

Professional and family caregivers' attitudes towards involuntary treatment in community-dwelling people with dementia

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Abstract

Aims: The aim of this study was to gain insight into professional and family caregivers' attitudes towards involuntary treatment in community-dwelling people with dementia (PwD).

Background: The number of PwD with complex care needs living at home is increasing rapidly. In some situations, caregivers provide care against the will of PwD, referred to as involuntary treatment, which includes non-consensual care, psychotropic medication and physical restraints.

Design: A cross-sectional study.

Methods: A total of 228 professional (nursing staff, general practitioners (GPs) and other healthcare professionals such as physical therapists and psychologists) and 77 family caregivers of PwD completed the Maastricht Attitude Questionnaire—Home Care. This questionnaire measures attitudes towards involuntary treatment and perceived restrictiveness of and experienced discomfort in using involuntary treatment. Data were collected in the Netherlands between June and November 2016.

Results: Family caregivers and GPs had more positive attitudes towards involuntary treatment than nursing staff and other healthcare professionals, indicating that they are more accepting of involuntary treatment. A more positive attitude was associated with higher perceived caregiver burden and being a family caregiver. Family caregivers and GPs found the use of involuntary treatment less restrictive and indicated feeling more comfortable when using these measures.

Conclusion: It is important to account for the differences in attitudes and foster dialogue among professional and family caregivers to find common ground about alternatives to involuntary treatment. These results will inform the development of an intervention that aims to prevent involuntary treatment in home care.

KEYWORDS

caregivers, dementia, home care, involuntary treatment, non-consensual care, nursing, physical restraints, psychotropic medication

1 | INTRODUCTION

Dementia is a growing problem: more than 230.000 people with dementia (PwD) currently live in the Netherlands, which is expected to double in 2040. Most people with dementia age in place (70%) and require extensive assistance from family caregivers, social support and professional home care (Alzheimer Nederland, 2017). In addition to professional home care PwD and their informal caregivers can receive support from models of dementia case management in the Netherlands (MacNeil Vroomen et al., 2016). Dementia case managers provide long-term support and guidance for both community-dwelling PwD and their family caregivers based on their individual needs (Van Mierlo, Meiland, Van Hout, & Dröes, 2014). People with dementia are usually referred to a dementia case manager by their general practitioner (GP) to stimulate ageing in place for as long as possible.

Everyday dementia care at home is becoming increasingly complex and more than half of the informal caregivers perceive the care for their loved one as being difficult and burdensome (Alzheimer Nederland, 2017). It can be quite challenging for caregivers to deal with the changes in behaviour and cognition of PwD and to provide the right, desired care. High caregiver burden can lead to the inability to deal with difficult situations and family caregivers often feel the necessity to find an acute solution, although this might not always appear to be the most optimal option in the long term. The care for PwD involves several ethical and legal dilemmas. How do we create a balance between providing quality of care and safety while maintaining the dignity and autonomy of people living with dementia? Should we lock the door to prevent people from going outside, or respect their freedom with the risk that they get lost? These dilemmas can lead to difficult situations where caregivers provide care against the will of people with dementia (PwD). Forcing people to eat, using physical restraints and administering psychotropic medication to reduce agitation are examples of involuntary treatment (Hamers, Bleijlevens, Gulpers, & Verbeek, 2016) or coercive care (Gjergberg, Hem, Førde, & Pedersen, 2013).

In this article, these types of treatment will be referred to as involuntary treatment. Involuntary treatment is defined as treatment provided by professional or family caregivers without the consent of the client and/or to which the client opposes and can be divided into: (a) non-consensual care; (b) psychotropic medication; and (c) physical restraints (Hamers et al., 2016). Non-consensual care includes all types of care used against the wishes of the client, such as imposing restrictions on daily life choices and activities. Examples of non-consensual care are forced administration of medication, food and fluid, washing or bathing against one's will and restricting communication or transportation. Psychotropic medication is medicine capable of affecting the mind, emotions and behaviour and is often used in PwD to treat neuropsychiatric symptoms (Nijk, Zuidema, & Koopmans, 2009). Antidepressants, antipsychotics and benzodiazepines are psychotropic medications commonly prescribed to PwD (Defrancesco, Marksteiner, Fleischhacker, & Blasko, 2015; Guthrie,

Why is this research needed?

- There are clear indications that involuntary treatment is commonly used in the care for people with dementia.
- The use of involuntary treatment may be ineffective in providing safety, has several side effects and can even be harmful.
- There is a lack of knowledge about the attitudes of professional and family caregivers towards involuntary treatment use and new insights are needed to decrease the use of involuntary treatment.

What are the key findings?

- Family caregivers and general practitioners had more positive attitudes towards the use of involuntary treatment than nursing staff and other health care professionals and therefore are more accepting of the use of involuntary treatment.
- A more positive attitude towards involuntary treatment was associated with higher perceived burden and being a family caregiver.
- Family caregivers and general practitioners found non-consensual care and physical restraints less restrictive and indicated feeling more comfortable when using these measures compared with nursing staff and other health care professionals.

How should the findings be used to influence policy/practice/research/education?

- Additional research should be aimed at exploring why professional and family caregivers' attitudes towards involuntary treatment differ and how they can be influenced.
- These findings can be the basis for developing an intervention aimed at reduction and/or prevention of involuntary treatment usage in community-dwelling people with dementia.

