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Forced treatment and care in home-dwelling persons with dementia: a cross-sectional study

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Abstract

Background: The use of forced treatment and care of home-dwelling persons with dementia is a universally important topic. These patients are completely dependent on care from others to continue living at home.

Aim: This study aimed to gain insights into formal decisions related to the forced treatment and care of home-dwelling persons with dementia.

Design and sample: This is a cross-sectional study, based on formal decisions of forced treatment and care of home-dwelling persons with dementia in Norway between January 1, 2015, and December 31, 2016.

Methods: Descriptive statistical analysis. Statistically significant associations suitable for binary logistic regression were presented as odds ratios with 95% confidence intervals.

Ethical considerations: Approved by The Regional Committee for Medical and Health Research Ethics, and by the Norwegian Centre for Research.

Results: We found 108 formal decisions of forced treatment and care of persons with dementia. Decisions of admission represented 57% of the data, other medical and safety decisions 27%, and assistance with activities of daily living 16%. In most cases, physicians were responsible for the decisions (77%), but nurses and family members were often involved.

Discussion and conclusion: This study demonstrated a prevalence rate of formally documented decisions of forced treatment and care much lower than findings in previous studies. Poor documentation may constitute a risk for the safety and wellbeing of persons with dementia. Although physicians were usually responsible for the decisions, nurses and family members were often involved in the process. Family participation in forced treatment and care raises ethical dilemmas. More research on the experiences of nurses, PWDs and family members with forced treatment and care is needed to aid ethical, legal, and clinically challenging decision-making processes.

Key words: Key words: ethics and dementia, forced treatment and care, coercion, restraint, home care, involuntary treatment, refusal treatment and care.

Introduction

Dementia affects cognitive functions such as memory, insight, and logical thinking, and in affected persons, it leads to dependency on others for activities of daily living (ADL) (1, 2). The condition is associated with increased human and economic costs for the persons affected and their families (2), in addition to unmet care needs related to personal safety, personal hygiene, and maintaining a meaningful daily structure (3, 4). Dependency in ADL and disruptive behavior has been reported to be associated with resistance to care (5-7) and is described as common in home-dwelling persons with dementia (PWD) (8). Resistance to care combined with unmet needs, patient safety, and the need for providing respite to informal caregivers, challenge health professionals and families to consider forced treatment and care at home. Eventually, placement in a nursing home or assisted living facility often becomes necessary for PWD, and research reports that moving is often done involuntarily (9-11). (5, 12). Home healthcare in Norway is publicly funded (13) and initiatives of welfare-technology have been presented as means to prolong the possibility for PWD to remain living at home (14-16). With a growing population of home-dwelling PWD dementia that are dependent on formal and informal care, the topic is increasingly important. Therefore, it is relevant to examine the use of forced treatment and care for this population.

Background

Forced treatment and care has also been described in literature as restraint, resistiveness to care, use of force, involuntary care, non-consensual care, coercion, paternalism, and treatment refusal (5, 7, 17-19). Literature searches revealed a scarcity of studies that examine the use of forced treatment and care in home healthcare, and research is recent and limited (7, 20, 21). A recent systematic review that included eight studies reported use of restraint between 5-24% (5). In the study of Moermans et al. (7) involuntary treatment was reported to be used in 52% of the older adults receiving home healthcare.

The application of core ethical principles such as autonomy and vulnerability in the context of dementia is both guided and regulated by legislation (22-24). In empirical research and political guidelines for dementia care, autonomy is linked closely to self-determination, empowerment, and a person's right to choose (25-28). Ethical frameworks for dementia-care emphasize the need for balance among autonomy, dignity, and vulnerability in care for PWDs (25, 28). The theory of vulnerability questions the failure to acknowledge vulnerability as a universal human condition in political guidelines and legal theories, as well as a tendency to promote self-determination as the more important value (29). A failure to acknowledge vulnerability at the structural level may increase unmet care needs (25, 29).

There is no universal understanding of what forced treatment and care constitutes because of differences in definitions, policies, and laws (5, 7, 17, 30-32). In Norway, legislation has regulated the interpretation of patient rights and ethical principles such as autonomy and dignity since 2009 (22). These regulations aim to secure the quality of care by preventing and reducing coercion and by covering the unmet care needs of persons who lack the capacity to consent. In this study, forced treatment and care is defined to occur in a scenario in which *interventions of treatment and care are carried out, despite the resistance of the patient, and/or against the patient's will or knowledge* (33).

