrup, 1997). Dementia care practices also need to have a personal orientation that encompasses assessing the capacity to consent, autonomy against vulnerability, and the risk of suffering from unmet health needs. The content of these assessments has to be adjusted to meet the values and needs of the person with dementia. Included in clinical competence is the capability, opportunity and motivation of the health professional to provide professional dementia care.

*Ethical competence* refers to an understanding of what especially the principles of autonomy and vulnerability for persons with dementia may look like (Abma & Bendien, 2019; Delgado Rodriguez, 2017; Rendtorff & Kemp, 2000); how these may be balanced against physical health needs when encountering resistance to care. This requires knowledge, training, expectations of accountability, and inter-professional collaboration. Nurses and other health professionals need ethical competence to balance ethics, nursing practice and laws.

*Legal competence:* Updated and thorough knowledge about laws and regulations that guide dementia care is crucial. It includes knowledge of the responsibilities of the health professional in charge for care, such as nurses in charge of ADL assistance for home-dwelling persons with dementia (Helsedirektoratet [Norwegian Directorate of Health], 2015; Pasient- og brukerettighetsloven [The Patient and User Rights Act], 1999). This needs to be complemented by knowledge of policy (Helse og omsorgdsdepartementet [The Ministry of Health and Care Services], 2020; Helsedirektoratet [Norwegian Directorate of Health], 2017a) and local organizational structures for care management such as expectations for collaboration in “VIPS” or “TIME” meetings. Health professionals need to know the implications for decision-making and authority imposed by the emergence of new roles, particularly in primary health teams, advanced clinical nurses, coordinators, etc. They also need to possess knowledge of the legal status of the advanced directives and relevant laws in their country. There is also a legal responsibility of managers and chief executives that entails responsibility for having quality services and sufficient recourses to prevent the use of involuntary treatment and care, that nurses working in home and health care services should be aware of (Helsedirektoratet [The Norwegian Directorate of Health], 2017; Ledelses og kvalitetsforskriften [Regulations concerning management and quality], 2016).

Care, and the value of what effective dementia care is, is reflected and symbolized by current *organizational structures* (Bourdieu, 1977, 1991), encompassing structures for collaboration, responses when challenges are highlighted, the division of power and responsibilities that correspond with reality, and the true flexibility to perform care. The *cultural context*; policies, laws, language, and discourses guiding and influencing dementia care practices in the place of history and time are also highly important (Archer, 1998; Bourdieu, 1977, 1991). Embedded in the cultural context is also the symbolic importance of co-decision, collaboration, and respect for the individual person with dementia`s own preferences and capacities. Care practices characterized by quality professional judgment require experience, training, and competence (Alvsvåg, 2013, 2018; Martinsen, 1993, 2005).

The complexity of dementia care for home-dwelling persons with dementia places high expectations and demands on health professionals, and especially on nurses` professional judgement, which requires clinical, ethical, and legal competence (Syse, 2013; Østenstad, 2011). The resistance to nursing care model provides one approach to the factors that must be accounted for in future nursing care for home-dwelling persons with dementia.

## 9.3 Policies, ideologies and potentials of care

Clinical care practices related to resistance to care and the use of forced treatment and care are guided by policies, ideologies, and organizational structures that may influence them. Additionally, economic incentives are proven essential such as the day-fines introduced in the Coordination reform to make discharge from the hospitals to the municipalities faster (Helse og omsorgdsdepartementet [The Ministry of Health and Care Services], 2009). Our findings indicate that there are strong political and professional dementia care policies guiding practice that illuminate autonomy, self-determination, and integrity more than health risks and vulnerability when providing care to home-dwelling persons with dementia.

### 9.3.1 Language and communication

Bourdieu noted that language contains symbols that reflect values embedded in structures, such as the frameworks guiding clinical practice (Bourdieu, 1991). Practice theory considers language to be a strong symbolic identifier of class, position and power in society. However, the underlying values, structures and mechanisms for the legitimation of domination and power may be difficult to uncover (Bourdieu, 1991). What complicates communication between health professionals is that what has validity and value in one setting is not necessarily recognized as valuable from another. Which values carry moral weight differ (Jelstad Løvaas, 2022).

Our findings from Article 2 and 3 demonstrated that the nurses emphasized communication with the persons with dementia that had a calm approach, using few words and trying to adapt information to the patient`s condition. Through professional education, nurses and other health care professionals are expected to master communication with patients and colleagues (Forskrift om felles rammeplan for helse- og sosialfagutdanninger (Regulations concerning the Framework Plan for Health and Socialwork educations], 2017). General guidelines for communication in nursing care are also informed i.e. by the content of the International Council of Nurses Code of Ethics for Nurses (2012). They emphasize the nurse-patient relationship and that nurses should diminish distance by using a language adapted to the person`s ability to understand and communicate respect for the patient by including them in decision. Martinsen (2005) supports this notion and emphasizes that through conversation the nurse can use language to meet the patient with compassion.

Health professionals are also expected to master inter-professional communication (Forskrift om felles rammeplan for helse- og sosialfagutdanninger (Regulations concerning the Framework Plan for Health and Socialwork educations], 2017).  At the same time, inadequate communication between health professionals has been found to be one of the main threats to patient safety (Moi, Søderhavn, Marthinsen, & Flateland, 2019). The development of communication tools such as ISBAR (Moi et al., 2019) have attempted to improve communication by structuring it. Nevertheless, findings of present study suggested that communication between colleagues and especially between different professions, that perhaps had different professional perspectives, could be challenging. Our findings identified a perceived lack of communication and mutual understanding between nurses and general practitioners regarding when risk and vulnerability should be assessed or acted upon among home-dwelling persons with dementia who resist care. Gastmans has emphasized that the ethical dilemmas faced in nursing care, such as the development of resistance to care, goes through a process of care and time, and it is linked to daily life issues such as hygiene, eating, intimacy, etc. (Gastmans, 2013b, p. 144). This process of time can be recognized in our findings where care to persons with dementia that resisted it was described as a continuous task , over months or years, wherein situations could become urgent, but wherein they usually were predicted. Communication during these care processes can become challenging; it *"requires more than taking the right decision at a certain moment; it implies a continuous involvement"*(Gastmans, 2013b, p. 144).

