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Involuntary treatment in dementia care at home: Results from the Netherlands and Belgium

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Abstract

Aims and objectives: To gain insight into the request, use and associated factors of involuntary treatment in people with dementia (PwD) receiving professional home care in the Netherlands and Belgium.

Background: Most of the PwD remain living at home as long as possible. Due to complex care needs, this can result in an increased risk for care provided against the wishes of the client and/or to which the client resists, referred to as involuntary treatment.

Design: Secondary data analyses of two cross-sectional surveys.

Methods: Dementia case managers and district nurses filled in a questionnaire for each PwD in their caseload. This study included data of 627 PwD receiving professional home care in the Netherlands and 217 in Belgium. The same methodology (questionnaire and variables) was used in both samples. Descriptive statistics and multi-level logistic regression analyses were used to analyse the data. The study adhered to the STROBE checklist.

Results: More than half of the PwD (50.7%) living at home received involuntary treatment (Belgium 68.2% and the Netherlands 44.7%). 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.

Conclusions: Involuntary treatment is often used in PwD, which is in line with previous findings indicating dementia as a risk factor for involuntary treatment use. More research is needed to gain insight into variations in prevalence across other countries, which factors influence these differences and what countries can learn from each other regarding prevention of involuntary treatment.

1 | INTRODUCTION

With the ageing population, dementia is a significant healthcare challenge worldwide (Prince et al., 2013; Wu et al., 2016). Dementia is a clinical syndrome characterised by progressive cognitive and functional impairment. Most people with dementia (PwD) experience at least one of the following neuropsychiatric symptoms: agitation (e.g. aggression, irritability, restlessness), psychosis (e.g. hallucinations, delusions) and mood disorders (e.g. depression, anxiety, apathy) (Ballard & Corbett, 2010; Unson, Flynn, Glendon, Haymes, & Sancho, 2015; Wu et al., 2016). As a result, PwD experience difficulties expressing their needs and wishes, which can lead to restless behaviour or restiveness to care (Galik, Resnick, Vigne, Holmes, & Nalls, 2017). Dealing with these symptoms and changes can be very challenging for PwD and their caregivers (Ballard & Corbett, 2010; Etters, Goodall, & Harrison, 2008). The majority (70%) of PwD age in place and wish to stay home as long as possible, where they feel comfortable and safe (Morley, 2012). Most Western countries support this by an active "Ageing in place" policy (Afram et al., 2015). However, maintaining PwD to live at home is challenging due to an increasing complexity of care as well and the need for extensive assistance from family caregivers, social support and professional home care (Unson et al., 2015). Multiple studies have shown that many family caregivers experience stress, frustration and/or high caregiver burden (Ballard & Corbett, 2010; Bleijlevens, Wagner, Capezuti, & Hamers, 2016; Chiao & Hsiao, 2015; Etters et al., 2008). The needs for care can differ between PwD and their caregivers, which can lead to situations in which caregivers provide care against the will of the client and/or to which the client resists.

Caregivers may choose "quick but potentially harmful solutions," such as physical restraints or other measures that can negatively affect the PwDs' quality of life (Hamers, Bleijlevens, Gulpers, & Verbeek, 2016; Moermans et al., 2018). Several terms are used in current literature to describe the process in which care is provided against the will of the client or when the client resists, such as restraints (Scheepmans, Dierckx de Casterlé, Paquay, Van Gansbeke, & Milisen, 2017), coercion (Gjerberg, Hem, Forde, & Pedersen, 2013), resistiveness to care (Galik et al., 2017; Spigelmyer, Hupcey & Kitko, 2018) and involuntary treatment (Hamers et al., 2016; Mengelers et al., 2019; Moermans et al., 2018). In this study, measures to which the client resists and/or does not provide consent for are defined as involuntary treatment. Involuntary treatment includes (a) physical restraints, defined as "any action or procedure that prevents a person's free body movement to a position of choice and/or normal

What does this paper contribute to the wider global clinical community?