Clark, & McCowan, 2010). Physical restraints are "actions or procedures that prevent a person's free body movement to a position of choice and/or normal access to his/her body by the use of any method, attached or adjacent to a person's body that he/she cannot control or remove easily" (Bleijlevens, Wagner, Capezuti, & Hamers, 2016). Examples of physical restraints include waist belts, a (wheel) chair with a locked tray table, special sheets and full-enclosure bedrails (Gulpers et al., 2011).

Most studies reporting on (types of) involuntary treatment focus on physical restraints and/or the use of psychotropic medication and were conducted in the nursing home setting. Literature about

the use of involuntary treatment in home care is scarce, especially about non-consensual care, its effects and the attitudes of professional and family caregivers towards the use of involuntary treatment and non-consensual care (de Veer, Francke, Buijse, & Friele, 2009; Hamers et al., 2016; Scheepmans, de Casterlé, Paquay, Van Gansbeke, & Milisen, 2017). Hamers et al. (2016) conducted the first study assessing the prevalence of all types of involuntary treatment in PwD living at home and showed that 39% of older people with cognitive impairment experience at least one type of involuntary treatment. In case of involuntary treatment use, non-consensual care was most commonly used (80%), followed by psychotropic medication (41%) and physical restraints (7%). In 74% of the cases, involuntary treatment was used by family caregivers. General practitioners and other healthcare professionals were less likely to use involuntary treatment (Hamers et al., 2016). Important factors associated with involuntary treatment use were living alone, caregiver burden, ADL dependency, cognitive status and a diagnosis of dementia (Hamers et al., 2016). The study by Scheepmans et al. (2017) indicated that restraints were used in 24.7% of older adults receiving home care; however, in this study restraints included both physical restraints and non-consensual care. Like the findings of Hamers et al. (2016), restraints were most often used by family caregivers.

1.1 | Background

Dilemmas encountered in dementia care are often associated with behavioural symptoms such as verbal and physical agitation, apathy and depression (Volicer & Hurley, 2003). These behavioural symptoms can be challenging for caregivers to deal with, causing distress that can threaten the safety and comfort of PwD and their caregivers by leading to resistance to care and the use of non-consensual care. Resistance to care includes any behaviour with which PwD resist or oppose caregiving efforts and puts PwD at risk of involuntary treatment use (Galik, Resnick, Vigne, Holmes, & Nalls, 2017; Volicer & Hurley, 2003). The most common reasons for involuntary treatment are preserving safety, increasing the time a PwD can live at home and providing caregiver respite (Scheepmans et al., 2017). However, involuntary treatment can sometimes be an unsafe practice and can even be harmful. To inhibit behavioural symptoms in PwD psychotropic medication are often prescribed, although the intended effects of these medications have not been supported and they are associated with several adverse effects such as drowsiness, dizziness, ataxia and impaired psychomotor functioning (Guthrie et al., 2010). Physical restraints are often used in PwD to prevent falls, although studies have shown that these measures do not lower the risk of falls or fall-related injuries (Capezuti et al., 2007; Evans, Wood, & Lambert, 2003; Gulpers et al., 2011). In addition, physical restraints may lead to immobility, incontinence, agitation and even death (Hamers & Huizing, 2005; Miles & Irvine, 1992). These potential negative effects clearly indicate that involuntary treatment should be prevented, and alternatives are needed.

Most studies describing the use of involuntary treatment, especially physical restraints and psychotropic medication, in nursing

homes settings. It is important, however, to gain more insight into involuntary treatment in the client's home since dementia care is shifting from institutional settings to home care. To prevent and eliminate the current use of involuntary treatment in home care, it is important to understand the attitudes of professional and family caregivers involved in home care for PwD. Attitudes about the necessity of involuntary treatment will likely differ since they are influenced by perceptions, experiences and how we value one's safety, autonomy and freedom. Professional and family caregivers hold contrasting views on issues such as non-consensual care and the need for medication of PwD (Hughes, Hope, Reader, & Rice, 2002). These differences may be attributed to family caregivers seeking to reduce their own burden while not fully understanding the negative implications for the PwD. Moreover, professional and family caregivers have different views on what is considered a physical restraint or other types of involuntary treatment (Hamers, Gulpers, & Strik, 2004; Koch, Nay, & Wilson, 2006). In some cases, caregivers may not be aware or realize that the care they provide constitutes involuntary treatment. Although a fixation belt may be considered by caregivers as restrictive, other actions such as hiding medication may not be considered involuntary treatment. To support future efforts to eliminate and prevent involuntary treatment use it is necessary to first gain insight into attitudes towards these practices from both professional and family caregivers of PwD living at home.

2 | THE STUDY

2.1 | Aims

The aim of the study was to explore the attitudes and opinions of professional and family caregivers towards the use of involuntary treatment in PwD living at home.

The following research questions were formulated:

- Do attitudes towards involuntary treatment in general and the use of non-consensual care, psychotropic medication and physical restraints specifically differ between professional and family caregivers?
- What influences caregivers' attitudes towards involuntary treatment?
- What are professional and family caregivers' perceptions on how restrictive non-consensual care, psychotropic medication and physical restraints are for PwD and do perceptions differ between caregivers?
- What are the perceptions of professional and family caregivers about how uncomfortable they would feel when using non-consensual care, psychotropic medication and physical restraints and do perceptions differ between caregivers?

2.2 | Design

A cross-sectional study assessing caregivers' attitudes towards involuntary treatment was conducted in the south of the Netherlands.