This study aimed to offer insights into formal decisions of forced treatment and care for home-dwelling PWDs.

Research questions:

- 1) What is the prevalence rate of formal decisions of forced treatment and care for home-dwelling PWD?
- 2) Which forced treatment and care interventions are used on home-dwelling PWDs?
- 3) Who are involved in making decisions pertaining to forced treatment and care for home-dwelling PWD?

Materials and methods

Study design and setting

This is a cross-sectional study based on formal decisions of forced treatment and care for home-dwelling PWDs in Norway made between January 1, 2015, and December 31, 2016. These decisions of forced treatment and care are limited to somatic healthcare. The term “home-dwelling” is related to PWDs that live in ordinary or assisted housing, and both types of housing are considered private homes. Assisted and ordinary housing are subject to the same regulations in law (34) and provide the same right to receive home care support. Residents in assisted housing pay rent and ordinary deductibles for the services (35).

Data collection

Preparation for data collection, which included the development of a pilot data-collection guideline, was done in collaboration with multiple County Governor’s offices (Figure 1). Given the personal nature of the data and for data protection purposes, each County Governor’s Office 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.

Data collection was initiated with a formal letter to all 17 County Governor’s offices with information about the study. An envelope with pre-paid postage and a return address was attached to the 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 County Governor’s office were available for questions regarding the data-collection process. After the suggested submission date passed, the non-responding County Governor’s offices were contacted via telephone or e-mail.

Eight County Governor’s Offices anonymized the data before sending them to the principal researcher. To broaden the data collection, the principal researcher collected the data from one county Governor’s office herself with advance permission from The Regional Ethical Committee for Medical and Health Research Ethics 2017/788.