- Involuntary treatment is commonly used in home care, especially with PwD, although this study indicated differences in prevalence between the Netherlands and Belgium.
- Living alone, functional dependency, cognitive impairment and family caregiver burden are risk factors for involuntary treatment use in PwD receiving professional home care.
- Family caregivers play a crucial role in the request, and use of involuntary treatment at home and interventions should be investigated to inform professional and family caregivers of alternatives.

access to his/her body by the use of any method that is attached or adjacent to a person's body and that he/she cannot control or remove easily" (Bleijlevens et al., 2016), (b) psychotropic medication, defined as "drugs that act directly on the central nervous system, affecting mood, cognition and behaviour" (Moermans et al., 2018; Voyer, Cohen, Lauzon, & Collin, 2004) and (c) nonconsensual care, measures that restrict the client's freedom of living (e.g. hiding the telephone or car keys, or forced administration of food or hygiene) (Gastmans & Milisen, 2006; Hamers et al., 2016).

2 | BACKGROUND

Caregivers may use involuntary treatment because they believe that these measures can prevent falls, wandering and aggressive behaviour (Lach & Chang, 2007) or postpone nursing home admission (Scheepmans et al., 2017). Another reason for caregivers to use involuntary treatment is to respite from other caregiving activities (Scheepmans et al., 2017). However, it may be questioned if these reasons justify the use of involuntary treatment, since some types of involuntary treatment are not used correctly, for too long or have shown to be ineffective (Stubbs, Brefka, & Denkinger, 2015). Involuntary treatment is associated with negative effects including aggression, agitation (Konno, Kang, & Makimoto, 2014) and even injuries (Evans, Wood, & Lambert, 2003; Hofmann & Hahn, 2014).

Involuntary treatment is also in conflict with the values of person-centred dementia care that emphasises high-quality, individualised interpersonal care, which incorporates recognition, respect and trust (Fazio, Pace, Flinner, & Kallmyer, 2018). Although studies on involuntary treatment in home care are scarce, recent findings indicated that involuntary treatment is frequently used in people with cognitive impairment living at home (Hamers et al., 2016; Mengelers et al., 2019; Moermans et al., 2018). With the growing population of PwD and the increased risk of involuntary treatment due to increasing complexity and care demands, it is urgent to gain more insight into involuntary treatment among PwD.

This study aimed to gain insight into involuntary treatment use in PwD, in contrast to previous studies which focused on involuntary treatment use in people with a cognitive impairment in general (e.g. due to dementia, congenital brain injury, stroke or brain tumour). We investigated the prevalence and associated factors of involuntary treatment, and the stakeholders involved in the request and use of involuntary treatment in PwD.

3 | METHODS

3.1 | Sampling and setting

We conducted secondary data analyses of two cross-sectional surveys: one study conducted in the south of the Netherlands (Hamers et al., 2016) and one study conducted in the eastern part of Belgium (Moermans et al., 2018). Together, these studies include data of involuntary treatment use among 2031 people with cognitive impairment receiving professional home care. The study in the Netherlands was replicated in Belgium using the same methodology and (in)dependent variables. Data in the Netherlands were collected between April–July 2014 and in Belgium between April–July 2017. Previous studies indicated that cognitive impairment and a diagnosis of dementia are risk factors for involuntary treatment use. Therefore, the current study focuses on PwD since this group is especially at risk for involuntary treatment use. In contrast to the original studies, this study only included people with a formal diagnosis of dementia as determined by a physician (e.g. GP, geriatric specialist, psychiatrist or neurologist), living at home and receiving professional home care. A formal diagnosis of dementia was determined by a physician, often a general practitioner (GP), geriatric specialist or neurologist. To gain insight into the client's cognitive functioning (e.g. memory, orientation, language), a GP usually uses the Mini-Mental State Examination, where a score below 24 (range 0–30) indicates cognitive impairment (Cockrell & Folstein, 1988; Mitchell, 2009). Based on these results, the GP can refer the client to a specialist, where a battery of neuropsychological tests is conducted. Sometimes, a MRI scan and/or a lumbar puncture to examine the client's cerebrospinal fluid are taken as well to provide a formal diagnosis.