2.3 | Participants

Both professional and family caregivers were included if they were involved in the care for PwD living at home. A family caregiver could be a spouse, relative, neighbour or friend. Professional caregivers were divided into GPs, nursing staff and other healthcare professionals. Nursing staff included care assistants, (district- and specialized) nurses and dementia case managers. Other healthcare professionals included among others physical therapists, psychologists, social workers, physician assistants and professionals with management roles. When we refer to professional caregivers, GPs, nursing staff and other healthcare professionals are all included. Forty-three dementia case managers distributed questionnaires for this study. Dementia case managers coordinate the care for PwD and their family caregivers with a network of other professional caregivers (Reilly et al., 2015). Dementia case managers provided the work addresses of all GPs ($N = 310$) in their network and questionnaires were sent to GPs' offices. Questionnaires for nursing staff and other healthcare professionals ($N = 366$) and family caregivers ($N = 292$) were distributed in-person by dementia case managers. In total, 968 questionnaires were distributed. An overview of the distribution of questionnaires is provided in Figure 1.

2.4 | Data collection

Data were collected in the south of the Netherlands between June and November 2016 using the Maastricht Attitude Questionnaire—Home Care (MAQ-HC), a self-administered attitude questionnaire on involuntary treatment use. All questionnaires were distributed in a packet including an information letter and a self-addressed, stamped return envelope. The information letter included the aim of the study and the definition of involuntary treatment. It was emphasized that

participation in the study was entirely voluntary and that anonymity was guaranteed.

2.5 | The Maastricht attitude questionnaire – Home care

The MAQ-HC was developed for this study, based on the Maastricht Attitude Questionnaire (MAQ) on restraint use in nursing homes (Boscart, Hamers, & Bleijlevens, 2015; Hamers et al., 2009; Haut, Kolbe, Strupeit, Mayer, & Meyer, 2010). The first part of the MAQ-HC consists of 60 statements to measure attitudes towards the use of involuntary treatment. The items are grouped into four subscales based on pre-defined constructs as reported in Hamers et al. (2016): involuntary treatment in general (20 items), non-consensual care (15 items), psychotropic medication (13 items) and physical restraints (12 items). Examples of statements are “The safety of people with dementia is more important than the freedom of people with dementia” and “Physical restraints reduce the quality of life of people with dementia”. Each item has to be rated on a 5-point Likert scale ranging from “totally disagree” to “totally agree”. Some items have to be recoded so that for every item a higher score represents a more positive attitude towards involuntary treatment. A more positive attitude towards involuntary treatment can be interpreted as being more accepting of involuntary treatment. The subscale scores are calculated by adding up all scores of the items in that subscale divided by the number of items in that subscale. The total subscale scores range from 1 to 5, with a higher score indicating a more positive attitude towards involuntary treatment. Conversely, a lower score indicates a more negative attitude towards involuntary treatment. The second part of the MAQ-HC measures caregivers' perceptions on how restrictive (not restrictive, moderately restrictive or very restrictive) they find involuntary treatment for PwD and how uncomfortable (not

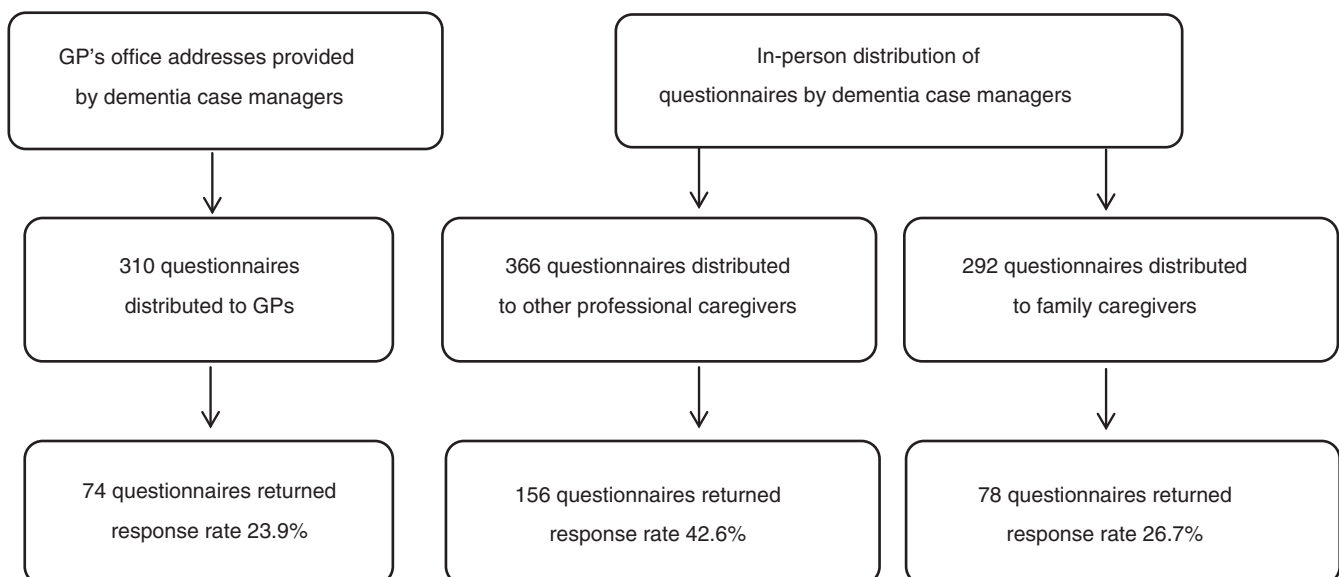


FIGURE 1 Flow chart describing the distribution of questionnaires

uncomfortable, moderately uncomfortable or very uncomfortable) they would feel when using involuntary treatment with PwD. The items are grouped into three subscales: non-consensual care (11 items), psychotropic medication (1 item) and physical restraints (13 items). Table 4 provides an overview of all types of involuntary treatment included in the second part of the MAQ-HC. We collected socio-demographic variables (age, gender, hours of care per week for PwD and perceived caregiver burden). For family caregivers, we additionally collected data about their relationship with the PwD and the living situation; for professional caregivers' data on years of working experience and current role were collected.