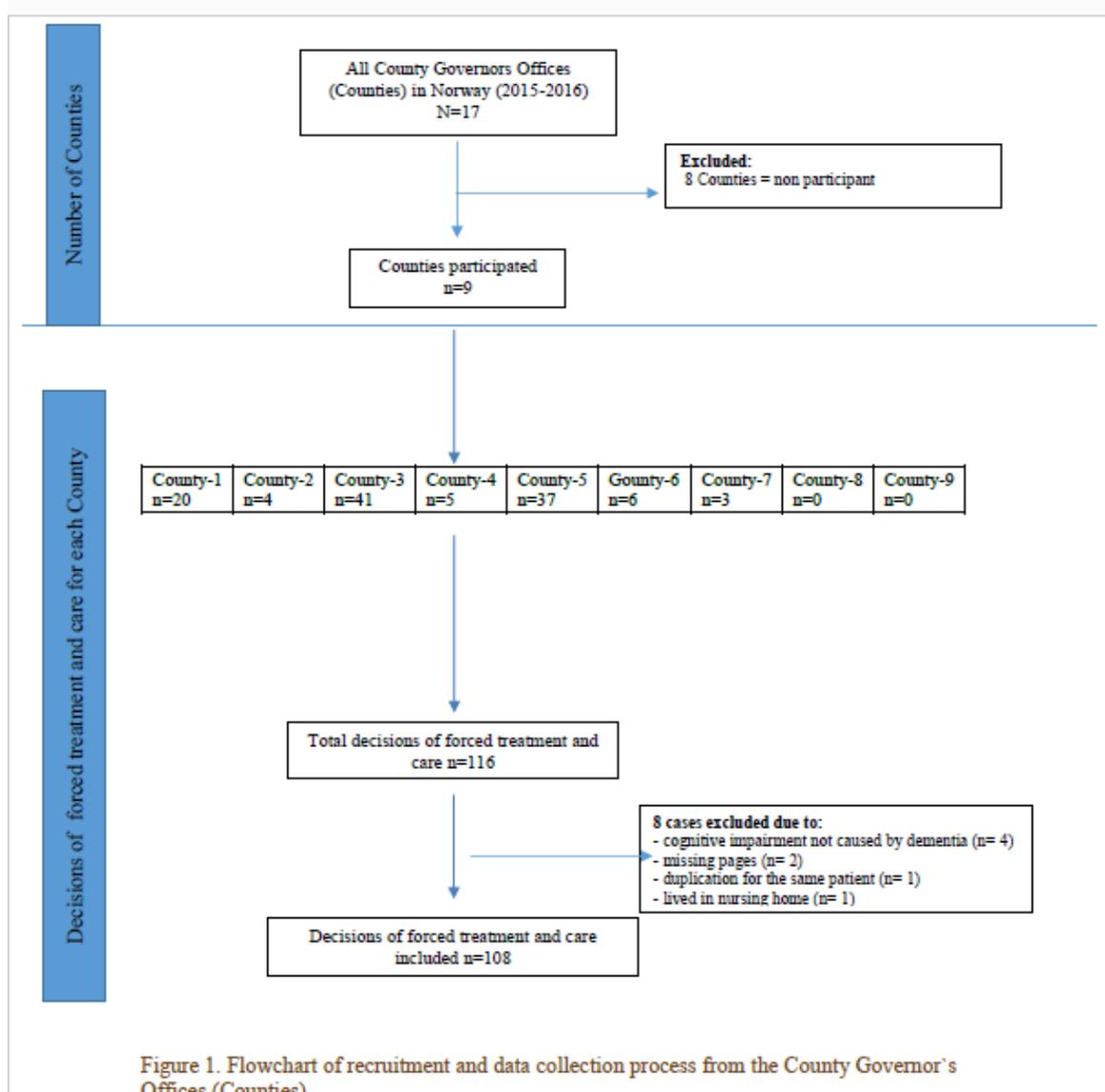


Figure 1. Flowchart of recruitment and data collection process from the County Governor's Offices (Counties).

Data collection instrument

A form for decisions of forced treatment and care has been developed by the national health authorities in Norway to safeguard that such decisions are processed and documented according to law (34). The instrument is a guide for decision-making that consists of 16 close- and open- ended questions (Figure 2). The law requires that trust-building interventions are carried out before the use of forced treatment and care (22), and these interventions are not discussed in the present article.

When decisions of 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 County Governor's Office, who serves as the regional supervisory health authority (22).

Content of standardized form for decisions of 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 carry out 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 the 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

Figure 2. Content of standardized form for decision of forced treatment and care.

Operational definitions

Age was presented in a categorical variable based on the median age of 79 years (range 34-99).

Question number six 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. In the present study, due to limited numbers in some of the categories, the eight options were recoded into the three categories shown in Figure 2.

If more than one option was checked for question number six, the entire text was read to identify the main 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.

Statistical analysis

Descriptive statistics were calculated for all variables. Categorical data were expressed in terms of numbers and percentages, and continuous data were expressed in terms of mean, standard deviation, median, and range.

Crude associations between pairs of categorical data were assessed with 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 < .05 were considered statistically significant. All analyses were performed using SPSS version 26 (IBM Corp., NY, USA). The results of the chi-square analysis are not presented in this article, but they can be obtained by request.

Statistically significant associations suited for binary logistic regression were presented as odds ratios (OR) with 95% confidence intervals [CI]. In the logistic regression analysis, categorical data (age, sex, livings 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 dependent categorical variables. Statistically significant results were modeled by performing multiple logistic regression analysis with possible associated variables and presented as adjusted odds ratios (AOR) with 95% CI.

All tests were two-sided. P-values < .05 were considered statistically significant. All analyses were performed using SPSS version 26.

Literature search

An extended literature review was done together with a senior librarian in Academic search elite, Ovid Psycinfo, Ovid Medline, Cinahl, and Ovid Embase.

Ethical considerations and approvals

This document-based study did not involve direct contact with patients or healthcare professionals. The study was granted ethical approval from Regional Ethics Committee (REK) (reference number 2017/788). Moreover, it was presented to and received no objections from the Norwegian Centre for Research Data (NSD) (reference number 54897).

Results

We found that 108 formal decisions of forced treatment and care were made in Norway during the 24-month period. Nine of 17 (all) County Governor's offices participated in the study, and they represented small (<100,000), medium-sized (100–500,000) and large counties (>500,000) spread across the country. Overall, the data represented more than 50% of the counties at the time, but there were substantial internal variations in terms of the numbers of decisions (Figure 1).

The mean age of the PWDs in the decisions was 77.5 years, with a median age of 79 (range 34–99) years. Sixty-nine percent of the PWDs described in the decisions of forced treatment and care were women (Table 1).

Among the decisions of forced treatment and care, 62% were made for PWDs who lived in ordinary housing (of these, 32% lived alone and 23% with family). The remaining 38% lived in assisted housing with staff present 24/7.