In both countries, we included people with a cognitive impairment via professional caregivers. In the Netherlands, eligible participants were selected if they received care from a dementia case manager (van Mierlo et al., 2016), an independent professional caregiver, often with a nursing background, who coordinates the care for PwD. In Belgium, eligible participants were included if they received professional nursing care at home from and had a Weckx score of at least two on the items disorientation in time and place (Lepeleire, Paquay, & Jacobs, 2005). In both countries, the organisation of home care is divided into regions. For the Dutch sample, 26 regions were included in which 30 dementia case managers provide professional home care. For the Belgium sample, 28 regions were included as defined by the home care organisation (White Yellow Cross).

3.2 | Measures

The primary outcome of this study was involuntary treatment use, consisting of physical restraints, psychotropic medication and nonconsensual care. A questionnaire was developed to assess involuntary treatment use and possible associated factors. The questionnaire used was an adapted version of a tool used to assess the use of physical restraints in institutional settings, which included a detailed list of examples of physical restraints with an reported interrater reliability of 1.0 (Gulpers et al., 2011; Huizing, Hamers, Gulpers, & Berger, 2009). Table 1 provides an overview of the involuntary treatments included in our questionnaire. Dementia case managers and district nurses filled in the questionnaire for every selected PwD in their caseload (Hamers et al., 2016; Moermans et al., 2018). No incentives were provided for participating in this study.

3.3 | Data collection

Besides the use of involuntary treatments, the person who requested and applied involuntary treatment was recorded (family caregiver, nurse, GP, psychologist or social worker). Sociodemographic factors including age, sex and living situation (alone or together) were collected of PwD. To assess functional and cognitive ability, two subscales (Activity of Daily Living-Hierarchy [ADL-H]) and Cognitive Performance Scale [CPS]) from the Resident Assessment Instrument Minimum Data Set (RAI-MDS) in the Netherlands (InterRAI, 2002), and the Inter Resident Assessment Instrument Home Care Belgium (InterRAI HC) (FOD Volksgezondheid Veiligheid van de Voedselketen en Leefmilieu, 2016) in Belgium were used. The ADL-H assesses four ADL activities (mobility, eating, toilet use and hygiene) using a 7-point Likert scale with scores ranging from 0 (independent)–6 (totally dependent). The CPS addresses short-term memory, decision-making, making oneself understood, coma and eating dependency. Scores range from 0 (intact)–6 (very severe impairment) (Morris et al., 1994). Finally, the Self-Perceived Pressure from Informal Care Scale (SPPIC) was used to assess family caregiver burden. Scores range from 0–9 with a

TABLE 1 Involuntary treatments used

	The Netherlands (n = 627)	Belgium (n = 217)	Total (n = 844)
Types of involuntary treatment[†,‡] *Number of measures (number of PwD receiving the measure, percentage in relation to PwD who receive involuntary treatment*	511 (n = 280, 44.7%)	378 (n = 148, 68.2%)	889 (n = 428, 50.7%)
Physical restraints	34 (n = 20, 7.1%)	92 (n = 59, 39.9%)	126 (n = 79, 18.5%)
1. Waist belt in (wheel)chair	1	9	10
2. Waist belt in bed	0	3	3
3. Wrist or ankle ties	0	1	1
4. Chair with fixed tray table	5	6	11
5. Deep, overturned or reclined chair[a]	13	6	19
6. Chair on a board	0	0	0
7. Locked (wheel)chair	8	15	23
8. Bilateral fully enclosed bedrails[b]	6	48	54
9. Special sheet[c]	0	3	3
10. Sleep suit[d]	1	1	2
Psychotropic medication	(n = 113, 40.4%)	(n = 61, 41.2%)	(n = 174, 40.7%)
Nonconsensual care	364 (n = 226, 80.7%)	225 (n = 128, 86.5%)	589 (n = 354, 82.7%)
1. Forced or camouflaged administration of medication	24	21	45
2. Hiding medication[e]	146	63	209
3. Forced food or fluid intake	6	15	21
4. Forced hygiene[f]	45	55	100
5. Restricting communication[g]	41	19	60
6. Locking a door[h]	13	27	40
7. Electronic supervision[i]	4	7	11
8. Shutting off gas or electricity[j]	47	3	50
9. Removing transportation[k]	37	14	51
10. Removing walking aids	1	1	2