2.6 | Ethical considerations

This study was reviewed and approved by the Medical Ethics Test Committee (16-N-117) of the hospital (June, 2015).

2.7 | Data analyses

Prior to analyses, negative items ($N = 27$) were reverse coded so that for every item a higher score represents a more positive attitude towards involuntary treatment. Missing items were substituted by the participant's mean on that scale if the total number of missing items for that person were no greater than 20%. If more than 20% of the items were left blank, no scores were imputed for that scale. Descriptive statistics including means, standard deviations, percentages and frequencies were used to provide an overview of demographic characteristics and to summarize attitudes towards involuntary treatment and perceptions on how restrictive the caregivers view involuntary treatment for PwD and how uncomfortable caregivers feel when using involuntary treatment. One-way ANOVAs were conducted to investigate differences between the four groups of caregivers in attitudes towards involuntary treatment in general, non-consensual care, psychotropic medication and physical restraints. One-way ANOVAs were also conducted to examine differences in perceived restrictiveness of and experienced discomfort in using involuntary treatment among the four groups of caregivers. If statistically significant differences in attitudes were found, post hoc analyses with correction for multiple testing were conducted to identify which groups differed from each other. Independent samples t test analyses were conducted to investigate whether family caregivers not living with PwD had different attitudes towards involuntary treatment than family caregivers living with PwD. Multiple regression analyses were conducted to investigate the relationship between caregivers' characteristics and attitudes towards involuntary treatment use. The dependent variable was attitude towards involuntary treatment. Independent variables were age, gender, hours of care per week for people with dementia, perceived burden and professional (GP, nursing staff or other healthcare professional) versus family caregiver. All analyses were conducted using the Statistical Package for the Social Sciences (SPSS version 23; IBM, Chicago, IL, USA). A

p -value of ≤ 0.05 was considered statistically significant, unless stated otherwise.

2.8 | Validity, reliability and rigour of the MAQ-HC

The first version of the MAQ-HC consisted of two parts: (a) 67 statements to measure attitudes towards involuntary treatment and (b) 25 items to measure attitudes towards restrictiveness and discomfort of involuntary treatment. This version was pilot tested by 15 professional and family caregivers. Based on pilot testing some changes were made in the first part of the questionnaire: eight statements were deleted because of overlap with other items or because the items were not appropriate, four statements were rewritten because they were unclear, and one statement was added. No adjustments were made to the second part of the MAQ-HC. The second version of the MAQ-HC, as described in the methods section and used for distribution, consisted of 60 items in the first part and 25 items in the second part. Completing the MAQ-HC was feasible (in 25 min) and face validity was good.

Based on reliability analyses, four items from the subscale "involuntary treatment in general", one item from the subscale "non-consensual care", two items from the subscale "psychotropic medication" and one item from the subscale "physical restraints" in the first part of the second version of the MAQ-HC were deleted. This resulted in the final version of the MAQ-HC that was used for analyses. All four subscales in the first part of the final MAQ-HC: involuntary treatment in general (16 items, Cronbach's $\alpha = 0.78$); non-consensual care (14 items, Cronbach's $\alpha = 0.76$); psychotropic medication (11 items, Cronbach's $\alpha = 0.78$); and physical restraints (11 items, Cronbach's $\alpha = 0.82$) indicated good reliability. No changes were made to the second part of the final MAQ-HC. The subscales non-consensual care (11 items, Cronbach's $\alpha = 0.79$) and physical restraints (13 items, Cronbach's $\alpha = 0.84$) about restrictiveness and the subscales non-consensual care (11 items, Cronbach's $\alpha = 0.84$) and physical restraints (13 items, Cronbach's $\alpha = 0.86$) about discomfort indicated good reliability as well.

3 | RESULTS

3.1 | Sample characteristics

Of the 968 questionnaires distributed, 308 (31.8%) questionnaires were returned. Three cases were deleted from analyses due to incomplete socio-demographic data ($N = 2$) or >50% missing data on the outcome measures of the MAQ-HC ($N = 1$). The final sample ($N = 305$) consisted of 109 nursing staff, 74 GPs, 45 other healthcare professionals and 77 family caregivers. Participants ranged in age from 19–92 years (mean = 49.7, SD 14.8). Seventy-six per cent of the participants ($N = 231$) were female. Table 1 provides an overview of the characteristics per group.

3.2 | Attitudes of professional and family caregivers towards involuntary treatment

For all four subscales, the mean scores of professional and family caregivers varied between 2.37 and 3.44, indicating rather neutral attitudes towards the use of involuntary treatment. Table 2 summarizes the attitudes of nursing staff, GPs, other healthcare professionals and family caregivers on all four subscales. First, family caregivers and GPs had more positive attitudes towards involuntary treatment in general and more positive attitudes towards all three types (non-consensual care, psychotropic medication and physical restraints) when compared with nursing staff. Family caregivers had more positive attitudes towards involuntary treatment in general and non-consensual care and physical restraints compared with other healthcare professionals. Finally, GPs had more positive attitudes towards involuntary treatment in general compared with other healthcare professionals. Attitudes of family caregivers living with PwD did not significantly differ from attitudes of those not living with PwD.