Table 1. Characteristics of the 108 decisions of forced treatment and care in home-dwelling PWD in Norway (2015-2016).

	n (%)
Age mean (SD)	77.5 (13.36)
Gender (female) n = 105	74 (69)
Living condition	
<i>Ordinary housing</i>	67 (62)
<i>Assisted housing</i>	41 (38)
Types of decisions of forced treatment and care	
Admission to a health institution, nursing home, or hospital	62 (57)
Other medical and safety decisions	29 (27)
<i>Medical and dental treatment</i>	16 (15)
<i>Detention and other safety precautions</i>	13 (12)
Assistance with ADL	17 (16)
Involved in the decisions	
Family involvement described in the intervention	91 (84)
Interdisciplinary collaboration described in the intervention	89 (82)
Physicians/dentist as the professional responsible n = 107	83 (77)
Nurse/other as the professional responsible n = 107	24 (22)

SD: standard deviation; ADL: activities of daily living. Numbers and percentages in italics refers to subgroups of the main variable above. Reported as n with percentage or mean ± SD

Table 2. Binary logistic regression analysis of the likelihood of decisions pertaining to forced treatment and care.

Variables	All decisions N = 108	Decisions of forced admission n = 62	Other forced medical and safety decisions n = 29		
	n (%)	n (%)	Odds ratio	Adjusted odds ratio	n (%) Odds ratio Adjusted odds ratio
Age (≤79 years)	55 (51)	35 (57)			13 (48)
Gender (female)	74 (69)	41 (66)			19 (66)
Living situation ordinary housing(1) assisted housing (1)	67 (62) 41 (38)	56 (90) 6 (10)	30 [10-88]	42 [12-147]	6 (21) 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).

Among the decisions of forced treatment and care, decisions of forced admission to a health institution (57%) were the most common. This was followed by other medical and safety decisions (27%), where the numbers of decisions of the different types of coercion were as follows: medical treatment n = 11, dental treatment n = 3, detention (locked doors by key or code locks) n = 9, other safety precautions n = 4, where 3 of the decisions were use GPS. Assistance with ADL accounted for 16% of the decisions (Table 1).

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

In a logistic regression analysis, we found that PWDs who lived in ordinary housing had 30 times higher odds of being coercively admitted to a health institution compared to PWDs who

lived in assisted housing ($p < 0.001$) (Table 2). When we adjusted for age and gender by multiple logistic regression, only living situation remained significant.

PWDs living in assisted housing had 13 times higher odds of being subjected to other forced medical or safety decisions than PWDs living in ordinary housing ($p < 0.001$) (Table 2). Adjusted for age and gender by multiple logistic regression, only living situation remained significant.

Decisions pertaining to assistance with ADL showed no significant associations with the other variables.

Family involvement in the decision-making process was frequent (84%). Interdisciplinary collaboration was common (82%) as well, and the professional responsible for the decision of forced treatment and care was most often a physician or dentist. Physicians and dentists were responsible for 77% (physicians = 80, dentists = 3) of all decisions of forced treatment and care, and for almost all (98%) decisions of forced admission. Nurses and other healthcare professionals were responsible for 22% (Nurses = 24, others = 3) of all decisions of forced treatment and care. There were no significant associations among interdisciplinary collaboration, family involvement, and the given decision of forced treatment and care (Table 2).

Logistic regression analysis (Table 2) showed that PWDs were 64 times more likely to be coercively admitted to a health institution by a physician than by a nurse (OR = 64, 95% CI [8–500], $p < 0.001$). In a multiple logistic regression analysis adjusted for age, gender, and living situation, age and gender were not significant. In the multiple logistic regression analysis, the adjusted odds ratio (AOR) for the professional responsible (physician/dentist) for decisions of forced treatment and care decreased to AOR 39, 95% CI [4–380], $p = 0.003$, and living situation (ordinary housing) was significant with an AOR of 31, 95% CI [8–121], $p < 0.001$, indicating that both variables were significantly associated with forced admission. However, in both the OR and AOR analyses, the confidence interval was wide, which caused uncertainty about the result. Therefore, the results should be interpreted with caution (Table 2).