[a]Chair preventing getting up.

[b]Bilateral fully enclosed bedrails and placing the bed against the wall to prevent leaving it.

[c]Fitted sheet including a cover enclosing the mattress to prevent leaving the bed independently.

[d]Clothing that prevents an older adult from self-undressing.

[e]Hiding away all types of medication (both prescription and over-the-counter medication) to prevent access to own medication.

[f]Forced hygiene or restraint during hygienic care.

[g]For instance, taking away telephone, hiding mail, restricting visitors, cutting off access to Internet.

[h]Locking all doors from the house or room to prevent leaving it.

[i]For instance, personal alarms, sensors and surveillance cameras.

[j]To prevent, for instance, cooking, heating stove or microwave oven.

[k]For instance, taking away car keys, inactivating car or bike.

[†]Number of measures (number of PwD receiving the measure and percentages are calculated in relation to people who received involuntary treatment).

[‡]Percentages are calculated in relation to people who received involuntary treatment.

higher score indicating greater perceived burden (Pot, Deeg, Van Dyck, & Jonker, 1998). The relationship between the client and family caregiver was also documented. We used the Strengthening The Reporting of Observational Studies in Epidemiology (STROBE) checklist for cross-sectional studies when writing our manuscript (von Elm et al., 2014) (Appendix S1).

3.4 | Ethics

The Dutch study was exempt from human subjects review because only anonymous data from health records were used (Hamers et al., 2016). The Belgium study was reviewed and approved by an institutional review board (Moermans et al., 2018).

3.5 | Statistical analysis

The prevalence of involuntary treatment was calculated by adding the scores of all individual measures reported and dichotomised as 0 (absent) or 1 (present). The same procedure was used to calculate the prevalence of physical restraints, psychotropic medication and nonconsensual care individually. Descriptive statistics were calculated for all variables. To gain insight into factors associated with involuntary treatment use, a random-intercept logistic regression analysis with region as second-level random factor was conducted. We used multi-level logistic regression because the data can be regarded as "clustered" and the assumption of independent data might be violated. Clients are nested within regions (specific home care teams and professional caregivers), and the culture, policy and agreements regarding involuntary treatment use can differ between these regions. Because of these differences, correlations within clusters might be induced by variation between clusters. Therefore, we used multi-level analysis. All background characteristics (age, gender, living situation, cognitive and functional status, caregiver burden and country) were included as independent variables and the use of involuntary treatment (present or absent) as the dependent variable. A backward procedure was performed in which factors $p > .10$ were removed one by one, with the least contributing factor being removed first. All analyses were conducted with SPSS, version 25 (SPSS, Inc). A p-value ≤ 0.05 was considered statistically significant.

4 | RESULTS

4.1 | Sample

Analyses were conducted of a total sample of 844 people with a formal diagnosis of dementia. The sample consisted of 627 PwD receiving professional home care in the Netherlands and 217 in Belgium. The mean age was 82.0 (SD 6.7), ranging from 51–102. The majority of the participants were female (60.1%). Table 2 shows the characteristics for the total sample and for the Netherlands and Belgium separately.