3.3 | Relation between caregivers' characteristics and their attitudes towards involuntary treatment

Multiple linear regression analyses showed that attitude towards involuntary treatment was positively associated with perceived burden and type of caregiver. Family caregivers were more accepting of involuntary treatment compared with nursing staff, GPs and other healthcare professionals. Caregivers who sometimes, often or always experienced burden were more accepting of involuntary treatment than people who never or rarely experienced burden. The results of the multiple linear regression analyses are shown in Table 3.

3.4 | Caregivers' perceptions about restrictiveness of and experienced discomfort in using involuntary treatment

Table 4 provides an overview of mean item scores about perceived restrictiveness and experienced discomfort in using non-consensual care, psychotropic medication and physical restraints. In general, the

TABLE 1 Sample characteristics

	Nursing staff	General practitioners	Other healthcare professionals	Family caregivers
N	109	74	45	77
Age	42 (SD 12.6) Range 19–66	47 (SD 10.4) Range 27–63	45 (SD 11.2) Range 22–65	65 (SD 11.5) Range 45–91
Gender				
Male	5 (5%)	41 (55%)	2 (4%)	26 (34%)
Female	104 (95%)	33 (45%)	43 (96%)	51 (66%)
Hours per week caregivers take care of people with dementia				
1–5 hr	25 (23%)	60 (81%)	26 (58%)	15 (20%)
6–10 hr	19 (18%)	6 (8%)	7 (16%)	17 (22%)
11–15 hr	8 (7%)	4 (5.5%)	2 (4%)	13 (17%)
16–20 hr	10 (9%)	—	1 (2%)	8 (10%)
>20 hr	47 (43%)	4 (5.5%)	9 (20%)	23 (30%)
Missing				1 (1%)
Perceived caregiver burden				
Never	9 (8%)	1 (1.5%)	3 (7%)	2 (3%)
Seldom	18 (17%)	4 (5.5%)	11 (24%)	7 (9%)
Now and then	69 (63%)	44 (59.5%)	21 (47%)	43 (56%)
Often	13 (12%)	23 (31%)	8 (18%)	21 (27%)
Always	—	2 (2.5%)	2 (4%)	4 (5%)
Years of experience	19 (SD 12.2)	21 (SD 9.2)	22 (SD 12.1)	—
Relation				
Spouse	—	—	—	33 (43%)
Non-spouse	—	—	—	42 (54%)
Missing				2 (3%)
Living together				
No	—	—	—	42 (55%)
Yes	—	—	—	35 (45%)

TABLE 2 Attitudes towards involuntary treatment

	Nursing staff	General practitioners	Other healthcare professionals	Family caregivers	p-value (ANOVA)
Involuntary treatment	2.88 (0.43) ^{b,d}	3.27 (0.39) ^{a,c}	2.97 (0.44) ^{b,d}	3.28 (0.33) ^{a,c}	<0.001
Non-consensual care	2.97 (0.44) ^{b,d}	3.25 (0.42) ^a	3.04 (0.43) ^d	3.44 (0.46) ^{a,c}	<0.001
Psychotropic medication	2.88 (0.44) ^{b,d}	3.19 (0.54) ^a	2.94 (0.48)	3.17 (0.39) ^a	<0.001
Physical restraints	2.37 (0.53) ^{b,d}	2.83 (0.42) ^a	2.55 (0.53) ^d	3.02 (0.54) ^{a,d}	<0.001

Note. Items were rated on a 5-point Likert scale indicating one as a negative attitude and five as a positive attitude. Reported scores are mean scores and standard deviations. Corrected $\alpha \leq 0.002$.

^aSignificantly different from nursing staff.

^bSignificantly different from GPs.

^cSignificantly different from other healthcare professionals.

^dSignificantly different from family caregivers.

mean scores of all caregivers about perceived restrictiveness of non-consensual care, psychotropic medication and physical restraints varied between 1.87–2.50, indicating that overall these types of involuntary treatment are considered moderately restrictive. Similar results were found about feeling uncomfortable when using involuntary treatment, with mean scores varying between 1.84–2.40, indicating that all caregivers feel moderately uncomfortable when using involuntary treatment. Table 5 summarizes the results of the ANOVA analyses of the mean subscale scores about perceived restrictiveness of and experienced discomfort in using non-consensual care, psychotropic medication and physical restraints.

Family caregivers and GPs perceived non-consensual care and physical restraints less restrictive for PwD and indicated feeling more comfortable when using these measures than nursing staff. Results

also indicated some differences between family caregivers and other healthcare professionals: family caregivers perceived non-consensual care and physical restraints less restrictive and indicated feeling more comfortable in using non-consensual care compared with other healthcare professionals. Finally, GPs indicated feeling less uncomfortable in using non-consensual care compared with other healthcare professionals. No differences were found about perceived restrictiveness of and discomfort in using psychotropic medication between the four groups.

4 | DISCUSSION

Study findings indicate that family caregivers and GPs have similar attitudes towards involuntary treatment and are more accepting of involuntary treatment than nursing staff and other healthcare professionals. A positive attitude towards the use of involuntary treatment is associated with high caregiver burden and type of caregiver (being a family caregiver). Family caregivers and GPs perceived non-consensual care and physical restraints less restrictive for PwD and indicated feeling more comfortable when using these measures compared with nursing staff. Finally, family caregivers found non-consensual care and physical restraints less restrictive than other healthcare professionals and both GPs and family caregivers indicated feeling more comfortable when using non-consensual care compared with other healthcare professionals.