### *Communication about everyday ethical problems*

Our findings are limited with regards to the exact communication that occurs between nurses and other collaborating health professionals. The findings identified that communication between the nurse and the physician was mainly done via digital messages. Nurses reported that mutual understanding and communication with regards to the urgency related to i.e. hygiene and risk of wounds was challenging.

In the focus group interviews the nurses used quotidian lay language to describe health issues related to situations of resistance to care. This choice of language is desirable and necessary in communication with persons with dementia, and in collaboration with other colleges that do not have health education. We do not know whether the same language was used in communication with i.e. physicians. However, there is a concern that communication about everyday problems may not be understood as intended. Gastmans (2013a, p.147) refers to Moody (1992) when he notes that everyday ethical problems as they appear in persons with dementia may be neglected by an approach that is too narrowly focused on time and the requirements of immediate action. Perhaps less if the communication is digital. Descriptions of slow deterioration may not be recognized, validated, nor be easy to respond to and may therefore result to be less powerful.

Bourdieu states that professional practices are influenced by the traditional hierarchical habitus and dispositions of society, and we may assume that nurses and physicians bring different types of cultural and symbolic power (knowledge) into the discussion. This could influence the understanding of the everyday ethical problems. Symbolic power is power that can be exercised only if it is recognized (Bourdieu, 1991, p. 170). The severity of everyday problems must be recognized to lead to reaction.

The language invoking the bioethical and biomedical principles such as autonomy, beneficence, and no harm were mainly developed from experiences in the acute care settings (Gastmans, 2013a). The central question using the principles approach is always *what is to be done* (Gastmans, 2013a, p. 147). Equally, relatively new communication tools in health care, such as ISBAR (Introduction, Situation, Background, Assessment and Recommendation), were also developed to safeguard communication in acute settings (Institute for health care Improvement, 2013). That means that important features of the language used in communication in many hospital and home health care settings are time-limited and action-focused, as they are concerned with decisions of urgency. Previous research has noted that while a common language of person-centered care is emerging there is a need to clarify the operationalization in everyday care practice situations (McCormack et al., 2015). We argue that this need to include communication about everyday ethical problems. The overall findings in our study indicate that there is a communication problem around the gravity of everyday ethical and clinical problems among the different stakeholders within home health and care services, especially related to ADL assistance and between nurses and general practitioners. The language used to describe health needs in everyday situations of resistance to care may be part of the explanation.

Previous research has successfully evaluated inter-professional approaches to dementia care, such as the “TIME” and “VIPS” models (Myhre, Lichtwarck, & Bergh, 2018; Røsvik, Kirkevold, Engedal, Brooker, & Kirkevold, 2011). A recent report indicated that Primary Health Teams projects in Norway can result in improved communication between the general practitioner`s office and home health and care services, typically through the nurse of the team. However, it requires effective structures of collaboration to prevent the process of reaching the general practitioner from becoming even longer (Abelsen et al., 2022, p. 11). In Article 3 we found that the nurses valued VIPS meetings, but that they were seldom conducted. We argue that different working languages between emergency and continuous care may curtail communication between professionals working from different perspectives. Further, it is my opinion that there is urgent work to be done to clarify nurses’ roles and responsibilities in home health and care services related to everyday situations of resistance to care. If there are no structures that value collaboration, discussion, and responses to reported situations of resistance to care or in everyday ethical problems, or if there is no validation of nurses’ concerns, then nurses and other caregivers are rendered powerless and with a hopeless task when describing their challenges with situations of resistance.

### *The concept of involuntary treatment and care*

Communicating about *forced treatment and care* and *person-centered care* within the same discourse is a demanding task. This includes communication in clinical practice, legislation, and research. The concepts used for forced treatment and care (no: tvang) in the current discourse in Norwegian legislation are negatively laden, as they perhaps should be, because applying them in practice entails very intrusive measures for the person involved (NOU 2019:14, 2019). However, a more nuanced debate has also been called for (Fixdal & Aulie, 2021). This is also precisely why it is important that these phenomena are discussed openly, because with ethically sensitive subjects comes the danger of silencing and taboo. The general opinion of the health authorities is that it is not possible to reduce the use of coercion without recognizing and documenting it (NOU 2019:14, 2019).

Words are important; however, their meaning is dynamic, as political and cultural correctness change over time (Bourdieu, 1991). When we communicate about the phenomenon of forced treatment and care in clinical practice, it is also crucial that we talk about the same situations and interventions. In the focus group interviews the nurses were reluctant to use the concepts related to coercion or forced treatment and care. However, they did describe situations of admission and personal hygiene that were not voluntarily. The present study has suggested that the concepts currently used, namely coercion, restraint, and forced treatment and care, may not be not recognized as suitable, legitimate or perhaps politically correct to describe the phenomenon in clinical care practices. The low prevalence of formal decisions of forced treatment and care in Article 1 supports this notion.

Equally, when we conduct research, it is important to be certain that it is the same phenomenon that is discussed, both when communicating with different professional groups that may have different perspectives, and in discussion with researchers and policymakers within and across national and professional borders. We found that previous research has described what we have defined as forced treatment and care in many ways. This has provided us with new insight, and there seem to be geographical and cultural differences regarding what language about the phenomenon can be justifiably used.

Researchers from Maastricht University in The Netherlands have been using the concept of involuntary treatment to refer to what in this thesis is described as forced treatment and care (Mengelers et al., 2020). Within their definition, they have made the following additional sub-divisions of involuntary treatment: physical restraint, psychotropic medication, and nonconsensual care (Bleijlevens et al., 2016; Hamers et al., 2016; Moermans et al., 2018). Their work has developed in parallel with the development of the present study. We suggest an exploration of whether their concept or definition may be more fitting. With the addition of “care,” we argue that “involuntary treatment and care” (no: ufrivillig omsorg og behandling) could be a superior concept relative to forced treatment and care (no: tvang) in Norwegian when communicating about the phenomenon, both in clinical practice and in research.