4.2 | Involuntary treatment

Table 1 presents all involuntary treatments used. In total, 889 individual measures of some type of involuntary treatment were used in 428 (50.7%) PwD. The majority of PwD received one ($n = 200$), two ($n = 99$) or three ($n = 69$) involuntary treatments. In two PwD, 10 involuntary treatments were used. A total of 126 physical restraints were used in 79 people. One hundred and seventy-four people received psychotropic medication and 589 measures of nonconsensual care were used in 354 people. The most common measures included hiding medication, forced hygiene, restricting communication (e.g. taking away the telephone or withholding mail), preventing transportation (e.g. taking away care keys or inactivate car or bike)

and shutting off gas or electricity. Involuntary treatment was more used in Belgium (68.2%) than in the Netherlands (44.7%) (OR = 1.65, 95% CI 1.01–2.69, p-value = .047). Nonconsensual care was the most common type of involuntary treatment (82.7%), followed by psychotropic medication (40.7%). Physical restraints were the least frequently used (18.5%).

4.3 | Associated factors

The results of the random-intercept logistic regression model in Table 3 indicate that involuntary treatment use was associated with living alone (OR = 1.57, 95% CI 1.11–2.22, p-value = .011), higher ADL dependency (OR = 1.33, 95% CI 1.16–1.53, p-value < .001), lower cognitive ability (OR = 1.71, 95% CI 1.47–1.97, p-value < .001), greater family caregiver burden (OR = 1.08, 95% CI 1.02–1.15, p-value = .013) and receiving home care in Belgium (OR = 1.65, 95% CI 1.01–2.69, p-value = .047). There was no evidence supporting that age and gender were associated with involuntary treatment use (p-value of .70 and .95, respectively). Region was included in the multi-level logistic regression as second-level random factor, with an ICC value of 0.05 and p-value of .105. The differences between regions were not greater than the differences within regions. Although the ICC value was small according to Cohen (1998) and the results of multi-level analysis were the same as those of logistic regression analysis, based on a-priori theoretical reasons (e.g. that there can be differences in culture, policy and agreements between regions), conducting multi-level analysis was preferred because it is more complete.

4.4 | Request and use of involuntary treatment

Of the 428 PwD receiving involuntary treatment, in 79.0% of the cases it was requested by the family caregiver and in 73.6% used by the family caregiver. Nurses requested involuntary treatment in 38.8% of the cases and used it in 57.9% of the cases. Finally, GPs requested the use of involuntary treatment in 30.4% of the cases and used it in 13.6% of the cases. Both in the Netherlands and Belgium, family caregivers most often requested the use of involuntary treatment (78.2% and 80.4%, respectively). Although in the Netherlands family caregivers mainly used (72.9%) involuntary treatment, in Belgium involuntary treatment was most frequently used by nursing staff (81.1%). Finally, involuntary treatment is least often used by GPs in both the Netherlands (12.1%) and Belgium (16.2%), as shown in Table 4.

5 | DISCUSSION

Involuntary treatment is common practice in PwD receiving professional home care. In one out of two PwD, at least one measure of involuntary treatment was used. In both the Netherlands and Belgium,

	The Netherlands	Belgium	Total	
Variable	*n* = 627	*n* = 217	*n* = 844	*p*-value
Age, mean (*SD*)	81.5 (6.8)	83.4 (6.4)	82.0 (6.7)	<.001
Women, *n* (%)	366 (58.4%)	141 (65.0%)	507 (60.1%)	.002
Living alone, *n* (%)	292 (46.6%)	57 (26.3%)	349 (41.4%)	<.001
Cognition[†], mean (*SD*)	3.2 (1.3)	4.0 (1.4)	3.4 (1.3)	<.001
Median (25th, 75th percentile)	3 (2, 4)	5 (3, 5)	3 (2, 5)	
ADL[‡], mean (*SD*)	1.8 (1.3)	3.2 (1.3)	2.1 (1.5)	<.001
Median (25th, 75th percentile)	2 (1, 3)	3 (3, 4)	2 (1, 3)	
Caregiver burden[§], mean (*SD*)	6.1 (2.6)	5.0 (3.2)	5.8 (2.8)	<.001
Median (25th, 75th percentile)	7 (4, 8)	5 (2, 8)	6 (4, 8)	

Note: Categorical variables were analysed using chi-square tests; continuous variables were analysed using independent sample *t* tests.