The finding that family caregivers are more accepting of involuntary treatment than nursing staff and other healthcare professionals is similar to previous findings that involuntary treatment is most often used and requested by family caregivers (Hamers et al., 2016). It is reasonable to assume that those with more positive attitudes towards involuntary treatment are more likely to use involuntary treatment in complex situations. These differences can be explained by different ethical perspectives and views of how to balance the best interests of PwD with practices such as coercion and the need for medication (Hughes et al., 2002).

According to Hughes et al. (2002), family caregivers experience that they have to restrict the activities of PwD for the sake of safety, not only because of their duties towards the PwD but also

TABLE 3 Multiple regression analyses on caregivers' characteristics and attitudes towards involuntary treatment

	Unstandardized coefficients		Standardized coefficients	
	B	SE	β	p-value
Age (years)	-0.001	0.002	-0.027	0.939
Gender ^a				
Male vs. female	-0.004	0.056	-0.005	0.684
Hours of care for people with dementia per week ^b				
<10 hr vs. at least 10 hr	-0.077	0.046	-0.095	0.097
Perceived burden ^c				
Never/rarely vs. sometimes/often/always	0.124	0.054	0.119	0.023
Type of caregiver (reference = family) ^d				
Nursing staff	-0.451	0.068	-0.539	<0.001
General practitioners	-0.151	0.070	-0.161	0.031
Other healthcare professionals	-0.368	0.078	-0.320	<0.001

Note. ^aReference = male (coded as 0), female (coded as 1).

^bReference = <10 hr (coded as 0), at least 10 hr (coded as 1).

^cReference = never/rarely (coded as 0), sometimes/often/always (coded as 1).

^dReference = family.

TABLE 4 Opinions about degree of restrictiveness and discomfort to involuntary treatment (descriptives)

	Nursing staff	General practitioners	Other healthcare practitioners	Family caregivers
Restrictiveness				
<i>Non-consensual care</i>				
1. Withholding aids, for example, walking aids	2.93 (0.26)	2.73 (0.48)	2.89 (0.32)	2.41 (0.79)
2. Withholding the telephone	2.72 (0.49)	2.26 (0.66)	2.58 (0.58)	2.33 (0.72)
3. Forced administration of food/fluids	2.59 (0.58)	2.54 (0.55)	2.41 (0.62)	1.91 (0.70)
4. Forced hygiene	2.52 (0.55)	1.99 (0.67)	2.43 (0.63)	1.87 (0.62)
5. Forced administration of medication	2.45 (0.63)	2.12 (0.60)	2.34 (0.57)	1.84 (0.59)
6. Withholding car(keys)	2.32 (0.73)	2.20 (0.76)	2.22 (0.80)	1.89 (0.85)
7. Withholding the mail	2.24 (0.71)	2.11 (0.73)	2.16 (0.74)	1.93 (0.76)
8. Hidden administration of medication, for example, in food	1.94 (0.74)	1.70 (0.68)	1.75 (0.72)	1.56 (0.66)
9. Shutting off gas	1.94 (0.64)	1.76 (0.74)	1.89 (0.75)	1.75 (0.77)
10. Hiding away medication (painkillers)	1.72 (0.65)	1.61 (0.62)	1.80 (0.66)	1.63 (0.71)
11. Hiding away prescribed medication	1.60 (0.64)	1.57 (0.60)	1.60 (0.69)	1.47 (0.70)
<i>Psychotropic medication</i>				
12. Use of psychotropic medication	2.17 (0.58)	2.01 (0.67)	2.29 (0.63)	1.99 (0.63)
<i>Physical restraints</i>				
13. Fixation belt	2.94 (0.25)	2.86 (0.38)	2.84 (0.37)	2.67 (0.99)
14. Vest with fixation belt	2.89 (0.31)	2.80 (0.41)	2.76 (0.52)	2.44 (0.69)
15. Wrist belt	2.87 (0.39)	2.66 (0.53)	2.80 (0.55)	2.77 (0.59)
16. Ankle belt	2.87 (0.41)	2.62 (0.68)	2.78 (0.56)	2.75 (0.62)
17. Tightly tucked sheet	2.84 (0.39)	2.66 (0.65)	2.82 (0.39)	2.55 (0.69)
18. Special sheet	2.72 (0.51)	2.41 (0.66)	2.47 (0.63)	2.08 (0.80)
19. Deep/overturned chair	2.52 (0.55)	2.24 (0.59)	2.36 (0.61)	1.99 (0.72)
20. (Wheel) chair on a board	2.50 (0.65)	1.91 (0.71)	2.27 (0.72)	1.86 (0.71)
21. (Wheel) chair with locked tray table	2.50 (0.62)	1.99 (0.61)	2.18 (0.68)	1.67 (0.71)
22. Bilateral bedrails	2.49 (0.65)	2.27 (0.58)	2.53 (0.55)	2.11 (0.70)
23. Sleep suit	2.42 (0.67)	2.34 (0.67)	2.36 (0.61)	2.11 (0.76)
24. Camera surveillance	1.72 (0.68)	1.76 (0.72)	1.73 (0.72)	1.67 (0.69)
25. Sensor mat	1.28 (0.49)	1.32 (0.53)	1.44 (0.55)	1.37 (0.54)
Discomfort				
<i>Non-consensual care</i>				
1. Withholding aids, e.g. walking aids	2.84 (0.36)	2.55 (0.65)	2.87 (0.41)	2.53 (0.99)
2. Withholding the telephone	2.73 (0.52)	2.15 (0.70)	2.64 (0.61)	2.32 (0.83)
3. Forced administration of food/fluids	2.64 (0.48)	2.57 (0.58)	2.66 (0.57)	2.01 (0.81)
4. Forced hygiene 2.59 (0.51)	2.07 (0.73)	2.77 (0.42)	2.00 (0.74)	
5. Forced administration of medication	2.51 (0.60)	2.20 (0.68)	2.57 (0.59)	1.95 (0.73)
6. Withholding the mail	2.30 (0.74)	1.92 (0.81)	2.09 (0.79)	2.04 (0.85)
7. Withholding car (keys)	2.09 (0.81)	1.74 (0.73)	2.00 (0.83)	1.77 (0.85)
8. Hidden administration of medication, for example, in food	2.06 (0.79)	1.84 (0.76)	1.93 (0.76)	1.59 (0.76)
9. Hiding away medication (painkillers)	1.53 (0.72)	1.41 (0.62)	1.67 (0.71)	1.53 (0.72)
10. Shutting off gas	1.60 (0.70)	1.44 (0.60)	1.71 (0.76)	1.61 (0.79)
11. Hiding away prescribed medication	1.59 (0.68)	1.34 (0.56)	1.56 (0.73)	1.37 (0.63)
<i>Psychotropic medication</i>				
12. Use of psychotropic medication	2.06 (0.68)	1.84 (0.69)	2.29 (0.63)	1.91 (0.77)