### 9.3.2 Mismatch between policy, guidelines and the potentials of care

Policies of aging at home and person-centered care are widely promoted and accepted (Helse- og omsorgsdepartementet [The Ministry of Health and Care Services], 2018; World Health Organization, 2017). However, although the state is responsible for care for those who cannot care for themselves in Norway, family members and volunteer workers carry the main responsibility in real life and are increasingly expected to continue to contribute to securing future dementia care (Helse og omsorgstjenesteloven [The Health and Care Services Act], 2011; Helsedirektoratet [Norwegian Directorate of Health], 2017b; Vossius et al., 2015). The challenges of placing substantially more responsibility on family members will only increase with demographic developments (Blix et al., 2021; Browne et al., 2017). In our findings from both Article 2 and 3 there were reported situations where family members helped health professionals in trying to deescalate or avoid situations of resistance. On the other side, the nurses also referred to situations where the presence of the family member made access to, and caring for the patient, more difficult. Our study suggests that family involvement and issues related to privacy also intensify the challenges of nursing care in home health and care services.

The findings from present study indicate that nurses consider the *idea of aging at home* to be a desirable solution for most persons with dementia. A previous study exploring persons with dementia`s point of view supports the notion that persons with dementia want to live at home (Fæø, Husebo, Bruvik, & Tranvåg, 2019). In present study, person-centered care seemed to be embedded in the described care practices, but with a focus on individual choice and trust-building. However, our findings also demonstrated that providing quality dementia care was experienced as challenging due to the insufficient flexibility and time and lack of care structures to provide care for persons with dementia who resist it. The findings demonstrated that effective dementia care, in the absence of either health deterioration or resistance, was not always possible to provide for the patients who resisted the most. Persons with dementia appeared to often draw the shortest straw with regards to health and care services when mixed with patients with little cognitive impairment. In light of our findings, we argue that there may possibly be a gap between the ideals of person-centered care, the application and understanding of law, and the existing care practices. Such a gap between the ideals of policy and practice as experienced by staff and service users has also been addressed in previous research (McCormack et al., 2015).

We argue that there is a disconnect between the strong emphasis on the individual person with dementia`s responsibility to be active and to be self-determined and the accountability of the state to take care of their needs. It can be argued that the communicated responsibility of the state to care for persons in vulnerable situations has diminished because the individual recourses of the person, self-determination, and activity to improve health has received increased attention, and perhaps even more importantly, it is considered a duty of the citizen (Mol, 2008)**.** In addition to leaving family with increased responsibilities, it may actually decrease the professional caretaker`s power to provide care, because the relationship to the patient has evolved from doing what the patient is not capable of to supporting the patient to self-care and to actively participate (Beedholm & Frederiksen, 2015, p. 159). This may in the next turn diminish the professional nurse's perceived opportunity and possibly his/her feeling of accountability to help.

This diminished "power to act" becomes especially visible in situations in which persons with dementia resist care. The nurses in our studies were committed to a deeply felt duty to enable the person with dementia to choose; however, when patients chose not to receive care but were in dire need, this became troublesome and burdensome for the nurses. Thus, the nurses who are there to provide assistance to those who are not capable of self-care or who strongly resist needed care are left in what Beedholm and Frederiksen describes as a "tension field of competing values" (Beedholm & Frederiksen, 2015, p. 159). Jelstad Løvaas (2022) refers to the assumption that values play an important role in guiding action. Based on our findings there seems to be a random and unfortunate synthesis of values from health policy structures that promote individualistic responsibility and choice, along with values of person-oriented care which may possibly overemphasize self-determination on behalf of vulnerability. It may fail to account for the real challenges that are present in the implementation of the aging in place policy for home-dwelling persons with dementia. Reflections upon current care practices may reveal the ambiguity and the plurality of interpretation of the mixed values. We lean on Jelstad Løvaas (2022) when we suggest that the implicit values embedded in the nursing care practices may thus not be compatible with the explicit values of the institutions of home health and care practices, nor with the values explicitly expressed in dementia policies, laws and regulations (Jelstad Løvaas, 2022, p. 16). The expectations and existence of moral and legal values and responsibilities, and their limitations, for both family members and health professionals, must be discussed and sorted out.

The increased marketization of health and care services has established enduring structures influencing care on the micro-level, particularly related to the allocated time for each visit and patients being able to choose between different public and private providers of home health care (Vabø, 2012). Recently, a "Trust-Reform" was launched by the Norwegian Government as a new re-emergence of trust-based steering in community care to resolve current and future challenges (Kommunal og moderniseringsdepartementet [The ministry of municipality and of modernization], 2021). One aim of this reform is to move the health decisions closer to the patient, investing more trust in the healthcare professional's judgment and curtailing bureaucracy (Regjeringen [The Government], 2022). If professional decisions are moved back closer to the patients, this means returning power to the executive level; however, it also implies that the individual health professional’s ability to balance between rules, needs and professional judgement of will become more demanding. Which forces and ideals that are driving dementia care will be important for the professional nurse`s judgement. The individual competencies of the staff who hold responsibility for persons with dementia will be reflected in the quality of care.

This does not mean that *the aging in place ideology is a bad idea,* but it has been argued that the government’s expectations of family or volunteer involvement is based on failing demographic assumptions (Blix et al., 2021) and that there is a need to discuss how roles and responsibilities should be divided in home health and care services (Higuchi Smith, Christensen, & Terpstra, 2002; Rasoal, Kihlgren, & Skovdahl, 2018; Tønnessen et al., 2020).The current structure imposes a great moral responsibility on the family and on individual health professionals. It also presents unresolved issues of accountability. Furthermore, where family’s responsibilities end and where the professional`s responsibility for care starts is unclear. We argue that values of autonomy and vulnerability must be understood within the perspective of person-centered care and law and need to include an assessment of risk for unmet care needs. Roles and responsibilities must be clarified between general practitioners, nurses, family members, and patients. Lastly, structures for collaboration and communication must be developed and maintained.

# 10. Conclusions and future perspectives

Health professionals providing nursing care have an important responsibility to promote autonomy, consider vulnerability and ensure quality care for home-dwelling persons with dementia.

We found that the following factors that seem to influence nursing care practices when encountering resistance to care from home-dwelling persons with dementia include *cultural context*, or policies for dementia care and laws, *organizational structural* circumstances, including structures for collaboration, division of responsibility and authority, understanding of role, the presence or absence of relevant *clinical, ethical, and legal competence*, and finally respect for the *person with dementia`s autonomy and expressed preferences*. Findings from present study suggest that all of these are embedded in nurses` professional judgement when met with resistance to care among home-dwelling persons with dementia. Nursing care practices are situated in a difficult balance between presenting themselves as competent professionals, which creates safety and trust, while also treating persons with dementia with respect and avoiding unnecessary paternalism.