Strengths and limitations of the study

The principal researcher (ÅG) previously worked as a case manager and controlled decisions of forced treatment and care forms at a County Governor's Office. We argue that this is a strength of the study in terms of understanding the data. Decisions of forced treatment and care that were poorly documented might have been followed up by local case managers. For a few of the decisions, several options were checked in response to question six (Figure 2). According to the principal researcher's experience, often, several options are checked to indicate the severity of the situation (e.g., pre medication and dental care, admission followed by detention). However, a limitation of this study is that it was not possible for our team to recheck the potential follow-ups that might have been done in the case management process. Differences between countries in how forced treatment and care is regulated, approached and registered was a challenge in this study, which made comparison of prevalence difficult.

Discussion

Summary of key results

We found 108 formal decisions of forced treatment and care for home-dwelling PWD in Norway. Forced admission was the most frequent decision, and physicians were usually the healthcare professionals responsible for these decisions. Interdisciplinary collaboration was common, and nurses and family members were often involved in the decisions.

Prevalence of reported forced treatment and care in home-dwelling PWD

Unexpectedly, only 108 decisions of forced treatment and care for home-dwelling PWDs were identified. With an estimated prevalence of 40,000 home-dwelling PWDs (11, 36), our study demonstrated a prevalence rate of less than 1% for formally documented decisions of forced treatment and care. This stands in contrast to previous studies that have reported use of coercion to be between 5% –52% (5, 7, 20, 21, 37). The deviance can possibly be ascribed to the fact that the data in these studies were based on experiences of families and healthcare professionals, whereas the data used in the present study was based on formally registered decisions of forced treatment and care. Nevertheless, the gap is noteworthy. We assume that our sample is representative for Norway because the nine participating County Governor's offices in this study represent counties from different geographical areas and of different sizes, and they do not differ substantially from the eight counties that did not participate in terms of the total numbers of decisions of forced treatment and care (38, 39).

The small number of forced treatment and care decisions could be considered as an indication of a well-functioning healthcare system that prevents coercive interventions by clear legal guidance and good quality care for home-dwelling PWD. For decades, attempts have been made to create sustainable home healthcare services for PWDs, however the sector continues to struggle with challenges of constant change and fragmentation in systems and in groups of care providers (40-42). Our assumptions about the lack of documentation are supported by national reports stating that both forced interventions and unmet care needs of home-dwelling PWDs are not registered (33). Lack of transparency in decisions of coercion is a threat to patient rights.

There may be various explanations for the small number of decisions of forced treatment and care in our study, here to be mentioned lack of understanding, lack of prioritization, and lack of clear guidelines. These are discussed as follows.

First, the health professionals understanding of the concepts of resistance to care and forced treatment and care may have implications for awareness, identification and registration of forced treatment and care (17, 19, 43). The ability to identify resistive behavior may be challenged in care situations where a PWD's resistance shifts within and between situations and may therefore appear irrational to observers. Boundaries between voluntary and forced situations can be blurred (44). This may cause that transitions from professional persuasion to coercion are not identified. Probably, undocumented interventions of coercion may have preceded a few of the decisions of forced admission documented in our study.

Second, healthcare professional may prioritize care over administrative routines. Time-consuming and bureaucratic documentation routines have been found to negatively influence the documentation of forced treatment and care (45). Home healthcare professionals have reported increased time pressure due to heavier patient load and higher documentation requirements (42). From a legal perspective, failure to document forced treatment and care or

unmet care needs imply a legal breach (22). Health-care services and professionals share strong responsibilities in terms of accounting for human vulnerability and documenting the care needs of PWDs with progressive illnesses and reduced capacity to consent (29, 42, 46).

Finally, lack of clear legislation and guidelines of how to meet resistance to care in home-dwelling PWD (18), may be another explanation to the lack of documentation. The consequence may be that either care is not given due to resistance, or that the PWD's rights to decide and resist are not respected. This is a problem, because if resistance is not documented, unmet care needs may neither be registered (47, 48). The limitations in legislation and guidelines may lead to failed home-visits with lack of support to PWD, which is found to be common in home healthcare (47). When the PWD does not see the consequences of declining necessary assistance due to progressed dementia, the health-care system must try to compensate (29, 34). Therefore, failed visits, or when a nurse is unable to gain access to provide care, must be identified, recorded and followed up (47). Guidelines must allow enable inter disciplinary discussions.