(Continues)

TABLE 4 (Continued)

	Nursing staff	General practitioners	Other healthcare practitioners	Family caregivers
<i>Physical restraints</i>				
13. Vest with fixation belt	2.90 (0.30)	2.72 (0.51)	2.71 (0.55)	2.46 (0.69)
14. Fixation belt	2.87 (0.41)	2.69 (0.55)	2.82 (0.39)	2.59 (0.69)
15. Ankle belt	2.84 (0.48)	2.57 (0.62)	2.73 (0.62)	2.77 (0.59)
16. Wrist belt	2.83 (0.48)	2.64 (0.65)	2.78 (0.56)	2.80 (0.55)
17. Tightly tucked sheet	2.78 (0.48)	2.57 (0.70)	2.69 (0.51)	2.51 (0.75)
18. Special sheet	2.60 (0.63)	2.28 (0.69)	2.42 (0.66)	2.13 (0.79)
19. (Wheel) chair on a board	2.39 (0.72)	1.78 (0.63)	2.16 (0.74)	1.77 (0.80)
20. Deep/overturned chair	2.33 (0.65)	2.07 (0.67)	2.22 (0.67)	1.97 (0.79)
21. Sleep suit	2.33 (0.73)	2.23 (0.75)	2.29 (0.76)	2.13 (0.79)
22. Bilateral bedrails	2.29 (0.70)	1.97 (0.68)	2.31 (0.70)	1.90 (0.78)
23. (Wheel) chair with locked tray table	2.21 (0.68)	1.65 (0.65)	2.02 (0.75)	1.65 (0.74)
24. Camera surveillance	1.63 (0.75)	1.64 (0.67)	1.60 (0.69)	1.63 (0.72)
25. Sensor mat	1.18 (0.43)	1.24 (0.49)	1.29 (0.55)	1.32 (0.58)

Note. Items were rated on a 3-point Likert scale indicating 1 as not restrictive/no discomfort and 3 as very restrictive and very discomforting. Reported scores are means (standard deviation). The scores are ordered in degree of restrictiveness and discomfort per scale from nursing staff perspective.

TABLE 5 Opinions about degree of restrictiveness and discomfort to involuntary treatment (ANOVA)

	Nursing staff	General practitioners	Other healthcare professionals	Family caregivers	p-value (ANOVA)
<i>Restrictiveness</i>					
Non-consensual care	2.27 (0.33) ^{b,d}	2.05 (0.35) ^a	2.20 (0.32) ^d	1.87 (0.39) ^{a,c}	<0.001
Psychotropic medication	2.17 (0.58)	2.01 (0.67)	2.29 (0.63)	1.99 (0.63)	<0.001
Physical restraints	2.50 (0.28) ^{b,d}	2.30 (0.32) ^a	2.41 (0.30) ^d	2.16 (0.42) ^{a,c}	<0.001
<i>Discomfort</i>					
Non-consensual care	2.23 (0.36) ^{b,d}	1.93 (0.41) ^{a,c}	2.23 (0.38) ^{b,d}	1.88 (0.51) ^{a,c}	<0.001
Psychotropic medication	2.06 (0.68)	1.84 (0.69)	2.29 (0.63)	1.91 (0.77)	<0.001
Physical restraints	2.40 (0.33) ^{b,d}	2.16 (0.38) ^a	2.31 (0.35)	2.13 (0.46) ^a	<0.001

Note. Items were rated on a 3-point Likert scale indicating 1 as not restrictive/no discomfort and 3 as very restrictive and very discomforting. Reported scores are means (standard deviation).

Corrected alpha \leq 0.003.

^aSignificantly different from nursing staff.

^bSignificantly different from GPs.

^cSignificantly different from other healthcare professionals.