Our findings indicate that there may be conflicting values expressed in policies, laws and embedded in existing structures for care. The manifestations of the value of self-determination and individual responsibility, and the risk of suffering and unmet care needs in nursing care practices are some of them. Vulnerability must be accounted for because it can impact the quality of and the accessibility to care services for home-dwelling persons with dementia and the trust society invests in these services. There are future challenges regarding how to professionally understand autonomy, dignity, and integrity and how this ought to be applied in care services for persons with dementia. It requires high levels of competence among the health and care professionals who are closest to the person with dementia to balance the respect for self-determination while identifying and acting on emerging needs. On the other hand, it also requires care structures that are in concordance with guiding policies and that reflect the values of collaboration and flexibility and that allow room for maintaining trust.

We found that coercion, restraint, and forced treatment and care are negatively laden concepts. There is a possibility that interventions of forced treatment and care are not documented, and that unregulated gray-zone care is provided because the interventions are not recognized as coercion. It is crucial to patient wellbeing and patient safety that challenges associated with resistance to care among home-dwelling persons with dementia are discussed openly. Systematic reflections upon care practices when encountering resistance may be one way to approach this. *Involuntary treatment and care* may be a better concept to use and “to think with” when doing research and when communicating about the phenomenon.

There are unattended challenges with respect to where family moral and legal responsibility ends and where health and care services moral and legal responsibilities start. In light of the coming trust reform, we argue that there is a need to illuminate this, especially considering the increased responsibility and expectations that are assigned to family members in future care for persons with dementia. The moral versus legal responsibility for home-dwelling persons with dementia should be explored and described.

Awareness of these challenges does not lead automatically to action. There may even exist different opinions about what knowledge and challenges that are legitimate between the organizational levels and professionals involved in health and care services to home-dwelling persons with dementia.

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# Appendix I

Ethical approvals Study 1

Åshild Gjellestad
Ulriksdal 10
5009 BERGEN

| | | | |
|---|---|---|---|
| Vår dato: 04.08.2017 | Vår ref: 54897 / 3 / HIT | Deres dato: | Deres ref: |

# Tilbakemelding på melding om behandling av personopplysninger

Vi viser til melding om behandling av personopplysninger, mottatt 26.06.2017.
All nødvendig informasjon om prosjektet forelå i sin helhet 10.07.2017.
Meldingen gjelder prosjektet:

| | |
|---|---|
| *54897* | *Oversikt og analyse av skriftlige vedtak om tvungen helsehjelp til hjemmeboende personer med demenssymptomer* |
| *Behandlingsansvarlig* | *VID vitenskapelig høgskole, ved institusjonens øverste leder* |
| *Daglig ansvarlig* | *Åshild Gjellestad* |

Etter gjennomgang av opplysninger gitt i meldeskjemaet og øvrig dokumentasjon, finner vi at prosjektet ikke medfører meldeplikt eller konsesjonsplikt etter personopplysningslovens §§ 31 og 33.

Dersom prosjektopplegget endres i forhold til de opplysninger som ligger til grunn for vår vurdering, skal prosjektet meldes på nytt. Endringsmeldinger gis via et eget skjema.

Vedlagt følger vår begrunnelse for hvorfor prosjektet ikke er meldepliktig.

Vennlig hilsen

Katrine Utaaker Segadal

Hildur Thorarensen

Kontaktperson: Hildur Thorarensen tlf: 55 58 26 54 / hildur.thorarensen@nsd.no
Vedlegg: Prosjektvurdering

*Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.*

# Personvernombudet for forskning

## Prosjektvurdering - Kommentar

Prosjektnr: 54897

Vi viser til opplysninger gitt i meldeskjema, samt epostkorrespondanse med prosjektleder i juli 2017.

Det overordnete målet med studien er å fremskaffe ny kunnskap om de etisk, juridisk- og faglig vanskelige situasjoner som oppstår når en hjemmeboende person med symptomer på demens, motsetter seg helsehjelp. Dette skal gjøres ved å analysere anonymiserte vedtak om tvangsbehandling, sendt til fylkesmennene for kontroll. Resultatene skal danne grunnlag for en oppfølgingsstudie av hvordan situasjoner der pasienter viser motstand ivaretas i hjemmetjenesten og hvordan pasientene opplever dette.

Opplysningene vil bli gjennomgått av dataeier før utlevering, slik at både direkte og indirekte identifiserende opplysninger fjernes helt. Prosjektleder vil således kun få tilgang til anonyme data.

Det har blitt understreket i dialog med prosjektleder at det ikke vil registreres noen personopplysninger i forbindelse med prosjektet. Ombudet kan derfor ikke se at prosjektet omfattes av meldeplikten etter personopplysningsloven. Personvernombudet legger til grunn at alle data som registreres i prosjektet er anonym ved at ingen enkeltpersoner kan identifiseres, hverken:
- direkte via personentydige kjennetegn (som navn, personnummer, epostadresse el.)
- indirekte via kombinasjon av bakgrunnsvariabler (som bosted/institusjon, kjønn, alder osv.)
- via kode og koblingsnøkkel som viser til personopplysninger (f.eks. en navneliste)Personvernombudet legger videre til grunn at navn/samtykkeerklæringer ikke knyttes til sensitive opplysninger.

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

| Region: | Saksbehandler: | Telefon: | Vår dato: | Vår referanse: |
|---|---|---|---|---|
| REK sør-øst | Leena Heinonen | 22845522 | 14.03.2018 | 2017/788<br>REK sør-øst C |
| | | | **Deres dato:** | **Deres referanse:** |
| | | | 19.02.2018 | |

Vår referanse må oppgis ved alle henvendelser

Åshild Gjellestad
VID vitenskapelige høgskole, Haraldsplass Diakonale sykehus

**2017/788 Oversikt og analyse av skriftlige vedtak om tvungen helsehjelp til hjemmeboende personer med demenssymptomer**
**Forskningsansvarlig: VID vitenskapelige høgskole, Haraldsplass Diakonale sykehus**
**Prosjektleder: Åshild Gjellestad**

Vi viser til søknad om utvidelsen av fritak fra taushetsplikten datert 19.02.2018 for ovennevnte forskningsprosje
helseforskningsloven § 11.