Another element to be considered is that coercion may not be documented at all, due to lack of awareness of what coercion constitutes, or to an acceptance of coercive practices remain undocumented. Probably, undocumented care needs and interventions of coercion may have preceded a few of the decisions of forced treatment ad care in our study.

Types of decisions

Forced admission to health institutions was the most frequent interventions in the present study (57 %). Admissions were mostly related to forced placement in nursing homes, only five decisions related to hospitalization were identified. The decisions of forced admission in this study described situations in which home healthcare and informal caregivers could no longer provide for a person's care needs, safety, and security. There were situations where the PWD could not be left alone, or where family members were physically endangered by the PWD. These challenging, complex and care intensive situations of care for home-dwelling PWDs that occurred prior to admission are consistent with findings reported in the literature (11, 49, 50). Forced admission to an institution affects the most fundamental rights of liberty and privacy of humans, and this measure should be used as the last resort. However, the right to necessary healthcare and to not suffer serious health-damage must simultaneously be considered for PWD because they may not understand the consequences of resistance to treatment and care (22). In some of the decisions of forced admission in present study, it was described how substantial measures were applied to allow the patient to live at home for as long as possible. The joint emphasis in the healthcare and human rights sectors on the severity of involuntary placement and the increased foci of user participation in later years (51, 52), could explain why the documentation of decisions of forced admission was superior to other forced decisions of treatment and care.

The category of other medical and safety decisions represented 27% of the 108 decisions. The medical decisions included concealing medication in food and administering insulin without warning. Previous studies have discussed the dilemmas and consequences of administering medication to PWDs in scenarios where they are restrained or not able to consent (6, 53). In the present study, cases of forced medication were divided almost equally between ordinary and assisted housing, whereas decisions of detention and other safety precautions were only made in assisted housing. Previous studies have demonstrated that safety precautions of detention to keep PWD from going outside, such as locked doors, bedrails, and misplacement of walking devices, are common interventions of restraint among home-dwelling PWD (5, 7, 21, 37). De-institutionalization of healthcare, and adoption of

“institution-like routines” in assisted housing can be part of the explanation of why decisions of forced detention were made for home-dwelling PWD in this study, although not permitted in law (54). Keeping PWD from leaving their home raises both ethical and legal issues of the right to self-determination and privacy (55). However, there are also practical challenges of how to keep home-dwelling PWD safe when they leave home (14).

We only identified three decisions of forced electronic surveillance with GPS for PWD in home healthcare. However, our data were from 2015 and 2016, and the numbers may have increased in later years. In our study, using a GPS was assessed as a superior solution to having one-on-one care, because the PWD did not wish companionship, but rather wanted to move freely. Electronic tracking managed only by family members was not included in our study. In recent reports sensors alarming family or health-professionals if PWD leave their homes at night, are assessed as especially useful (56). However, it has been questioned whether some devices may be more useful for the health care provider and for society than for the “user”(15). The use of electronic surveillance in home-dwelling PWD raises important ethical issues of consent, privacy and dignity (14, 15). In light of emphasis of welfare technology and the potential of the industry (16), ethical and legal inter disciplinary assessments concerning the use of electronic surveillance will become increasingly important.

Unexpectedly, only 16% of the decisions of forced treatment and care were related to assistance with ADL in present study. The decisions of assistance with ADL were mainly related to the prevention of infections, pain, or malnutrition. The low prevalence of forced assistance with ADL stands in contrast to the findings of previous studies where ADL-dependency has been strongly related to involuntary treatment (Moermans, 2018, Scheepmans et al, 2018). The low numbers give reason to worry because resistance to assistance to ADL can be assumed to occur prior to forced admission, for PWD.

A person-centered practice is strongly recommended in homecare of PWD (1) and is a lawfully established approach to dementia care in Norway (27). However, most home healthcare services in Norway are based on individual time- managed care contracts (13, 40), where time to care is predefined. In home healthcare, the time set aside for assistance, and the PWDs understanding of the situation, does not necessarily correspond. Thus, the need for adjustment of time and the coordination of staff recourses may be a logistical challenge in care for PWD. The time pressure may result in that health professionals provide assistance only with medically necessary needs, and downgrade needs that are not considered urgent (42, 57). Further, the medicalization of tasks in home healthcare leads to increased need for specialized knowledge among nurses (58). This may result in scenarios where less educated staff provide assistance with ADL. Such staff members may not have knowledge of how to provide person-centered care, or awareness of where the limits of coercion are crossed. Organizational structures that require collaboration among health professionals of different work areas is therefore fundamental.