^dSignificantly different from family caregivers.

because this “safety first” is expected by other family members. Another possible explanation for the differences in attitudes is perceived caregiver burden. Caregiver burden is positively associated with the use of involuntary treatment (Hamers et al., 2016) and our study also indicates an association between higher caregiver burden and a positive attitude towards the use of involuntary treatment. In our study, 32% of the family caregivers indicated that they often or always find the care for PwD burdensome, whereas for nursing staff and other healthcare professionals only 12% and 22%, respectively, indicated that they often find the care for PwD burdensome. Finally, family caregivers perceived non-consensual care and physical restraints less restrictive to PwD and indicated feeling less discomfort when using these types of involuntary treatment compared with

nursing staff and other healthcare professionals. All these factors may explain why family caregivers have a more positive attitude towards involuntary treatment and more often use involuntary treatment. Although the attitudes and perceptions towards the use of involuntary treatment differed, results also indicated some similarities between professional and family caregivers: all caregivers considered physical restraints the most restrictive type of involuntary treatment and indicated feeling the most discomfort when using physical restraints. In addition, the order of restrictiveness of involuntary treatment use and feelings of discomfort when using involuntary treatment are more or less similar between the four groups: withholding aids and the telephone were considered the most restrictive types of non-consensual care and fixation belts, wrist- and

ankle belts are considered the most restrictive types of physical restraints by all caregivers. These types of involuntary treatment are the least requested and applied (Hamers et al., 2016; Scheepmans et al., 2017).

There are no previously published studies to compare the results of this study concerning professional and family caregivers' attitudes towards involuntary treatment use in PwD living at home. Differences in attitudes between nursing staff and other healthcare professionals versus family caregivers may be explained by knowledge of the negative effects since poor knowledge about physical restraints is related to more positive attitudes towards restraint use (Karlsson, Bucht, Eriksson, & Sandman, 2001). Almost 42% of family caregivers believed that the use of physical restraints is unavoidable, and the majority of family caregivers consider physical restraints as appropriate and is willing to use them with a relative (Estévez-Guerra et al., 2017). Family caregivers are often not aware of regulations to prohibit or minimize involuntary treatment and the harmful physical and psychological effects (Kurata & Ojima, 2014; Estévez-Guerra et al., 2017).

The consequences and effects of physical restraint use in nursing homes are well known, including immobility, depression, aggression and even death (Evans et al., 2003; Gulpers et al., 2011). These effects are probably similar in home care, however little is known about the use and effects of other types of involuntary treatment, especially non-consensual care. This might explain why the use of physical restraints is regulated heavily in institutional settings, while legislation about the use of (other types of) involuntary treatment in home care is currently lacking in the Netherlands. When new clients are being referred for home care an individual care plan accounts for their needs and wishes, including advanced directives. Providing client-centered care is a common discussion. However, the use of involuntary treatment, its effects and possible alternative interventions are not common subjects of discussion between professional and family caregivers and clients beforehand. Usually this is only discussed when problems arise, or clients show resistance to care; then a solution is usually sought on the spot, if necessary with external expertise. Some caregivers might not be aware that they provide involuntary treatment, such as locking a door when leaving the house or hiding medication. Also, some types of involuntary treatment such as providing medication, assisting with feeding and hiding car keys might be considered as necessary interventions and there is a lack of consensus about what constitutes "good" care. Future studies should focus on the frequency, outcomes, related issues and health impacts of involuntary treatment in home care, especially about non-consensual care. More research is needed on whether there are differences in negative consequences of involuntary treatment in the home environment versus the nursing home environment and how these differences are expressed. Understanding the potential hazards, dilemmas and alternatives to involuntary treatment is therefore warranted and should be the primary step in developing interventions to prevent involuntary treatment. It is important to foster dialogue between professional and family caregivers about the use of involuntary treatment and the decision-making process. The

ethical challenges involved in involuntary treatment at home need to be considered when developing policy concerning involuntary treatment use in home care. Finally, it is important to monitor the well-being of family caregivers and identify ways to reduce caregiver burden, since this is associated with the use of involuntary treatment.

4.1 | LIMITATIONS

This study has several limitations. First, we used a sample where case managers and district nurses were free to choose which caregivers would receive a questionnaire that can lead to selection bias. However, given the sensitive subject of this study, it was necessary that the questionnaires were distributed by a confidential, familiar person who family caregivers trust. Furthermore, this allowed us to include the total network of both professional and family caregivers involved in home care for PwD. Second, this study was conducted in the south of the Netherlands and it is uncertain to what extent our results are generalizable to the rest of the Netherlands or other countries. Due to previous studies conducted in this area, many care organizations and professional caregivers may have already been in contact with studies on involuntary treatment and especially physical restraints reduction. Prior experiences and awareness about negative consequences of involuntary treatment, especially physical restraints might have influenced attitudes particularly among nurses with work experience in nursing homes that restrict restraint use. Third, this study specifically focused on PwD receiving home care with the support of a dementia case manager and results may be different for PwD who are not supported by a case manager. Dementia care without a case manager lacks someone who organizes the care and supports both PwD and family caregivers. In these situations, the care for PwD might be even more complex and family caregivers may have a more positive attitude about the use of involuntary treatment.

The MAQ-HC was carefully developed based on prior data and with the help of family and professional caregivers and the scales indicated good reliability. However, there was only one item about the perceived restrictiveness of and experienced discomfort in administering psychotropic medication and thus results might be underpowered to draw definitive conclusions.

5 | CONCLUSION

Especially in home care, it is very important to include both professional and family caregivers because they are involved in the home care for PwD together. Family caregivers most often use and have the most positive attitudes towards involuntary treatment, indicating that interventions to prevent involuntary treatment use in PwD should focus on family caregivers. GPs also play an important role in the decision making of involuntary treatment use. Although they rarely use involuntary treatment in PwD, GPs are the ones advising and/or prescribing involuntary treatments, especially psychotropic medication. Further research is needed to investigate why attitudes

of professional and family caregivers towards involuntary treatment differ and to understand how these attitudes can be changed to reduce involuntary treatment in home care.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (<http://www.icmje.org/recommendations/>)]:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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