Det søkes følgende endring i prosjektet:

- en utvidelse av dispansasjonen fra taushetsplikt fra å gjelde saksbehandler hos Fylkesmannen i Oslo og Akersh

**Vurdering**
REK har vurdert den omsøkte endringenen, og har ingen forskningsetiske innvendinger til endringen slik den er

**Vedtak:**

Med hjemmel i Forskrift av 2.7.2009 nr. 989, Delegering av myndighet til den regionale komiteen for medisinsk
første ledd, har komiteen besluttet å gi fritak fra lovpålagt taushetsplikt fra å gjelde saksbehandler hos Fylkesma
uthente vedtak.

Dispansasjon fra taushetsplikt er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet isøkn

Dispansasjon fra taushetsplikt gjelder til 30.12.2025.

REK innvilger en utvidet dispansasjon fra taushetsplikten til prosjektleder Åshild Gjellestad.

Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknad, endringssø

Godkjenningen gjelder til 30.12.2025. Av dokumentasjonshensyn skal opplysningene oppbevares i 5 år etter pro

Klageadgang

REKs vedtak kan påklages, jf. forvaltningslovens § 28 flg. Eventuell klage sendes til REK sør-øst C. Klagefriste
klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Vi ber om at alle henvendelser sendes inn på korrekt skjema via vår saksportal: http://helseforskning.etikkom.no
post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen

Britt-Ingjerd Nesheim
Prof.dr.med.
Leder REK sør-øst C

Leena Heinonen
Rådgiver

Kopi: tove.giske@vid.no;
froydis.kristine.bruvik@haraldsplass.no

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

| Region: | Saksbehandler: | Telefon: | Vår dato: | Vår referanse: |
|---|---|---|---|---|
| REK sør-øst | Claus Henning Thorsen | 22845515 | 31.05.2017 | 2017/788/REK sør-øst C |
|  |  |  | **Deres dato:** | **Deres referanse:** |
|  |  |  | 28.03.2017 |  |

Vår referanse må oppgis ved alle henvendelser

Åshild Gjellestad
VID vitenskapelige høgskole, Haraldsplass Diakonale sykehus

**2017/788 Oversikt og analyse av skriftlige vedtak om tvungen helsehjelp til hjemmeboende personer med demenssymptomer**

**Forskningsansvarlig:** VID vitenskapelige høgskole, Haraldsplass Diakonale sykehus
**Prosjektleder:** Åshild Gjellestad

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 04.05.2017. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10.

## Prosjektomtale

*Prosjektet vil fremskaffe ny kunnskap om de etisk, juridisk- og faglig vanskelige situasjoner som oppstår når en hjemmeboende person med symptomer på demens, motsetter seg helsehjelp. I dette studiet vil vi innhente data fra anonymiserte vedtak om tvang etter pasient- og brukerettighetsloven kapittel 4a fra kommunehelsetjenesten, sendt til Fylkesmennene for kontroll. Det vil bli gjort kvantitative og kvalitative analyser av eksisterende empirisk dokumentasjon; Hva er omfang av dokumentert tvang og hvordan møtes motstand i hjemmetjenesten. Hvordan etterleves dagens regelverk i praksis. Design og metode: Kvantitativ og kvalitatv empirisk dokumentanalyse av anonymiserte vedtak om tvungen helsehjelp etter pasient- og brukerrettighetsloven kapittel 4a i 2015-2016, hentet fra alle Fylkesmenn i Norge. Det planlegges publisering av artikkel i tidskriftet nursing ethics*

## Vurdering

Helseforskningsloven gjelder for medisinsk og helsefaglig forskning, det vil si «virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom», jf. helseforskningsloven § 2, jf.§ 4.

Det overordnete målet med studien er å fremskaffe ny kunnskap om de etisk, juridisk- og faglig vanskelige situasjoner som oppstår når en hjemmeboende person med symptomer på demens, motsetter seg helsehjelp. Dette skal gjøres ved å analysere anonymiserte vedtak om tvangsbehandling, sendt til fylkesmennene for kontroll. Resultatene skal danne grunnlag for en oppfølgingsstudie av hvordan situasjoner der pasienter viser motstand ivaretas i hjemmetjenesten og hvordan pasientene opplever dette.

Komiteen mener, basert på den fremlagte dokumentasjon, at studien ikke har til formål å skaffe til veie ny kunnskap om helse og sykdom, slik dette forstås i helseforskningsloven § 4. Komiteen oppfatter prosjektet som helsetjenesteforskning.

Prosjektets gjennomføring er imidlertid avhengig av dispensasjon fra taushetsplikt.

REK er gitt myndighet til å kunne gi dispensasjon fra taushetsplikten for tilgang til opplysninger som er underlagt taushetsplikt etter forvaltningsloven § 13 d første ledd for forskning som ikke omfattes av helseforskningslovens virkeområde.

Komiteen har etter en helhetsvurdering kommet til at vilkårene for å gi fritak fra taushetsplikten foreligger. Komiteen oppfatter studien som samfunnsnyttig og mener studiens håndtering av personopplysninger ivaretar de registrertes velferd og integritet på en tilfredsstillende måte.

I forskningsprosjekter som ikke er underlagt forhåndsgodkjenningsplikten etter helseforskningsloven § 9, jf. § 2, tar REK kun stilling til spørsmålet om tilgang og utlevering av opplysningene som skal benyttes i forskningsprosjektet. Søker må avklare med personvernombud (PVO)/NSD om prosjektets behandlingsgrunnlag kan gis i form av meldeplikt etter personopplysningsloven § 31 eller konsesjonsplikt etter personopplysningsloven § 33. Komiteen forutsetter at gyldig behandlingsgrunnlag blir innhentet før opplysningene gjøres tilgjengelig for forskergruppen.

**Vedtak**

1. Etter søknad fremstår prosjektet ikke som medisinsk og helsefaglig forskning, og det faller derfor utenfor helseforskningslovens virkeområde, jf. helseforskningsloven § 2.

2. Med hjemmel i *Forskrift av 2.7.2009 nr. 989, 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 slik at saksbehandlere hos fylkesmennene kan gjennomgå vedtak om tvungen helsehjelp etter pasient-og brukerrettighetsloven § 4 a og sende ut disse i anonymisert form.

Dispensasjon fra taushetsplikt er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknad og protokoll.

Dispensasjon fra taushetsplikt gjelder til 30.12.2025.

Komiteens avgjørelse var enstemmig.