Another explanation to only 17 decisions of forced assistance with ADL found in our study, may be that nurses faced with resistance when providing ADL, respect the PWDs’ decisions to not accept care (45, 59). This may become problematic if PWDs’ capacity to consent and care needs, are not assessed simultaneously. These assessments are inevitably connected, and are necessary to identify whether the PWD understands the consequences of resisting to care or not (34, 60). It is imperative that PWDs who are at the risk of wounds or infections be provided the assistance necessary to maintain basic personal hygiene. This implies care from ethically, legally and clinically competent healthcare professionals.

A third explanation to a low prevalence of ADL decisions in our study could be the fact that family members are often left with the responsibility of assisting the PWD with this type of

care (5, 45, 48). The dilemma with resistance to assistance with care is also present when family provides this type of care (48). In our study we found that collaboration with family members was attempted as a measure to reduce resistance to ADL. In contrast to the use and effects of physical restraints, little is known about the use and effect of forced ADL assistance in PWD (7). We believe that forced assistance with ADL remains under-documented.

Involvement in decisions of forced treatment and care

Persons with dementia receive assistance from family members throughout the course of dementia (11), and the family provides substantial assistance and support (61).

Unsurprisingly, we found that family was involved in 84% of the decisions of forced treatment and care, which is a legal requirement as well (34). Previous research has reported that family plays an important role in both the initiation and application of forced treatment and care (5, 7, 52). The degree of involvement of family varied across patients, and we found no significant differences in terms of family involvement among the cases where a PWD lived alone, with family, or in assisted housing. Our study did not shed light on the nature of relationship between the family members involved in a decision and the PWD in question.

Family participation in forced treatment and care raises ethical and legal dilemmas with respect to the PWD being dependent on family care, exposed to family pressure, and in receipt of forced treatment and care by family members (62). Decisions related to participation in forced treatment and care, therefore, require awareness of legal and ethical guidelines and the use of caution to safeguard the needs of both the PWD and the family (34). It is not necessarily clear as to what is less damaging: a son who admits his mother to a nursing home through deception, such as a white or therapeutic lie, or a nurse who uses the same procedure (63). Furthermore, home-dwelling PWDs are vulnerable to abuse and exploitation because of their reduced capacity to take care of themselves and their dependency on others (64). Research on the experiences of home-dwelling PWDs with coercion is limited (9, 59). However, in the study by Koenig et al., of the experiences of moving to a nursing-, or a care-home, diverging opinions were expressed by patients and family members related to involvement in the decision, where the family caregivers wanted the older adult to move, while the older adults did not consider moving necessary (9).

Interdisciplinary collaboration, a legal requirement for executing invasive decisions of forced treatment and care, was frequent in our study (82%) (22). As expected, physicians and dentists were more often the responsible decision-makers compared to nurses or other types of healthcare workers (77% versus 22%). Regulations pertaining to forced treatment and care support this, assuming that many decisions are concerned with medical or dental treatment (34). However, legislation (22) also allows for other professionals to be responsible for decisions, such as decisions of assistance with ADL (34). We argue that it is likely that nurses or other healthcare workers, even if not formally responsible, initiated many of the decisions of forced treatment and care. Nurses often apply forced treatment that is decided by others (7, 65). They are also closer to the patients compared to the physicians. One can question whether the strong emphasis on physicians' responsibility for forced treatment in guidelines and legislations has reduced nurses' awareness and understanding of their responsibilities of securing care in these situations. Previous studies have found that nurses' decisions in situations involving physical restraint were focused on safety and were influenced by contextual factors, such as wishes of family and culture and opinions of other professionals (12, 65). We argue that development of organizational structures in home healthcare that enable closer multidisciplinary collaboration would improve patient rights by securing needed healthcare, create clarity of responsibilities and facilitate prevention of coercion (18).

Conclusions and need for future research

In light of the serious consequences that use of forced treatment and care have for home-dwelling PWD, their families and the services that provide it, it is important that more research be published on this topic. More knowledge is needed about the decision-making processes and the interdisciplinary collaboration occurring in situations that balance care needs, self-determination and coercion. Research on the experiences of nurses, PWDs and family members with forced treatment and care is needed to aid ethical, legal, and clinically challenging decision-making processes.

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Conflict of interest

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