[†]Cognitive Performance Score, range 0–6, with a higher scoring indicating more impairment.

[‡]Activity of Daily Living-Hierarchy, range 0–6, with a higher score indicating more dependency.

[§]Self-Perceived Pressure Informal care burden scale, range 0–9, with a higher score indicating higher perceived caregiver burden.

nonconsensual care is the most frequently used type of involuntary treatment (80.7% and 86.5%, respectively), followed by psychotropic medication (40.4% and 41.2%, respectively) and physical restraints were the least used (7.1% and 39.9%, respectively). Factors associated with involuntary treatment use were living alone, higher functional dependency, impaired cognitive functioning and greater

TABLE 3   Factors associated with involuntary treatment

Variables in the equation	B (*SE*)	OR (95% CI)	*p*-value
Living alone[†]	0.45 (0.18)	1.57 (1.11–2.22)	.011
Cognitive status[‡]	0.53 (0.08)	1.71 (1.47–1.97)	<.001
ADL dependency[§]	0.29 (0.07)	1.33 (1.16–1.53)	<.001
Informal caregiver burden[¶]	0.08 (0.03)	1.08 (1.02–1.15)	.013
Country[¶]	0.50 (0.25)	1.65 (1.01–2.69)	0.47

Note: Intraclass correlation coefficient (ICC) = .05.

Variables entered in step 1: gender, age, living situation, cognitive status, ADL dependency, self-perceived informal caregiver burden, country.

[†]Living alone (compared to living together)

[‡]Cognitive Performance Score, range 0–6, with a higher score indicating more impairment.

[§]Activity of Daily Living-Hierarchy, range 0–6, with a higher score indicating more dependency.

[¶]Self-Perceived Pressure by Informal Caregiver, range 0–9 with a higher score indicating more perceived burden.

[††]The Netherlands (0) or Belgium (1). Dependent variable is involuntary treatment: no (0) and yes (1).

family caregiver burden. In addition, involuntary treatment was more often used in Belgium (68.2%) compared to the Netherlands (44.7%). In both countries, involuntary treatment was most often requested by family caregivers.

This is the first study reporting on involuntary treatment use among people with a formal diagnosis of dementia receiving professional home care. The finding that involuntary treatment is used in half of the PwD seems to be higher compared to studies focusing on older people and/or people with cognitive impairment in general, reporting prevalence rates ranging from 24%–52% in Belgium (Moermans et al., 2018; Scheepmans et al., 2017) and 39% in the Netherlands (Hamers et al., 2016). This clearly indicates that PwD are particularly at risk for involuntary treatment use, which may be related to their higher functional dependency and impaired cognitive functioning. The finding that involuntary treatment use is associated with lower cognitive functioning, higher functional dependency and higher perceived family caregiver burden is in line with previous studies in home care (Hamers et al., 2016; Moermans et al., 2018; Scheepmans et al., 2017). Due to impaired cognitive and functional ability, the neuropsychiatric symptoms of dementia (Ballard & Corbett, 2010), caring for a PwD, have a great impact on the family caregivers, who may experience the care as a situation of long-lasting frustration and stress (Etters et al., 2008). The implementation of person-centred care is effective in decreasing neuropsychiatric symptoms in PwD, thereby increasing their quality of life (Kim & Park, 2017) and possibly preventing the use of involuntary treatment.