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jfr. helseforskningsloven § 10, tredje ledd og forvaltningsloven § 28. En eventuell klage sendes til REK sør-øst C. Klagefristen er tre uker fra mottak av dette brevet, jfr. forvaltningsloven § 29.

*Sluttmelding og søknad om prosjektendring*
Prosjektleder skal sende sluttmelding til REK sør-øst på eget skjema senest 30.06.2026, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK sør-øst dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Med vennlig hilsen

Britt- Ingjerd Nesheim
prof. dr. med
leder REK sør-øst C

Claus Henning Thorsen
Rådgiver

**Kopi til:**tove.giske@vid.no; froydis.kristine.bruvik@haraldsplass.no

# Appendix II

Invitation and information letter to County Governors

Fylkesmannen i [redacted]
Helse, omsorg -og sosialavdelinga
Postboks [redacted]

03.10.2017

## Forespørsel om deltakelse i forskningsprosjektet

Dette er en forespørsel til Helse- og sosialavdelingen, Fylkesmannen i [redacted] om å bidra med opplysninger til forskningsprosjektet: *Bruk av tvang ovenfor hjemmeboende eldre med kognitiv svikt og demens som motsetter seg helsehjelp*

Hovedansvarlig for prosjektet Stipendiat Åshild Gjellestad og (prosjektleder) ved VID vitenskapelige høgskole. Fylkesmannen i Hordaland bidrar til prosjektet, blant annet med samarbeid om datainnhentingen. Prosjektet er godkjent av REK, vedtak nr. 2017/788, og NSD, referansenr. 54897.

Målet er å fremskaffe ny kunnskap om vanskelige situasjoner som oppstår når en hjemmeboende person med symptomer på demens, motsetter seg helsehjelp. Resultatene skal danne grunnlag for en studie av håndteringen av slike situasjoner i hjemmetjenesten, og hvordan pasientene opplever dette.

Vi ønsker derfor å undersøke vedtak fra alle landets Fylkesmenn knyttet til bruk av tvang /tvungen somatisk helsehjelp hos hjemmeboende personer med demenssymptomer (PMD) etter kapittel 4a i pasient- og brukerettighetsloven.

Dataene vi ønsker å innhente fra Fylkesmannen er anonymiserte vedtaksskjema om tvungen helsehjelp etter pasient- og brukerettighetsloven kapittel 4a for hjemmeboende personer med demens, i årene 2015 og 2016, med tilhørende samtykkekompetansevurderinger.

Vi trenger følgelig hjelp fra Fylkesmannen i [redacted] til å finne aktuelle vedtak i Nestor og hente de ut av Ephorte (se vedlagte hjelpeskjema for fremgangsmåte) og til anonymisering. Vedtakene sendes per post direkte til forsker på følgende adresse:

*Åshild Gjellestad, VID vitenskapelige høgskole, studiested Haraldsplass, Ulriksdal 10, 5009 Bergen.*

Helse- og sosialavdelingen ved Fylkesmannen i Hordaland har vært pilot for datainnhentingen og kan kontaktes for metodiske spørsmål når det gjelder fremgangsmåten for å søke opp, hente ut og anonymisere de aktuelle vedtakene i henholdsvis Nestor og Ephorte.

Anonymiserte vedtaksskjema oppbevares i tråd med gjeldene regler (innelåst eller på forskningsserver) og makuleres etter prosjektslutt. Som mal for anonymisering kan dere bruke vedlagt fiktivt anonymisert skjema.

Vi håper dere har mulighet til å bidra med opplysninger til oss. Ved spørsmål om prosjektet ta kontakt med Åshild Gjellestad på telefon 93056925 eller e-post ashild.gjellestad@vid.no. Ved spørsmål om fremgangsmåte i Ephorte og Nestor ta kontakt med Grethe Høyland, tlf. 55572209, Fylkesmannen i Hordaland.

Det hadde vært fint om dere har anledning til å sende oss skjema i retur innen 15. november 2017.

Med vennlig hilsen

Åshild Gjellestad

PhD stipendiat
VID vitenskapelige høgskole
Ulriksdal 10
5009 Bergen

Frøydis Bruvik

PhD Hovedveileder
Forskningssjef
Haraldsplass Diakonale
Sykehus

Vedlegg

1. Hjelpeskjema for fremgangsmåte
2. Fiktivt anonymisert vedtak

# Appendix III

Guide for extracting decision of forced treatment and care from the case management systems Ephorte and Nestor at the CGOs

## Hjelpeskjema for fremgangsmåte- identifisering og uttrekk av aktuelle vedtak i Nestor og Ephorte

1. Søk opp 4a vedtak i Nestor, organiser etter virksomhet.
2. Aktuell periode 1.1.2015-31.12.2016 (2 år)
3. Registrer saksnummer for vedtak for helsehjelp til hjemmeboende personer. Dette kan være vedtak fra fastleger/legepraksiser, hjemmesykepleie, tannleger/tannpleier, allmennmedisinske senter, omsorgsboliger, bofelleskap m.fl. Ikke sykehjem.
4. Hente ut disse vedtakene fra Ephorte
5. Gjennomgå vedtakene og trekk ut vedtak som omhandler personer med demenssymptomer/kognitiv svikt (PMD) som er hjemmeboende/bor i bemannet/ubemannet omsorgsbolig (heldøgnbemannet omsorgsbolig markeres HBOB).
6. Det er funksjon, ikke diagnose som er kriterier for utvelgelse. Dette betyr at de kan ha flere diagnoser for eksempel nevrologi med demens, psykiatrisk lidelse og demens. Personer med bare psykisk utviklingshemming ekskluderes, men dersom personene <u>også</u> har demens inkluderes de.
7. Anonymisere: Ta vekk pasient, pårørendenavn + navn på helsepersonell. Ta vekk adresse og evt. navn på omsorgsbolig
8. La all tekst, alder på pasient, type helsepersonell (sykepleier, lege, tannlege, tannpleier etc.) involvert i vedtaket stå (både ansvarlig for, annet helsepersonell konferert, og overordnet faglig ansvarlig).
9. Legg ved evt. journal notat om samtykkekompetanse- anonymisert.
10. Merk med OPH dersom vedtaket er opphevet.
11. Skriv på om vedtaket gjelder kvinne (F) eller mann (M).
12. Skriv på om det er heldøgnsbemannet omsorgsbolig med kode HBOB.
13. Send til forskers jobbadresse. *Åshild Gjellestad, VID vitenskapelige høgskole, studiested Haraldsplass, Ulriksdal 10, 5009 Bergen*

# Appendix IV

The standardized form for decision-making process was developed by the national health authorities and is available online (Helsedirektoratet [The Norwegian Directorate of Health], 2019). The English translation used in present study builds on Sparby et al.`s translation (Sparby et al., 2016) and was further adapted by Åshild Gjellestad.