This study also confirms previous findings that family caregivers play a crucial role in the request and use of involuntary treatment (Hamers et al., 2016; Moermans et al., 2018; Scheepmans et al., 2017). Involuntary treatment use is mostly requested by

TABLE 4 Request and use of involuntary treatment

	The Netherlands	Belgium	Total
Dementia sample	n = 627	n = 217	n = 844
Involuntary treatment	n = 280 (44.7%)	n = 148 (68.2%)	n = 428 (50.7%)
Requested by[†]			
Family caregiver	219 (78.2%)	119 (80.4%)	338 (79.0%)
Nurses	93 (33.2%)	73 (49.3%)	166 (38.8%)
General practitioner	59 (21.1%)	71 (48.0%)	130 (30.4%)
Psychologist	17 (6.1%)	1 (<1%)	18 (4.2%)
Social worker	5 (1.8%)	1 (<1%)	6 (1.4%)
Applied by[†]			
Family caregiver	204 (72.9%)	111 (75.0%)	315 (73.6%)
Nurses	128 (45.7%)	120 (81.1%)	248 (57.9%)
General practitioner	34 (12.1%)	24 (16.2%)	58 (13.6%)

[†]Multiple people could be involved in the request and application of involuntary treatment in one person; therefore, percentages do not add to 100%.

family caregivers. Professional caregivers are considered "visitors" at someone's home and they may feel obliged to accept the demands of family caregivers, for example locking a door or forcing the client to take a shower (Scheepmans et al., 2017). In addition, according to Belgian legislation only registered nurses or general practitioners are authorised to use most measures (e.g. physical restraints, psychotropic medication) that we refer to as involuntary treatment (Moermans et al., 2018). This may also explain why nurses apply involuntary treatment more often than they request it. Finally, caregivers may not always be aware that they provide involuntary treatment, such as hidden administration of medication in the pudding or hiding car keys, which could also explain why it is more often used than requested by nurses. Some may argue that these measures are necessary interventions and there is no consensus regarding what constitutes "good" care (Mengelers et al., 2019). Family caregivers have different ethical perspectives and attitudes towards involuntary treatment: they find physical restraints and nonconsensual care less restrictive for PwD and feel more comfortable using these measures compared to nursing staff (Mengelers et al., 2019). Due to a lack of knowledge regarding the negative outcomes of involuntary treatment, family caregivers are often not aware of the harmful effects and therefore more willing to use these measures (Kurata & Ojima, 2014; Mengelers et al., 2019).

Providing care for a PwD is often a task that continues day and night and puts a lot of pressure on family caregivers, who often feel highly burdened (Ballard & Corbett, 2010; Etters et al., 2008). They often feel the need to use involuntary treatment for the sake of safety, although multiple studies have shown that measures such as physical restraints are ineffective in preserving safety and are associated with immobility, depression, aggression and even death (Evans & Fitzgerald, 2002; Lach & Chang, 2007). To prevent or reduce involuntary treatment, it is important to motivate both professional and family caregivers to apply a person-centred care approach, along with continuous training and education (Kim & Park, 2017; Konno et al., 2014). Other key elements to support PwD and their caregivers

are a trusting relationship, one single point of contact (e.g. dementia case manager) and a tailored care plan (Karlsson et al., 2015).

The finding that involuntary treatment is more often used in Belgium than the Netherlands is due to the higher prevalence of physical restraints in Belgium, particularly the use of bedrails and locked (wheel)chairs, which is more prevalent in Belgium than in the Netherlands. The Dutch and Flemish Belgians have similar demographic characteristics (e.g. proportion of age and gender, native language and social economic status) and are geographically adjacent, and differences in the organisation of health care between these two countries (Kringos, Boerma, Hutchinson, & Saltman, 2015) should be studied to investigate its effect on involuntary treatment use. All PwD from the Dutch sample were selected via the dementia case manager, while in Belgium they were selected by nurses from the home care organisation, which may cause some differences in background characteristic. In the Netherlands, anyone with (a suspicion of) dementia can receive support from a dementia case manager, who coordinates the care for PwD and their family caregiver and provides emotional guidance and support (Van Mierlo, Meiland, Van Hout, & Dröes, 2014). However, whereas the original studies included people with cognitive impairment, we only selected people with a formal diagnosis of dementia (determined by a physician). The procedure of diagnosing dementia is similar in the Netherlands and Belgium (as described above) so the groups of PwD in the Netherlands and Belgium should be comparable. In addition, in the analyses we controlled for confounding factors such as differences in background characteristics. Finally, the use of restraints has received a lot of attention in (the south of) the Netherlands in recent years and a national policy that will go into effect in January 2020 aims to prevent involuntary treatment use. National differences in involuntary treatment use and possible causes and explanations for these differences should be studied further.