Exempt from public disclosure pursuant to Freedom of Information Act section 13, first subsection, pursuant to The Public Administration Act section 13, first subsection

# DESICION TO PROVIDE HEALTHCARE TO PATIENT WITHOUT CAPACITY TO CONSENT WHO RESISTS HEALTHCARE

## Patient and User Rights Act Chapter 4A, section 4A-5

*NB! Read the instructions last in the form prior for completion of the form. The form must be completed electronically-the boxes expand as needed.*

**1.Responsible for decision (decision maker)** pursuant to section 4A-5 first subsection

| | | | |
|---|---|---|---|
| | | | |

Name position/profession telephone address

Organization (name, address)

**2. Who the decision applies to (patient)**

Family name, first name Date of Birth

Address Telephone number

**3. Description of health status, health intervention that is considered and how the patient resists health care** pursuant to section 4A-2 pursuant to section 4A-3

**4. Assessment of capacity to consent related to intended healthcare measures/intervention and if capacity to consent is considered permanent or transitory pursuant to section** 4A-2 first subsection, pursuant to section 4-3 fourth subsection

**4.1 Justification**

**4.2 Who assessed capacity to consent**

**5. Description of trust building/alternative interventions without use of coercion, or justification for why trust building/alternative interventions have not been used**
pursuant to section 4A-3 first subsection

**6. Description of coercive measures/interventions to be used** pursuant to section 4A-4

| | Tick | Frequency | Further description of intervention |
|---|---|---|---|
| a. Admission to health institution | | | |
| b. Detention in health institution | | | |
| c. Movement restricting interventions | | | |
| d. Use of prescription drugs | | | |
| e. Intervention into the body | | | |
| f. Alarm systems | | | |
| g. Nursing and care or other interventions | | | |
| h. Dental treatment | | | |

**7. For considerable intervention: assessment from other qualified professional** pursuant to section 4A-5 second subsection

Assessment

Name Position/profession Telephone

**8. Professional assessment of whether conditions to use coercive healthcare measures/intervention is met** pursuant to section 4A-3 second subsection, letter a-c

**8.1 Failure to provide healthcare can result in serious health damage (justification)**

**8.2 If healthcare is considered necessary (justification)**

**8.3 The intervention is proportionate to the need of healthcare (justification)**

**9. Information from next of kin stating what the patient would have wanted** pursuant to section 4A-5 fourth subsection

**10. Overall assessment** pursuant to section 4A-3 third subsection

**11. Time frame for decision** pursuant to section 4A-5 first subsection

| | | | |
|---|---|---|---|
| Start date for decision: | | End date for decision: | |

**12. Notification of decision sent to** pursuant to section 4A-6 second subsection

| | | |
|---|---|---|
| The patient | | |
| The patient`s next of kin | | |
| Health professional responsible for administrative decisions | | |
| | name | address |

**13. Copy of decision sent to:** pursuant to section 4A-6

| | |
|---|---|
| Responsible County Governor where decision is made. Follow link to find address<br>http://www.fylkesmannen.no/ | |

**14. Signature and date of decision:**

| | |
|---|---|
| | |
| Place, date | name |

**15. Attachments**

| Nr. | Content (journalnotat) | From | Date |
|---|---|---|---|
| 1 | | | |
| 2 | | | |
| 3 | | | |

**16. Information about right of appeal**

*The patient or patient´s next of kin has a right of appeal to this decision. The deadline is 3 weeks from the concerned had or should have had information about the decision. The appeal is directed to the County Governor, but is sent to the institution/organization that has made the decision (municipality, health care institution etc). Parties of the case have access to the documents regarding the decision, if not otherwise decided by law.*
*If the decision is changed in favor of party, the concerned shall be admitted full cover of relevant legal costs that have been necessary to change the decision, unless the change is a result of the party`s own circumstances, or because of circumstances outside of the party and case management control, or other special circumstances speak against it.*

# Appendix V

Ethical approval Study 2

NSD NORSK SENTER FOR FORSKNINGSDATA

# Vurdering

**Referansenummer**

515138

**Prosjekttittel**

Health professionals decision-making when met with resistance to care from home-dwelling persons with dementia

**Behandlingsansvarlig institusjon**

VID vitenskapelige høgskole / Fakultet for helsefag / Fakultet for helsefag Bergen

**Prosjektansvarlig (vitenskapelig ansatt/veileder eller stipendiat)**

Åshild Gjellestad, ashild.gjellestad@vid.no, tlf: 93056925

**Type prosjekt**

Forskerprosjekt

**Prosjektperiode**

01.06.2020 - 01.01.2025

**Vurdering (2)**

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**07.05.2021 - Vurdert**

NSD har vurdert endringen registrert 04.05.2021.

Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet med vedlegg den 07.05.2021. Behandlingen kan fortsette.

Transkriptør er databehandler i prosjektet. NSD legger til grunn at behandlingen oppfyller kravene til bruk av databehandler, jf. art 28 og 29.

OPPFØLGING AV PROSJEKTET
NSD vil følge opp underveis (hvert annet år) og ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet/pågår i tråd med den behandlingen som er dokumentert.

Lykke til videre med prosjektet!

**12.06.2020 - Vurdert**

Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet

12.06.2020 med vedlegg. Behandlingen kan starte.

MELD VESENTLIGE ENDRINGER
Dersom det skjer vesentlige endringer i behandlingen av personopplysninger, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. Før du melder inn en endring, oppfordrer vi deg til å lese om hvilke type endringer det er nødvendig å melde:
https://nsd.no/personvernombud/meld_prosjekt/meld_endringer.html

Du må vente på svar fra NSD før endringen gjennomføres.

TYPE OPPLYSNINGER OG VARIGHET
Prosjektet vil behandle alminnelige kategorier av personopplysninger frem til 01.01.2025.

LOVLIG GRUNNLAG
Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 og 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse som kan dokumenteres, og som den registrerte kan trekke tilbake. Lovlig grunnlag for behandlingen vil dermed være den registrertes samtykke, jf. personvernforordningen art. 6 nr. 1 bokstav a.