This study includes several limitations. First, it was conducted in specific regions in the Netherlands and Belgium, so one should be wary of generalising these results nationally or to other countries.

However, region was included in the multi-level logistic regression as second-level random factor, and the ICC value of 0.05 indicates that the differences between regions were not greater than the differences within regions. In future studies on involuntary treatment use, if region is considered as a second-level factor, the variables related to region that can be included to explain the variance of region are, for example, the norm of professional caregivers' attitudes regarding involuntary treatment use, and the organisation's policy or regulations regarding involuntary treatment use. Participants in the Netherlands were included by dementia case managers, whereas in Belgium participants were included if they received professional nursing care at home and met criteria of disorientation in time and place. Between the two countries, there were some differences in background characteristics, mainly ADL dependency and cognitive functioning. These differences may have been caused by different ways of inclusion and approaches to dementia care. Strength of this study is that data on involuntary treatment use were collected in the same way in both countries, by a questionnaire filled in by professional caregivers for PwD within their caseload. The same definitions and measures were used to collect data on involuntary treatment use. Another strength of this study is that it presents results from a large sample of PwD ($n = 844$), who are particularly at risk for involuntary treatment use (Lang et al., 2017).

6 | CONCLUSIONS

Involuntary treatment is often used in PwD living at home. The finding that involuntary treatment use is associated with living alone, functional dependency, cognitive impairment and family caregiver burden is consistent with previous studies concerning involuntary treatment use and indicates that PwD are especially at risk for involuntary treatment use. This study indicated national differences in involuntary treatment use between the Netherlands and Belgium, especially with regard to physical restraints. More research is needed to gain insight into variations in prevalence across other countries, what causes these variations and what countries can learn from each other regarding prevention of involuntary treatment. Family caregivers have a crucial role in the request, and use of involuntary treatment use at home and opportunities should be investigated to engage in the conversation with professional caregivers to find possible alternatives. Insight into the decision-making process regarding involuntary treatment use, the consequences of these measures and the use of alternative interventions should be the first steps for the development of an intervention to prevent or reduce involuntary treatment in dementia care at home.

7 | RELEVANCE TO CLINICAL PRACTICE

Involuntary treatment is commonly used in PwD receiving professional home care in the Netherlands and Belgium. This manuscript is especially valuable for professional caregivers such as nurses and GPs who focus on providing person-centred dementia care. Involuntary treatment is not only common in home care for PwD, it occurs in other settings, including hospitals (Kalula & Petros, 2016; Lay, Nordt, & Rossler, 2011) or nursing homes (Gjerberg et al., 2013; Gulpers et al., 2011; Wagner et al., 2007) and in other people in need of care too, including mental health care (O'Brien & Golding, 2003; Pelto-Piri, Kjellin, Lindvall, & Engstrom, 2016) and care for people with intellectual disabilities (Fitton & Jones, 2018). These studies often refer to coercive measures, resistiveness to care or restraints to describe care against the client's will and/or to which the client resists. These results confirm the need for an approach to support professional and family caregivers in finding ways to prevent and reduce involuntary treatment. Professional caregivers need to apply a person-centred care approach with an individualised tailored-made care plan, along with continuous education and coaching. Professional and family caregivers should work together to find alternatives to involuntary treatment and support each other in this process.

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