PERSONVERNPRINSIPPER
NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen om:

- lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen
- formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke viderebehandles til nye uforenlige formål
- dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet
- lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet

DE REGISTRERTES RETTIGHETER
Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20).

NSD vurderer at informasjonen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

FØLG DIN INSTITUSJONS RETNINGSLINJER
NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og eventuelt rådføre dere med behandlingsansvarlig institusjon.

OPPFØLGING AV PROSJEKTET
NSD vil følge opp underveis (hvert annet år) og ved planlagt avslutning for å avklare om behandlingen av personopplysningene pågår i tråd med den behandlingen som er dokumentert.

Lykke til med prosjektet!

# Appendix VI

Invitation and information letter to focus group interviews

Consent form for participation in focus and individual interviews

# Forespørsel om deltagelse i forskningsprosjektet:

## Beslutningsprosesser hos helsepersonell i møte med motstand mot helsehjelp hos hjemmeboende personer med demens

**Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å** *Utforske helsepersonells beslutningsprosesser i vurdering av omsorgsbehov for hjemmeboende personer med demens som motsetter seg helsehjelp.*

Prosjektet er en del av et pågående doktorgradsprosjekt om «Bruk av tvungen helsehjelp hos hjemmeboende personer med demens (NSD 54897, REK 2017/788). VID vitenskapelige høgskole, fakultet for helsefag, Bergen er ansvarlig for prosjektet.

**Hvorfor får du spørsmål om å delta?**
Du blir invitert til å delta i prosjektet fordi du jobber i hjemmesykepleien og har erfaring med å gi pleie, omsorg og behandling til personer med demens.

**Hva innebærer det for deg å delta?**
Deltagelse i prosjektet innebærer at du deltar i et fokus-gruppe intervjuer med 5-8 personer fra hjemmetjenestene. Intervjuet vil fortrinnsvis foregå på din arbeidsplass, og vil etter planen foregå fra kl 13.30-15. Fokusgruppeintervjuet vil vare fra 60-90 minutter og vil bli ledet av prosjektleder. Intervjuene vil bli tatt opp på lydbånd og skrevet om til tekstfiler. Det åpnes også for å gjennomføre noen individuelle intervjuer. Dersom det på grunn av Covid-19 situasjonen blir begrensinger i fht. fysisk oppmøte, vil intervjuet gjennomføre digitalt.

I prosjektet vil vi registrere bakgrunnsinformasjon som alder, kjønn, utdanning, type stilling, og arbeidserfaring i hjemmesykepleien. Disse dataene vil kun være bakgrunnsinformasjonen for prosjektet. Dine svar vil ikke bli koblet til identifiserbare opplysninger om deg når forskningen presenteres eller publiseres.

Dersom du velger å delta i prosjektet, undertegner du samtykkeerklæringen på siste side.

**Det er frivillig å delta**
Det er frivillig å delta i prosjektet. Som deltagere kan du når som helst trekke ditt samtykke tilbake uten å oppgi noen grunn og uten at det vil ha noen negative konsekvenser for deg. Alle dine personopplysninger vil da bli slettet.

**Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger**
Opplysningene deg vil kun brukes til formålet vi har fortalt om i dette skrivet. Opplysningene vil behandles konfidensielt, i samsvar med personvernregelverket. Kun prosjektleder vil ha tilgang til data. Anonymiserte tekstfilene fra intervjuene vil bli analysert sammen med prosjektets veileder: Frøydis Bruvik, Trine Oksholm, og Herdis Alsvåg.

**Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?**

Opplysningene anonymiseres når prosjektet avsluttes/oppgaven er godkjent, noe som etter planen er 31.01.2025. Lydfiler vil slettes ved prosjektslutt.

**Dine rettigheter**
Så lenge du kan identifiseres i datamaterialet har du rett til: *innsyn i hvilke personopplysninger som er registrert om deg, og å få utlevert en kopi av opplysningene, å få rettet personopplysninger om deg, å få slettet personopplysninger om deg, og å sende klage til 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.

**Hvor kan jeg finne ut mer?**
Kontaktinformasjon for spørsmål til studien, eller ønsker å benytte deg av dine rettigheter: Prosjektansvarlig Åshild Gjellestad, telefon 93 05 69 25/ epost: ashild.gjellestad@vid.no

Kontaktinformasjon om personvern i prosjekter: Forskningsadm / VID vitenskapelige høgskole, Christine M. Lukash: epost christine.myrdal.lukash@vid.no telefon: 51 51 62 42.

Kontaktinformasjon om vurdering av personopplysningsbehandling i prosjektet knyttet til personvernregelverket: NSD – Norsk senter for forskningsdata AS telefon: 55 58 21 17/ epost personverntjenester@nsd.no

Med vennlig hilsen

*Prosjektansvarlig*
Åshild Gjellestad

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# Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet:
"Beslutningsprosesser hos helsepersonell i møte med motstand mot helsehjelp hos hjemmeboende personer med demens", og har fått anledning til stille spørsmål.

Jeg samtykker til deltagelse prosjektet

-----------------------------------------------------------------------------------------------------------------
(Signert av prosjektdeltaker, dato)
-

## Vedlegg. 1. Forespørsel om deltagelse i forskningsprosjektet:

Beslutningsprosesser hos helsepersonell i møte med motstand mot helsehjelp hos hjemmeboende personer med demens

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Jeg samtykker til deltagelse prosjektet

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(Signert av prosjektdeltaker, dato)

# Article 1

Gjellestad, Å., Oksholm, T., & Bruvik, F. (2020). Forced treatment and care in home-dwelling persons with dementia. *Nursing Ethics*, https://doi.org/10.1177/0969733020948107

# Article 2

Gjellestad, Å., Oksholm, T., Alvsvåg, H., & Bruvik, F. (2022). Trust-building interventions to home-dwelling persons with dementia who resist care. *Nursing Ethics*, https://doi.org/10.1177/09697330211041745

# Article 3

Gjellestad, Å., Oksholm, T., Alvsvåg, H., & Bruvik, F. Autonomy Conquers All: A Thematic Analysis of Nurses' professional judgement encountering Resistance to Care from Home-Dwelling Persons with Dementia. Under review. *BMC health services research*. Submitted 04.january.2022.